PROFESSIONAL DOCTORATES

Young people's experiences of managing type 1 diabetes

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Young people's experiences of managing type 1 diabetes

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Contents

Section 1

Declarations, Abstract, and Acknowledgements

Declaration

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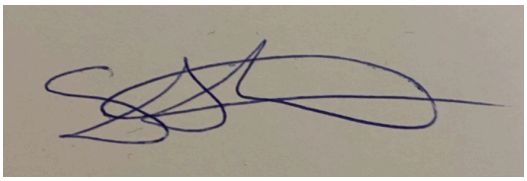

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Young people's experiences of managing type 1 diabetes

Thesis Abstract

This thesis uses a qualitative design to explore the experiences of adolescents with type 1 diabetes (AT1D) regarding their diabetes management.

The literature review involved a systematic review of the literature on adolescents' experience of diabetes management, and a meta-synthesis of their findings. Adolescents described barriers to diabetes management including a lack of knowledge, skills, support and resources to feel equipped to manage their diabetes. They reported becoming overwhelmed by the complex regime and levels of responsibility, which was enhanced when parents intermittently took over control. This sometimes led to resentment and rebellion, resulting in deliberate mismanagement. Non-deliberate mismanagement included adolescents' belief that they could intuitively determine their blood glucose levels without monitoring them as per their regime. Implications include researching the concept of intuitively monitoring blood glucose levels and increasing knowledge and resources for adolescents to feel self-efficacious.

Five adolescent-caregiver dyads were interviewed about their experiences of using a blood glucose monitor in the empirical paper. Thematic analysis of this data found themes of: Practicalities of using the device, where participants evaluated the device and it's impacts on diabetes outcomes; Emotional consequences relating to mostly reduced anxiety yet the potential for guilt and shame; Choice/Control regarding their diabetes management practices; Social responses, where participants described the device as allowing them to be discreet to maintain social relationships and feel like a 'normal teen'; and Responsibility, whereby participants described the need for responsible use of the device and the potential for conflicts with caregivers when this is not achieved. Future implications include research into

those with issues managing their diabetes or the newly diagnosed and providing supportive communication training to service providers and family members.

The final paper examines contributions to theory development and clinical practice and summaries areas requiring further research.

Acknowledgements

I would like to thank the North Wales Clinical Psychology Programme for the training and guidance received during my Doctorate training. Particularly, I would like to thank the research team including Dr Mike Jackson and Dr Chris Saville for their ongoing support during this write up. I would also like to thank my supervisors who have supported me in developing the thesis idea, conducting the research, analysing the data and writing up the findings. These supervisors were Dr Mike Jackson, Dr Renee Rickard, and Dr Sarah Bailey-Rogers.

I would also like to thank my fellow cohort colleagues who have provided encouragement during tough times, including during the Coronavirus pandemic and subsequent lockdown. I would like to think we all supported each other to get through such an unprecedented and difficult time to conduct research. Particularly, I would like to thank Jessica Ashworth for her unrelenting support and positive messages. I would also like to thank Jessica Brady for her support in the early stages of the research.

I would also like to thank my amazing husband and children for supporting me to achieve my goals and career pursuit. The unwavering support they have shown me for nearly a decade will not be forgotten. Without their understanding and support this thesis and subsequent doctorate would not be possible. So, thank you Craig for giving me priority over the laptop (when everyone was fighting for it!) and time and space to write this thesis. Your understanding and patience regarding my career aspirations have allowed me to succeed. Thank you, Dylan and Harri, for showing me sensitivity and maturity during this process. Finally, thank you to my little girl giving me kicks and nudges from within to encourage me and keep me on track.

Section 2

Literature Review

Diabetes Research and Clinical Practice

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[3] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.
Reference to a chapter in an edited book:
[4] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-Publishing Inc; 2009, p. 281–304.
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[5] Cancer Research UK. Cancer statistics reports for the UK, http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/; 2003 [accessed 13 March 2003].
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Data statement

Adolescents' perceptions of barriers to their diabetes management: a meta-synthesis

Short Title: Adolescents' perceptions of barriers to diabetes management

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Abstract

The aim of this literature review was to synthesise qualitative studies reporting adolescents' perspectives of their barriers to management of type 1 diabetes treatment. An electronic literature search utilising ProQuest, EbscoHost (Cinahl and Medline), and Web of Knowledge and a hand-search of reference lists revealed 17 articles. Reasons for barriers to management included a lack of resources, knowledge, skills, and self-belief to complete diabetes self-care appropriately. Many adolescents held beliefs that they could intuitively judge their blood glucose levels via their symptoms, rather than objectively measuring their levels. Adolescents described diabetes as a burdensome condition with a complex regime which resulted in high levels of responsibility. When this responsibility was too extreme, or parents took over responsibility unexpectedly adolescents would become burnt out and lose confidence in their ability to perform self-care. Many found accepting their condition difficult and engaged in denial and avoidance, enhanced by their inability to consider future

consequences of their mismanagement. Finally, some reported a fear of hypoglycaemia as a reason for mismanaging their diabetes care. Implications include the need for further research to clarify the extent of these factors, and the development of effective clinical responses.

Keywords: Adolescent; experiences; type 1 diabetes; non-adherence

1. Introduction

Adolescence is a developmental period marked by physical, psychological, and social transitions [1]. Adolescents face multiple transitions and sources of stress including puberty, changing schools, increased demands and expectations and conflicts with family [2]. Accumulative stress can have a negative effect on adolescents' health behaviours [3], with teenagers not meeting dietary recommendations regarding fruit and vegetable consumption [4,5]. Additionally, adolescence is a time when many individuals begin exploring alcohol and drug use [6] which can lead to altered brain development, cognitive impairment, and poor mental health [7].

For adolescents with type 1 diabetes (AT1D), these factors can impact on their ability to manage their diabetes. Diabetes self-care is complex and demanding; less than one third of adolescents manage keep their blood glucose (BG) levels within the recommended range of

4-7mmol/L [8]. Factors such as stress, growth, and exercise impact on individuals' BG levels [9].

Diabetes self-care is observable, contributing to feelings of stress and social awkwardness in adolescents. Many AT1D want to fit in with peers and avoid the social stigma of completing self-care tasks [10,11], with perceptions of peer reactions to their self-care impacting on adherence behaviours [12,13].

Many adolescents undergo a period of psychological adaptation to their diagnosis including denial of the condition, impacting on management behaviours [14], with diabetes and its management seen as a burden. A study of participants with T1D aged between 8-17 reported an association between perceived level of burden and symptoms of depression [15]. Research has shown an association between depression and a decline in youth diabetes adherence behaviours [16,17,18]. Further, diabetes distress, the emotional distress specific to the burden of diabetes and its management is more common than depression among individuals with diabetes and more strongly associated with a decline in diabetes self-care [19]. Diabetes distress concerns the expected emotional response to a demanding and life-threatening condition such as fear, anxiety, and threat, rather than a psychopathology [20]. Heightened diabetes distress has been associated with severity of symptoms and the need to administer insulin via injection [21].

Some adolescents experience body image crises and a desire to lose weight. AT1D have a higher risk for eating disorders which has been associated with poorer glycaemic control [22]. Others deliberately withhold their insulin to lose weight [23].

Whilst it is apparent adolescents face many barriers to managing their diabetes which can detrimentally affect their health, there is limited qualitative research examining these factors. Existing research focuses on BG levels as a measure of adherence or singular aspects of treatment fidelity such as dietary compliance. Previous research heavily relies on self-

report measures to draw conclusions based on correlations between adherence scores and various measures. The aim of this research was to focus on what adolescents describe as factors that affect their ability to adhere to their diabetes regime to draw meaningful clinical implications from the findings.

While the term 'adherence' can be contentious and will be referred to as management where possible, adherence will be used in instances such as search terms and reporting studies that use the term adherence.

2. Objective

The primary aim is to synthesise qualitative data reporting adolescents' views of factors affecting their diabetes management. Therefore, this review examines only papers that have used a qualitative method such as interviews and focus groups to explore adolescents' understandings and experiences. To ensure current relevance, papers published within the last 20 years were the focus of this review.

3. Methods

3.1 Search Strategy

A systematic search of three electronic databases (Web of Science; Ebsco Host, (specifically, Cinhal and Medline); and ProQuest) was conducted in April 2020 and updated in December 2020. The following search terms were used: (adolesc* OR youth OR teen* OR "young adult") AND (diabetes OR "type 1 diabetes" OR mellitus) AND (treatment OR intervention OR therapy OR manag* OR self-care) AND (adher* OR compl* OR barriers). The following limitations were applied to the search: peer reviewed articles published in

English between 2000-2020. Finally, a hand search of reference lists and citations revealed further articles which were screened for relevance.

3.2 Eligibility Criteria

Articles were required to meet the following inclusion criteria:

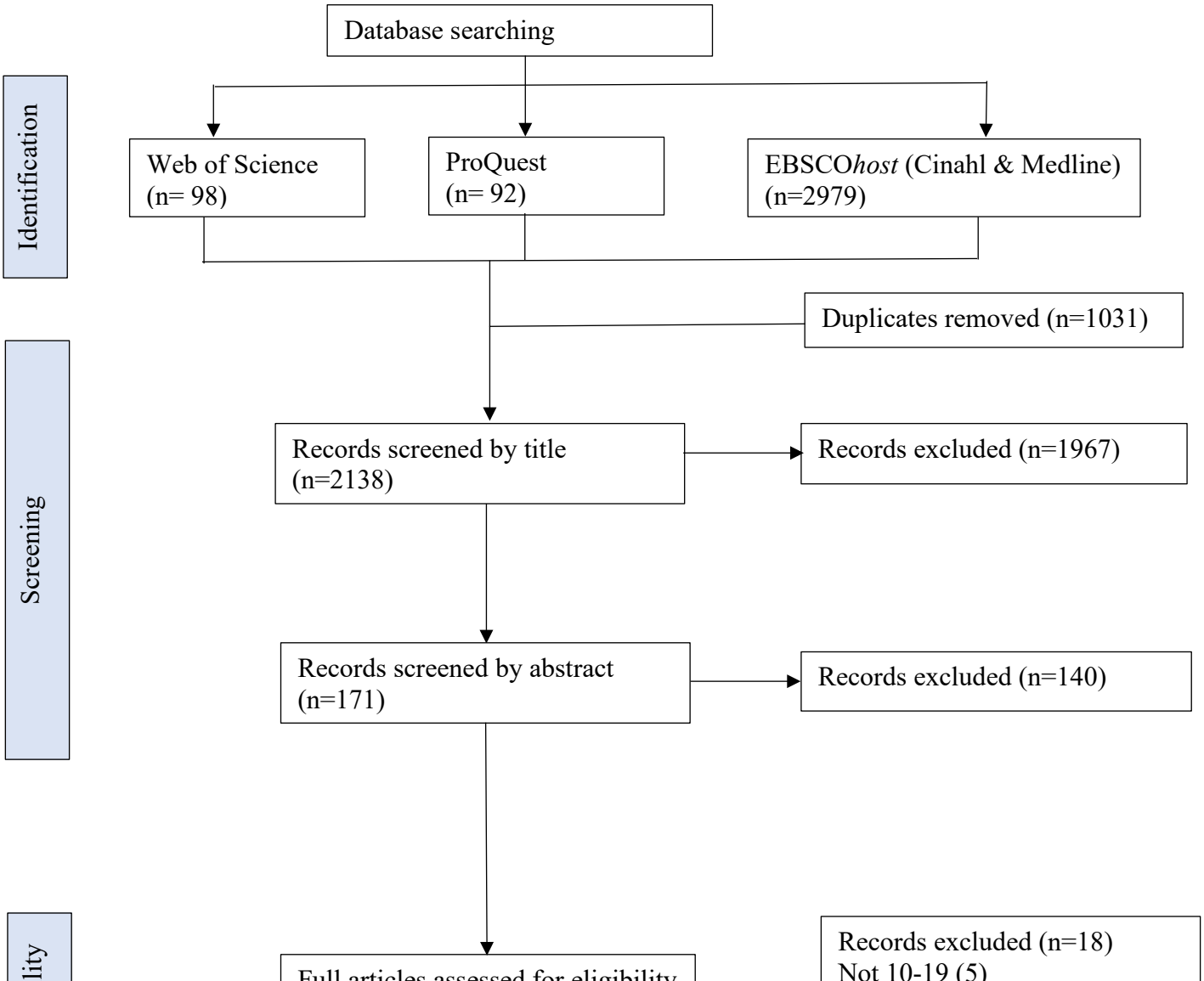
- Peer reviewed articles written in English published between 2000-2020
- Participants aged 10-19 with type 1 diabetes and no other physical or mental health diagnosis
- Qualitative studies reporting adolescent experiences of diabetes management
- Studies clearly separated adolescent data from parent/service providers' data

Articles subject to the exclusion criteria were not included in the final review. These articles fell outside the inclusion criteria, described caregiver/healthcare providers' views, or evaluations of interventions for diabetes management.

3.3 Screening process

Selection of appropriate articles for the final review were determined using a four-step process: screening by title, abstract, full article review, and hand-searching reference lists and citations (Figure 1). The initial search retrieved 3,169 potential articles across the three databases which were screened by title. This resulted in 171 articles for abstract screening, which revealed 31 articles for full-text screening. Full-text screening revealed 12 papers for final review. Finally, a hand-search of reference lists and citations identified five papers for a final review of 17 papers (Table 1).

Figure 1. PRISMA flow diagram of screening process



Reference Country	Year	Sample characteristics	Data collection	Data analysis
Dickinson[24] (USA)	2000	10 females aged 16-17	Unstructured interview	Interpretive Phenomenological Analysis (IPA)
Weinger, o'Donnell, & Ritholz[25] (USA)	2001	10 males, 14 females from two diabetes summer camps	3 same-sex focus groups	'Set procedure for qualitative analysis'
Karlsson, Arman, & Wikblad[26] (Sweden)	2008	14 males, 18 females aged 13-17	Semi-structured interview (SSI)	Phenomenological Analysis
Vilkund & Wikblad[27] (Sweden)	2009	31 adolescents aged 12-17	Open-ended interview	Content Analysis (CA)
Ivey, Wright, & Dashiff[28] (USA)	2009	8 males, 20 females aged 11-15	10-minute parent-teen interactions about a diabetes task selected by teen as source of conflict	CA
Zinn[29] (USA)	2012	10 males, 11 females aged 15-18	Focus groups	Qualitative analysis developing themes

Wang, Brown, & Horner[30] (Taiwan)	2013	8 males, 6 females mean age 14.20 (SD=1.2)	SSI	IPA
Hillard et al[31] (USA)	2014	20 adolescents aged 15-17	SSI	Descriptive Analysis
Griffith[32] (UK)	2014	6 adolescents aged 12-17	SSI	IPA
Hapunda, Abubakar, de Vijver, & Pouwer[33] (Zambia)	2015	10 adolescents aged 12-18	SSI	Thematic Analysis (TA)
Chilton & Pires-Yfantouda[34] (UK)	2015	7 males, 6 females aged 13-16	SSI	Grounded Theory
Castensoe-Seidenfaden et al[35] (Denmark)	2016	4 males, 5 females aged 15-19	SSI	TA
Rechenberg, Grey, & Sadler[36] (USA)	2018	13 males, 16 females aged 10-16	SSI	TA
Shahbazi, Ghofranipour, Amiri, & Rajab[37] (Iran)	2018	12 adolescents aged 14-19	In-depth interviews and focus group	CA
Fragoso, Cunha, Fragoso, & de Araujo[38] (Brazil)	2019	4 males, 10 females aged 12-18	SSI	CA
Anderson, Marshall, & Tulloch-Reid[39] (Jamaica)	2019	5 males, 14 females, mean age 14	Focus groups	TA
Gurkan & Bahar[40] (Turkey)	2020	18 adolescents aged 11-17	SSI	CA

Table 1. Study characteristics

3.4 Data analysis

A meta-synthesis approach was used to analyse the data; this approach has been reported as providing a balance between an objective framework guided by a rigorous research approach, and insights and interpretations provided by the researcher [41]. Further, the meta-synthesis with theory-development approach [42] was employed to derive theory from the synthesis of the individual studies.

The first author (SW) read each article included in its entirety then re-read them and made annotations of comments, questions, and initial coding ideas (Appendix 5D). Codes were derived from direct participant quotations within the study (primary data) and authors' paraphrasing of participant quotations (secondary). Data regarding study authors' interpretations of quotations were excluded from the analysis. Primary and secondary data codes were tabulated, and colour coded to identify themes (Appendix 5D). Equal weight was given to primary and secondary data codes. Relationships between themes were then conceptualised to determine any processes to drive theory development. Themes were reviewed continuously until completion of the written report.

3.5 Quality assurance

Full articles were assessed for eligibility by SW and the second author (RR) separately. Articles included in the final review were assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (Table 2) by SW and RR separately. RR assessed a random sample of 10 papers. Discrepancies existed for three papers but were regarding either 'unknown' or 'no' results; agreement was reached following discussion at each of these stages. The CASP provides a method of assessing the strength of qualitative studies to ensure any large variances in study strength are considered during results interpretation. Papers were rated as strong if two or less scores resulted in no/unknown and moderate if three to five were rated as no/unknown. Whilst most studies were rated as

strong, consideration of the relationship between the researcher and participants was the most common item not reported.

	Paper																
CASP item	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40
Clear aims?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate qualitative methodology?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate research design?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate recruitment strategy?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Suitable data collection?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓
Consideration of researcher-participant relationship?	✓	×	✓	✓	✓	✓	×	✓	×	✓	×	?	×	✓	×	×	×
Consideration of ethical issues?	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	?
Rigorous data analysis?	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	?	✓	×	✓
Clear statement of findings?	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Valuable research?	S	S	S	S	S	S	S	S	S	S	M	S	S	S	S	S	S

Table 2. CASP checklist results (S=Strong; M=Moderate)

4. Results

The following themes were identified across the studies: Social Pulls; Responsibility; Present-Focused; Diabetes Distress; Rebellion; Coping Strategies; Perceived Lack of Ability; and Misguided Beliefs/Intentions. These were conceptualised as fitting into two superordinate themes: Challenges and conflicts and Skills-based barriers to diabetes management.

Superordinate theme 1: Challenges and conflicts

Theme 1. Social Pulls

Most papers discussed adolescents being torn between their desires to be social and interact with their friends in a meaningful way, and their need to complete diabetes self-care. This conflict came up for them in several ways:

Subthemes:

Wanting to fit in

Adolescents placed fitting in with peers, not standing out from the crowd, and being a 'normal teenager' above their diabetes self-care.

"I panic more about not being able to do things everyone else can do…with my friends and that"

Adolescents faced the dilemma of whether to engage in activities to the detriment of their health or refrain from engaging in them which led to resentment about their diagnosis.

Social Priorities

Adolescents discussed prioritising activities with friends above diabetes self-care. They described knowing what tasks they needed to do, but not completing them as it would mean missing out on spending time with friends.

"If I go out for a whole day to skateboard, I really don't think about it. I'd rather just not stop and take the time to do it…I could I just don't. I just want to do my day how I want"

Identity

Some adolescents resented the diabetes becoming a part of their identity. They referred to parents asking only about their symptoms rather than how their day had been.

"It's like it's the defining factor of me…I want it to be the opposite way around, I want me to be the defining factor of me rather than the diabetes"

Perception of Peer Responses

Other adolescents feared the responses of peers if they were to discuss or complete self-care tasks. They feared being perceived by their peers as 'not normal' so they would either not discuss needing to complete self-care, or not discuss having diabetes altogether.

"You have to keep up with your friends. If you fail this, then you feel excluded from them. For example, everyone eats ice cream, if you do not, it becomes weird"

For many, this concern seemed to largely over-ride other considerations of self-care.

Embarrassing/Overt Tasks

Similarly, some adolescents described feeling embarrassed about the overt nature of having to inject in public or leave their current situation to find somewhere to inject. Some described not administering insulin to avoid the embarrassment. Others refused to wear insulin pumps or glucose monitors because they could be seen and heard:

"I don't need something bleeping during the day, like, drawing attention to me"

"When I'm in a very crowded place, I make sure I go somewhere where, like, the bathroom and go into a stall and do it by myself, but if not, I will just ignore it for a few"

It seems adolescents with diabetes fear their condition defining them and imposing restrictions on their ability to socialise with peers, evoking potential negative responses from peers. This appears to contribute as a barrier to diabetes management as a way of maintaining their relationships with peers.

Theme 2. Responsibility

Many studies reported adolescents' views of their need to take responsibility for their diabetes management. This was often overwhelming for adolescents with many confused about changing levels of responsibility expected of them.

Subthemes:

Ambiguous Expectations for Responsibility

Some adolescents described feeling frustrated when their parent took over responsibility without being asked, leaving them feeling less autonomous and in control:

"It pisses me off when my parents interfere…so I don't care to take my insulin"

"My mom doing a lot less…not telling me to check my blood sugar, not packing stuff, not really doing anything…"

Relinquishing Responsibility

Other adolescents suggested they were able to manage their diabetes tasks but would pass the responsibility back to parents or healthcare providers at the earliest opportunity.

"…when I'm at home, then I'm more relaxed and let Mum take over the responsibility, automatically, and then, it's usually what she has in mind that's better".

Too Much Too Soon

Many adolescents described feeling overwhelmed by the responsibility of managing their diabetes alone and felt the level of responsibility changed drastically within a short time. They also related this to the timing of responsibility during adolescence, a period which they described as having its own stressors alongside diabetes stress.

They made suggestions for how the transition should occur:

"Preparation for the transition could have been improved if I could have slowly been doing things on my own, that way I would already be used to going to the doctors on my own".

Theme 3. Present-Focused

Adolescents were described across many papers as being present-focused rather than considering the long-term consequences of their actions. Many adolescents reported either not caring about their future health or being unable to grasp the abstract nature of it. Therefore, self-care decisions were based on the immediate benefits of fitting in with peers and socialising, rather than the future consequences on health.

"I don't really care what the consequences are at the moment"

"Well, I'm not going to die from a high blood sugar, but I might lose toes when I'm fifty. Who cares?"

It seems adolescents' developmental stage influences their ability to consider the future implications of their barriers to diabetes management, resulting in present-focused choices based on immediate gain. Normal development conflicts over responsibility seem heightened for these young people.

Theme 4. Diabetes Distress

It seems the combination of oscillating between social pulls and the responsibility and desire to have well managed diabetes becomes overwhelming, leading to feeling burnt out. Adolescents described wanting time off from thinking about their condition and the stress resulting from the complexities of the management practices.

Subthemes:

Wanting 'Time Off'

Many adolescents described a desire to get a break from having to manage their diabetes all the time. They described shutting off from the diabetes tasks when they wanted time off from all the responsibilities.

Burden of Complex Regime

The need for time off was reinforced by the complexity of the diabetes regime. Adolescents described the impact that self-management tasks have on their lives:

"I need to be very honest to tell you I really hate this disease. It's like a chain that I am trapped by"

"It is a real torture for me to measure my blood sugar, to open it, to change the tip. It destroys my life for 5-10 minutes"

Theme 5. Rebellion

It seems when adolescents become overwhelmed and burnt out by their diabetes responsibilities, they attempt to regain an element of control by becoming rebellious or avoiding their responsibilities as a way of coping.

Subthemes:

Teaching Parents a Lesson

Several adolescents described feeling resentful about the intrusion from their parents in the form of questioning and accusations, and would become deliberately mismanage their diabetes to get back at their parent:

"But if they yell, I just get mad at them, then it's their fault I eat candy"

"My mom gets on my back about diabetes. I'm like 'that sucks [there] goes a day now when I'm not going to do what you want"

Weinger, O'Donnell and Ritholz (2001) noted 'a few of the boys mentioned 'teaching their parents a lesson' by eating any hidden food they discovered'.

Ignoring Advice from people without diabetes

Others felt they did not need to listen to advice given by healthcare providers as they did not have diabetes themselves and were basing their advice on what they had learnt from a book rather than their experience of what life is truly like when living with diabetes.

"I try to listen to them [Diabetes Specialist Nurse with diabetes] more than just the normal doctor who doesn't have it who just went to school for it"

Theme 6. Coping Strategies

Subthemes:

Denial/Rejection of diabetes and regime

Many adolescents denied their diabetes as a way of coping with the pressures of the regime.

"…[I] always think what's the point putting myself through this if I don't have it?"

"Sometimes I'll skip checking my blood sugar or giving myself insulin because I just don't want it, I don't want to have this at all."

Others did not engage in management practices as they held onto the belief a cure would be found which would resolve them of their responsibilities.

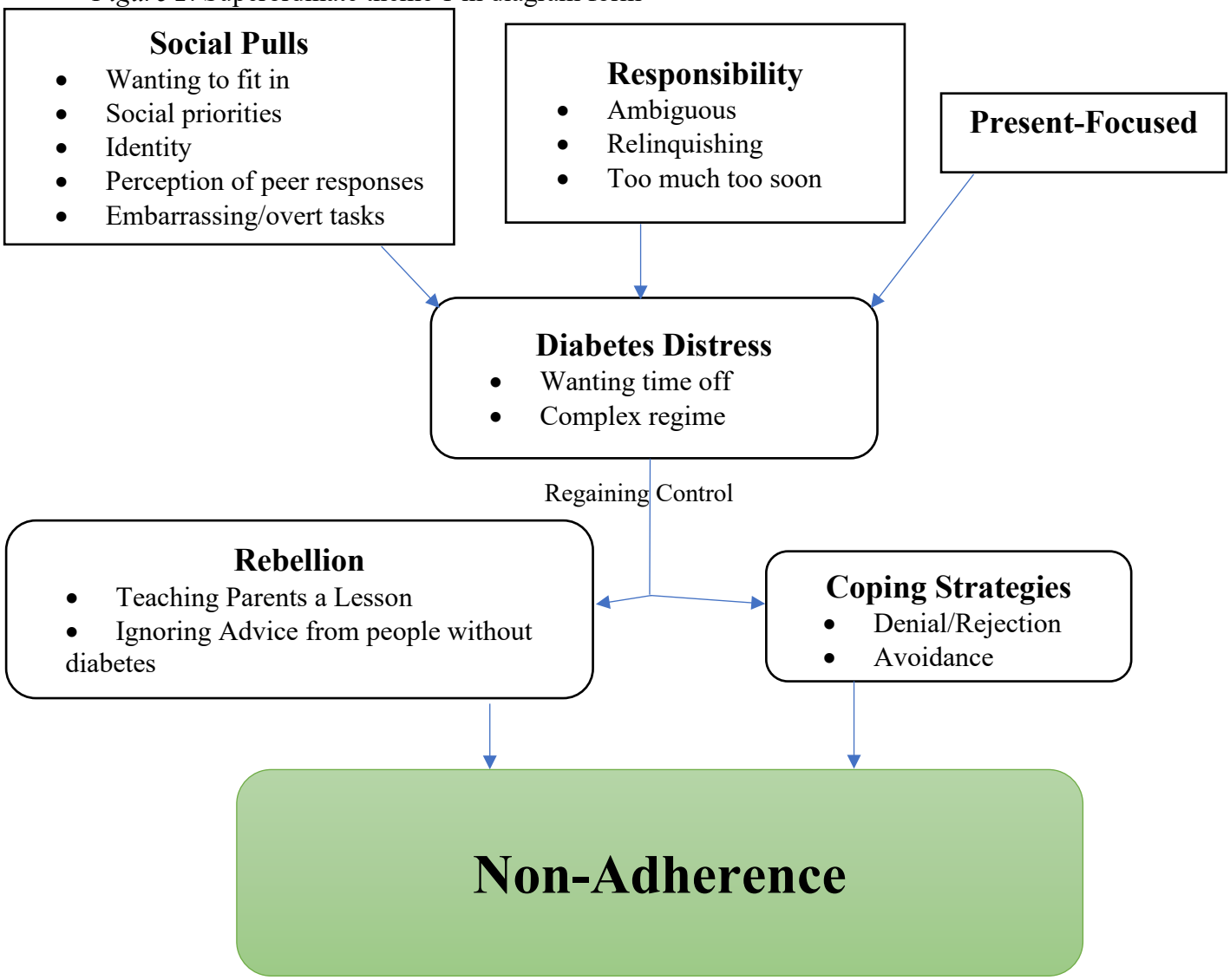
"There's a part of me that wants to believe there will be a cure, it will just magically stop or it's not really diabetes…I think that's a reason for me not wanting to inject and test"

Avoidance as Coping Strategy

Some adolescents described avoiding clinics to avoid the uncomfortable discussions and questioning that would occur. Others were avoiding their management tasks to avoid the discomfort, pain and inconvenience that comes with it.

Overall, it seems many adolescents go through a process of being overwhelmed by the, often confusing, levels of responsibility imposed on them by their diabetes and their desire to be like everyone else. This seems to also be influenced by their developmental stage, often leading them to be present-focused rather than being able to consider abstract health consequences in the future. It seems this leads to burn out, where they feel unable to cope with their condition and the pressures that come with it. Some adolescents then attempt to regain a sense of control by either rebelling against others and the regime or employing coping strategies such as avoidance. This process appears to contribute to a decline in diabetes management. This is illustrated visually in Figure 2.

Figure 2. Superordinate theme 1 in diagram form



Superordinate theme 2: Skills-based mismanagement

Theme 1. Perceived Lack of Ability

Many papers reported that adolescents expressed a lack of knowledge regarding how to manage their diabetes in certain situations and this impacted on their self-belief. Further, some described being challenged by others such as school staff, making self-care more difficult.

Subthemes:

Lack of Knowledge/Skills/Information

Some adolescents felt they had missed the information about self-care due to their age at diagnosis and their parent taking responsibility previously. They reported not knowing how to manage their diabetes in the context of their adolescence. For example, knowing how to adjust their regime to account for activities such as drinking alcohol or sports:

"…it can be difficult (to do sports) because when the blood sugar starts to drop or if it is too high when I start to work out, if I need to take insulin at all or if I shouldn't…I haven't received any support on the matter. I still have trouble with it"

Lack of Resources/Support

Some adolescents reported a lack of money or correct food available to follow the dietary requirements. Others were impeded from completing self-care by school staff who lacked awareness of their needs:

"I had my pump out and was taking insulin, he [teacher] comes over and he's like 'I'm gonna take your ipod from you' and pulls on the cord right as I'm taking insulin. I tried to explain that it was a pump after he pulled it and he was like 'I still need to take it from you'. I'm like 'this is for diabetics. I'm diabetic. I need insulin'. He looked at me like 'oh'"

Lack of Confidence/Self-Belief

Others reported lacking confidence in their abilities to manage their diabetes effectively.

"…at that moment, there was so much information in front of me and the time was so inadequate. I was worried so much, how could I keep all this information in my mind"

Theme 2. Misguided Beliefs/Intentions

Many papers reported adolescents inadvertently mismanaging their diabetes due to incorrect beliefs about how best to manage their condition. Sometimes this arose from a lack of information, such as this adolescent describing his cigarette use:

"…cigarette smoking is not harmful to diabetes. On the contrary, it is healthy…my blood sugar drops when I smoke…I measure my blood sugar and it shows 300. Then I smoke a cigarette and I check my blood sugar ten minutes later and it shows 70…"

Subthemes:

Avoiding Hypos

Some were deliberately ran their BG at a higher level than recommended to avoid unwanted symptoms of hypoglycaemia. Many adolescents reported the symptoms of hypoglycaemia as either too distressing and uncomfortable or more dangerous to manage than becoming hyperglycaemic. They would, therefore, rather knowingly change their management practice to avoid 'hypos':

"…hypoglycaemia scares me. Nausea is so scary, awful beyond belief. So, I eat too much"

"If I am driving a car, my blood sugar is too low- that's dangerous…that is also why I prefer to have slightly elevated blood sugar"

Relying on Intuition/Symptoms/Guesswork

Others rely on how they feel within their body to determine whether they need to adjust their insulin rather than doing a BG test. They believe they can determine their levels effectively through their symptoms (or lack of).

"Usually, I get to feel it, then I eat something, so it goes back to normal, but then when it comes back it goes too high"

"I haven't checked my sugar for a long time. I feel it's enough to sense my body. I'm not so stupid to be unaware of my discomfort"

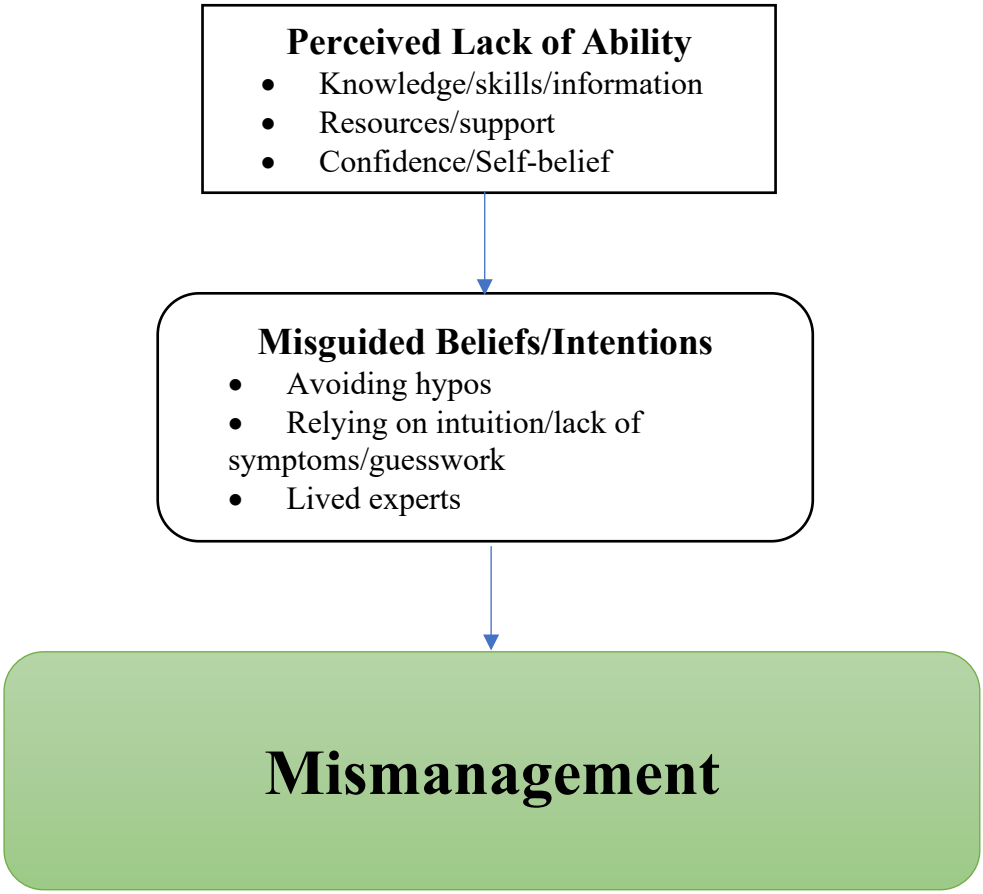
Lived Experts

Whereas, for others mismanagement resulted from a belief they were the lived experts of their condition and were best placed to make decisions regarding management tasks. Karlsson, Arman and Wikblad (2008) reported 'The teenagers stated they were their own experts in managing diabetes activities…they did not abandon their own decisions about insulin doses, regardless of what their parents thought'.

"When I have high blood glucose, my parents tell me to take a small amount of insulin, but I take what I want when they aren't looking. Sometimes it's too much, but that's not very often"

In summary, many adolescents report a lack of knowledge and skills to manage their condition appropriately, coupled with a lack of resources and support. This appears to contribute to a lack in self-belief, which may lead to adolescents developing their own ideas and skills regarding diabetes management, which do not correlate with medical recommendations, giving the impression of deliberate lack of diabetes management and at the same time, an inflated sense of own expertise and insight.

Figure 3. Superordinate theme 2 in diagram form



5. Discussion

It appears several factors act as barriers to adolescents' diabetes management; partly from being present-focused and feeling overwhelmed by the complex regime and burden of responsibility for self-care without a break. For others it is due to a lack of knowledge and skills regarding managing their condition in differing situations, or a lack of belief in their abilities. This can result in adolescents wanting time off and to be able to pass the responsibility to others. For some, this leads to avoidance to regain control of their situation, or rebellious actions to teach others a lesson about their 'nagging'. However, a resounding theme amongst the literature regarded adolescents' deliberate mismanagement of their

diabetes to avoid the unpleasant symptoms of hypoglycaemia, or from misguided beliefs about their ability to manage their condition through intuition and previous experience alone.

Consistent with the findings from this review, previous research has described adolescents placing importance on their social interactions with peers [43,44] and the rebellious actions many young people take during adolescence [45,46]. Research has described adolescents as present-focused rather than considering the long-term consequences of their actions, particularly regarding health behaviours [47,48,49], in part due to underestimating their chances for negative outcomes [50].

Additionally, in concurrence with the current findings, research has described adolescence as a time of unique stress [51,52,53] with the addition of a long-term health condition such as diabetes as an additional stressor [54]. Diabetes distress has been described as feelings of hopelessness and powerlessness, frustration, and high levels of burnout [20]. This mirrors the current findings that adolescents found the burden of their diabetes regime overwhelming and tiring.

Hypoglycaemia has been described as a major burden to individuals with diabetes [55] with symptoms such as palpitations, seizures, and coma [56]. Research into the deliberate mismanagement to avoid hypoglycaemia has focused on dietary and exercise requirements rather than BG monitoring and insulin administration.

Research into the concept of relying on intuition and experience to guide diabetes self-care practices is limited. Many adolescents reported that they know their body and can detect their BG level through bodily sensations, rather than relying on glucose monitoring to determine their level to administer the correct insulin. However, research has shown individuals with diabetes can often unknowingly be hyperglycaemic or hypoglycaemic with a lack of symptoms [57]. This has been associated with duration of diabetes, glycaemic control, and an increased sensitivity to insulin [58].

This synthesis has clarified two specific factors which contribute to adolescents' diabetes mismanagement: their misguided beliefs regarding their ability to intuitively know their levels, coupled with their fear of hypoglycaemia are particularly important aspects for healthcare providers to consider.

6. Theoretical and Clinical Implications

This research has given an understanding of barriers to diabetes management from adolescents' perspectives, providing the opportunity to develop services to directly address the issues raised by AT1D themselves. This could lead to increased trust and communication between AT1D and healthcare providers, allowing healthcare providers to navigate roadblocks to management in a time-effective and appropriate way. Healthcare providers should consider the recommendations made by adolescents regarding how to transition to responsible self-care to avoid disengagement through burnout. Support for parents regarding effective communication might protect against rebellious behaviour to 'teach them a lesson' for interfering or 'nagging'. Education for school staff would help them provide more informed support.

This research revealed that adolescents feeling ill-equipped to manage their diabetes through a lack of knowledge and support has a major influence on diabetes management. Healthcare providers could re-deliver self-care training during adolescence as young people may have missed the initial information given at diagnosis due to their age or not know how to manage their diabetes effectively alongside their unique lifestyle of adolescence.

7. Limitations

This review examining all eligible studies within the last 20 years revealed only 17 articles. Therefore, the interpretations are based on limited evidence. The articles included in this review sampled different age groups with some focusing on late adolescence. Sample sizes ranged from five to 31.

SW was new to using TA and conducting research within the field of diabetes. Nonetheless, quality assurance methods were used when conceptualising themes such as continuous reflection and development with RR and MJ, ensuring themes were not missed and were defined in a manner appropriate to the data. However, the CASP used to assess study quality is subjective in its interpretation, which may have influenced the studies being rated mostly as 'high quality'. The PRISMA Checklist is an alternative quality assessment tool with more objective assessment criteria which may provide more objective results.

8. Research Implications

This review has highlighted a reliance in previous research on inventories and self-report measures correlated with a metabolic measure of management; further qualitative research conducted through interviews or focus groups is warranted. Specifically, research focusing on adolescents' beliefs about their ability to manage their diabetes without checking their BG levels or calculating carbohydrate levels within meals.

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'Blood glucose monitoring device and me': Young people living with diabetes and their caregivers' perspectives of their use

Short Title: 'Blood glucose monitor and me': perspectives from young people living with diabetes and their caregivers

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Author Contributions

This research was conducted and written by Sophia Williams. Dr Sarah Bailey-Rogers supported the development of ideas and interview structure as well as the recruitment of participants. Dr Renee Rickard and Dr Mike Jackson supported the data analysis and production of the written report by reviewing drafts and providing feedback.

Abstract

Background: Type 1 diabetes is a serious, life-long condition requiring individuals to monitor their blood glucose (BG) levels to ensure they stay within a safe range. Until recently, BG was tested by individuals pricking their fingers to test blood samples. Continuous glucose monitors (CGMs) are inserted into the skin to continuously measure BG levels within the interstitial fluid, drastically reducing the number of finger-prick tests per day. **Aims**: To explore how two glucose monitors (Libre and G6) are received by adolescents with type 1 diabetes (AT1D) and their caregivers. **Participants**: Five AT1D aged 11-17 (two male; three female); five caregivers (two male; three female). **Methods**: Semi-structured interviews were conducted via telephone and analysed using thematic analysis. **Results**: Both devices are generally well tolerated and are described as easy and convenient to use. Participants appreciate the continuous data and trends to determine patterns in their BG levels, leading to increased knowledge and power. Participants reported a general reduction in anxiety and improved social interactions. One participant using a Libre described increased pressure and guilt if they forgot to scan the device regularly. Similarly, some participants described being exposed by their data when shared with others. All participants described a need to use the device effectively; however, caregivers reported frustrations when AT1D were not using their device properly. **Conclusions**: The devices reviewed provide an easy, convenient method of monitoring blood glucose levels which aids social interactions due to their discreetness. Whilst generally reducing anxiety, there is potential for increased pressure due to data sharing.

Keywords: glucose monitoring device; paediatric

Introduction

Diabetes is a serious, life-long condition that requires many adjustments to individuals with diabetes' and caregivers' lives [1]. Individuals must monitor their blood glucose (BG) level and adjust the amount of insulin administered accordingly. Significant diabetes management is required to prevent health complications such as kidney failure, blindness, heart disease, stroke, and amputation [2].

Type 1 diabetes diagnosis occurs more in childhood than adulthood; the UK has the highest prevalence of children with type 1 diabetes in Europe [3] with 28,300 children and young people diagnosed in England and Wales [2].

Children and young people go through many physiological changes which affect their ability to keep their BG level within range [4]. They also experience increased pressures such as transition to high school and increased responsibility, alongside a shift towards placing importance on their social interactions [5]. These factors make diabetes management notoriously difficult, with dire consequences for their long-term health. Specifically, adolescents have the lowest fidelity rates for BG monitoring [6]. BG monitoring (BGM) technology was introduced to ease the distress and commitment of multiple daily finger-prick BG tests [7].

Two main BGMs are used in the NHS: Continuous glucose monitors (CGM) such as the Dexcom G6 (Appendix 5B) and the FreeStyle Libre Flash (Appendix 5B). Libres were initially self-funded but subsequently funded by the NHS in 2017. BG levels are automatically measured every minute and stored at 15-minute intervals for up to 8 hours [8]. Alternatively, CGMs store readings at 5-minute intervals and offer the user an alarm function which alerts individuals with diabetes should they become hypoglycaemic [9]. The Libre requires the user to scan the device with a sensor at least once every eight hours to see the past 24 hours of trends, whereas the CGM provides continuous data readings on the screen

[8]. As the readings provided by both devices are from the interstitial fluid, which is a few minutes behind the blood readings, individuals are advised to manually check their BG level by finger-pricking at least once daily [10].

Previous research has indicated BGM technology is effective at monitoring BG and keeping BG levels within range (4-7mmol/L). Research examining adults', adolescents', and caregivers' experiences of BGM use reported participants valuing the trends in data provided by the device and this leading to a better understanding of the immediate effects of insulin, food, and exercise on their BG level [11]. However, participants also described feelings of failure when alarms activated. A review examining studies reporting children's, adults', caregivers', and care providers' experiences of BGM use found that while some felt empowered by their device, others found the device burdensome and a visible sign of their condition, making them feel different to others [12]. There were mixed results regarding the impact of the device on relationships with others.

Limited research into the Libre suggested positive reviews with improvements in quality of life (QOL) [13,14]. CGMs are also considered 'generally acceptable', with no negative impacts on QOL [15,16]. However, downsides include skin irritation and excessive alarms [17]. Further, frequent false alarms can lead to 'alarm fatigue', whereby individuals ignore the alarms or turn them off altogether [18].

BGM technology is expensive; accordingly, most research has included HbA1c levels (measure of average BG levels over three months) to determine whether the technology is effective and, therefore, cost effective. Additionally, there is limited research focusing on adolescent experiences of BGM use. This study aims to add to previous research findings regarding the lived experiences of using a BGM which has huge health implications but the potential for negative consequences for

QOL. A review of Libre use suggested young individuals found the device easy to use but 25% of participants discontinued use due to limited sensor duration and discrepancies between readings provided by the device and finger-pricking [19]. Research regarding the Dexcom G6 focuses on accuracy and cost-effectiveness rather than user experience. The present research focuses on adolescents with type 1 diabetes (AT1D)'s and caregivers' personal experiences of using the technology rather than the medical and economic implications. This research uses thematic analysis to describe and interpret themes arising in open discussions about their experience of using this technology.

Methods

Sample

AT1D, (aged 10-18), and their caregiver who attend the local Paediatric Diabetes Service and have been using any BGM for at least six months.

Sample recruitment

Information about the study, written in English and Welsh, was posted to all eligible AT1D and their caregivers separately discussing the purpose of the study and detailed information regarding what participating would entail. Interested participants notified the research team via email. Only participants whose caregiver also consented to participating and vice versa were considered eligible for the study. Where two caregivers indicated an interest, the participating parent was randomly selected.

Information sheets were sent to 55 AT1D and 55 parents. Six AT1D-parent dyads indicated an initial interest (response rate of 11%), but one pair did not respond to further contact. Five AT1D-parent dyads were included in the final study. Participants received a £30 amazon gift card to thank them for their time.

Participants

AT1D: Three females and two males aged between 11 and 17.

Caregivers: Three females and two males. See Table 1 for participant descriptions.

Data collection

Semi-structured interviews were conducted in October 2020 via telephone due to COVID-19 restrictions. This method was chosen to enable open discussions with participants regarding their experiences. Telephone interviews have been reviewed as a suitable method for qualitative research [20]. Interviews were conducted by the first author (SW) who did not work at the diabetes clinic, were recorded with consent, and later transcribed. An interview schedule guided the discussion (Appendix 5C) and was developed by SW and the second author (SBR) who worked in the diabetes clinic and had knowledge of relevant issues in practice.

Data analysis

A hybrid of descriptive and interpretive Thematic Analysis (TA) was used, following Braun and Clarke's six step model of TA [21] (Table 2). TA is a flexible method that allows a rich description of the data which provides the reader with a sense of the predominant and important themes [22]. It has been reviewed as appropriate for descriptive and interpretive research [23].

It was expected that AT1D may have different experiences to their caregivers. Adolescent and caregiver data were analysed separately to maximise sensitivity to the nuances of their different perspectives. All six steps were undertaken for the adolescent data initially, and then for the caregiver data.

Interviews were transcribed verbatim and direct quotations were used to determine and define themes. Whole transcripts were read individually, then re-read and annotated with comments to form the initial coding (Appendix 5D). The initial codes were then tabulated for all transcripts within each participant group and re-read to discover potential themes. Potential themes were colour coded (Appendix 5D) and reviewed to determine whether any needed merging or defining differently. Subsequently, themes and subthemes were conceptualised and defined (Appendix 5D). Finally, the themes were reviewed to determine their coherence, specificity, and comprehensiveness, and were defined and named.

Quality assessment

SW and SBR coded transcripts individually; SW then developed themes and shared these with the third (RR) and fourth (MJ) authors who gave their individual reflections on the themes. Themes were then evaluated and developed further to reach inter-researcher agreement and iteration back to texts.

Reflective statement

This research takes an essentialist approach, whereby the experiences, meanings and realities of the participants are reported [20]. It also follows an inductive approach deriving themes from the data itself, rather than being driven by the researchers' theoretical interests. This allows analysis to fit the data rather than a pre-determined theory [22]. Analysis considered both explicit and latent meanings, according to the semantic depth of the emerging themes.

SW had worked in the healthcare setting for many years, giving her experience of diabetes consequences and had experience of a family member dying from diabetes complications. These factors developed her interest in diabetes research, particularly

discovering the experiences of managing diabetes and its impacts on QOL. SBR had worked as a Clinical Psychologist within the diabetes team for several years and had experience of treating young people adjusting to their condition. The other authors had no clinical experience with diabetes per se.

Ethics

The study received ethical approval from Bangor University's School of Psychology Ethics Committee and NHS Ethics and Research and Development approval from the local health board (Appendix 5A). AT1D details were accessed at an NHS base using a secure database. Letters were sent out from the NHS base. Participant questionnaires and interviews were transcribed using a code rather than names. All participants signed consent forms and caregivers signed assent forms for those aged under 16. Participants were fully debriefed at the end of their interview. SW was a trainee Clinical Psychologist and used her skills to identify signs of distress. One participant was advised to speak to the psychologist within the diabetes team for diabetes-related stressors, and their GP for general stressors.

Results

Interviews varied in length, with adolescents' interviews typically lasting around 20 minutes, whereas caregivers' interviews lasted 30-40 minutes. Adolescents tended to remain factual in their answers, describing the practicalities of using the device, rather than exploring their experiences on a deeper, more reflective level. Caregivers were more reflective in their answers, for example considering the impact of the device on their quality of life and their relationship with their child. All participants identified as White British; only one participant reported being a single parent.

Young peoples' experiences

Five themes were conceptualised from the data: Practicalities of using the device; Emotional consequences of using the device; Control/Choice; Social implications, and Responsibility. Three themes were divided into subthemes (Table 3).

Practicalities of using device

This theme pertained to the features of the BGM and practicalities of using the device, alongside outcomes for diabetes symptoms and management.

Device

All young people described finding their BGM easy, quick, and convenient to use:

"…now, it's just a check on my phone, so it's a lot better than I expected", YP3

This suggests the ease and convenience of use may have a positive impact on their QOL.

Participants appreciated the features of the BGM such as storing and showing data for a sustained period to view trends in the data. They reported finding this useful as it allowed them to have a continuous source of data, rather than static data at limited timepoints.

"…before this I was used to knowing what my level was when I tested, never in between. I never knew if it was going up or down…I'd inject but it might have been going down really quickly and then I'd end up hypoing", YP2

Participants were able to detect patterns in their BG levels which helped them discover why they typically went out of range, suggesting they valued the importance of understanding their condition more.

Diabetes Outcomes

This subtheme related to the BGM enabling the young people to gain better control of their diabetes, their symptoms, and their diabetes management. This was often discussed in relation to the practical features of the device allowing the patterns in the data to be deciphered.

"…it's explained a lot of things and fixed a lot of issues that wouldn't have been able to be fixed without being able to see, the 8 hours before each scan", YP1

Participants reported learning more about effective diabetes management and efficiency regarding their self-care. Hence, the continuous data and provision of trends provided increased knowledge which seemed to lead to an increased feeling of power and autonomy.

Prior experience

Young people discussed their experiences of their current BGM in relation to previous models of BGM they had used, or previous methods of checking their BG levels. They reported improvements in reliability and size of device from the previous to current BGM model. All young people compared the BGM positively to the pain and inconvenience of finger-pricking to get BG levels. It might be that any improvement on the previous methods would be evaluated favourably.

Emotional consequences of using device

This theme related to young participants' emotional responses to using the device, and the consequences of using it such as questioning from parents or feelings of guilt when they had not used it effectively.

Anxiety

The young people felt the device and its provision of data allowed them to feel less anxious and safer when not with caregivers.

"…when I don't have it on, I do find that I'm a lot more anxious. I almost don't feel as safe without it", YP2

This suggests a level of dependency on the device to feel safe as well as helping with anxiety. Dependence may be an unavoidable consequence of the device being effective in providing readings and alarms notifying participants of potentially dangerous BG levels.

Guilt/shame

One young person felt the ease of use of the device removed some of the stress associated with its use. However, others found the device and its supply of data led to increased 'pressure', revealing times when their levels were out of range.

"Sometimes it can feel more pressuring having all the data there 'cos then you see a lot more of it, so you see the good and the bad bits", YP4

This suggests the availability of data can also be negative, with participants potentially feeling exposed by their data and what it suggests about their diabetes management.

Another participant, using a Libre, suggested a lack of data and trends revealed they had not scanned as often as they should have, leading to feelings of guilt/shame:

"when I forget to scan, I look at my data at the end of the day and it's pretty much empty- then you end up kind of feeling like shit…I should have been scanning and I haven't so now I don't know what's been happening", YP2

This could reflect something specific to the Libre, allowing more potential for making this mistake.

Control/choice

This theme regarded the level of control young people felt they had over the device and choice over how to manage their diabetes. Some felt having the device allowed them a choice about how they managed their diabetes:

"I've got an alarm set for whenever it reaches 3.9. Usually, I wouldn't get symptoms until it's 2.8, but with the alarm going off a bit earlier, it lets me sort it quicker", YP3

Others felt the device allowed them the choice over how much they were preoccupied by their condition:

"...you can just check it and sort of, move on, without having to think about it too much", YP4

It seems use of the devices results in an increased level of power and control. Participants generally felt it gave them control over how soon they would be alerted about their levels, leading to increased control over their diabetes symptoms and outcomes. The device also seemed to enable participants to take time out from worrying about their BG levels.

Social implications of using device

All young people discussed this theme which seemed to be of high importance. They wanted to fit in with peers and appear 'normal' rather than sticking out from the crowd and valued being able to be discreet with their diabetes management.

Fitting in with peers

This was the most common subtheme; young people valued having the freedom and independence to live the same sort of life as their peers.

"'I don't tend to feel like I'm different", YP1

"I didn't mind injections so much, it was the blood tests, cos I'd carry it in my bag, so if I was out with mates and wanted to check my blood glucose I'd have to stop, get it out, and do all this…", YP3

Young people liked that the device and its associated systems, such as being connected to their phone or watch, allowed them to be discreet with diabetes care.

"…if I'm in a lesson I won't be checking my phone constantly, so the notifications coming through on my wrist are fantastic", YP3

It seems the participants valued blending in with peers, which the device facilitated. The device allowed the young people to fit their diabetes management around their life, rather than fitting their life around their diabetes management.

Managing questions from others

This was a subtheme where participants differed in their experiences. Some felt the questions they received from peers were manageable whereas others found the questions more difficult to manage:

"…sometimes you don't want to wear short sleeved tops cos you know you're gonna get questions, or people pointing at it… that can be a bit shit", YP2

It appears the physical presence of the device may highlight the participants' condition and its management practices. It may be that those who had not shared their condition with others found the resultant questioning difficult to manage.

Responsibility

Young people discussed the importance of responsible use of the device to get the most benefit from it and the risk of placing too much responsibility on the device and becoming reliant on it.

"use the facilities…the directional trends of your levels, 24/7, and the alert system to alert if your bloods are high or low…use them effectively, as I found, the more you use them, and change them if your bloods are low all the time or high all the time, it helps", YP1

Participants may recognise the link between the work put into the device, such as reviewing the trends provided, and the outcomes of increased knowledge and power to keep their BG levels within the desired range.

Caregiver experiences

Although analysis of adolescent and caregiver data was conducted separately on the premise that their experiences would differ, caregivers described similar experiences to their children. They discussed similar themes but considered additional aspects (Table 4). For brevity, only new themes/subthemes or those with distinctly different content will be discussed here.

Practicalities of using device

System around the device

As with the young people, parents described the connectivity of the device to their mobile phones as useful, reassuring, and convenient. However, they also described use of the systems around the device as enhancing their experience of the device. These included websites such as Diasend to inform them what the trends in data meant about their child's diabetes control, and the support they receive from the diabetes team and school in using the device more effectively.

It appears caregivers appreciate a systemic approach to managing their child's care and see the importance of enhancing their knowledge.

Emotional consequences of using device

This theme related to how caregivers responded emotionally to their child using a BGM and contained similar subthemes to their children.

Anxiety

Many caregivers described a reduction in anxiety through the device providing continuous data and trends to enable better control of their child's diabetes, and a peace of mind that the device will alert them if their child's BG levels were out of range. It seems the device enables most caregivers to reduce their own alert levels as they appeared to have faith in the device to alert them, particularly at night. Again, this suggests a risk of dependence on the device, which may be an inevitable consequence of the device allowing caregivers to reduce their care tasks overnight.

However, some described feeling increased anxiety due to wanting to get their child's BG level to produce a perfectly lined graph, which they agreed was impossible to achieve:

"To get that line to lie straight is damn near impossible", P5

This suggests the features such as graphs many produce difficulties for caregivers with perfectionist traits.

Frustration

Although parents described reduced anxiety through increased knowledge of their child's BG levels, some also discussed feelings of frustration when they became aware their child's levels were out of range, but their child was not acting to correct it:

"It's frustrating when the alarm goes off and she doesn't take any notice of it at all, she'll just literally carry on playing on her computer game", P5

"I get quite frustrated when she's got the device and she's ignoring it", P4

It seems that the device highlights their child's mismanagement, which may fracture their relationship due to increased frustrations.

Nagging

Following from the previous subtheme, some parents discussed the impact this frustration had on their relationship with their child due to 'nagging' to respond to the device:

"…he got fed up…of me texting 'your blood sugar looks low, are you doing anything?'", P3

"Sometimes it has caused problems where she thinks I'm on her case, but that's because she's not doing what she should be doing with the device", P4

This may mirror a more controlling, authoritarian parenting style in some, where caregivers reported 'taking over' the diabetes care tasks.

However, other parents found that use of the device and its information-sharing features allowed open communication with their child and less nagging:

"…when he got the CGM, it was like manna from heaven because I could see he was alright, I wasn't having to ask him all the time", P3

"If that alarm goes off…we can text her 'do you know that you're low? What are you going to do about it?' and she might say 'I've done something, I've had a jelly baby'", P5

Overall, it seems that the response caregivers take towards knowing their child's current BG level can result in either a positive or negative communication style with their child, impacting on their relationship.

Responsibility

The final theme identified by parents concurred with young people regarding the need to use the device responsibly, however, it appeared to hold more importance with caregivers. They discussed the transition between them holding ultimate responsibility for their child's diabetes and its management, and their child taking responsibility for their own care. Some caregivers suggested the device enabled them to take a step back and allow their child to take on more responsibility:

"I think it gives them the ability to own their Diabetes", P2

Other caregivers found the passing of responsibility to be more of a difficult and flexible transition over time, with more responsibility with the young person at certain times than others:

"I had to give him his own independence, and that was very difficult. I was having to trust he was looking after it and checking his blood sugars", P3

"…sometimes I have to ring the school and say she's really high and she's not picked up on it", P4

Some caregivers talked about needing to maintain some responsibility rather than relinquishing all faith and reliance in the device.

"…if he goes in an area with bad signal, he loses data and then you think, ooh, if he's ok", P1

"At first it's more work for the parent because you're relying on a device to make sure it's working…because you're relying on technology, aren't you?", P4

Some discussed this in relation to them becoming deskilled if they over-rely on the device:

"…Before this came along, I had to trust I would know whenever something was wrong…your phone might break, or the app not work- so you have to be able to do both. You

can't be 100% reliant on it… you'd be completely reliant on the Dexcom and you'd forget how to do it the other way", P3

It seems caregivers oscillate between wanting to have knowledge and control over their child's diabetes care and the need to allow their child to develop skills in autonomous self-care. It appears this manifest as caregivers attempting to pass over responsibility to their child but maintaining access to the data so they can intervene if required. This implies a complex process of learning to trust their child to take responsibility over time. Some caregivers appear to be able to take a gradual approach to their child's increasing independence, whereas others find this more difficult and take over control again. This may lead to adolescents losing faith in their ability to be autonomous with self-care.

Discussion

The results showed both types of BGM are generally well received by young people and their caregivers and have a positive impact on QOL. Young people and their caregivers discussed similar aspects regarding their experiences; they valued the ease and convenience of use and its associated features, and how this impacted on their diabetes outcomes and management. They generally agreed that it had a positive impact on their anxiety although some young people discussed that the availability of data could become pressuring when they had been less adherent with the device. Caregivers and young people also concurred that the device positively impacted the young people's social interactions, allowing them to fit in with peers and feel like a "normal" teenager. However, they differed in the importance they placed on this. Young people prioritised social benefits and being able to be discreet with their diabetes management. Caregivers placed more importance on the consideration of responsibility for the young person's diabetes and transitioning responsibility to their child as

they mature. Caregivers also feared the consequences of relinquishing all control to the device and becoming deskilled in their BG testing practice.

This research partially upholds previous findings that the availability of data has the potential to become distressing for individuals [25]. Some young people viewed the increased data positively through its impact on their knowledge and power to control their diabetes. However, others' views concurred with previous findings that whilst the technology is a great alternative to finger-pricking, as technology developed, so has the intrusion [17]. The adapting technology allows others to link into their BGM data, enabling scrutiny and criticism regarding their readings. Further, it supports findings that adolescents feel guilty about 'bad numbers' and the frustration with friends and family focusing on their diabetes management tasks [26].

Previous research has reported the difficulties experienced by parents regarding the transition of responsibility [27]. Sullivan-Bolyai et al [27] reported that participants suggested the goal was to 'strike a balance but still be in the driving seat' and suggest a gradual transition towards adolescent independence and autonomy, with this transition commencing in the preteen years. Our research showed caregivers often took over control when they felt their child wasn't adhering enough with their self-care. Previous research has suggested this more controlling parenting style can impact adolescents' self-efficacy [28] and may be reinforced by service providers who focus on HbA1c levels at clinic appointments rather than general management behaviours and acknowledging difficulties [27].

Strengths and limitations

Limitations included a disproportionate number of participants using the Libre device and one participant being much younger than the others, reducing the homogeneity of the sample. This limits the ability to generalise the findings.

Additionally, interviews were conducted over the telephone, impacting on the ability to observe body language shown by participants and development of rapport. This may have resulted in the lack of reflection and depth from participants during interviews, who appeared to report more factual than emotional experiences. The interview schedule may also have influenced the participants' responses by inducing shorter, more factual answers. Additional prompter questions focusing on the emotional experiences of participants may have led to longer, more detailed, and reflective responses.

All participants who volunteered to take part reported generally good control and effective diabetes management; it is unknown whether those who chose not to participate had poor experiences with the device or had more difficulties managing their diabetes. Additionally, all participants were from similar ethnic groups and socioeconomic status. The diabetes clinic is within a more diverse area of the health board, suggesting the potential that participants from different socioeconomic groups did not volunteer to take part.

Strengths included the inclusion of experiences from two fathers, as often mothers respond to invitations to feedback experiences of their child's condition, or research targets the experiences of mothers. Therefore, the experiences of fathers are often overlooked or unreported.

While participants remained mostly factual in their responses, SW's position outside the diabetes care team may have enabled participants to give authentic expression of their experiences. This was enhanced by the transcripts and quotes being anonymised.

Clinical and research implications

The overwhelming clinical finding was that BGMs are valued by adolescents and caregivers. Nevertheless, one dyad described difficulty using the Libre, however, there was convergence for the rest of the data. The findings suggest clinicians should consider the impact of how caregivers and clinicians respond to the availability and sharing of data and what conclusions they make about AT1D's management practices. Teams should consider the potential of families becoming over-reliant on the device and deskilled to check their BG level manually should the device fail or be temporarily unavailable.

Additionally, clinicians may discuss with families who will take ultimate responsibility for using the device appropriately, and the process of transition towards adolescent autonomy, particularly in the context of transitioning from paediatric to adult care. They should consider their focus on HbA1c levels on the management styles of parents and how this impacts adolescents' self-efficacy.

From this research, a leaflet is being developed using quotations from the young participants. This will be available during clinics for future young individuals considering using a BGM.

Participants were relatively experienced with their diabetes and appeared to have their condition well managed; future research with young people who have poorer diabetes control is warranted to decipher whether the device is still well received. Additionally, further research with users of the Libre would enable evaluation of the nuances between using a CGM versus a Libre.

Conclusion

This research has shown within the small sample studied that the two BGMs are well received by adolescents and caregivers due to its ease and convenience of use. AT1D reported a positive impact on their socialisation and both adolescents and caregivers found

the provision of data reassuring. However, it is not without drawbacks as it requires responsible use without becoming deskilled in manual practices. Those using the Libre may experience increased pressure through the requirement to scan regularly and potential for increased caregiver interference. This poses future research questions such as the differences in experiences of those using the Libre versus the G6, and the experiences of those newly diagnosed.

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Table 1.

Table 1. Participant descriptions

Participant	Age	Gender	Current device	Age at diagnosis	Years diagnosed	Caregiver relationship
YP1	16	Male	G6 (CGM)	9	7	Mother
YP2	17	Female	Libre	15	2	Mother
YP3	17	Male	G6	2	15	Father
YP4	15	Female	G6	8	7	Mother

YP5	11	Female	G6	6	5	Father

Table 2.

Table 2. Braun and Clarke's six-step model to TA [21,24]

Phase	**Process**	**Examples of steps for each phase**
1	Familiarising oneself with the data	Listening to audiotape of interview; reading transcript; making notes on data; highlighting potential items of interest.

2	Generating initial codes	Development of descriptive and interpretative codes
3	Searching for themes	Reviewing coded data to identify areas of similarity and overlap between codes; identify broad topics or issues around which codes cluster; collapsing or clustering of codes.
4	Reviewing potential themes	Developing themes are reviewed in relation to coded data and entire data set; check themes against collated extracts of data; final reread of all data to determine whether themes meaningfully capture entire data set.
5	Defining and naming themes	Defining what is unique about each theme; summarising essence of each theme; selecting extracts to present and analyse.
6	Producing the report	Writing report to present themes that connect logically, build on previous themes and tell a coherent story about the data.

Table 3.

Table 3. Themes conceptualised from adolescent data

Themes	Subthemes
Practicalities of using device	Device
	Diabetes Outcomes
	Prior Experiences

Emotional consequences of using device	Anxiety Guilt/shame
Choice/control	
Social responses to using device	Fitting in with peers Managing questions from others
Responsibility	

Table 4.

Table 4. Themes conceptualised from parent data

Themes	Subthemes
Practicalities of using device	Device
	Diabetes Outcomes

	Prior experience
	System around the device
Emotional consequences of using device	Anxiety Frustration Nagging
Social implications of using device	Fitting in with peers/living normal life Managing questions from others
Responsibility	

Section 4

Contributions to Theory and Clinical Practice

Contributions to Theory and Clinical Practice

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Introduction

The literature review examined barriers to diabetes management with all aspects of type 1 diabetes care from the adolescents' perspective. Accordingly, it analysed data regarding aspects of self-care such as checking blood glucose levels, counting the

carbohydrate content of meals, administering insulin, and fidelity to exercise and dietary recommendations. Its focus was on the adolescent population due to the difficulties associated with this period of development. The empirical paper also focused on adolescents with type 1 diabetes but aimed to examine the experience of using a relatively new device that measures blood glucose levels without the need for repeated finger-prick testing.

The aim for this paper is to focus further on the underlying research question for this thesis, regarding adolescents' experiences of managing their diabetes. It will explore implications from the literature review and empirical paper regarding theory development, clinical practice and future research.

Implications for theory development

Mismanagement resulting from misinformation, lack of knowledge and resources

Three main theories emerged from this thesis. Firstly, difficulties managing diabetes may be a result of misguided intentions resulting from a lack of knowledge, resources, and support, rather than intentional mismanagement. The findings from the literature review suggested that many young people experience a lack of knowledge and skills regarding diabetes management for several reasons. Some suggested that as they were young at diagnosis, they did not receive the formal training as this was directed to their parent who then took responsibility for diabetes management. This is supported in previous research looking at healthcare providers' level of information sharing with parents and children with diabetes which found information was given to parents of younger individuals rather than the individual themselves (Lochrie, Wysocki, Burnett, Buckloh & Antal, 2008). However, there is little research regarding the impact this has on management behaviours or how to address the issue of a lack of knowledge.

Others reported a lack of resources in the form of appropriate food or money to buy food which is supported by previous research (Hayes-Bohn, Neumark-Sztainer, Mellin & Patterson, 2004). Whilst others reported a lack of support to enable them to complete self-care. For example, some adolescents reported a lack of knowledge by school staff making diabetes management difficult as they had to explain themselves in front of peers. Previous research has reported similar findings with school staff's diabetes awareness lacking and young people not having faith in their teachers to be able to intervene if necessary, with appropriate care (Hayes-Bohn et al., 2004). Melton and Henderson (2007) found that 22% of secondary schools surveyed lacked staff trained about diabetes care.

Others reported being directly prevented from completing diabetes management tasks due to a similar lack of understanding by school staff. Whilst previous research has shown that some students are not allowed to administer their insulin in class (Tang & Ariyawansa, 2007) and students having to adapt their treatment due to a lack of cooperation from school (Bodas, Marin, Amillategui, & Arana, 2008), previous research has not, to our knowledge, indicated a direct obstruction to attempts at self-care by school staff. Nonetheless, lower HbA1c (blood glucose levels) are reported when adequate support is given to students. This suggests that when support is provided at school this has a positive effect on diabetes management and long-term health.

However, previous research has not examined whether this lack of knowledge, resources and support leads adolescents to develop their own theories of diabetes management such as reading their symptoms rather than testing their blood glucose levels manually. Prior research has shown that individuals with non-insulin dependent diabetes may not adhere to taking their medication if they are asymptomatic (Murphy & Kinmonth, 1995), however, research into the mismanagement of type 1 diabetes treatment due to a perceived

lack of symptoms has not been researched. To our knowledge, this is a novel finding worthy of further research.

Purposeful mismanagement through fear of hypoglycaemia

The second theory related to more purposeful mismanagement arising from a fear of hypoglycaemia. This phenomenon is common among individuals with diabetes (Wild, von Maltzahn, Brohan, Christensen, Clouson & Gonder-Frederick, 2007) and has been widely reported in prior research. Scales such as the Children's Hypoglycemic Fear Scale (Kamps, Roberts, & Varela, 2005) have been developed to assess for this. Practices to avoid hypoglycaemia such as refraining from exercise (Brazeau, Rabasa-Lhoret, Strychar, & Mircescu, 2008) and eating more foods high in carbohydrates (Böhme, Bertin, Cosson, Chevalier, & GEODE group, 2013) have been reported. Therefore, the findings from this research add to previous theory regarding the existence of a fear of hypoglycaemia among individuals with diabetes driving them to engage in mismanagement of their condition.

Varying or advanced responsibility expectations leading to burnout and reduced self-efficacy

The third theory related to responsibility expectations and diabetes burnout relating to diabetes management. Specifically, varying responsibility expectations, unexpected and temporary removal of responsibility, and responsibility imposed too soon results in adolescents feeling inadequate to complete diabetes management alone. This may then lead to diabetes burnout or a rejection of responsibility. This theory was noted across both papers within this thesis, suggesting it may be a common difficulty experienced by adolescents with diabetes.

Whilst the concept of diabetes burnout has been developed for many decades (Hoover, 1983; Polonsky, 1999), it has not been studied in relation to feelings of inadequacy as a result of fluctuating or ambiguous responsibility expectations. Recent research looking at sources of diabetes distress among adults with diabetes suggested an association between feelings of inadequacy with self-management tasks and diabetes distress (Fisher et al., 2016). Additionally, research has noted a lack of support as a source of diabetes burnout among adults with diabetes (Abdoli, Hessler, Smither, Miller-Bains, Burr, & Stuckey, 2020). Another recent study reviewing blogs made by individuals with diabetes concurred that diabetes burnout leads to a detachment from diabetes care and occurs in part from the 'demanding life' of diabetes (Abdoli, Jones, Vora & Stuckey, 2019). However, they also attributed it to a response to failing to achieve their desired 'perfect' blood glucose readings and other life stressors. Hence, research into the causes of diabetes burnout has focused on the adult population and has not related the cause to fluctuating or confusing responsibility expectations leading to feelings of inadequacy.

An association has been noted between an increase in responsibility for condition management and a lack of management among adolescents (Miller & DiMatteo, 2013). However, dyadic agreement between parent and child regarding responsibility expectations has been associated with better glycaemic control, but in pre-adolescents (Anderson et al., 2009). Further, the transfer of responsibility from mother to child has been researched as being led by child age, pubertal status and self-efficacy, with a gradual transition regarded as the most effective for adherence (Palmer et al., 2009). However, research regarding fluctuating levels of responsibility expected of the adolescent population has not been reported. Quantitative research using structural equation modelling from measure outcomes has, however, suggested that interference from parents can lead to feelings of inadequacy and defiance among young individuals with diabetes (Goethals et al., 2019). Interference may

relate to parents taking over responsibility unexpectedly or may be in the form of questioning and accusations. Therefore, further research examining the specific relationship between unexpected changes in responsibility expectations and resulting adolescent diabetes management would help elucidate this further.

Implications for clinical practice

Supportive communication to reduce guilt, shame and resentment

The AT1D within the empirical study and the studies reported within the literature review described feelings of shame and guilt regarding their diabetes management. For some, shame resulted from the overt nature of completing diabetes management in public, particularly in front of their peers. For others, the feelings of shame were initiated by communications with others about their management tasks. For example, adolescents reported feeling shame or guilt when attending clinics due to the questioning about their data within the blood glucose monitor. For others this shame was aroused by questioning from their parents. In both situations, adolescents generally reported feeling under attack from those questioning them, which either led to feelings of resentment or such shame that they engaged in avoidance. This took the form of either avoiding clinics altogether or disengaging from the conversations within the clinic appointments. This is supported by a quantitative study that showed a relationship between a more controlling communication style and defiance and disengagement from treatment (Goethals et al., 2019).

Therefore, it seems pertinent to deliver training to healthcare providers and parents regarding supportive communication with AT1D to reduce the likelihood of disengagement. Goethals et al (2019) suggested that when a supportive communication style is used by parents this leads to an increase in internalisation of responsibility among young individuals

with diabetes, resulting in better fidelity. Another quantitative study examining the effects of autonomy-supportive communication styles by both parents and healthcare providers found an improvement in fidelity and supported the need for interventions to increase such skills among parents and providers (Goethals et al., 2020).

Suggestions for assessing responsibility expected of young individuals with diabetes

Following on from the theme of fluctuating responsibility, many adolescents also reported the need for developmentally appropriate levels of responsibility to match their age and adolescent status. Some adolescents related unachievable expectations of responsibility to becoming burnt out and overwhelmed, ultimately resulting in disengagement such as not completing management tasks or passing responsibility to others. Adolescents suggested that responsibility be a transitional process over time to prevent them becoming overwhelmed. Previous research has suggested a need for 'readiness to change' for young adults to become autonomous and compliant with diabetes self-care, and that this is influenced by their level of development (Anderson & Wolpert, 2004). Hanna and Decker (2010) suggest the level of responsibility placed upon adolescents is an individual one which should develop over time. They suggest the level of responsibility placed with adolescents should be assessed by measuring the degree of independence an adolescent has rather than assessing whose role it is to complete and make decisions about diabetes management. Therefore, it seems pertinent to re-evaluate how responsibility levels are determined both in clinic and at home, to ensure responsibility is based on developmental stage and the independence and autonomy levels of individuals.

This can be facilitated by providing training to healthcare teams regarding assessing for independence and barriers to acceptance of responsibility among adolescents, rather than a focus on enforcing the young person takes responsibility at a certain age or within a

specified timeframe. Importantly, an idiosyncratic approach to increased responsibility is required. Healthcare providers can then relay their suitable expectations of responsibility during clinic, for parents to support at home. It is hoped that using a developmentally aware method of assessing adolescents' readiness for change will identify potential barriers to responsibility and, therefore, fidelity. This will encourage a problem-solving approach to the transition to responsibility rather than chastising AT1D for their inability to adhere to treatment, resulting in feelings of shame or defiance, ultimately resulting in further lack of management. This may also support parents and healthcare providers to allow adolescents 'time off' from their diabetes responsibilities during times when they are overwhelmed by other pressures of adolescence such as exams or conflicts with peers. This would be welcomed by AT1D who stated within the empirical research that they desired time off from their responsibilities.

Interventions aimed at increasing acceptance of diagnosis

The literature review revealed that many adolescents go through a stage of denying their condition and rejecting its associated management practices. This supports previous research studying participants across the lifespan who also reported lack of management due to denial of the condition as a result of psychological stress or low health literacy (Hinder & Greenhalgh, 2012). Another study reporting on individuals with diabetes (type not specified) suggested denial occurs for several reasons including not being able to gain good control of their blood glucose levels, the abrupt change in lifestyle resulting from diagnosis, and the stigma associated with a diabetes diagnosis (da Silva, de Souza, Böschemeier, da Costa, Bezerra, & Feitosa, 2018). They also suggested that diagnosis of a chronic condition mirrors the stages of mourning, going through a process of denial before reaching acceptance. Thus,

it seems pertinent to deliver interventions to assist individuals with diabetes with transitioning from a position of denial to one of acceptance.

Various therapies exist, but the two main therapeutic approaches which have been evaluated in research are Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT). CBT examines associations between thoughts, emotions and behaviours in an attempt to break maintenance thought/behaviour cycles that impact on a person's quality of life. CBT has been evaluated as being an effective intervention for managing chronic conditions, particularly in reducing distress and improving self-management (Halford & Brown, 2009; Graham, Gouick, Krahe, & Gillanders, 2016).

Regarding type 1 diabetes, a model of CBT focusing on depression and adherence (CBT-AD) has been developed that is rooted in traditional CBT but adapted to include techniques for people with chronic illnesses (Esbitt, Batchelder, Tanenbaum, Shreck, & Gonzalez, 2015). Markowitz, Carper, Gonzalez, Delahanty and Safren (2012) reported clinically meaningful reductions in depression scores and improvements in treatment adherence, glucose monitoring and blood glucose levels in an adult population with depression and type 1 diabetes who received CBT-AD. Further, when combined with motivational interviewing, CBT has been shown to produce significant improvements in the frequency of blood glucose testing and blood glucose levels in a pilot study with adolescents with type 1 diabetes (Stanger, Ryan, Delhey, Thrailkill, Li, Li, & Budney, 2013).

ACT is a newer form of CBT, regarded as a 'third wave' therapy which focuses on thoughts, but rather than attempting to change faulty thoughts as with CBT, ACT attempts to change the relationship with the thoughts. For example, individuals with diabetes learn to detach from their thoughts and see them as transient events rather than facts. ACT also focuses on individuals' values and maintaining actions that work towards achieving those values. It uses metaphors to describe theories and is a more active approach. It has also been

reviewed to be effective for use with individuals with chronic conditions (Graham, Gouick, Krahe, & Gillanders, 2016; Graham, Simmons, Stewart, & Rose, 2015).

Further, a study examining the use of ACT within a sample of adults with Type 2 diabetes found significant improvements in reported self-care and good satisfaction with the intervention (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007). A study using ACT with children with diabetes aged seven to 15 found reduced perceived stress and increased special health self-efficacy among participants as a result of increased acceptance of their condition (Moazzezi, Moghanloo, Moghanloo, & Pishvaei, 2015). Therefore, both CBT and ACT have shown to be effective in improving individuals' levels of depression, increasing diabetes management behaviours and increasing their level of acceptance of their condition. Use of these interventions among adolescents with diabetes could prove helpful for those disengaging from self-care through denial and rejection of their condition.

Interventions to target fear of hypoglycaemia

As noted previously, adolescents within studies reported in the literature review described deliberate mismanagement of their diabetes due to a fear of becoming hypoglycaemic and experiencing the difficult symptoms associated with it. Published research regarding interventions targeting fear of hypoglycaemia mainly focuses on parents' fears of hypoglycaemia. However, a recent study has evaluated a group education intervention aimed at reducing fear of hypoglycaemia as a barrier to physical activity among adults with type 1 diabetes (Brennan, Brown, Leslie, & Ntoumanis, 2021). The participants reported a reduction in diabetes-specific barriers to physical activity, including a fear of hypoglycaemia, and improved confidence to manage their blood glucose levels. Interestingly, a recent study reported a case study of an adult with type 1 diabetes who received an

intervention that combined the use of a glucose monitor, a symptom record based on techniques used within CBT, and a multimodal group intervention based on ACT (Pontow, Theil, & Diefenbacher, 2020). Like the adolescents within the literature review studies, the participant changed their diabetes care practices due to their fear of hypoglycaemia. The authors found that the participant learned to differentiate their symptoms of anxiety from those resulting from their low blood glucose levels.

Whilst research has not been conducted on the use of CBT or ACT to treat fear of hypoglycaemia specifically, it seems that these interventions may hold promise based on the above case study. Further, CBT is a commonly used intervention for individuals with phobias, with specific models and interventions having been developed for phobias such as social phobia (Huppert, Roth, & Foa, 2003). CBT has also been reported to result in changes in neural activity among adults with a phobia of spiders (Paquette et al., 2003). Therefore, clinicians within diabetes teams may wish to consider delivering interventions such as CBT to treat the fear of hypoglycaemia that adolescents describe as being an important factor in their lack of fidelity to diabetes treatment protocol.

Consideration of AT1D relying on intuition to guide management practices

Finally, clinicians may wish to consider the findings from the literature review that adolescents do not adhere to their diabetes regime, particularly checking their blood glucose levels or counting carbohydrates, as they believe that they are able to use their intuition to guide whether their blood glucose levels are out of range and, therefore, whether to administer insulin. Whilst it appeared that many adolescents had been able to rely on intuition without major negative effects in the short-term, there is evidence to suggest that their actions are not without long-term effects. Research examining the symptoms of hyperglycaemia found that 90% recognised symptoms, suggesting that 10% did not (Warren, Deary, & Firer,

2002). The authors also found that symptoms were more likely to be reported at lower blood glucose levels in participants with normal awareness of hypoglycaemia. This suggests that those with an impaired awareness of hypoglycaemia were also at risk of not recognising the signs of hyperglycaemia as quickly as those without impaired awareness.

A review looking at unawareness of hypoglycaemia found a prevalence rate of between 19-25% among individuals with type 1 diabetes and identified risk factors such as increasing age and duration of diabetes (Graveling & Frier, 2010). Further, they reported associated risks such as declines in cognitive ability, severe hypoglycaemia, and even death. Additionally, research has suggested that factors influencing unawareness of hypoglycaemia include internal factors such as denial and symptom beliefs, and external factors such as distraction and substance use (Firer, 2014). Therefore, it seems pertinent to provide education and training to adolescents believing that they will instinctively know their blood glucose levels, and therefore if they are becoming hyper- or hypoglycaemic, to prevent its serious consequences.

Implications for future research

In addition to the implications for research noted within the theory development section above, several additional implications were noted. All participants in the empirical study had been diagnosed with diabetes for several years and had experience of managing the condition with a less technologically advanced device which was often larger and less accurate. Many had experience of managing their diabetes using only finger-prick tests which was described as painful, inconvenient, and time-consuming. Thus, participants had a negative prior experience to compare their current BGM to, possibly creating a more positive view of the BGM. Future research with newly diagnosed AT1D with no prior

knowledge or experience of other methods of blood glucose monitoring would identify whether the devices are well received in the absence of negative prior experiences.

Similarly, all study participants reported generally well controlled diabetes and good management. It is unknown whether participants with poor diabetes outcomes or difficulties with diabetes management would evaluate the device in a similar, positive manner. Future research with AT1D who report struggling with diabetes management and/or blood glucose levels that frequently fall outside of the recommended range is warranted.

Finally, participants within the study were not homogenous with regards to the device they were describing. Only one participant was using a Libre device which requires multiple daily scans, and they reported feelings of guilt and shame when they had forgotten to scan their device. It is unclear whether this was an idiosyncratic experience, or one common to many Libre users. Further research with AT1D using the Libre would clarify this research question and identify any nuances between the two main types of device used within this population. Any common difficulties experienced by users of one device over the other might suggest the promotion of the favoured device to support a preserved quality of life for young individuals using a blood glucose monitoring device.

Reflections

Conducting research during a global pandemic was challenging on a number of levels. There was less physical support in the form of research workshops and the opportunity to discuss issues with supervisors in person when the opportunity arises. This was further compounded by increased restrictions placed on the methodology. For example, the lockdown imposed in March 2020 led to a cessation in working from NHS bases unless

absolutely necessary. Therefore, interviews needed to be conducted via telephone instead of the preferred method of face to face. This led to a reduction in rapport-building as the researcher was unable to use their clinical skills to encourage engagement such as smiling at participants and offering supportive gestures and body language when participants were discussing difficult topics. The researcher reflected that this may have led to a superficial level of data collection whereby participants remained factual, rather than reflective allowing for a more interpretive analysis.

However, the researcher also reflected on the positive aspects of conducting research during a pandemic and lockdown. It may be that some participants opened up more over the telephone as they were not inhibited by the pressure of speaking to a stranger in person about difficult personal experiences. Similarly, the younger participants may be more comfortable with telephone communication as this is often a common method of communication amongst young people. Further, being under lockdown meant a removal of time spent commuting for work, providing more time in the day to focus on research. Additionally, the researcher was not required to book rooms for interviews which resulted in timely data collection within a period of two weeks.

The researcher reflected on the methodological challenges of evaluating an intervention, such as the use of a medical device, within the adolescent population. These included potential difficulties with recruitment to the study, as there was a response rate of 11%, which may have been higher than usual due to caregiver interest from the advert, encouraging the young people to take part. There was then a difficulty in getting the young people engaged enough within the interview to be able to reflect on their own experiences to a deeper level than the factual experiences they described. Again, this may be influenced by their developmental age. Dewey (1933) suggests reflection is a complex, intellectual and emotional undertaking that requires time to develop to do well.

The researcher also reflected that the dyadic design worked well in order to elucidate convergence and divergence between the experiences of adolescents and their caregivers as a whole. However, further, detailed exploration of the nuances within the dyads may have been helpful if there had been the space within the paper to analyse and report on this.

Conclusions

The literature review and empirical paper have highlighted important issues that AT1D face when trying to manage their diabetes. The literature review highlighted the lack of research into AT1D's descriptions of barriers to diabetes management, with research either focusing on caregivers' and service providers' ideas, or on correlative studies using restrictive measures. The review highlighted nuances between deliberate mismanagement and non-intentional mismanagement as a result of other factors such as a lack of knowledge and skills. I believe an important finding regarding deliberate mismanagement due to a fear of hypoglycaemia is worthy of consideration within the clinical setting, rather than chastising young individuals for their lack of diabetes management.

However, the empirical paper revealed promising insights into the use of glucose monitoring technology to aid some of the difficulties experienced by young people in managing their diabetes. Although some issues were discussed in relation to the responses from others to their data. It is hoped that the findings from this study will aid the development of supportive communication training for service providers and family members to reduce the feelings of guilt experienced by young people when their data reveals they have not been managing, allowing open discussions about barriers instead. Finally, it is hoped that future research will focus more on adolescents' experience, allowing services to be tailored to consider the issues relevant to them today.

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Section 5

Appendices

Appendix 5A.

Approvals and permissions

Ethical approval granted for 2020-16744 'Blood glucose monitoring technology and me': paediatric patient and caregiver perspectives

E

ethics@bangor.ac.uk
Tue 26/05/2020 11:12

To:

- Sophia Williams

Dear Sophia,

2020-16744 'Blood glucose monitoring technology and me': paediatric patient and caregiver perspectives

Your research proposal number 2020-16744
has been reviewed by the School of Psychology Ethics and Research Committee
and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

NHS
Health Research Authority

Qualitative Protocol Development Tool

This protocol has regard for the HRA guidance and order of content

FULL/LONG TITLE OF THE STUDY

'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.

SHORT STUDY TITLE / ACRONYM

'Blood glucose monitoring device and me'

PROTOCOL VERSION NUMBER AND DATE

0.1 May 2020

RESEARCH REFERENCE NUMBERS

IRAS Number: 282995

SPONSORS Number:

FUNDERS Number:

NHS
Health Research Authority

SHORT TITLE/ACRONYM

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: Date:
...../...../.....

.....

Name (please print):

.....

Position:

.....

Chief Investigator:

Signature: Date:
...../...../.....

.....

Name: (please print):

.....

LIST of CONTENTS

KEY STUDY CONTACTS

Chief Investigator	Dr Renee Rickard, r.rickard@bangor.ac.uk, 01248 383778
Principal Investigator	Sophia Williams. Seu8ae@bangor.ac.uk, 07885 621176
Sponsor	Huw Ellis, Huw.ellis@bangor.ac.uk, 01248 383229
Joint-sponsor(s)/co-sponsor(s)	
Funder(s)	
Key Protocol Contributors	Sophia Williams, Renee Rickard
Committees	

STUDY SUMMARY

It may be useful to include a brief synopsis of the study for quick reference. Complete information and, if required, add additional rows.

Study Title	'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.
Internal ref. no. (or short title)	'Blood glucose monitoring device and me'
Study Design	Qualitative study using Interpretative Phenomenological Analysis.
Study Participants	Paediatric patients, aged 10-18, under the care of the Diabetes team who have been using a blood glucose monitoring device for at least 6 months. One parent/caregiver for each patient participant.
Planned Size of Sample (if applicable)	3-7 patient-parent pairs, giving a total of 6-14 participants.
Follow up duration (if applicable)	N/A
Planned Study Period	August 2020 – August 2021
Research Question/Aim(s)	The objective for this research is to determine whether the blood glucose monitoring technology used by diabetic patients to monitor their blood glucose levels is acceptable to patients and carers. When considering acceptability, this is regarding quality of life, and is not concerned with how effective the technology is for diabetic control.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations	**FINANCIAL AND NON FINANCIALSUPPORT**

providing funding and/or support in kind for this study)	**GIVEN**
	None

ROLE OF STUDY SPONSOR AND FUNDER

The study sponsor is Bangor University. The principal investigator is a doctorate student at Bangor University, completing the DClinPsy. This research is part of their thesis and as such is sponsored by Bangor University. The student receives supervision and guidance from the university, including the Chief Investigator, Dr Renee Rickard.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

None

PROTOCOL CONTRIBUTORS

The North Wales Clinical Psychology Programme research team have approved the study protocol. They give guidance regarding the study design and feasibility. From there, Dr Renee Rickard, acting as academic supervisor, assists (through supervision) with study design, data analysis and interpretation, and manuscript writing. Dr Sarah Bailey-Rogers, acting as clinical supervisor, assists in study design, conduct, sample collection, and development of interview questions. Dissemination will be supported by the programme and Dr Renee Rickard. It is hoped that an information leaflet will be designed using the words from participants (with consent) that can be given to future paediatric patients to help them understand the journey they may go on from a service user's perspective. Although the research project is part of the Principal Investigator's thesis, and therefore they have the final decisions on aspects of the study, they will be strongly supported by the programme to make these decisions.

KEY WORDS: Paediatric; patient; diabetes; blood glucose monitor; treatment

STUDY FLOW CHART

Month	Activity
February 2020	Project design finalisation NWCPP approval
	Ethics proposal/IRAS initiation
May 2020	School of Psychology, Bangor University Ethics proposal/IRAS initiation
	Await approval
June 2020	NHS ethics submission
July 2020	Await approval
August 2020	Participant recruitment
September 2020	Participant interviews
October 2020	Participant interviews
November 2020	Type up interview transcripts
December 2020	Type up interview transcripts
January 2021	Data Analysis- initial coding
February 2021	Data Analysis- initial coding
March 2021	Data analysis- themes/categories
April 2021	Data interpretation

May 2021	Thesis Draft Submission
	Await feedback
	Complete amendments
	Thesis Deadline
June 2021	Thesis VIVA

SHORT TITLE/ACRONYM

STUDY PROTOCOL

'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.

1 BACKGROUND

Diabetes is a serious, life-long condition that requires many adjustments to the patient's life and that of their caregivers (NICE, 2016; Pintus & Ng, 2019). It occurs when blood glucose levels become elevated because the body is unable to metabolise it. Type 2 diabetes is where the body does not produce enough insulin, and is usually managed by diet changes, weight loss, smoking cessation, and oral medication. Type 1 diabetes results from an auto-immune response where the pancreas stops producing insulin altogether. Therefore, insulin needs to be provided through multiple injections per day. This in turn requires the patient to monitor their blood glucose (BG) level, and adjust the amount of insulin administered accordingly. Strict control of patients' BG level is required to prevent short and long-term complications, such as kidney failure, blindness, heart disease, stroke and amputation (National Paediatrics Diabetes Audit (NPDA), 2019).

Type 1 diabetes is more common among children and young people, and the UK has the highest prevalence of children and young people with Type 1 diabetes in Europe (Lacobucci, 2013), with 28,300 children and young people with Type 1 diabetes in England and Wales (NPDA, 2019). Additionally,10,800 children and young people were admitted to hospital in the year from 2014 to 2015, with over 90% of admissions for those with Type 1 diabetes (NPDA, 2017). Increased admission rates were noted in females and adolescents, particularly for Diabetic Ketoacidosis (DKA) not related to initial diagnosis (NPDA, 2017). A further finding was a 64% increased risk for DKA admissions (not related to initial diagnosis) for children and young people who had been diagnosed 3-9 years prior to the audit (NPDA, 2017). Teens are notorious for rebelling against the diabetes regime which can have dire consequences for their long-term health (Zhang et al., 2018); specifically, adolescents have the lowest adherence rates for BG monitoring (Miller et al., 2015). This is unsurprising given the huge commitment diabetes management has on their lives, including the requirement to attend the diabetes clinic at least 4 times per year, where their BG levels and overall diabetes management will be scrutinised, they are advised to have something on their person that notifies others of their medical condition, and they are required to complete at least 5 capillary BG tests per day (NICE, 2016).

BG monitoring technology was introduced as a way to attempt to ease the distress and commitment of multiple finger-prick BG tests per day (Campbell, Murphy, Stewart, Biester, & Kordonouri, 2018; NICE, 2017). Although patients are still required to conduct finger-prick BG tests daily, this is dramatically reduced when using BGM technology.

The technology was initially reviewed to be a great alternative, but as technology developed, so did the intrusion (Adolffson, Parkin, Thomas & Krinelke, 2018).

Two main types used in Betsi Cadwaladr University Health Board (BCUHB)- continuous glucose monitors (CGM) and the FreeStyle Libre Flash (Libre for short). The Libre measures the interstitial fluid and is applied to the skin, usually the upper arm. It is a small disc that contains a flexible fibre that is inserted around 5mm into the skin, which is described as painless. BG levels are automatically measured every minute and stored at 15-minute intervals for up to 8 hours. They can be read at any time by scanning the sensor with the reader, which can be done over the clothes. The reader is rechargeable and must be recharged every 7 days. A mobile app can also be used to store BG level data. The Libre does not provide real-time continuous BG monitoring, or a hypoglycaemia alarm (NICE, 2017). The benefits of the Libre are that they can provide readings for periods when the patient is not scanning, for example when they are sleeping, and it does not require calibration with the patient's blood samples (NICE, 2017).

CGMs differ in that they offer real-time BG levels continuously, with alarms that operate if the patient becomes hypoglycaemic (where the BG levels become too low). They are offered to patients who have frequent, severe hypoglycaemia, are unable to recognise the serious nature of the consequences, and/or who may be unable to recognise and communicate their symptoms. This includes neonates and pre-school aged children, and children and young people who participate in high levels of physical exercise (NICE, 2019). Libre were initially self-funded, but in BCUHB in 2018 they became NHS-funded (are therefore more widely available and used). CGM remains provided if patients fulfil the NICE guidance criteria stated above. Although the addition of alarms may seem of benefit, research suggests frequent false alarms can lead to 'alarm fatigue', whereby patients ignore the alarms or turn them off altogether (Adolfsson et al., 2018).

Previous research has determined that BGM technology is an effective tool for BG monitoring and control, and is generally tolerated. The Libre received more positive reviews with improvements in quality of life (QOL; Edge et al., 2017; Al Hayek, Robert and Al Dawish, 2017), however, research regarding this particular BG technology is limited and therefore caution must be taken regarding its conclusions. CGM technology is also considered 'generally acceptable', with no negative impacts on QOL (Diabetes Research in Children Network, 2006; Hommel et al., 2014). Joubert and Reznik (2012) reported that after 26 weeks of CGM use, most parameters of QOL remained unchanged. Therefore, this suggests there are no improvements in QOL either. Kashmer and colleagues (2009) noted downsides to CGM including skin irritation and excessive alarms. Further, the adapting technology allows for others to link in to their BGM data, opening up to the possibility of further scrutiny and criticism regarding their readings. Markowitz and colleagues (2012) support this, finding youth on CGM showed higher anxiety than youth using the traditional BG monitoring practices. Additionally, the increased level of data can become overwhelming for patients (Markowitz et al., 2012) and caregivers alike (Kashmer et al., 2009). Parents with increased worry regarding their child's diabetes control completed more BG checks per day and were more likely to want CGM (Kashmer et al., 2009), suggesting a possible link between parent anxiety and CGM use. Previous research has focused on patients' views, with some interviews of caregivers. One paper noted caregivers' views regarding the

patient's QOL were vastly different to patients', suggesting incongruence between their perceived benefits of the technology (Diabetes Research in Children Network, 2006).

BGM technology is expensive (for example the FreeStyle Libre is £57.95 for the reader, plus another £57.95 for the disposable sensor which must be replaced fortnightly; NICE, 2017).As such, much research has included HbA1c measures (blood glucose levels) to determine whether the technology is effective at monitoring BG levels, and therefore warrants the costs. However, this research wants to keep away from the medical implications of the technology and focus solely on patients' and caregivers' experience of using the technology. With this in mind, a qualitative approach will be used in the form of Interpretative Phenomenological Analysis, as this will allow for researchers to determine participants' experiences in a natural, unstructured way. This research hopes to add to previous research findings regarding the acceptability and quality-of-life effects of using BG technology, particularly following the introduction of the Libre being provided by the NHS in recent years.

It is hypothesised that the initial benefits to diabetes control may dwindle as burden is realised over time. It is also hypothesised that patient and caregiver perceptions may differ vastly, which will have implications regarding educating patients and caregivers on open communication to ease mutual understanding of the experience of BG technology.

2 RATIONALE

Blood glucose monitoring technology is relatively novel and is adapted at a fast pace. Previously available to patients who self-funded, it has become available on the NHS within the health board within the past 2-3 years. Previous research has suggested the technology is effective for diabetes control but has not considered quality of life comprehensively. The limited studies that examine the quality of life impact suggest no negative impacts, but also suggest no positive impacts. Diabetes management adherence amongst adolescents is notoriously lower, which is why we wanted to look at this population. Some of the limited previous research looking at the technology asks about parent views, and we believe it is useful to discover whether patients and parents have differing views. As the technology is still new, it may be that initial reviews of the technology were met with overly positive responses, as it was a new and improved method of collecting blood glucose data (rather than multiple finger pricks per day). However, now that the technology is becoming more widely used and people are getting used to it, they may be more able to look at the negative impacts on quality of life. This information would be useful for care providers to know, so that they can be proactive regarding barriers to the technology. It may also allow care providers to advise parents about the potential negative aspects of the technology. On the other hand, if the response is mostly positive, this will provide useful support for the technology being not only effective medically, but also for improving patient and carer quality of life.

3 THEORETICAL FRAMEWORK

Aim: To describe the theoretical framework for the study.

- A clear explanation of the proposed approach and why it is suitable to address the gaps outlined in the BACKGROUND section.
- Briefly outline a system of concepts, from published literature, that frames your study.
- Can be presented either visually or textually.

4 RESEARCH QUESTION/AIM(S)

The objective for this research is to determine whether the blood glucose monitoring technology used by diabetic patients to monitor their blood glucose levels is acceptable to patients and carers. When considering acceptability, this is regarding quality of life, and is not concerned with how effective the technology is for diabetes control.

4.1 Objectives

The objective for this research is to determine whether the blood glucose monitoring technology used by diabetic patients to monitor their blood glucose levels is acceptable to patients and carers. When considering acceptability, this is regarding quality of life, and is not concerned with how effective the technology is for diabetes control. As a secondary objective, we would like to see whether or not the views of patients and caregivers differ, and whether the views differ amongst patients of different ages.

4.2 Outcome

We would like to determine if the blood glucose monitoring technology is acceptable to patients and caregivers when considering their quality of life and wellbeing.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

This research seeks to find out whether blood glucose monitoring technology has an impact on patient and carer quality of life. The null hypothesis would be that the technology has no effect on quality of life. The alternative hypothesis is that the technology can impact on quality of life.
The research will use qualitative analysis in the form of interpretative phenomenological analysis. This method has been chosen as it revolves around gaining knowledge about a participant's experience of a particular aspect of their life. It allows for minimal intervention from the researcher, so than an unbiased view of someone's experience can be gathered.

July-August/September will be the recruitment phase. Patients will be given an information leaflet about the study when they attend diabetes clinic. The leaflet will contain the researchers' contact details for any questions. If COVID-19 prevents clinics from running, the leaflet will be sent out in the post to all patients that meet the criteria (have used the technology for a period of at least 6 months). The leaflet will also explain that we would like to learn about caregivers' experiences, so will be asking to interview a parent too. Therefore, for either a parent or patient to take part, the other would also have to take part. If more than one parent wishes to take part, random selection will determine who will participate. We hope to recruit 3-7 pairs (6-14 participants in total). This number will be sufficient to gain a significant amount of data, hopefully reach saturation (no new information being gathered from subsequent interviews), and not be too much data to be overwhelming within the time frame.

October-February will be the participant interview phase. Participants will be invited to attend an NHS location convenient to them, including the diabetes clinic location if preferred. They will be asked to complete a short questionnaire regarding diabetic quality of life. This will take around 10-15 minutes. The participants will then do the semi-structured interview with the researcher. This will involve around 5 questions and take up to an hour. This interview will be audio recorded (with consent). If COVID-19 prevents face to face interviews then recorded telephone interviews will be conducted with the same timeframe. The short questionnaire could be completed over the telephone on the same day as the interview, or via post.

March-April would be the data analysis phase, with May being the report writing phase. Data analysis will be primarily carried out by the PI, under the supervision of the two supervisors. This will assist in determining researcher bias by looking to achieve similar results among the PI and supervisors. One supervisor is not part of the diabetes team and therefore has no vested interest in the research results going in any particular way. The data will be coded after transcription, with codes then analysed for themes. Between-participant comparisons will be made between the two primary groups: patients and carers. Transcripts will be stored on a secure NHS computer, and audio recordings will be deleted as soon as transcribed. For ease of analysis, the transcripts may be printed for coding. If this occurs, the printed transcripts will be stored in a locked drawer in a secure NHS building.

6 STUDY SETTING

The participant interviews will take place at an NHS base convenient to participants, including the clinic that they normally attend for diabetes management/care. This is to relieve any additional stress to participants, by meeting at a place convenient to them. If COVID-19 prevents this, telephone interviews will be conducted and recorded. The PI will be at a secure NHS building, using an NHS telephone should this occur. Data transcription and analysis by the PI will occur at a secure NHS building, local to the PI.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

Participants will be selected from the Child Health Diabetes Clinic. A lower age boundary is 10, and upper age boundary of 18. Patients are required to have been using blood glucose monitoring technology for a period of at least 6 months. A parent/caregiver of selected children will also be selected, so there will be a patient and parent pair. Where more than one parent wishes to take part, random selection will identify the parent to take part. There is no upper age limit for parents.

7.1.1 Inclusion criteria

Patients: Male or female, between the age of 10-18, diabetic patient using blood glucose monitoring device for at least 6 months. Any SES and ethnicity.

Parent/carer: Male or female, any age, has a child who fits eligibility criteria and is taking part in the study. Any SES and ethnicity.

7.1.2 Exclusion criteria

Patient: outside of age range, does not use a blood glucose monitoring device/has not used one for a period of at least 6 months.

Parent/carer: does not have a child participating in the study, does not have knowledge of their child's blood glucose monitoring device use.

Unfortunately, as the PI and CI do not speak Welsh, participants wishing to conduct the interview in Welsh (or any other language other than English) will be excluded.

7.2 Sampling

Convenience sampling will be used by advertising the study to eligible paediatric patients and their caregivers who attend their regular diabetes clinic. Interested participants will need to be in patient-parent pairs. If more than one parent is interested, random selection will determine who takes part. If more than 14 participants wish to take part, random selection will determine who takes part.

7.2.1 Size of sample

We hope to recruit 3-7 pairs (6-14 participants in total). This number will be sufficient to gain a significant amount of data, hopefully reach saturation (no new information being gathered from subsequent interviews), and not be too much data to be overwhelming within the time frame.

7.2.2 Sampling technique

Convenience sampling will be used by advertising the study to eligible paediatric patients and their caregivers who attend their regular diabetes clinic. Interested participants will need to be in patient-parent pairs. If more than one parent is interested, random selection will determine who takes part. If more than 14 participants wish to take part, random selection will determine who takes part. This number will be sufficient to gain a significant amount of data, hopefully reach saturation (no new information being gathered from subsequent interviews), and not be too much data to be overwhelming within the time frame.

7.3 Recruitment

Eligible participants who attend Diabetes Clinic will be given details of the study and asked if they wish to take part. Interested participants will be given the participant information sheet detailing the study and their rights, and contact details for the researcher, should they have questions prior to agreeing to take part.

7.3.1 Sample identification

The diabetes team already holds an electronic database which includes information regarding their name, age, date of diabetes diagnosis, and how long they have been on the blood glucose monitoring technology. This will be accessed by Dr Sarah Bailey-Rogers (Clinical Psychologist based within the paediatric diabetes team) to identify potential participants. No medical records will be examined. Suitable patients will then be sent the participant information sheet about the study in the post (If COVID-19 is preventing face to face clinics), or given out at clinic. This sheet will explain the nature of the study and that a parent is also being requested for participation. Therefore, interested parent participants will be self-selected. If more than one parent wishes to take part, random selection will identify the parent to take part. Participants will be given a £20 amazon gift card for taking part in the study, as a payment of gratitude for their time.

7.3.2 Consent

A participant information sheet and introductory leaflet describing the study will be given/sent out to potential participants. This will detail what is expected from them as a participant, and what their rights are (for example, to leave the study at any time and that if their participation/non-participation will have no effect on the care they receive). We don't expect to be seeking consent from any vulnerable group. Gillick competence will be employed to determine whether patients have capacity to consent to participate in the study. If people have not indicated their choice after 2 weeks, contact will be made again via post. If a participant indicates they are uncertain after asking questions, a period of one week will be given for participants to consider the study. Information leaflets will be adapted to be age appropriate. They will also include contact details for participants to ask verbal questions. If the diabetes clinic is still running (if COVID-19 is not preventing it), then the PI or their supervisor can be available during some clinics to describe the study and answer questions in person. Information sheets, consent forms and debrief sheets will be available in English and Welsh.

8 ETHICAL AND REGULATORY CONSIDERATIONS

This research is not expected to raise any significant risk of harm to the participants or researchers. However, this research may be the first time that paediatric patients have been given the opportunity to discuss their experiences of using the technology, and this may bring up some feelings they didn't realise they had. If this should occur, participants will be advised to speak to their GP, or given the option to talk to Dr Sarah Bailey-Rogers, the clinical psychologist within the diabetes team.

Mild physical discomfort may arise as a result of sitting and being interviewed for up to an hour. Should this become apparent, participants will be offered a break to walk around.
There is a small risk that patients may have differing views to their parents which could cause conflict. For this reason, and to aid in the free discussion, patients and parents will be interviewed separately and not be told the content of each other's interview. Participant quotations will be made non-identifiable before publication, with participant consent. Finally, if COVID-19 is preventing face to face contact then the interviews would be telephone recorded instead with participant consent. This will be done from a secure NHS building and could potentially occur while the researcher is alone in the building. However, the researcher is familiar with the building and the lone worker policy within it.

No management issues are envisaged as the clinical supervisor works within the team and the whole team are on board with the research project. The clinical supervisor has granted permission to use the site.

The PI will be working within the ethical obligations of their role in the NHS.

8.1 Assessment and management of risk

This research is not expected to raise any significant risk of harm to the participants or researchers. However, this research may be the first time that paediatric patients have been given the opportunity to discuss their experiences of using the technology, and this may bring up some feelings they didn't realise they had. If this should occur, participants will be advised to speak to their GP, or given the option to talk to Dr Sarah Bailey-Rogers, the clinical psychologist within the diabetes team.

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No management issues are envisaged as the clinical supervisor works within the team and the whole team are on board with the research project. The clinical supervisor has granted permission to use the site.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

The study has received initial approval from the North Wales Clinical Psychology programme, of which the researcher is a doctoral student. The study will then receive approval from the School of Psychology's ethics committee, at Bangor University. The study will then gain approval from NHS REC, and R&D concurrently.

- Substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement at site.
- All correspondence with the REC will be retained.
- The Principal Investigator will notify the REC of the end of the study.

Regulatory Review & Compliance

Before any site can enrol patients into the study, the Principal Investigator will ensure that appropriate approvals from participating organisations are in place. Specific arrangements on how to gain approval from participating organisations are in place and comply with the relevant guidance.

For any amendment to the study, the Principal Investigator, in agreement with the sponsor will submit information to the appropriate body in order for them to issue approval for the amendment. The Principal Investigator will work with sites (R&D departments at NHS sites as well as the study delivery team) so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

Amendments

Any ammendments to the protocol will be agreed with the study sponsor (Bangor University) and comply with the regulations set out below regarding NHS involvement:

For studies involving the NHS:

If the sponsor wishes to make a substantial amendment to the REC application or the supporting documents, the sponsor must submit a valid notice of amendment to the REC for consideration. The REC will provide a response regarding the amendment within 35 days of receipt of the notice. It is the sponsor's responsibility to decide whether an amendment is substantial or non-substantial for the purposes of submission to the REC.

Amendments also need to be notified to the national coordinating function of the UK country where the lead NHS R&D office is based and communicated to the participating organisations (R&D office and local research team) departments of participating sites to assess whether the amendment affects the NHS permission for that site. Note that some amendments that may be considered to be non-substantial for the purposes of REC still need to be notified to NHS R&D (e.g. a change to the funding arrangements).

The Principal Investigaor will be responsible for communicating any ammendments to all parties involved- Bangor University school ethics committee, NHS REC and R&D.

8.3 Peer review

The study protocol has been reviewed and approved by the North Wales Clinical Psychology Programme. The data analysis and manuscript will be reviewed by the Principal Investigator's two supervisors, the Cis (clinical psychologists).

8.4 Patient & Public Involvement

The research involves patient and carer participants, and as such involves members of the public for data sourcing. However, they are not involved in any other aspects of the research. Nonetheless, it is hoped that a leaflet will be produced using participant quotes, which will be given to subsequent patients beginning blood glucose monitoring technology. In this sense, members of the public may be involved in some aspect of the dissemination of the findings.

8.5 Protocol compliance

Accidental protocol deviations can happen at any time. They will be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

8.6 Data protection and patient confidentiality

Patient confidentiality requirements will be adhered to as per the Data Protection Act 1998 and GDPR requirements.

Personal data will be in the form of participant names on the consent forms. If these are paper copies they will be kept in a locked file in a secure NHS building. If COVID-19 prevents face to face contact, then the consent forms will be created electronically and stored on a secure NHS computer in a password protected document.
Participants will be assigned a code which will be on the pre-interview questionnaire, instead of the participant name. The audio recordings will be transferred to a secure NHS computer immediately and then deleted from the audio recorder. This will be the case regardless of whether the interviews are

conducted face to face and audio recorded, or over the telephone and recorded through a secure telephone-recording system. An NHS telephone within a secure NHS building would be used. The recordings will then be deleted from the computer on completion of the research project (after 3 months). Transcripts of audio interviews will be anonymised and participants codes used instead. Any identifiable information will be removed before publication. Any direct quotations published in the report will be under a pseudonym with prior consent from the participant.

Personal data will be in the form of participants' names on the consent form. This will be reviewed by only the principal investigator and academic supervisor if necessary. This is also the case for the audio recordings/transcripts. No access to medical records is required for the purpose of the study. Recruitment will begin by viewing a database of patients kept by the diabetes team. This will be done to screen for potential participants that meet inclusion criteria. As this database is held by one of the supervisors, this information will not be viewed by anyone outside of the research team. The consent form will include an option to consent to having their quotations anonymously published as a result of the research. Participants will have the option to decline this aspect of consent.

Audio recordings of the interviews will be transferred to a secure NHS computer and deleted from the audio recorder. It will then be typed into a transcript by the principal investigator using the secure NHS computer in a secure NHS building. The word document will be password protected and the audio file deleted from the computer. The transcript may then be printed for ease of analysis (for themes). If this is done, the paper files will be stored in a locked file within a secure NHS building. This will be done by the principal investigator. The academic supervisor may view the transcripts if the principal investigator requires assistance with analysis. This would occur using a secure NHS computer within the university building.

The audio recordings will be deleted from the computer once they have been transcribed. Transcripts of the audio recorded interviews will be stored on a secure NHS computer within a secure NHS building until the study has been written up and assessed and the Viva passed. The Viva is expected to take place in June 2021. Therefore, it is expected that the data will be deleted from the NHS computer soon after this date (by the start of July 2021).

8.7 Indemnity

The North Wales Clinical Psychology Programme, Bangor University, holds the relevant insurance for this study.

8.8 Access to the final study dataset

The principal investigator will be responsible for analysing the data and writing the manuscript and will therefore have access to the final study dataset. The Cis (two supervisors named previously) will review the data analysis and manuscript and offer guidance. Therefore, they too may have access to the final study dataset to ensure validity of findings by the principal investigator.

9 DISSEMINIATION POLICY

9.1 Dissemination policy

This research is part of a Clinical Psychology Doctoral degree, and as such, will remain the property of Bangor University. The aim is for the research manuscript to be published in a relevant research journal. The manuscript will also be available in Bangor University's library of theses projects. Study participants

will be given the option to receive a summary of the research findings on study completion. It is also hoped that an information leaflet using the study findings will be developed and made available to future paediatric diabetes patients. This will be made available at diabetes clinics across the health board. The study dataset will not be made available for public viewing.

9.2 Authorship eligibility guidelines and any intended use of professional writers

The principal investigator will be granted authorship of the final study, alongside the Cis, Dr Renee Rickard and Dr Sarah Bailey-Rogers.

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11. APPENDICIES

11.1 Appendix 1- Required documentation

CVs of research team.

Participant information sheets- separate ones for younger patients, adolescent patients, and parents/carers.

Consent form.

Debrief sheets- separate ones for younger patients, adolescent patients, and parents/carers.

Indemnity insurance certificate.

11.2 Appendix 2 – Schedule of Procedures

Month	Activity
February 2020	Project design finalisation NWCPP approval
	Ethics proposal/IRAS initiation
May 2020	School of Psychology, Bangor University Ethics proposal/IRAS initiation
	Await approval
June 2020	NHS ethics submission
July 2020	Await approval
August 2020	Participant recruitment
September 2020	Participant interviews
October 2020	Participant interviews
November 2020	Type up interview transcripts
December 2020	Type up interview transcripts
January 2021	Data Analysis- initial coding
February 2021	Data Analysis- initial coding
March 2021	Data analysis- themes/categories
April 2021	Data interpretation
May 2021	Thesis Draft Submission
	Await feedback

	Complete amendments
	Thesis Deadline
June 2021	Thesis VIVA

13.3 Appendix 3 – Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

List details of all protocol amendments here whenever a new version of the protocol is produced.

Protocol amendments must be submitted to the Sponsor for approval prior to submission to the REC.

Appendix 5B.

Images

Libre

Image taken from https://www.freestylelibre.co.uk/libre/

CGM

Image taken from https://www.usmed.com/blog/types-of-cgm-system/

Appendix 5C.

Research Documents

Young Person Interview Schedule

Please tell me what is has been like to use your blood glucose monitoring device?

What did you think life would be like being on a device ? Was this how it actually was?

Has there been anything particularly good or bad about being on a blood glucose monitor?

How does it feel to use the device ? (Eg safe, different, uncomfortable).

Did your feelings and/or experience of using the device change over time?

Finally, what advice would you give to other young people who are about to start using a blood glucose monitoring device ?

Adolescent (16-18) Interview Schedule

Please describe your experiences of using your blood glucose monitoring device.

What were your expectations when you started using the device ? How did these differ to your actual experiences ?

What has been helpful or unhelpful about using the device?

How does it feel to use the device ? (Eg safe, different, trapped, being attached to the device).

Did your feelings and/or experience of using the device change over time?

Finally, what would your advice be to anyone else going on it?

Caregiver Interview Schedule

Please describe your experiences of your child using a blood glucose monitoring device.

What were your expectations when your child started using the device ? How did these differ to your actual experiences ?

What has been helpful or unhelpful about using the device?

How does it feel to have your child using the device ? (Eg safe, less anxious, more anxious).

Did your feelings and/or experience of your child using the device change over time?

Finally, what would your advice be to other parents whose child is about to start using a blood glucose monitoring device ?

GIG CYMRU NHS WALES
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PRIFYSGOL BANGOR UNIVERSITY

Dear Patient,

We are writing to you to see if you would like to take part in our study. We are looking at paediatric Diabetes patients' and their parent's or carer's views of using blood glucose monitoring technology. You have got this letter because you are a patient at the child Diabetes clinic.

This is an exciting opportunity for you to tell us what life using the technology is like so that we can learn more about it. We would give you a £20 amazon gift card to thank you for your time.

If you think you would like to take part, please take a look at the information sheet. If you are still interested after taking a careful look at the information sheet, you can ask your parent to contact us to let us know.

We will also be asking your parent what life is like with a child using a blood glucose monitoring device, so we would be asking both of you questions separately. This means that you would both need to agree to take part for either of you to take part. You can talk to each other to help you decide if you want to take part.

We only need 3 or 4 patients and 3 or 4 parents to take part. If more people than this want to take part, we will choose the pairs (a patient and their parent) randomly.

If you do not want to take part, you do not need to do anything, and it will not change the care you get from the Diabetes team.

Take care,

Dr Sarah Bailey-Rogers Sarah.bailey-rogers@wales.nhs.uk
Supervising Sophia Williams seu8ae@bangor.ac.uk
Trainee Clinical Psychologist/Principal Investigator for this research

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

PRIFYSGOL BANGOR UNIVERSITY

Dear Patient,

We are writing to you to invite you to take part in a piece of research that we are doing. We are looking at paediatric Diabetes patients' and their parent's or carer's views of using blood glucose monitoring technology. You are receiving this letter because you are a patient at the child Diabetes clinic. This is an exciting opportunity for you to share your experiences with us so that we can learn more about what life using the technology is like. We would give you a £20 amazon gift card as a way of thanking you for your time.

If you are interested in taking part, please take a look at the participant information sheet enclosed. If you are still interested after taking a careful look at the information sheet, you can contact me on the email address below. If you don't have email, you can let the Diabetes team know that you are interested, and they will ask me to contact you. As we are looking at patients views as well as their parent or carer's views, both you and your parent/carer would be taking part. This means that both of you would need to agree to taking part for either of you to be able to take part. Please feel free to discuss this amongst yourselves to decide if you both want to take part.

We only need 3-4 patients and 3-4 parents to take part in the study. If more people than this want to take part, we will choose the patient-parent pairs randomly.

If you do not wish to take part, you do not need to do anything, and it will not affect the care you receive from the Diabetes team.

Take care,

Dr Sarah Bailey-Rogers Sarah.bailey-rogers@wales.nhs.uk
Supervising Sophia Williams seu8ae@bangor.ac.uk
Trainee Clinical Psychologist/Principal Investigator for this research

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University Health Board

PRIFYSGOL BANGOR UNIVERSITY

Dear Parent/carer,

We are writing to you to invite you to take part in a piece of research that we are doing. We are looking at paediatric Diabetes patients' and their parent's or carer's views of using blood glucose monitoring technology. You are receiving this letter because your child is a patient at the child Diabetes clinic. Your child has also received their own version of this letter.

This is an exciting opportunity for you to share your experiences with us so that we can learn more about what life using the technology is like. We would give you a £20 amazon gift card as a way of thanking you for your time.

If you are interested in taking part, please take a look at the participant information sheet enclosed. If you are still interested after taking a careful look at the information sheet but have some questions you want answering before you decide, you can contact me on the email address below. If you don't have email, you can let the Diabetes team know that you are interested, and they will ask me to contact you.

As we are looking at patients views as well as their parent or carer's views, both you and your child (who uses a blood glucose monitoring device) would be taking part. Therefore, you would both need to consent to be taking part in the study for either of you to be able to take part. Please feel free to discuss this amongst yourselves to decide if you both want to take part. We are looking to recruit 3-4 patients and 3-4 parents/carers; if more than this number show interest, we will select 3-4 pairs at random.

If you do not wish to take part, you do not need to do anything, and it will not affect the care you receive from the Diabetes team.

Take care,

Dr Sarah Bailey-Rogers Sarah.bailey-rogers@wales.nhs.uk
Supervising Sophia Williams seu8ae@bangor.ac.uk
Trainee Clinical Psychologist/Principal Investigator for this research

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University Health Board

PRIFYSGOL BANGOR UNIVERSITY

Annwyl Glaf,

Rydym yn ysgrifennu atoch i weld a hoffech chi gymryd rhan yn ein hastudiaeth. Rydym yn edrych ar farn cleifion 'Diabetes pediatreg' a barn eu rhiant neu eu gofalwr ar ddefnyddio technoleg monitro glwcos yn y gwaed. Mae'r llythyr hwn gennych oherwydd eich bod yn glaf yn y clinig Diabetes plant.

Mae hwn yn gyfle cyffrous i chi ddweud wrthym sut beth yw bywyd gan ddefnyddio'r dechnoleg fel y gallwn ddysgu mwy amdano. Byddem yn rhoi cerdyn rhodd amazon gwerth £20 i chi i ddiolch i chi am eich amser.

Os ydych chi'n meddwl yr hoffech chi gymryd rhan, edrychwch ar y daflen wybodaeth. Os oes gennych ddiddordeb o hyd ar ôl edrych yn ofalus ar y daflen wybodaeth, gallwch ofyn i'ch rhiant gysylltu â ni i roi gwybod i ni.

Byddwn hefyd yn gofyn i'ch rhiant sut beth yw bywyd gyda phlentyn yn defnyddio dyfais monitro glwcos yn y gwaed, felly byddem yn gofyn cwestiynau i'r ddau ohonoch ar wahân. Mae hyn yn golygu y byddai angen i'r ddau ohonoch gytuno i gymryd rhan i'r naill neu'r llall ohonoch gymryd rhan. Gallwch chi siarad â'ch gilydd i'ch helpu chi i benderfynu a ydych chi am gymryd rhan.

Dim ond 3 neu 4 claf a 3 neu 4 rhiant sydd eu hangen arnom i gymryd rhan. Os yw mwy o bobl na hyn eisiau cymryd rhan, byddwn yn dewis y parau (claf a'i riant) ar hap.

Os nad ydych am gymryd rhan, nid oes angen i chi wneud unrhyw beth, ac ni fydd yn newid y gofal a gewch gan y tîm Diabetes.

Cofiwn cynes,

Dr Sarah Bailey-Rogers Sarah.bailey-rogers@wales.nhs.uk
Goruchwylio Sophia Williams seu8ae@bangor.ac.uk
Seicolegydd Clinigol dan Hyfforddiant / Prif Ymchwilydd ar gyfer yr ymchwil hon

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PRIFYSGOL BANGOR UNIVERSITY

Annwyl Glaf,

Rydym yn ysgrifennu atoch i'ch gwahodd i gymryd rhan mewn darn o ymchwil yr ydym yn ei wneud. Rydym yn edrych ar farn cleifion 'Diabetes pediatreg' a barn eu rhiant neu eu gofalwr ar ddefnyddio technoleg monitro glwcos yn y gwaed. Rydych chi'n derbyn y llythyr hwn oherwydd eich bod chi'n glaf yn y clinig Diabetes plant. Mae hwn yn gyfle cyffrous i chi rannu eich profiadau gyda ni fel y gallwn ddysgu mwy am sut beth yw bywyd gan ddefnyddio'r dechnoleg. Byddem yn rhoi cerdyn rhodd amazon gwerth £ 20 i chi fel ffordd o ddiolch i chi am eich amser.

Os oes gennych ddiddordeb mewn cymryd rhan, edrychwch ar y daflen wybodaeth cyfranogwyr sydd wedi'i hamgáu. Os oes gennych ddiddordeb o hyd ar ôl edrych yn ofalus ar y daflen wybodaeth, gallwch gysylltu â mi ar y cyfeiriad e-bost isod. Os nad oes gennych e-bost, gallwch roi gwybod i'r tîm Diabetes fod gennych ddiddordeb, a byddant yn gofyn imi gysylltu â chi. Gan ein bod yn edrych ar farn cleifion yn ogystal â barn eu rhiant neu ofalwr, byddech chi a'ch rhiant / gofalwr yn cymryd rhan. Mae hyn yn golygu y byddai angen i'r ddau ohonoch gytuno i gymryd rhan er mwyn i'r naill neu'r llall ohonoch allu cymryd rhan. Mae croeso i chi drafod hyn ymysg eich gilydd i benderfynu a yw'r ddau ohonoch eisiau cymryd rhan.

Dim ond 3-4 claf a 3-4 rhiant sydd eu hangen arnom i gymryd rhan yn yr astudiaeth. Os yw mwy o bobl na hyn eisiau cymryd rhan, byddwn yn dewis y parau cleifion-rhieni ar hap.

Os nad ydych am gymryd rhan, nid oes angen i chi wneud unrhyw beth, ac ni fydd yn effeithio ar y gofal a gewch gan y tîm Diabetes.

Cofiwn cynes,

Dr Sarah Bailey-Rogers Sarah.bailey-rogers@wales.nhs.uk
Goruchwylio Sophia Williams seu8ae@bangor.ac.uk
Seicolegydd Clinigol dan Hyfforddiant / Prif Ymchwilydd ar gyfer yr ymchwil hon

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PRIFYSGOL BANGOR UNIVERSITY

Annwyl Riant / gofalwr,

Rydym yn ysgrifennu atoch i'ch gwahodd i gymryd rhan mewn darn o ymchwil yr ydym yn ei wneud. Rydym yn edrych ar farn cleifion 'Diabetes pediatreg' a barn eu rhiant neu eu gofalwr ar ddefnyddio technoleg monitro glwcos yn y gwaed. Rydych chi'n derbyn y llythyr hwn oherwydd bod eich plentyn yn glaf yn y clinig Diabetes plant. Mae'ch plentyn hefyd wedi derbyn ei fersiwn ei hun o'r llythyr hwn.

Mae hwn yn gyfle cyffrous i chi rannu eich profiadau gyda ni fel y gallwn ddysgu mwy am sut beth yw bywyd gan ddefnyddio'r dechnoleg. Byddem yn rhoi cerdyn rhodd amazon gwerth £ 20 i chi fel ffordd o ddiolch i chi am eich amser.

Os oes gennych ddiddordeb mewn cymryd rhan, edrychwch ar y daflen wybodaeth cyfranogwyr sydd wedi'i hamgáu. Os oes gennych ddiddordeb o hyd ar ôl edrych yn ofalus ar y daflen wybodaeth ond bod gennych rai cwestiynau yr ydych am eu hateb cyn i chi benderfynu, gallwch gysylltu â mi ar y cyfeiriad e-bost isod. Os nad oes gennych e-bost, gallwch roi gwybod i'r tîm Diabetes fod gennych ddiddordeb, a byddant yn gofyn imi gysylltu â chi.

Gan ein bod yn edrych ar farn cleifion yn ogystal â barn eu rhiant neu ofalwr, byddech chi a'ch plentyn (sy'n defnyddio dyfais monitro glwcos yn y gwaed) yn cymryd rhan. Felly, byddai angen i'r ddau ohonoch gydsynio i gymryd rhan yn yr astudiaeth er mwyn i'r naill neu'r llall ohonoch allu cymryd rhan. Mae croeso i chi drafod hyn ymysg eich gilydd i benderfynu a yw'r ddau ohonoch eisiau cymryd rhan. Rydym yn edrych i recriwtio 3-4 o gleifion a 3-4 o rieni / gofalwyr; os yw mwy na'r nifer hwn yn dangos diddordeb, byddwn yn dewis 3-4 pâr ar hap.

Os nad ydych am gymryd rhan, nid oes angen i chi wneud unrhyw beth, ac ni fydd yn effeithio ar y gofal a gewch gan y tîm Diabetes.

Cofiwn cynes,

Dr Sarah Bailey-Rogers Sarah.bailey-rogers@wales.nhs.uk
Goruchwylio Sophia Williams seu8ae@bangor.ac.uk
Seicolegydd Clinigol dan Hyfforddiant / Prif Ymchwilydd ar gyfer yr ymchwil hon

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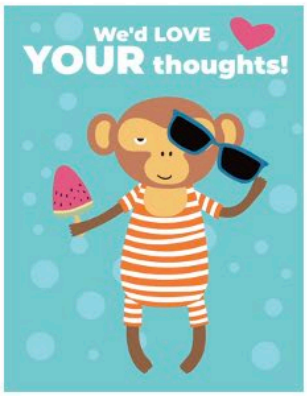
PRIFYSGOL BANGOR UNIVERSITY

We would like to hear from you!



/

Study Title:
'Blood glucose monitoring device and me'.

We would like to ask whether you and one of your parents would be interested in taking part in a research study.
It is really important that you understand what the study is about, why we are doing the study, and what it would involve for you before you decide whether to take part or not.
Please read this sheet carefully for more information, and as any questions you have if anything isn't clear. You are welcome to email me using either email address at the end of this sheet or ask a member of the Diabetes Team to let me know that you would like me to contact you. Thank you for reading this.

Why are we doing this research?

We are looking at what young people and their parents think about using blood glucose monitoring devices (eg. Libre or CGM device). We want to understand what using this technology is like for you and your family. We will not be looking at your diabetes control.

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What would we ask you to do?

We would like to ask you a few questions about what your life is like using your blood glucose monitoring device. You can have as much time as you need to answer the questions, but to give you an idea, we don't think it will take longer than an hour. There are no right or wrong answers and it is not a test. Separately, we would also like to ask your parent the same questions.

If you are happy to take part, we would ask you the questions on your own so that you can say everything that you want to. Also, to take part, both you and a parent would need to say yes to you taking part. As we are interviewing patients and their parent, both you and a parent would need to want to take part for either of you to be able to do it.

We will also ask you to complete a short Diabetes questionnaire (PedsQL). You may have seen this before.

**Due to COVID-19, we will not be able to do the interviews face to face, so we would like to interview over the telephone instead. We will be doing the interviews at a time that suits you, during September-October 2020.*

If you decide to take part in the study, the process will look a bit like this:

Decide to take part

- Let us know you want to take part and we'll send out a consent form
- You sign consent form
- Parent signs consent form
- Return form to us in stamped envelope

Do the interview

- Complete the PedsQL Diabetes questionnaire over the phone
- Do the interview over the phone (maximum 1 hour)

See the results?

- If you would like to see the results of the study, we can send them to you by post when they are ready

Why have you been asked to take part?

We are asking all children and young people between the age of 10 and 18 who have been using a blood glucose monitoring device for at least 6 months if they would like to take part. You would be one of at least 6 people, a mixture of patients and their parent, helping us with this study.

Do you have to take part?

No, you do not have to take part if you do not want to and it will not change anything about the care you get from the Diabetes team if you take part or not. You can stop the questions and choose not to take part at any point, and that's OK! If you choose to leave the study, any information you have already given will be destroyed and not used in the research.

What are the benefits of taking part?

We hope this research will let us know what it is like for children and young people with Type 1 Diabetes to use a blood glucose monitoring device. We hope this will make it easier to tell new patients what using the technology is like. We would also give you a £20 amazon gift card for taking part in the study.

What are the risks of taking part?

We don't think there are any risks to taking part, but we know that this might be the first time you have talked about what life is like using the technology and this may bring up some feelings you didn't realise you had. If this happens, we would talk to you about talking to your medical team, GP or Paediatric Clinical Psychologist about your feelings. If you have any concerns about the study itself that you do not wish to raise with the researcher or Diabetes team, you can ask your parent to email the research manager at Bangor University: huw.ellis@bangor.ac.uk.

Will the information you give be kept private?

Yes. We will make sure that your name is not on any of the scripts that we type up from the interview. Anything that would make it clear that it is you answering the questions would be taken out before publishing the findings.

How will we do the interview and keep it safe?

This research is being done by a Clinical Psychology student at Bangor University (Sophia Williams). Sophia is being supervised by Dr Sarah Bailey-Rogers, the Psychologist you usually see at clinic. Sophia will be doing the interview with you. As we will be asking your parent the same questions, we will be asking them not to be in the room during your interview. However, if there is another parent or adult that you would like in the room with you, then that is OK. We want to listen to everything you say so we'll record the interview. The recording will be kept safely on a password protected computer. Any paper files will be locked away.

**Due to COVID-19, we would like to interview you over the telephone and record the interview through the telephone. This will be done using secure software and an NHS telephone.*

What will happen to the results of the study?

As Sophia is also a student at Bangor University, the research paper will be marked by the university. Sophia Williams will be typing up the interviews so that she can analyse your answers to see what important things you are saying. Anything with your personal details on will be kept securely by Dr Sarah Bailey-Rogers (Sophia's supervisor) for 3 years. Anything without your personal information on (that comes from this study) will be kept securely by Dr Sarah Bailey-Rogers for 10 years. It will then be destroyed.

The research paper could be published in a journal at a later date so that more people can understand how children and young people feel about using blood glucose monitoring devices. If you agree, we may like to use the words you have said in the research paper. If we did this, we would make sure that no one knows it is your words, by changing the name or using a code name.

We would like to make a leaflet using the information you give that can be given to new patients to help them prepare for using a blood glucose monitoring device.

What do I need to do now?

If you do not want to take part, simply do nothing! If we do not hear from you, we will assume you do not wish to take part and that's OK!

But if you would like to take part or ask any questions to help you decide, please contact either Sophia (the researcher) or Dr Sarah Bailey-Rogers. You can do this by asking your parent to email us on:

Seu8ae@bangor.ac.uk *for Sophia Williams*

Sarah.bailey-rogers@wales.nhs.uk *for Dr Sarah Bailey-Rogers*

If you email us to ask questions or let us know you want some time to think about it, we will give you a reminder after two weeks of you contacting us to check whether you would like to take part or not.

As we are interviewing only 3 or 4 patient-parent pairs, we may have more people interested than we can interview. If this happens, we will select the pairs at random. We will contact you by email to let you know whether or not you have been selected to take part.

If you do decide to take part and you are one of the patient-parent pairs randomly selected, we will send out a consent form for you to sign to say that you are happy to take part. Your parent will also need to sign this to say they are happy for you to take part, and they will also sign their own form to say they are happy to do their own interview. There will be a stamped envelope for you to send this back to us. As none of the research team speak Welsh, the interview will be done in English.

Thank you,

Sophia Williams
Trainee Clinical Psychologist

Being supervised by Dr Sarah Bailey-Rogers, Paediatric Clinical Psychologist, and Dr Renee Rickard, Clinical Psychologist.

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Study Title:
'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.

We would like to ask you to take part in a research study, sponsored by Bangor University. Please read this sheet for more information. You are welcome to email me using the email address at the end of this sheet or ask a member of the Diabetes team to let me know that you would like me to contact you.

We are looking at what young people and their parents think about using blood glucose monitoring devices (eg. Libre or CGM device). We want to understand what using this technology is like for you and your family. We will not be looking at your diabetes control.

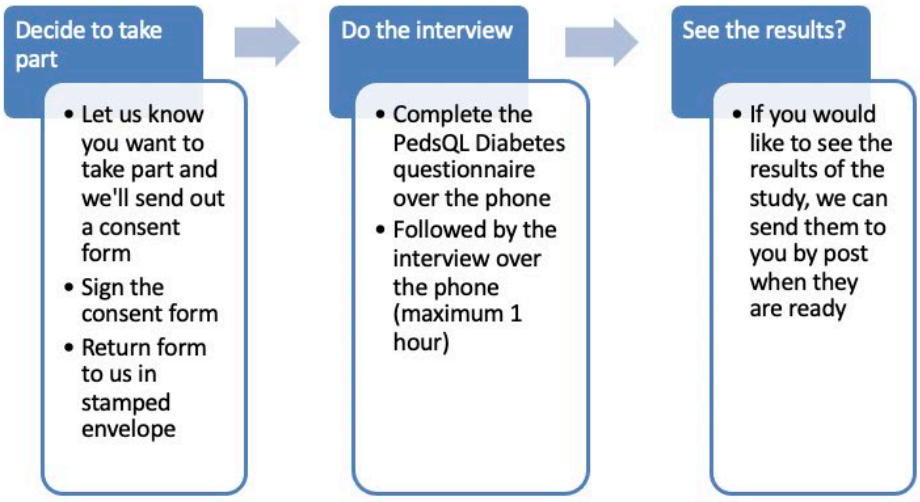
What would we ask you to do?

We would like to ask you a few questions about what your life is like using your blood glucose monitoring device. You can have as much time as you need to answer the questions and there are no right or wrong answers. To give you an idea, the interview will take up to an hour at most. Separately, we would also like to ask your parent the same questions. If you are happy to take part, we would ask you the questions on your own so that you can say everything that you want to. As we are interviewing patients and one of their parents, both of you would have to want to take part for either of you to be able to take part.

We will also ask you to complete a short Diabetes questionnaire (PedsQL) which you may have seen before.

**Due to COVID-19, we will not be able to do the interviews face to face, so we would like to interview over the telephone instead. We will be doing the interviews at a time that suits you, during September-October 2020.*

If you decide to take part in the study, the process will look like this:



Why have you been asked to take part?

We are asking all children and young people between the age of 10 and 18 who have been using a blood glucose monitoring device for at least 6 months if they would like to take part.

Do you have to take part?

No, you do not have to take part if you do not want to and it will not change anything about the care you get from the Diabetes team if you take part or not. You can stop the questions and choose not to take part at any point, and that's OK! If you choose to leave the study, any information you have already given will be destroyed and not used in the research.

What are the benefits of taking part?

We hope this research will let us know what it is like for young people with Type 1 Diabetes to use a blood glucose monitoring device. We hope this will make it easier to tell new patients what using the technology is like. We would also give you a £20 amazon gift card for taking part in the study.

What are the risks of taking part?

We don't think there are any risks to taking part, but we know that this might be the first time you have talked about what life is like using the technology and this may bring up some feelings you didn't realise you had. If this happens, we would talk to you about talking to your medical team, GP or Paediatric Clinical Psychologist about your feelings. If you have any concerns about the study itself that you do not wish to raise with the researcher or Diabetes team, you can direct them to the research manager at Bangor University: huw.ellis@bangor.ac.uk.

Will the information you give be kept private?

Yes. We will make sure that your name is not on any of the scripts that we type up from the interview. Anything that would make it clear that it is you answering the questions would be taken out before publishing the findings.

How will we do the interview and keep it safe?

This research is being done by a Clinical Psychology student at Bangor University (Sophia Williams). Sophia is being supervised by Dr Sarah Bailey-Rogers, the Psychologist you usually see at clinic. Sophia will be doing the interview with you. As we will be asking your parent the same questions, we will be asking them not to be in the room during your interview. However, if there is another parent or adult that you would like in the room with you, then that is OK.
We want to listen to everything you say so we'll record the interview. The recording will be kept safely on a password protected computer. Any paper files will be locked away.

**Due to COVID-19, we would like to interview you over the telephone and record the interview through the telephone. This will be done using secure software and an NHS telephone.*

What will happen to the results of the study?

As Sophia is also a student at Bangor University, the research paper will be marked by the university. Sophia Williams will be typing up the interviews so that she can analyse your answers to see what important things you are saying.

Anything with your personal details on will be kept securely by Dr Sarah Bailey-Rogers (Sophia's supervisor) for 3 years. Anything without your personal information on (that comes from this study) will be kept securely by Dr Sarah Bailey-Rogers for 10 years. It will then be destroyed.

The research paper could be published in a journal at a later date so that more people can understand how young people feel about using blood glucose monitoring devices. If you agree, we may like to use your words in the research paper. If we did this, we would make sure no one knows it is you, by changing the name or giving you a code name.

We would like to make a leaflet using the information you give that can be given to new patients to help them prepare for using a blood glucose monitoring device.

What do I need to do now?

If you do not want to take part, simply do nothing! If we do not hear from you, we will assume you do not wish to take part and that's OK!

But if you would like to take part or ask any questions to help you decide, please contact either Sophia (the researcher) or Dr Sarah Bailey-Rogers via email on:

Seu8ae@bangor.ac.uk *for Sophia Williams*

Sarah.bailey-rogers@wales.nhs.uk *for Dr Sarah Bailey-Rogers*

If you email us to ask questions or let us know you want some time to think about it, we will give you a reminder after two weeks of you contacting us to check whether you would like to take part or not.

As we are interviewing only 3 or 4 patient-parent pairs, we may have more people interested than we can interview. If this happens, we will select the pairs at random. We will contact you by email to let you know whether or not you have been selected to take part.

If you do decide to take part and you are one of the patient-parent pairs randomly selected, we will send out a consent form for you to sign to say that you are happy to take part. Your parent will also sign their own form to say they are happy to do their own interview. There will be a stamped envelope for you to send this back to us. Regrettably, none of the research team speak Welsh, so the interview will be done in English.

Thank you.

Sophia Williams
Trainee Clinical Psychologist under the supervision of Dr Sarah Bailey-Rogers, Clinical Psychologist

A note on GDPR

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

How will we use information about you?

We will need to use information from you for this research project. This information will include your initials. People will use this information to do the research. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information by asking one of the research team.

Who can I contact if I have a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer. The research team can give you details of the right Data Protection Officer.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

Participant Information Sheet- Parent/Caregiver

Study title

'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.

Invitation and brief summary

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to take part.

We are looking at children and young people with Type 1 Diabetes and their caregivers' experiences of using a blood glucose monitoring device (eg Libre or CGM device). We want to understand what using this technology is like for patients, and also the impact it can have on the family as a whole. We recognise that there is a difference between technology being effective for medical purposes, and its impact on quality of life and wellbeing.

What would taking part involve?

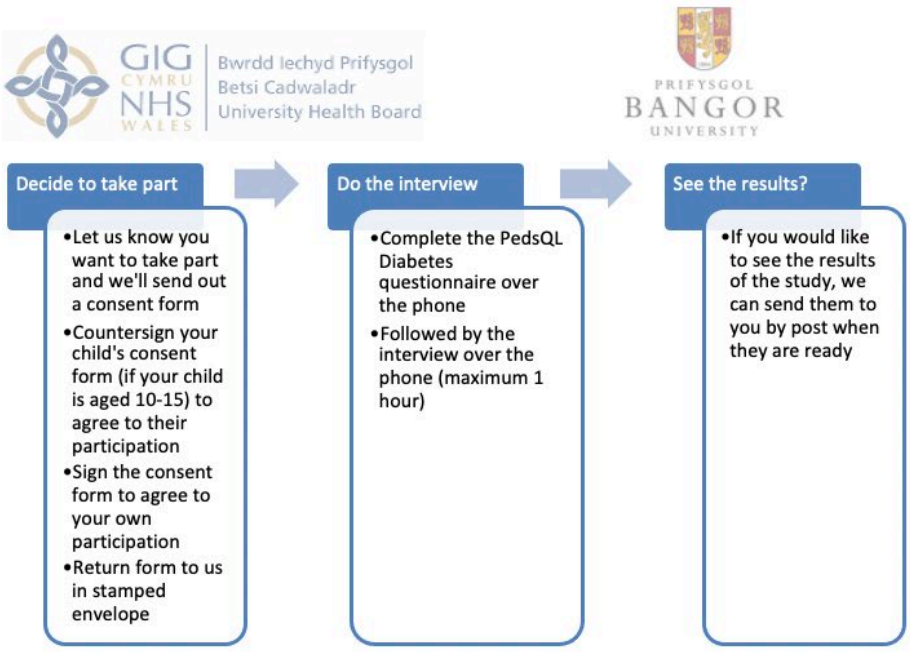
We would like you to take part in a single interview with a researcher. We will ask minimal questions to allow you to explain your views on using the device without interruption or too much guidance in any particular direction. We will be conducting the interviews over the telephone at a time that suits you. We will be interviewing young patients and also one of their caregivers/parents. The interviews will be done separately so that you are free to discuss anything you feel is important about using blood glucose monitoring technology.

We will also ask participants to complete a short Diabetes questionnaire (PedsQL) looking at your quality of life and wellbeing.

There is no set time for the interviews, you can have as long as you need to tell us about your experiences of the technology. However, we envisage that it will take no longer than an hour.

**Due to COVID-19, we will not be able to do the interviews face to face, so we would like to interview over the telephone instead. We will be doing the interviews at a time that suits you, during September-October 2020.*

If you decide to take part in the study, the process will look like this:



Why have you been asked to take part?

We are asking all children and young people between the age of 10 and 18 who have been using a blood glucose monitoring device for at least 6 months if they would like to take part.
We are also asking for a parent/caregiver of the child/young person to take part. For younger patients the caregiver will also be required to consent to their child's participation in the study.

Do you have to take part?

No, you do not have to take part if you do not want to and it will not change anything about the care you and your family get from the Diabetes team if you take part or not. All participants are free to leave the study at any time without any repercussions. If you choose to leave the study, any information you have already given will be destroyed and not used in the research.

What are the possible benefits of taking part?

Your participation in this research will tell us about any potential difficulties patients and caregivers experience when using a blood glucose monitoring device, which can then be considered when preparing new patients for using the technology. It will also help us understand how the device can impact other areas of your life and quality of life and wellbeing. We hope that this will make it easier for patients and their families to discuss any difficulties with staff. Similarly, this research will help service providers understand the benefits of the technology so that this can be explained to new patients.

What are the possible disadvantages and risks of taking part?

There are no expected severe risks with taking part in this research. However, we recognise that this may be the first time someone has given you the space to talk about your experience, and this may bring up some feelings you didn't realise you had. If this should occur, we would give you advice about what to do next, such as talking to the medical team, your GP, or Paediatric Clinical Psychologist linked with the Diabetes team. If you have any concerns about the study itself that you do not wish to raise with the researcher or Diabetes team, you can direct them to the research manager at Bangor University: huw.ellis@bangor.ac.uk.

Will the data you give be kept confidential?

Yes. All data will be anonymised before analysis, and no identifying information will be published. Anything that would make it clear that it is you answering the questions would be taken out before publishing the findings. We will not share the results of any pre-interview questionnaires with your GP or anyone else but may advise you to contact your GP if the questionnaire reveals anything of concern.

How will the data you provide be recorded, stored and protected?

This research is being done by a Clinical Psychology student at Bangor University (Sophia Williams). Sophia is being supervised by Dr Sarah Bailey-Rogers, the Psychologist you usually see at clinic. Sophia will be doing the interview with you. As we will be asking your child the same questions, we will be asking them not to be in the room during your interview, so that you are both able to speak freely during your interviews.

We want to listen to everything you say so we'll record the interview. The audio files will be stored on a password protected computer and any paper files will be stored in a locked cabinet.

**Due to COVID-19, we would like to interview you over the telephone and record the interview through the telephone. This will be done using secure software and an NHS telephone.*

What will happen to the results of the study?

As Sophia is also a student at Bangor University, the research paper will be marked by the university, but all confidentiality measures will be applied. Sophia Williams will be typing up the interviews so that she can analyse your answers to see what important things you are saying. Anything with your personal details on will be kept securely by Dr Sarah Bailey-Rogers (Sophia's supervisor) for 3 years. Anything without your personal information on (that comes from this

study) will be kept securely by Dr Sarah Bailey-Rogers for 10 years. It will then be destroyed.

The research paper could be published in a journal at a later date so that more people can understand how children and young people and their caregivers feel about using blood glucose monitoring devices. If you consent, we may like to use your words in the research paper. If we did, we would anonymise it so that no one knows it is you.

It is hoped that an information leaflet will be developed as a result of this research that can be given to new patients and caregivers as an aid to preparing them for using a blood glucose monitoring device.

What do I need to do now?

If you do not want to take part, simply do nothing! If we do not hear from you, we will assume you do not wish to take part and that's OK!

But if you would like to take part or ask any questions to help you decide, please contact either Sophia (the researcher) or Dr Sarah Bailey-Rogers via email on:

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Sarah.bailey-rogers@wales.nhs.uk *for Dr Sarah Bailey-Rogers*

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As we are interviewing only 3 or 4 patient-parent pairs, we may have more people interested than we can interview. If this happens, we will select the pairs at random. We will contact you by email to let you know whether or not you have been selected to take part.

If you do decide to take part and you are one of the patient-parent pairs randomly selected, we will send out a consent form for you to sign to say that you are happy to take part. Your child will also sign their own form to say they are happy to do their own interview. If your child is aged between 10-15, we will ask you to countersign their consent form, stating that you consent to them taking part in the study. There will be a stamped envelope for you to send this back to us. Regrettably, none of the research team speak Welsh, so the interview will be done in English.

Thank you.

Sophia Williams

Trainee Clinical Psychologist under the supervision of Dr Sarah Bailey-Rogers, Clinical Psychologist

A note on GDPR

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

How will we use information about you?

We will need to use information from you for this research project. This information will include your initials. People will use this information to do the research. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information by asking one of the research team.

Who can I contact if I have a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer. The research team can give you details of the right Data Protection Officer.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

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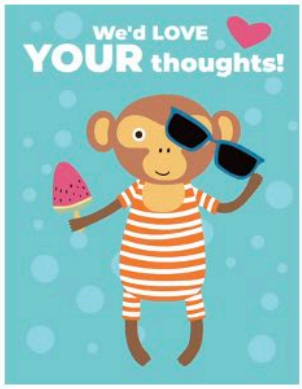
Hoffem glywed gennych!



Teitl yr astudiaeth:
'Dyfais monitro glwcos yn y gwaed a fi'.

Hoffem ofyn a fyddai gennych chi ac un o'ch rhieni ddiddordeb mewn cymryd rhan mewn astudiaeth ymchwil.
Mae'n bwysig iawn eich bod chi'n deall beth yw pwrpas yr astudiaeth, pam rydyn ni'n gwneud yr astudiaeth, a'r hyn y byddai'n ei olygu i chi cyn i chi benderfynu a ddylech chi gymryd rhan ai peidio.
Darllenwch y daflen hon yn ofalus i gael mwy o wybodaeth, ac fel unrhyw gwestiynau sydd gennych os nad yw unrhyw beth yn glir. Mae croeso i chi anfon e-bost ataf gan ddefnyddio naill ai cyfeiriad e-bost ar ddiwedd y daflen hon neu ofyn i aelod o'r Tîm Diabetes roi gwybod imi yr hoffech imi gysylltu â chi. Diolch am ddarllen hwn.

Pam rydyn ni'n gwneud yr ymchwil hon?

Rydym yn edrych ar farn pobl ifanc a'u rhieni am ddefnyddio dyfeisiau monitro glwcos yn y gwaed (ee dyfais Libre neu CGM). Rydyn ni eisiau deall sut beth yw defnyddio'r dechnoleg hon i chi a'ch teulu. Ni fyddwn yn edrych ar eich rheolaeth ar ddiabetes.

Beth fyddem ni'n gofyn ichi ei wneud?

Hoffem ofyn ychydig o gwestiynau ichi am sut beth yw eich bywyd gan ddefnyddio'ch dyfais monitro glwcos yn y gwaed. Gallwch gael cymaint o amser ag sydd ei angen arnoch i ateb y cwestiynau, ond i roi syniad i chi, nid ydym yn credu y bydd yn cymryd mwy nag awr. Nid oes unrhyw atebion cywir nac anghywir ac nid yw'n brawf. Ar wahân, hoffem ofyn yr un cwestiynau i'ch

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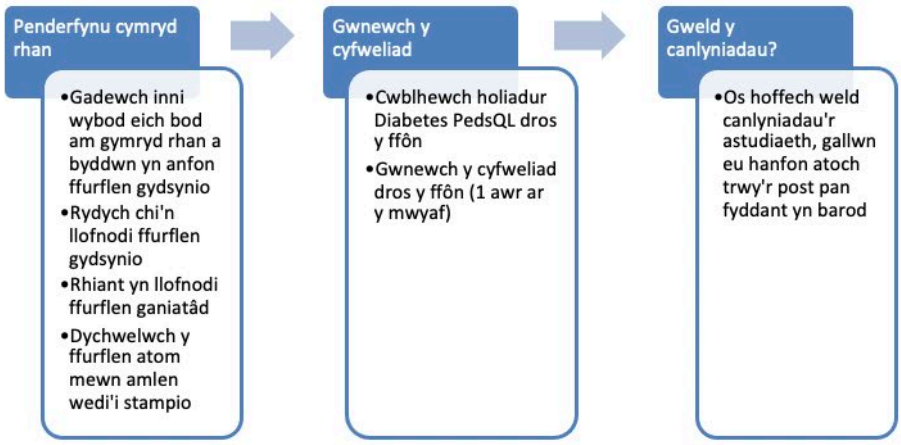
rhiant hefyd. Os ydych chi'n hapus i gymryd rhan, byddem yn gofyn y cwestiynau i chi ar eich pen eich hun fel y gallwch chi ddweud popeth rydych chi eisiau ei wneud. Hefyd, i gymryd rhan, byddai angen i chi a rhiant ddweud ie i chi sy'n cymryd rhan. Gan ein bod yn cyfweld cleifion a'u rhiant, byddai angen i chi a rhiant fod eisiau cymryd rhan er mwyn i'r naill neu'r llall ohonoch allu ei wneud.

Byddwn hefyd yn gofyn ichi lenwi holiadur Diabetes byr (PedsQL). Efallai eich bod wedi gweld hyn o'r blaen.

* Oherwydd COVID-19, ni fyddwn yn gallu cynnal y cyfweliadau wyneb yn wyneb, felly hoffem gyfweld dros y ffôn yn lle. Byddwn yn cynnal y cyfweliadau ar adeg sy'n addas i chi, yn ystod Medi-Hydref 2020.

Os penderfynwch gymryd rhan yn yr astudiaeth, bydd y broses yn edrych ychydig fel hyn:



Pam y gofynnwyd ichi gymryd rhan?

Rydym yn gofyn i bob plentyn a pherson ifanc rhwng 10 a 18 oed sydd wedi bod yn defnyddio dyfais monitro glwcos yn y gwaed am o leiaf 6 mis a hoffent gymryd rhan. Byddech chi'n un o leiaf 6 o bobl yn gymysgedd o gleifion a'u rhiant, yn ein helpu gyda'r astudiaeth hon.

Oes rhaid i chi gymryd rhan?

Na, nid oes rhaid i chi gymryd rhan os nad ydych chi eisiau gwneud hynny ac ni fydd yn newid unrhyw beth am y gofal a gewch gan y tîm Diabetes os cymerwch

ran ai peidio. Gallwch chi atal y cwestiynau a dewis peidio â chymryd rhan ar unrhyw adeg, ac mae bynnag'n iawn! Os dewiswch adael yr astudiaeth, bydd unrhyw wybodaeth rydych wedi'i rhoi eisoes yn cael ei dinistrio ac ni chaiff ei defnyddio yn yr ymchwil.

Beth yw manteision cymryd rhan?

Gobeithiwn y bydd yr ymchwil hon yn rhoi gwybod i ni sut brofiad yw i blant a phobl ifanc â Type 1 Diabetes ddefnyddio dyfais monitro glwcos yn y gwaed. Gobeithiwn y bydd hyn yn ei gwneud hi'n haws dweud wrth oleifion newydd sut beth yw defnyddio'r dechnoleg. Byddem hefyd yn rhoi cerdyn rhodd amazon gwerth £20 i chi am gymryd rhan yn yr astudiaeth.

Beth yw'r risgiau o gymryd rhan?

Nid ydym yn credu bod unrhyw risgiau i gymryd rhan, ond rydym yn gwybod efallai mai dyma'r tro cyntaf i chi siarad am sut beth yw byw'r gyda'r ddefnyddio'r dechnoleg ac efallai y bydd hyn yn codi rhai teimladau oad oeddech chi'n sylweddoli bod gennych chi. Os bydd hyn yn digwydd, byddem yn siarad â chi am siarad â'ch tîm meddygol, meddyg teulu neu Seicolegydd Clinigol Pediatreg am eich teimladau. Os oes gennych unrhyw brydero am yr astudiaeth ei hun oad ydych am ei chadi gyda'r ymchwilydd neu'r tîm Diabetes, gallwch ofyn i'ch chiant anfon e-bost at y cheolwr ymchwil yn Mhrifysgol Bangor: huw.ellis@bangor.ac.uk.

A fydd y wybodaeth a roddwch yn cael ei chadw'n breifat?

Ydw. Byddwn yn sicrhau nad yw'ch enw ar unrhyw un o'r sgriptiau rydyn ni'n eu teipio o'r cyfweliad. Byddai unrhyw beth a fyddai'n ei gwneud yn glir eich bod yn ateb y cwestiynau yn cael ei dynnu allan cyn cyhoeddi'r canfyddiadau.

Sut y byddwn yn gwneud y cyfweliad a'i gadw'n ddiogel?

Mae'r ymchwil hwn yn cael ei wneud gan fyfyriwr Seicoleg Glinigol yn Mhrifysgol Bangor (Sophia Williams). Mae Sophia yn cael ei goruchwylio gan Dr Sarah Bailey-Rogers, y Seicolegydd rydych chi fel arfer yn ei weld yn y clinig. Bydd Sophia yn gwneud y cyfweliad gyda chi. Gan y byddwn yn gofyn yr un cwestiynau i'ch chiant, byddwn yn gofyn iddynt beidio â bod yn yr ystafell yn ystod eich cyfweliad. Fodd bynnag, os oes chiant neu oedolyn arall yr hoffech chi yn yr ystafell gyda chi, yna mae hynny'n iawn. Rydyn ni am wrando ar baneth rydych chi'n ei ddweud felly byddwn ni'n recordio'r cyfweliad. Bydd y recordiad yn cael ei gadw'n ddiogel ar gyfrifiadur a ddiogelir gan gyfrinair. Bydd unrhyw ffeiliau papur yn cael eu cloi i ffwrdd.

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* Oherwydd COVID-19, hoffem eich cyfweld dros y ffôn a recordio'r cyfweliad trwy'r ffôn. Gwneir hyn gan ddefnyddio meddalwedd ddiogel a ffôn y GIG.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Gan fod Sophia befyd yn fyfyriwr ym Mhrifysgol Bangor, bydd y papur ymchwil yn cael ei farcio gan y brifysgol. Bydd Sophia Williams yn teipio'r cyfweliadau fel y gall ddadansoddi'ch atebion i weld pa bethau pwysig rydych chi'n eu dweud. Bydd unrhyw beth â'ch manylion personol arno yn cael ei gadw'n ddiogel gan Dr Sarah Bailey-Rogers (goruchwyliwr Sophia) am 3 blynedd. Bydd unrhyw beth heb eich gwybodaeth bersonol arno (sy'n dod o'r astudiaeth hon) yn cael ei gadw'n ddiogel gan Dr Sarah Bailey-Rogers am 10 mlynedd. Yna bydd yn cael ei ddinistrio.

Gellid cyhoeddi'r papur ymchwil mewn cyfnodolyn yn ddiweddarach fel y gall mwy o bobl ddeall sut mae plant a phobl ifanc yn teimlo am ddefnyddio dyfeisiau monitro glwcos yn y gwaed. Os ydych chi'n cytuno, efallai yr hoffem ni ddefnyddio'r geiriau rydych chi wedi'u dweud yn y papur ymchwil. Pe byddem yn gwneud hyn, byddem yn sicrhau nad oes unrhyw un yn gwybod mai eich geiriau chi ydyw, trwy newid yr enw neu ddefnyddio enw cod.

Hoffem wneud taflen gan ddefnyddio'r wybodaeth a roddwch y gellir ei rhoi i gleifion newydd i'w helpu i baratoi ar gyfer defnyddio dyfais monitro glwcos yn y gwaed.

Beth sydd angen i mi ei wneud nawr?

Os nad ydych chi am gymryd rhan, peidiwch â gwneud dim! Os na fyddwn yn clywed gennych, byddwn yn tybio nad ydych am gymryd rhan ac mae hynny'n iawn!

Ond os hoffech chi gymryd rhan neu ofyn unrhyw gwestiynau i'ch helpu chi i benderfynu, cysylltwch â naill ai Sophia (yr ymchwilydd) neu Dr Sarah Bailey-Rogers. Gallwch wneud hyn trwy ofyn i'ch rhiant anfon e-bost atom ar:

Seu8ae@bangor.ac.uk i Sophia Williams

Sarah.bailey-rogers@wales.nhs.uk ar gyfer Dr Sarah Bailey-Rogers

Os bydd wn anfon e-bost atom i ofyn cwestiynau neu roi gwybod i ni eich bod am gael peth amser i feddwl amdano, byddwn yn eich atgoffa ar ôl pythefnos i chi gysylltu â ni i wirio a hoffech chi gymryd rhan ai peidio.

Gan ein bod yn cyfweld â 3 neu 4 pâr rhwng cleifion a rhieni yn unig, efallai y bydd gennym fwy o bobl â diddordeb nag y gallwn eu cyfweld. Os bydd byn yn digwydd, byddwn yn dewis y parau ar hap. Byddwn yn cysylltu â chi trwy e-bost i roi gwybod ichi a ydych wedi'ch dewis i gymryd rhan ai peidio.

Os penderfynwch gymryd rhan a'ch bod yn un o'r parau cleifion-rhieni a ddewiswyd ar hap, byddwn yn anfon ffurflen gydsynio i chi ei llofnodi i ddweud eich bod yn barus i gymryd rhan. Bydd angen i'ch rhiant lofnodi byn befyd i ddweud ei fod yn barus ichi gymryd rhan, a byddant befyd yn llofnodi eu ffurflen eu hunain i ddweud eu bod yn barus i wneud eu cyfweliad eu hunain. Bydd amlen wedi'i stampio i chi ei banfon yn ôl atom ni. Gan nad oes yr un o'r tîm ymchwil yn siarad Cymraeg, bydd y cyfweliad yn cael ei wneud yn Saesneg.

Diolch,

Sophia Williams
Seicolegydd Clinigol dan Hyfforddiant

Yn cael ei oruchwylio gan Dr Sarah Bailey-Rogers, Seicolegydd Clinigol Pediatreg, a Dr Renee Rickard, Seicolegydd Clinigol.

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Rydyn ni eisiau clywed gennych chi!

Teitl yr Astudiaeth:
'Dyfais monitro glwcos yn y gwaed a fi': persbectifau cleifion pediatreg a rhoddwyr gofal o'u defnydd

Hoffem ofyn ichi gymryd rhan mewn astudiaeth ymchwil, a noddir gan Brifysgol Bangor. Darllenwch y daflen hon i gael mwy o wybodaeth. Mae croeso i chi anfon e-bost ataf gan ddefnyddio'r cyfeiriad e-bost ar ddiwedd y daflen hon neu ofyn i aelod o'r tîm Diabetes roi gwybod imi yr hoffech i mi gysylltu â chi.

Rydym yn edrych ar farn pobl ifanc a'u rhieni am ddefnyddio dyfeisiau monitro glwcos yn y gwaed (ee dyfais Libre neu CGM). Rydyn ni eisiau deall sut beth yw defnyddio'r dechnoleg hon i chi a'ch teulu. Ni fyddwn yn edrych ar eich rheolaeth ar ddiabetes.

Beth fyddem ni'n gofyn ichi ei wneud?

Hoffem ofyn ychydig o gwestiynau ichi am sut beth yw eich bywyd gan ddefnyddio'ch dyfais monitro glwcos yn y gwaed. Gallwch gael cymaint o amser ag sydd ei angen arnoch i ateb y cwestiynau ac nid oes atebion cywir nac anghywir. I roi syniad i chi, bydd y cyfweliad yn cymryd hyd at awr ar y mwyaf. Ar wahân, hoffem ofyn yr un cwestiynau i'ch rhiant hefyd. Os ydych chi'n hapus i gymryd rhan, byddem yn gofyn y cwestiynau i chi ar eich pen eich hun fel y gallwch chi ddweud popeth rydych chi eisiau ei wneud. Gan ein bod yn cyfweld â chleifion ac un o'u rhieni, byddai'n rhaid i'r ddau ohonoch fod eisiau cymryd rhan er mwyn i'r naill neu'r llall ohonoch allu cymryd rhan.

Byddwn hefyd yn gofyn ichi lenwi holiadur Diabetes byr (PedsQL) y gallech fod wedi'i weld o'r blaen.

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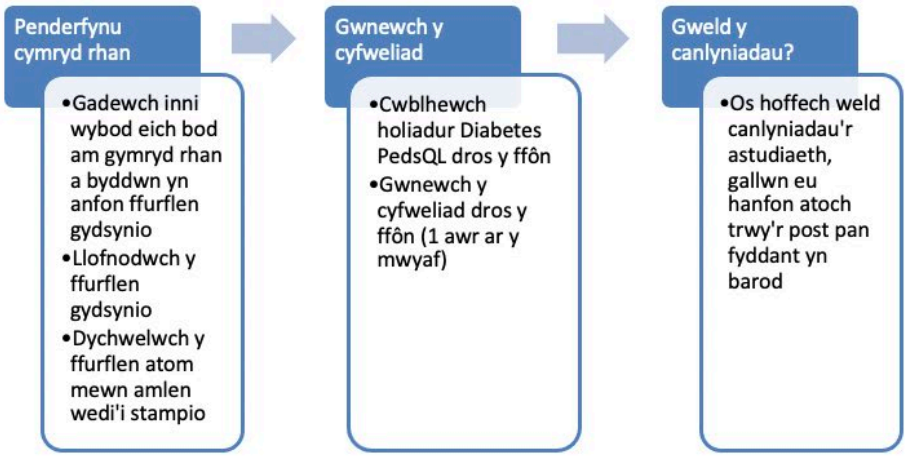
* Oherwydd COVID-19, ni fyddwn yn gallu cynnal y cyfweliadau wyneb yn wyneb. felly hoffem gyfweld dros y ffôn yn lle. Byddwn yn cynnal y cyfweliadau ar adeg sy'n addas i chi, yn ystod Medi-Hydref 2020.
Os penderfynwch gymryd rhan yn yr astudiaeth, bydd y broses yn edrych fel hyn:



Pam y gofynnwyd ichi gymryd rhan?

Rydym yn gofyn i bob plentyn a pherson ifanc rhwng 10 a 18 oed sydd wedi bod yn defnyddio dyfais monitro glwcos yn y gwaed am o leiaf 6 mis a hoffent gymryd rhan.

Oes rhaid i chi gymryd rhan?

Na, nid oes rhaid i chi gymryd rhan os nad ydych chi eisiau gwneud hynny ac ni fydd yn newid unrhyw beth am y gofal a gewch gan y tîm Diabetes os cymerwch ran ai peidio. Gallwch chi atal y cwestiynau a dewis peidio â chymryd rhan ar unrhyw adeg, ac mae hynny'n iawn! Os dewiswch adael yr astudiaeth, bydd unrhyw wybodaeth rydych wedi'i rhoi eisoes yn cael ei dinistrio ac ni chaiff ei defnyddio yn yr ymchwil.

Beth yw manteision cymryd rhan?

Gobeithiwn y bydd yr ymchwil hon yn rhoi gwybod i ni sut brofiad yw i bobl ifanc â Type 1 Diabetes ddefnyddio dyfais monitro glwcos yn y gwaed. Gobeithiwn y bydd hyn yn ei wneud bi'n haws dweud wrth gleifion newydd sut beth yw defnyddio'r dechnoleg. Byddem hefyd yn rhoi cerdyn rhodd amazon gwerth £ 20 i chi am gymryd rhan yn yr astudiaeth.

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Beth yw'r risgiau o gymryd rhan?

Nid ydym yn credu bod unrhyw risgiau i gymryd rhan. Ond rydym yn awyhod efallai mai dyma'r tro cyntaf i chi siarad am sut beth yw byw'yd wrth ddefnyddio'r dechnoleg ac efallai y bydd hyn yn codi rhai teimladau pad oeddech chi'n sylweddoli bod gennych chi. Os bydd hyn yn digwydd, byddem yn siarad â chi am siarad â'ch tîm meddygol, meddyg teulu neu Seicolegydd Clinigol Pediatreg am eich teimladau. Os oes gennych unrhyw bryderon am yr astudiaeth ei hun pad ydych am eu codi rydd'r ymchwilydd neu'r tîm Diabetes, gallwch eu cyfeirio at y cheolwr ymchwil ym Mhrifysgol Bangor: huw.ellis@bangor.ac.uk.

A fydd y wybodaeth a roddwch yn cael ei chadw'n breifat?

Ydw. Byddwn yn sicrhau nad yw'ch enw ar unrhyw un o'r sgriptiau rydyn ni'n eu teipio o'r cyfweliad. Byddai unrhyw beth a fyddai'n ei gwneud yn glir eich bod yn ateb y cwestiynau yn cael ei dynnu allan cyn cyhoeddi'r canfyddiadau.

Sut y bydd'wn yn gwneud y cyfweliad a'i gadw'n ddiogel?

Mae'r ymchwil hwn yn cael ei wneud gan fyfyriwr Seicoleg Glinigol ym Mhrifysgol Bangor (Sophia Williams). Mae Sophia yn cael ei goruchwylio gan Dr Sarah Bailey-Rogers, y Seicolegydd rydych chi fel arfer yn ei weld yn y clinig. Bydd Sophia yn gwneud y cyfweliad gyda chi. Gan y byddwn yn gofyn yr un cwestiynau i'ch rhiant, byddwn yn gofyn iddynt beidio â bod yn yr ystafell yn ystod eich cyfweliad. Fodd bynnag, os oes rhiant neu gedalyn arall yr hoffech chi yn yr ystafell gyda chi, yna mae hynny'n iawn.

Rydyn ni eisiau gwrando ar bopeth rydych chi'n ei ddweud felly byddwn ni'n recordio'r cyfweliad. Bydd y recordiad yn cael ei gadw'n ddiogel ar gyfrifiadur a ddiogelir gan gyfrinair. Bydd unrhyw ffeiliau papur yn cael eu cloi i ffwrdd.

** Oherwydd COVID-19, hoffem eich cyfweld dros y ffôn a recordio'r cyfweliad trwy'r ffôn. Gwneir hyn gan ddefnyddio meddalwedd ddiogel a ffôn y GIG.*

Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Gan fod Sophia befyd yn fyfyriwr ym Mhrifysgol Bangor, bydd y papur ymchwil yn cael ei farcio gan y brifysgol. Bydd Sophia Williams yn teipio'r cyfweliadau fel y gall ddadansoddi'ch atebion i weld pa bethau pwysig rydych chi'n eu dweud. Bydd unrhyw beth â'ch manylion personol arno yn cael ei gadw'n ddiogel gan Dr Sarah Bailey-Rogers (goruchwyliwr Sophia) am 3 blynedd. Bydd unrhyw beth heb eich gwybodaeth bersonol arno (sy'n dod o'r astudiaeth hon) yn cael ei gadw'n ddiogel gan Dr Sarah Bailey-Rogers am 10 mlynedd. Yna bydd yn cael ei ddinistrio.

Gellid cyhoeddi'r papur ymchwil mewn cyfnodolyn yn ddiweddarach fel y gall mwy o bobl ddeall sut mae pobl ifanc yn teimlo am ddefnyddio dyfeisiau monitro glwcos yn y gwaed. Os cytunwch, efallai yr hoffem ddefnyddio'ch geiriau yn y papur ymchwil. Pe byddem yn gwneud hyn, byddem yn sicrhau nad oes unrhyw un yn gwybod mai chi ydyw, trwy newid yr enw neu roi enw cod i chi.

Hoffem wneud taflen gan ddefnyddio'r wybodaeth a roddwch y gellir ei rhoi i gleifion newydd i'w helpu i baratoi ar gyfer defnyddio dyfais monitro glwcos yn y gwaed.

Beth sydd angen i mi ei wneud nawr?

Os nad ydych chi am gymryd rhan, peidiwch â gwneud dim! Os na fyddwn yn clywed gennych, byddwn yn tybio nad ydych am gymryd rhan ac mae hynny'n iawn!

Ond os hoffech chi gymryd rhan neu ofyn unrhyw gwestiynau i'ch helpu chi i benderfynu, cysylltwch â naill ai Sophia (yr ymchwilydd) neu Dr Sarah Bailey-Rogers trwy e-bost at:

Seu8ae@bangor.ac.uk i Sophia Williams

Sarah.bailey-rogers@wales.nhs.uk at gyfer Dr Sarah Bailey-Rogers

Os byddwch yn anfon e-bost atom i ofyn cwestiynau neu roi gwybod i ni eich bod am gael peth amser i feddwl amdano, byddwn yn eich atgoffa ar ôl pythefnos i chi gysylltu â ni i wirio a hoffech chi gymryd rhan ai peidio.

Gan ein bod yn cyfweld â 3 neu 4 pâr rhwng cleifion a rhieni yn unig, efallai y bydd gennym fwy o bobl â diddordeb nag y gallwn eu cyfweld. Os bydd hyn yn digwydd, byddwn yn dewis y parau ar hap. Byddwn yn cysylltu â chi trwy e-bost i roi gwybod ichi a ydych wedi'ch dewis i gymryd rhan ai peidio.

Os penderfynwch gymryd rhan a'ch bod yn un o'r parau cleifion-rhieni a ddewiswyd ar hap, byddwn yn anfon ffurflen gydsynio i chi ei llofnodi i ddweud eich bod yn barus i gymryd rhan. Bydd eich rhiant hefyd yn llofnodi ei ffurflen ei hun i ddweud ei fod yn barus i wneud ei gyfweliad ei hun. Bydd amlen wedi'i stampio i chi ei hanfon yn ôl atom ni. Yn anffodus, nid oes yr un o'r tîm ymchwil yn siarad Cymraeg, felly bydd y cyfweliad yn cael ei wneud yn Saesneg.

Diolch

Sophia Williams

Seicolegydd Clinigol dan Hyfforddiant dan oruchwyliaeth Dr Sarah Bailey-Rogers, Seicolegydd Clinigol

Nodyn ar GDPR

Mae GDPR yn sefyll am y Rheoliad Diogelu Data Cyffredinol. Yn y DU rydym yn dilyn y rheolau GDPR ac mae gennym gyfraith o'r enw Deddf Diogelu Data. Rhaid i'r holl ymchwil sy'n defnyddio data cleifion ddilyn deddfau a rheolau'r DU.

Sut y byddwn yn defnyddio gwybodaeth amdanoch chi?
Bydd angen i ni ddefnyddio gwybodaeth gennych chi ar gyfer y prosiect ymchwil hwn. Bydd y wybodaeth hon yn cynnwys eich llythrennau cyntaf. Bydd pobl yn defnyddio'r wybodaeth hon i wneud yr ymchwil. Ni fydd pobl nad oes angen iddynt wybod pwy ydych chi yn gallu gweld eich enw na'ch manylion cysylltu. Bydd gan eich data rif cod yn lle.

Byddwn yn cadw'r holl wybodaeth amdanoch yn ddiogel. Ar ôl i ni orffen yr astudiaeth, byddwn yn cadw rhywfaint o'r data fel y gallwn wirio'r canlyniadau. Byddwn yn ysgrifennu ein hadroddiadau mewn ffordd na all unrhyw un weithio allan ichi gymryd rhan yn yr astudiaeth.
Ble allwch chi ddarganfod mwy am sut mae'ch gwybodaeth yn cael ei defnyddio?
Gallwch ddarganfod mwy am sut rydyn ni'n defnyddio'ch gwybodaeth trwy ofyn i un o'r tîm ymchwil.

Gyda phwy y gallaf gysylltu os oes gennyf gŵyn?
Os ydych chi am gwyno am sut mae ymchwilwyr wedi trin eich gwybodaeth, dylech gysylltu â'r tîm ymchwil. Os nad ydych yn hapus ar ôl hynny, gallwch gysylltu â'r Swyddog Diogelu Data. Gall y tîm ymchwil roi manylion y Swyddog Diogelu Data cywir i chi.
Os nad ydych yn hapus â'u hymateb neu'n credu eu bod yn prosesu'ch data mewn ffordd nad yw'n gywir neu'n gyfreithlon, gallwch gwyno i Swyddfa'r Comisiynydd Gwybodaeth (ICO) (www.ico.org.uk neu 0303 123 1113).

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Taflen Gwybodaeth Cyfranogwyr - Rhiant / Rhoddwr Gofal

Teitl yr astudiaeth

'Dyfais monitro glwcos yn y gwaed a fi': persbectifau cleifion pediatreg a rhoddwyr gofal o'u defnydd.

Gwahoddiad a chrynodeb byr

Hoffwn eich gwahodd i gymryd rhan mewn astudiaeth ymchwil. Cyn i chi benderfynu mae angen i chi ddeall pam mae'r ymchwil yn cael ei wneud a beth fyddai'n ei olygu i chi. Cymerwch amser i ddarllen y wybodaeth ganlynol yn ofalus. Gofynnwch gwestiynau os nad yw unrhyw beth rydych chi'n ei ddarllen yn glir neu os hoffech chi gael mwy o wybodaeth. Cymerwch amser i benderfynu a ddylid cymryd rhan ai peidio.

Rydym yn edrych ar blant a phobl ifanc sydd â Type 1 Diabetes a'u profiadau 'caregivers' o ddefnyddio dyfais monitro glwcos yn y gwaed (ee Libre neu ddyfais CGM). Rydym eisiau deall sut beth yw defnyddio'r dechnoleg hon i gleifion, a hefyd yr effaith y gall ei chael ar y teulu cyfan. Rydym yn cydnabod bod gwahaniaeth rhwng bod technoleg yn effeithiol at ddibenion meddygol, a'i heffaith ar ansawdd bywyd a lles.

Beth fyddai cymryd rhan yn ei olygu?

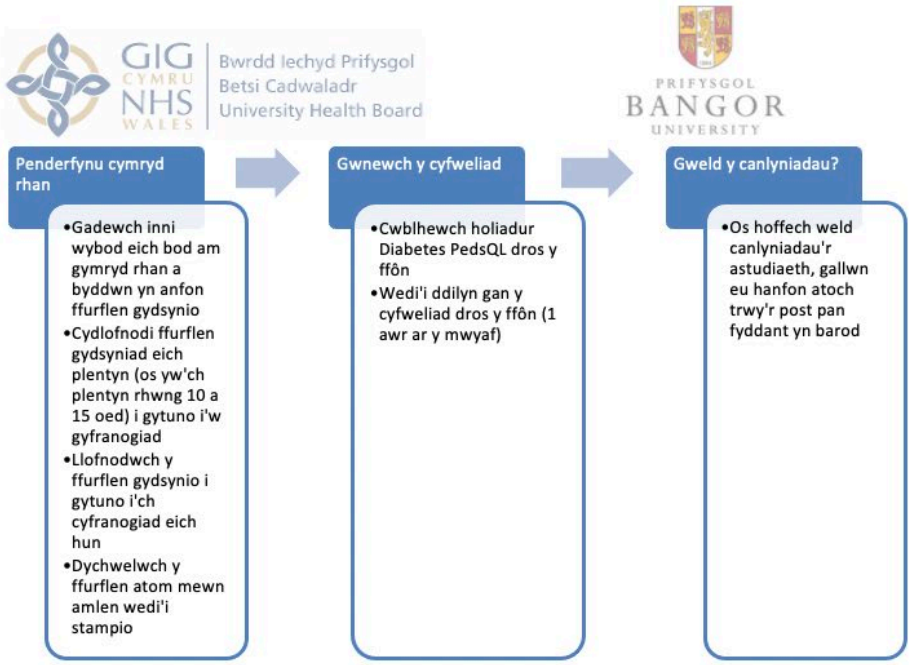
Hoffem i chi gymryd rhan mewn un cyfweliad ag ymchwilydd. Byddwn yn gofyn cyn lleied o gwestiynau â phosibl i ganiatáu ichi egluro'ch barn ar ddefnyddio'r ddyfais heb ymyrraeth na gormod o ganllawiau i unrhyw gyfeiriad penodol. Byddwn yn cynnal y cyfweliadau dros y ffôn ar amser sy'n addas i chi. Byddwn yn cyfweld cleifion ifanc a hefyd un o'u rhoddwyr gofal / rhieni. Bydd y cyfweliadau'n cael eu gwneud ar wahân fel eich bod chi'n rhydd i drafod unrhyw beth rydych chi'n teimlo sy'n bwysig ynglŷn â defnyddio technoleg monitro glwcos yn y gwaed.

Byddwn hefyd yn gofyn i'r cyfranogwyr lenwi holiadur Diabetes byr (PedsQL) yn edrych ar ansawdd eich bywyd a'ch lles.

Nid oes amser penodol ar gyfer y cyfweliadau, gallwch eu cael cyhyd ag y bydd angen i chi ddweud wrthym am eich profiadau o'r dechnoleg. Fodd bynnag, rydym yn rhagweld na fydd yn cymryd mwy nag awr.

** Oherwydd COVID-19, ni fyddwn yn gallu cynnal y cyfweliadau wyneb yn wyneb, felly hoffem gyfweld dros y ffôn yn lle. Byddwn yn cynnal y cyfweliadau ar adeg sy'n addas i chi, yn ystod Medi-Hydref 2020.*

Os penderfynwch gymryd rhan yn yr astudiaeth, bydd y broses yn edrych fel hyn:



Pam y gofynnwyd ichi gymryd rhan?

Rydym yn gofyn i bob plentyn a pherson ifanc rhwng 10 a 18 oed sydd wedi bod yn defnyddio dyfais monitro glwcos yn y gwaed am o leiaf 6 mis a hoffent gymryd rhan.
Rydym hefyd yn gofyn i riant / rhoddwr gofal y plentyn / person ifanc gymryd rhan. Ar gyfer cleifion iau, bydd gofyn i'r sawl sy'n rhoi gofal hefyd gydsynio i gyfranogiad eu plentyn yn yr astudiaeth.

Oes rhaid i chi gymryd rhan?

Na, nid oes rhaid i chi gymryd rhan os nad ydych chi eisiau gwneud hynny ac ni fydd yn newid unrhyw beth am y gofal rydych chi a'ch teulu yn ei gael gan y tîm Diabetes os ydych chi'n cymryd rhan ai peidio. Mae'r holl gyfranogwyr yn rhydd i adael yr astudiaeth ar unrhyw adeg heb unrhyw ôl-effeithiau. Os dewiswch adael yr astudiaeth, bydd unrhyw wybodaeth rydych wedi'i rhoi eisoes yn cael ei dinistrio ac ni chaiff ei defnyddio yn yr ymchwil.

Beth yw manteision posibl cymryd rhan?

Bydd eich cyfranogiad yn yr ymchwil hon yn dweud wrthym am unrhyw anawsterau posibl y mae cleifion a rhoddwyr gofal yn eu profi wrth ddefnyddio dyfais monitro glwcos yn y gwaed, y gellir ei ystyried wedyn wrth baratoi cleifion newydd ar gyfer defnyddio'r dechnoleg. Bydd hefyd yn ein helpu i ddeall sut y gall y ddyfais effeithio ar fywyd eraill o'ch bywyd ac ansawdd bywyd a lles. Gobeithiwn y bydd hyn yn ei gwneud yn haws i gleifion a'u teuluoedd drafod unrhyw anawsterau gyda staff. Yn yr un modd, bydd yr ymchwil hon yn helpu

darparwyr gwasanaeth i ddeall buddion y dechnoleg fel y gellir eglurо hyn i gleifion newydd.

Beth yw'r anfanteision a'r risgiau posibl o gymryd rhan?

Nid oes unrhyw risgiau difrifol disgwyliedig o gymryd rhan yn yr ymchwil hon. Fodd bynnag, rydym yn cydnabod efallai mai hwn yw'r tro cyntaf i rywun roi'r lle i chi siarad am eich profiad, ac efallai y bydd hyn yn codi rhai teimladau oad oeddech chi'n sylweddoli oedd gennych chi. Pe bai hyn yn digwydd, byddem yn rhoi cyngor i chi ar beth i'w wneud nesaf, megis siarad â'r tîm meddygol eich meddyg teulu, neu Seicolegydd Clinigol Pediatreg sy'n gysylltiedig â'r tîm Diabetes. Os oes gennych unrhyw bryderon am yr astudiaeth ei hun oad ydych am eu codi gyda'r ymchwilydd neu'r tîm Diabetes, gallwch eu cyfeirio at y cheolwr ymchwil yn Mhrifysgol Bangor: huw.ellis@bangor.ac.uk.

A fydd y data a roddwch yn cael ei gadw'n gyfrinachol?

Ydw. Bydd yr holl ddata yn ddienw cyn ei ddadansoddi, ac ni chyhoeddir unrhyw wybodaeth adnabod. Byddai unrhyw beth a fyddai'n ei gwneud yn glir eich bod yn ateb y cwestiynau yn cael ei dynnu allan cyn cyhoeddi'r canfyddiadau. Ni fyddwn yn rhannu canlyniadau unrhyw holiaduron cyn cyfweliad â'ch meddyg teulu oac unrhyw un arall oni gallwn eich cynghori i gysylltu â'ch meddyg teulu os yw'r holiadur yn datgelu unrhyw beth sy'n peri pryder.

Sut bydd y data rydych chi'n ei ddarparu yn cael ei gofnodi, ei storio a'i warchod?

Mae'r ymchwil hwn yn cael ei wneud gan fyfyriwr Seicoleg Glinigol ym Mhrifysgol Bangor (Sophia Williams). Mae Sophia yn cael ei goruchwylio gan Dr Sarah Bailey-Rogers, y Seicolegydd rydych chi fel arfer yn ei weld yn y clinig. Bydd Sophia yn gwneud y cyfweliad gyda chi. Gan y byddwn yn gofyn yr un cwestiynau i'ch plentyn, byddwn yn gofyn iddynt beidio â bod yn yr ystafell yn ystod eich cyfweliad, fel bod y ddau ohonoch yn gallu siarad yn rhydd yn ystod eich cyfweliadau.

Rydyn ni eisiau gwrando ar bopeth rydych chi'n ei ddweud felly byddwn ni'n recordio'r cyfweliad. Bydd y ffeiliau sain yn cael eu storio ar gyfrifiadur a ddiogelir gan gyfrinair a bydd unrhyw ffeiliau papur yn cael eu storio mewn cabinet sydd wedi'i gloi.

* Oherwydd COVID-19, hoffem eich cyfweld dros y ffôn a recordio'r cyfweliad trwy'r ffôn. Gwneir hyn gan ddefnyddio meddalwedd ddiogel a ffôn y GIG.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Gan fod Sophia hefyd yn fyfyriwr ym Mhrifysgol Bangor, bydd y papur ymchwil yn cael ei farcio gan y brifysgol, ond bydd pob mesur cyfrinachedd yn cael ei

gymhwyso. Bydd Sophia Williams yn teipio'r cyfweliadau fel y gall ddadansoddi'ch atebion i weld pa bethau pwysig rydych chi'n eu dweud. Bydd unrhyw beth â'ch manylion personol arno yn cael ei gadw'n ddiogel gan Dr Sarah Bailey-Rogers (goruchwyliwr Sophia) am 3 blynedd. Bydd unrhyw beth heb eich gwybodaeth bersonol arno (sy'n dod o'r astudiaeth hon) yn cael ei gadw'n ddiogel gan Dr Sarah Bailey-Rogers am 10 mlynedd. Yna bydd yn cael ei ddinistrio.

Gellid cynhaeddi'r papur ymchwil mewn cyfnodolyn yn ddiweddarach fel y gall mwy o bobl ddeall sut mae plant a phobl ifanc a'u teuluoedd gofal yn teimlo am ddefnyddio dyfeisiau monitro glwcos yn y gwaed. Os cydsyniwch, efallai yr hoffem ddefnyddio'ch geiriau yn y papur ymchwil. Pe bydden yn gwneud hynny, bydden yn ei enwi fel nad oes unrhyw un yn gwybod mai chi ydyw.

Y gobaith yw y bydd taflen wybodaeth yn cael ei datblygu o ganlyniad i'r ymchwil hon y gellir ei rhoi i gleifion a theuluoedd gofal newydd fel cymorth i'w paratoi ar gyfer defnyddio dyfais monitro glwcos yn y gwaed.

Beth sydd angen i mi ei wneud nawr?

Os nad ydych chi am gymryd rhan, peidiwch â gwneud dim! Os na fyddwn yn clywed gennych, byddwn yn tybio nad ydych am gymryd rhan ac mae hynny'n iawn!

Ond os hoffech chi gymryd rhan neu ofyn unrhyw gwestiynau i'ch helpu chi i benderfynu, cysylltwch â naill ai Sophia (yr ymchwilydd) neu Dr Sarah Bailey-Rogers

Nodyn ar GDPR
Mae GDPR yn sefyll am y Rheoliad Diogelu Data Cyffredinol. Yn y DU rydym yn dilyn y rheolau GDPR ac mae gennym gyfraith o'r enw Deddf Diogelu Data. Rhaid i'r holl ymchwil sy'n defnyddio data cleifion ddilyn deddfau a rheolau'r DU.

Sut y byddwn yn defnyddio gwybodaeth amdanoch chi?
Bydd angen i ni ddefnyddio gwybodaeth gennych chi ar gyfer y prosiect ymchwil hwn. Bydd y wybodaeth hon yn cynnwys eich llythrennau cyntaf. Bydd pobl yn defnyddio'r wybodaeth hon i wneud yr ymchwil. Ni fydd pobl nad oes angen iddynt wybod pwy ydych chi yn gallu gweld eich enw na'ch manylion cyswllt. Bydd gan eich data rif cod yn lle.
Byddwn yn cadw'r holl wybodaeth amdanoch yn ddiogel. Ar ôl i ni orffen yr astudiaeth, byddwn yn cadw rhywfaint o'r data fel y gallwn wirio'r canlyniadau. Byddwn yn ysgrifennu ein hadroddiadau mewn ffordd na all unrhyw un weithio allan ichi gymryd rhan yn yr astudiaeth.

Ble allwch chi ddarganfod mwy am sut mae'ch gwybodaeth yn cael ei defnyddio?
Gallwch ddarganfod mwy am sut rydyn ni'n defnyddio'ch gwybodaeth trwy ofyn i un o'r tîm ymchwil.

Gyda phwy y gallaf gysylltu os oes gennyf gŵyn?
Os ydych chi am gwyno am sut mae ymchwilwyr wedi trin eich gwybodaeth, dylech gysylltu â'r tîm ymchwil. Os nad ydych yn hapus ar ôl hynny, gallwch gysylltu â'r Swyddog Diogelu Data. Gall y tîm ymchwil roi manylion y Swyddog Diogelu Data cywir i chi.
Os nad ydych yn hapus â'u hymateb neu'n credu eu bod yn prosesu'ch data mewn ffordd nad yw'n gywir neu'n gyfreithlon, gallwch gwyno i Swyddfa'r Comisiynydd Gwybodaeth (ICO) (www.ico.org.uk neu 0303 123 1113).

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

PRIFYSGOL BANGOR UNIVERSITY

IRAS Project ID: **282995**

Participant Identification Number for this study:

ASSENT FORM (Young person 10-15)

Project title: 'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.

Name of Researcher: Sophia Williams, Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read the information sheet dated 27.7.20.... (version 6....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I consent to anonymous quotations of my words to be used in the publication of the findings.

   Yes ☐ No ☐
4. I agree to the interview being recorded through the telephone ☐
5. I would/would not like to receive a summary of the findings on project completion ☐
6. I agree to take part in this study ☐

_____	_____	_____
Name of Participant	Date	Signature

I consent for (Name)_____ to take part in this study

_____	_____	_____
Name of parent providing consent	Date	Signature

Version 2 27.7.20

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

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PRIFYSGOL BANGOR UNIVERSITY

IRAS Project ID: **282995**

Participant Identification Number for this study:

CONSENT FORM (Young person 16+)

Project title: 'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.

Name of Researcher: Sophia Williams, Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read the information sheet dated 27.7.20.. (version 7..) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I consent to anonymous quotations of my words to be used in the publication of the findings.

   Yes ☐ No ☐
4. I agree to the interview being recorded through the telephone ☐
5. I would/would not like to receive a summary of the findings on project completion. ☐
6. I consent to take part in this study ☐

Name of Participant	Date	Signature

Version 2 27.7.20

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

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PRIFYSGOL BANGOR UNIVERSITY

IRAS Project ID: **282995**

Participant Identification Number for this study:

CONSENT FORM (Parent/caregiver)

Project title: 'Blood glucose monitoring device and me': paediatric patients' and caregivers' perspectives of their use.

Name of Researcher: Sophia Williams, Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read the information sheet dated 14.7.20... (version...6..) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I consent to anonymous quotations of my words to be used in the publication of the findings.

   Yes ☐ No ☐
4. I agree to the interview being recorded through the telephone ☐
5. I would/would not like to receive a summary of the findings on project completion ☐
6. I consent to take part in this study ☐

Name of Participant	Date	Signature
_____	_____	_____

Version 3 27.7.20

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

PRIFYSGOL BANGOR UNIVERSITY

IRAS Project ID: **282995**

Participant Identification Number for this study:
Rhif uniaethiad cyfranogwr ar gyfer yr astudiaeth:

ASSENT FORM (Young person 10-15)

Ffurflen caniatad (unigolyn 10-15 oed)

Teitl y prosiect: Dyfais fonitro glwcos y gwaed a fi: persbectif y claf pediatrig a rhoddwyr gofal.

Enw'r ymchwilydd: Sophia Williams, Seicolegydd clinigol dan hyfforddiant

Please initial box

1. Dwi'n cadarnhau fy mod wedi darllen y ffurflen wedi dyddio .....(fersiwn.....) ar gyfer yr astudiaeth uchod. Rwyf wedi cael y cyfle i ystyried y gwybodaeth a gofyn cwestiynnau sydd wedi cael eu hateb yn foddhaol. ☐

2. Dwi'n deall bod fy nghyfraniad yn gwbl gwirfoddol a mae modd i mi dynnu allan o'r astudiaeth heb unrhyw eglurhad. Ni fydd y penderfyniad o dynnu allan yn cael unrhyw effaith ar fy ngofal iechyd na fy hawliau gyfreithiol. ☐

3. Dwi'n cytuno dros y defnydd o fy ngeiriau mewn ddyfyniadau dienw er mwyn cael cyhoeddi y canfyddiadau.

   Yes ☐ No ☐

4. Dwi'n cytuno i'r cyfweliad cael ei recordio dros y ffon ☐

5. Mi fyswn yn hoffi/ddim hoffi cael derbyn crynodeb or canfyddiadau ar ol ir prosiect dod i ben. ☐

6. Dwi'n cytuno i gymryd rhan yn yr astudiaeth. ☐

_____	_____	_____
Enw'r cyfranogwr.	Dyddiad	Llofnod

Dwi'n cytuno (enw)_____ yn cael cymryd rhan yn yr astudiaeth ya.

_____	_____	_____
Enw.	Dyddiad.	Llofnod

Version 2 27.7.20

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

PRIFYSGOL BANGOR UNIVERSITY

IRAS Project ID: **282995**

Participant Identification Number for this study:
Rhif uniaethiad cyfranogwr ar gyfer yr astudiaeth:

CONSENT FORM (Young person 16+)

ffurflen caniatad (unigolyn 16+)

Teitl y prosiect: Dyfais fonitro glwcos y gwaed a fi: persbectif y claf pediatrig a rhoddwyr gofal.

Enw'r ymchwilydd: Sophia Williams, Seicolegydd clinigol dan hyfforddiant

Please initial box

1. Dwi'n cadarnhau fy mod wedi darllen y ffyrflen wedi dyddio .....(fersiwn.....) ar gyfer yr astudiaeth uchod. Rwyf wedi cael y cyfle i ystyried y gwybodaeth a gofyn cwestiynnau sydd wedi cael eu hateb yn foddhaol. ☐

2. Dwi'n deall bod fy nghyfranaid yn gwbl gwirfoddol a mae modd i mi dynnu allan o'r astudiaeth heb unrhyw eglurhad. Ni fydd y penderfyniad o dynnu allan yn cael unrhyw effaith ar fy ngofal iechyd na fy hawliau gyfreithiol. ☐

3. Dwi'n cytuno dros y defnydd o fy ngeiriau mewn ddyfyniadau dienw er mwyn cael cyhoeddi y canfyddiadau.

Yes ☐ No ☐

4. Dwi'n cytuno i'r cyfweliad cael ei recordio dros y ffon ☐

5. Mi fyswn yn hoffi/ddim hoffi cael derbyn crynodeb or canfyddiadau ar ol ir prosiect dod i ben. ☐

6. Dwi'n cytuno i gymryd rhan yn yr astudiaeth. ☐

_____ _____ _____

Enw'r cyfranogwr. Dyddiad. Llofnod

Version 2 27.7.20
When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

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Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

PRIFYSGOL BANGOR UNIVERSITY

IRAS Project ID: **282995**

Participant Identification Number for this study:
Rhif uniaethiad cyfranogwr ar gyfer yr astudiaeth:

CONSENT FORM (Parent/caregiver)

Ffurflen caniatad (Rhoddwyr gofal/Rhiant)

Teitl y prosiect: Dyfais fonitro glwcos y gwaed a fi: persbectif y claf pediatrig a rhoddwyr gofal.

Enw'r ymchwilydd: Sophia Williams, Seicolegydd clinigol dan hyfforddiant

Please initial box

1. Dwi'n cadarnhau fy mod wedi darllen y ffyrflen wedi dyddio .....(fersiwn.....) ar gyfer yr astudiaeth uchod. Rwyf wedi cael y cyfle i ystyried y gwybodaeth a gofyn cwestiynnau sydd wedi cael eu hateb yn foddhaol. ☐

2. Dwi'n deall bod fy nghyfranaid yn gwbl gwirfoddol a mae modd i mi dynnu allan o'r astudiaeth heb unrhyw eglurhad. Ni fydd y penderfyniad o dynnu allan yn cael unrhyw effaith ar fy ngofal iechyd na fy hawliau gyfreithiol. ☐

3. Dwi'n cytuno dros y defnydd o fy ngeiriau mewn ddyfyniadau dienw er mwyn cael cyhoeddi y canfyddiadau.

4. Yes ☐ No ☐

5. Dwi'n cytuno i'r cyfweliad cael ei recordio dros y ffon ☐

6. Mi fyswn yn hoffi/ddim hoffi cael derbyn crynodeb or canfyddiadau ar ol ir prosiect dod i ben. ☐

7. Dwi'n cytuno i gymryd rhan yn yr astudiaeth. ☐

Enw'r cyfranogwr	Dyddiad	Llofnod

Version 2 27.7.20

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

Appendix 5D.

Data Analysis Process

Need references! (1) June 2014

3-7

ADOLESCENTS' EXPERIENCE OF DM1 AND POOR GLYCAEMIC CONTROL

35 ↓ underpinnings of diabetes management

Abstract

good paper!!

Objectives

The aim of the study was to explore adolescents' experiences of having diabetes mellitus (DM1) and poor glycaemic control.

Methods

Six adolescents aged 12-17 years undertook individual semi-structured interviews. Transcripts were analysed according to the principles of Interpretative Phenomenological Analysis (IPA).

Results

Participants described numerous intrapersonal and interpersonal conflicts as they struggled to accept and manage their diabetes. Participants described feelings of guilt and shame when their poor glycaemic control was exposed in the diabetes clinic. However, improvements in their glycaemic control were always short-lived, with participants struggling to maintain a regime. A cyclical pattern of deteriorating and improving glycaemic control was therefore described.

Conclusions

The impact of poor glycaemic control on the identities and relationships of these participants highlighted the need for further research. The clinical implications suggest the possible effectiveness of acceptance-based interventions and the potential benefits of developing training for healthcare professionals working with these adolescents.

subsequent process of abstraction, where areas of commonality and divergence both within and between transcripts were examined, super-ordinate themes were developed.

The quality and validity of the data analysis was guided by the frameworks outlined by Yardley (2008) and Elliot et al. (1999). The researcher's subjective recollections and perspectives were noted following each interview and efforts were made to bracket these to reduce subjectivity and allow the researcher to focus on the original data. Initial transcripts were also analysed simultaneously by another member of the research team (R.R.) who also examined the researcher's initial comments and themes to check their validity in relation to the transcripts (see Appendix 5C for a section of an annotated transcript).

Results

Four super-ordinate themes emerged from the analysis; 'impact on self', 'the social self', 'the self and relationships' and 'the cyclical nature of glycaemic control', which are summarized in Table 2. Pseudonyms have been used to denote the quotations.

[INSERT TABLE 2]

Theme 1: Impact on self

Many participants described experiencing a fragmentation of their sense of self as a result of having diabetes. This may be particularly salient during adolescence as this is a period when the sense of self is being developed (Blasi & Milton, 1991). Participants described struggling to establish a firm sense of self as they oscillated between rejecting their diabetes and subsequently having poor glycaemic control, to then wanting to adhere to their regimes and having improved glycaemic control. This is illustrated in a passage from Chloe who described that the intensity of this internal struggle resulted in a splitting of the self.

rejecting Diabetes + regime due to lack of sense of self/ identity.

"Sometimes it seems like there's two different people... like I'm angry at myself and then I'm angry at this... other per, other Chloe who's got diabetes... and... it's like it's weird... cos I don't want it I split like myself in two... and like sometimes... we both merge together and that's when my diabetes is really, really good" Chloe

angry about Diabetes.

In this extract Chloe described how having diabetes at times, felt like it divided her into two different people. She described how the opposing selves merged, when her glycaemic control was 'good', indicating that having poor glycaemic control may be pivotal when she feels split in two. In the following extract Chloe appeared confused as she described trying to preserve an identity, which was not dominated by her diabetes.

"It's like the defining factor of me... and I just don't, I want it to be the opposite way around, I want me to be the defining factor of me rather than the... diabetes" Chloe

lack of identity past D - resentment

This is similar to the following passage from Shaun, who rejected that diabetes was part of his identity and referred to it as something separate from himself. However, Shaun also acknowledges that he becomes more irritable when he has high blood glucose levels, which 'turns' him into a person who others dislike.

"Diabetes is nothing on my personality or whatever I am... Unless I am unless, unless I am a bit high... and which I turn into a... person you can't stand" Shaun

Many participants appeared to wrestle with the fact that having poor glycaemic control negatively impacted on their mood and behaviour, as highlighted in the following passage from Lucy.

"I get angry when I'm high... And... pretty dopey when I'm low... Just like I get confused" Lucy

ADOLESCENTS' EXPERIENCE OF DM1 AND POOR GLYCAEMIC CONTROL

In fact, all participants described how difficult it was to oscillate between having high and low blood glucose levels with many appearing to struggle to make sense of their identities and sense of selves when embroiled in these opposing states. This is highlighted in the following quote from Chloe, who describes that the anger she directs towards her diabetes becomes directed towards herself.

"Like I become more angry at, like at the other side of me... but then... it's the same person, like when I'm angry at the diabetes I'm angry at me...umm... and it's confusing" Chloe

confusion about anger
↳ overwhelmed by Dx diagnosis + what it means about her

In addition to anger, four participants described struggling with feelings of guilt and shame, which resulted in them feeling angry and scolding themselves when their health deteriorated and their poor glycaemic control was exposed to healthcare professionals or parents.

"You feel bad about yourself cos you really want to try your best with it but like... sometimes it's like stuff it doesn't matter but then thinking about it properly you have to control it right or you'll get ill" Lucy

Lack of motivation, resentment, Lack of care.

"I get angry with myself again then cos... I know I need to do better sometimes like now I get I'm high a lot" Sarah

Building on the feelings of guilt and shame, three participants went on to make more global negative evaluations about themselves, describing themselves as 'pathetic', 'horrible' and 'childish'. It is therefore important to consider the detrimental effect these negative beliefs could have on the developing self-esteem and forming identities of these adolescents as they transition into adulthood.

"I'm not strong enough and stuff to like battle myself like... So it makes me feel like I'm a weak person... because I've been ill and I can't make myself better" Amy

Lack of control

Lack of faith in self + abilities to overcome barriers.

battle between recognising health implications + lack of motivation leads to self-criticism & ↓ motivation.

"I feel umm disappointed in myself... like I'm a like not a poor excuse of a person, but just a weak person... like the motivation to be healthy should be enough for someone to just do their injections every single day... and look after themselves... it's like I'm, it's stupid, I feel stupid in myself" Chloe

It is also important to note that whilst participants described feeling extremely negative about themselves, this was juxtaposed with four participants imagining having a more positive self-concept if their glycaemic control were to improve. This highlighted the importance placed by participants on their glycaemic control and the effect this had on their sense of self and self-worth as well as a direct impact on their mood.

"I'm sure I'd feel better as a... person or how I am like with my moods and stuff" Sarah

"poor control" → low mood, self-criticism → ↑ barrier.

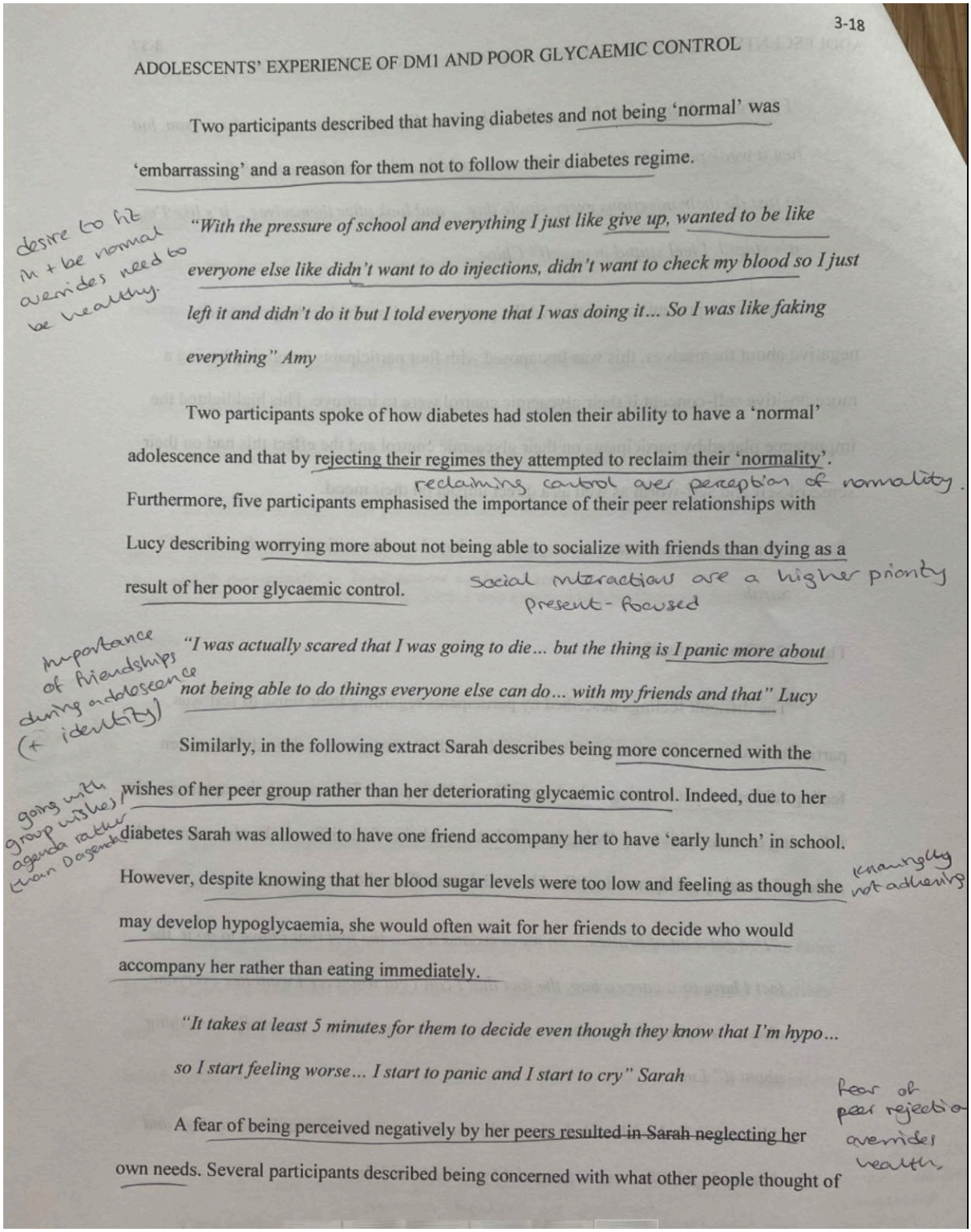
Theme 2: The social self

The difficult feelings described by participants regarding their sense of self was particularly acute in the context of their social worlds. A struggle was described between feeling 'different' yet wanting to be 'normal' with their peers. This struggle is captured in the following extracts with Lucy listing how diabetes made her feel different. Furthermore, both male and female participants described how diabetes affected their appearance.

"I've got a lot of bruises... on my arms and legs... the fact that I have to do it, the fact I have to... carry a bag, the fact that I can't eat whatever I want like everyone else... or I can't go drinking or go to a party or something... generally everything about it" Lucy

"Just the... look of the whole thing like marks on my tummy, marks on my legs and that, and I felt like... not a normal 14 year old girl" Amy

wanting to feel/be normal
fit in with peers.



3-18

ADOLESCENTS' EXPERIENCE OF DM1 AND POOR GLYCAEMIC CONTROL

Two participants described that having diabetes and not being 'normal' was 'embarrassing' and a reason for them not to follow their diabetes regime.

desire to fit in + be normal overrides need to be healthy.

"With the pressure of school and everything I just like give up, wanted to be like everyone else like didn't want to do injections, didn't want to check my blood so I just left it and didn't do it but I told everyone that I was doing it... So I was like faking everything" Amy

Two participants spoke of how diabetes had stolen their ability to have a 'normal' adolescence and that by rejecting their regimes they attempted to reclaim their 'normality'.

reclaiming control over perception of normality.

Furthermore, five participants emphasised the importance of their peer relationships with Lucy describing worrying more about not being able to socialize with friends than dying as a result of her poor glycaemic control.

Social interaction are a higher priority present-focused

importance of friendships during adolescence (+ identity)

"I was actually scared that I was going to die... but the thing is I panic more about not being able to do things everyone else can do... with my friends and that" Lucy

Similarly, in the following extract Sarah describes being more concerned with the wishes of her peer group rather than her deteriorating glycaemic control. Indeed, due to her diabetes Sarah was allowed to have one friend accompany her to have 'early lunch' in school.

going with group wishes/ agenda rather than Dagenkolb

However, despite knowing that her blood sugar levels were too low and feeling as though she may develop hypoglycaemia, she would often wait for her friends to decide who would accompany her rather than eating immediately.

knowingly not adhering

"It takes at least 5 minutes for them to decide even though they know that I'm hypo... so I start feeling worse... I start to panic and I start to cry" Sarah

A fear of being perceived negatively by her peers resulted in Sarah neglecting her own needs. Several participants described being concerned with what other people thought of

fear of peer rejection overrides health.

self-identity becomes negative with + without adherence.

them and compared themselves unfavourably with others. Three participants spoke of having a negative sense of self at a wider societal level.

"Cos well I'm a hindrance to the NHS... I'm a waste of tax... payers money" Shaun

"Like I've been like a horrible person, and like I feel sick with myself like how can you be making yourself ill... when there's so many people out there who are really, really ill, like people with terminal cancer or like people in Africa who have no food and water... but I've got the opportunity to... make myself better... and to be healthy... and like they don't have no chance at all but I do" Chloe

Theme 3: The self and relationships

All participants described how having poor glycaemic control negatively impacted on their relationships with parents or healthcare professionals. Indeed, all participants described having conflicts with their mothers, who encouraged them to improve their glycaemic control. For example, in the extract below Ben describes arguing with his mother about his blood sugar readings.

"Basically she says my numbers which I don't agree with and she goes I don't even know why I bother helping you [laugh]... Cos I always say no to everything... she says" Ben

Whilst many adolescents described not wanting help or input from family members, they also recognised that they found the help useful. This highlighted that these participants were very much in transition between childhood and adulthood as they grappled between wanting to elicit care from parents, enjoying being 'looked after" and also wanting to be independent.

ADOLESCENTS' EXPERIENCE OF DM1 AND POOR GLYCAEMIC CONTROL

"I don't like that they're constantly on me like do this do that but also I need them there to check" Amy

In response to their parents' questions and to avoid getting into trouble two participants described frequently lying to their parents about their adherence behaviours including their diet, insulin injections and blood glucose testing.

"Mum was like, or she'd ask when I get home, 'have you done the injection?' 'Yes'... it's just easy to say it" Amy

"I lie... but I think that's the worst thing you can do 'cos you just get into lies... like one big lie and you can't get out of it... So it sort of becomes a habit that I lie every time my blood isn't right" Lucy

Participants described that lying to their parents resulted in both inter-personal and intra-personal conflicts as they argued with their parents alongside feeling extremely guilty as they believed their parents no longer trusted them. It is therefore important to consider not only the effect these behaviours had on their relationships but also on the way the participants viewed themselves and their roles within relationships.

"I remember going to bed at night and... I couldn't sleep and I'd lie there for ages and think about everything I'd done and that I'd lied and just feel really bad about yourself and everything you've done" Lucy

"I felt awful because I was... like really upset and that because I felt like I had betrayed them kind of thing... Because with me doing everything wrong and that... because they trusted me to... do it myself" Amy

Poor adherence leads to guilt, shame + self-depreciation.

Participants described times when they were overwhelmed by feelings of guilt and shame about how their lies and poor glycaemic control effected family members.

↑ guilt due to impact on family system.

Furthermore, participants recognised that it was the consistency with which they told small lies that corroded their relationships in the longer term.

"I say sorry so often to them and like they don't think I mean it" Sarah

Similar to the feelings of guilt evoked when participants concealed the truth from their parents, many described intense feelings of shame when attending the diabetes clinic as the 'truth' about their lack of adherence behaviours was revealed. Whilst some participants considered health professionals to be helpful, many described being criticised by them as 'too much'. Furthermore, three participants believed that health professionals were angry with them, but were disingenuous in trying to conceal their true feelings and 'act ok about it'.

"It was just like how they spoke to me... they were like dismissive and... they'd always see like the negative... side of things rather than the what I'm doing... good" Chloe

"They don't give me a row but you feel the way they speak to you, you can just tell that they... want to go nuts with you type of thing" Lucy

It is important to consider whether these evaluations were accurate or whether the participants were projecting their negative evaluations of themselves onto professionals. In the following quotes Shaun and Chloe emphasise that as it was the professionals 'job' to care for them, thus indicating that professionals' did not understand the burdensomeness of diabetes as they were not diabetic themselves; evoking a sense of isolation and difference.

"It's her job... That's generally how I feel towards her" Shaun

"Doctors who haven't got it, it's like... they come into clinic and they think I'll tell you this and you're not doing well, you're not injecting... and they can just walk out of clinic and they're like... they're fine... it's like their job" Chloe

Shaun's lack of identification with professionals led him to ignore the guidance and advice provided.

lack of identification with HCP → rejection of advice.

"I just sort of sit there and listen, that's my bit... and then I leave... and I don't do anything that she says" Shaun

In addition to describing difficult relationships with healthcare professionals, many participants described attending clinic as a 'nerve wrecking' experience, because they knew their blood glucose levels would be shared with their parents. As illustrated in the following extracts, three adolescents described experiencing high levels of anxiety prior to attending clinic.

"It's just like this horrible like sick feeling you get before clinic... and then it feels like... I'm going to let them down, like I don't want to let them down" Chloe

"I know that I've been doing my bad habits and it's going to show in clinic like and they'd know the truth and stuff about things... and I just hate saying it" Amy

These participants described being 'exposed' in the diabetes clinic, indicating that attending was often a shaming experience, resulting in them feeling guilty and bad about themselves. Furthermore, in the following extract Lucy describes that the guilt evoked in clinic was not limited to herself as her mother also felt blamed, which in turn appeared to perpetuate Lucy's sense of guilt.

↑ shame
↳ giving up?

"I don't like to go there because... the truth comes out there all of it... If I've lied or something or if the blood's high it makes mum feel rubbish cos she feels to blame" Lucy

Theme 4: The cyclical nature of glycaemic control

The final theme represents the constantly changing and cyclical nature of the

thoughts, feelings, behaviours and glycaemic control of participants. All participants demonstrated knowledge of DM1 and the associated health complications, and initially described being motivated to adhere to their regimes. Furthermore, they described worrying about their futures and the complications associated with poor glycaemic control.

> *"Mum warns me a lot cos with my feet and my eyes and that cos there's damage or something to my eye already... and just with like... my organs and that... If I don't look after myself it will affect them too" Lucy*

However, although very knowledgeable of the risks involved with non-adherence, participants described that in reality they only managed to adhere to their regimes for short periods of time, before slipping back into poor glycaemic control.

> *"I'll start doing it for like two days and I'll lose motivation and then about a week later I'll check again and do it again for like two days" Sarah*

The inability of participants to adhere to their regimes in the long-term appeared to be perpetuated by oscillating between feeling distressed by their poor glycaemic control and then feeling ambivalent about adhering to the regime and 'giving up'. Perhaps reflecting their developmental stage, five adolescents portrayed a sense of indestructability, rebellion and ambivalence regarding risks, which in turn enabled them to stop adhering to their regimes.

> *"I don't really care what the consequences are at the moment" Shaun*

> *"I feel that because I'm diabetic... and I'm not supposed to eat loads of sugar and that, I do eat lots of sugar... Because I know I'm not supposed to, so I do" Amy*

Furthermore, their ambivalence appeared to be reinforced by hidden hopes that a diabetes cure would be found. Three participants fantasised that their diabetes was not real or permanent, which negatively impacted on their adherence behaviours.

"There's a part of me like that... that wants to believe that... there will be a cure , it will just magically stop or like it's not really diabetes, it's just something... in my pancreas... that's stopping the insulin... and they just haven't found it yet... I think that's a reason for me not wanting to inject... and test because... always think what's the point putting myself through this... if I don't have it" Chloe

mistrust in diagnosis/science/medicine? denial rejecting Diabetes.

"Well I don't know how long it will take them or if they are going to find a cure for it... I'd like them to find it before I sort of grow up" Lucy

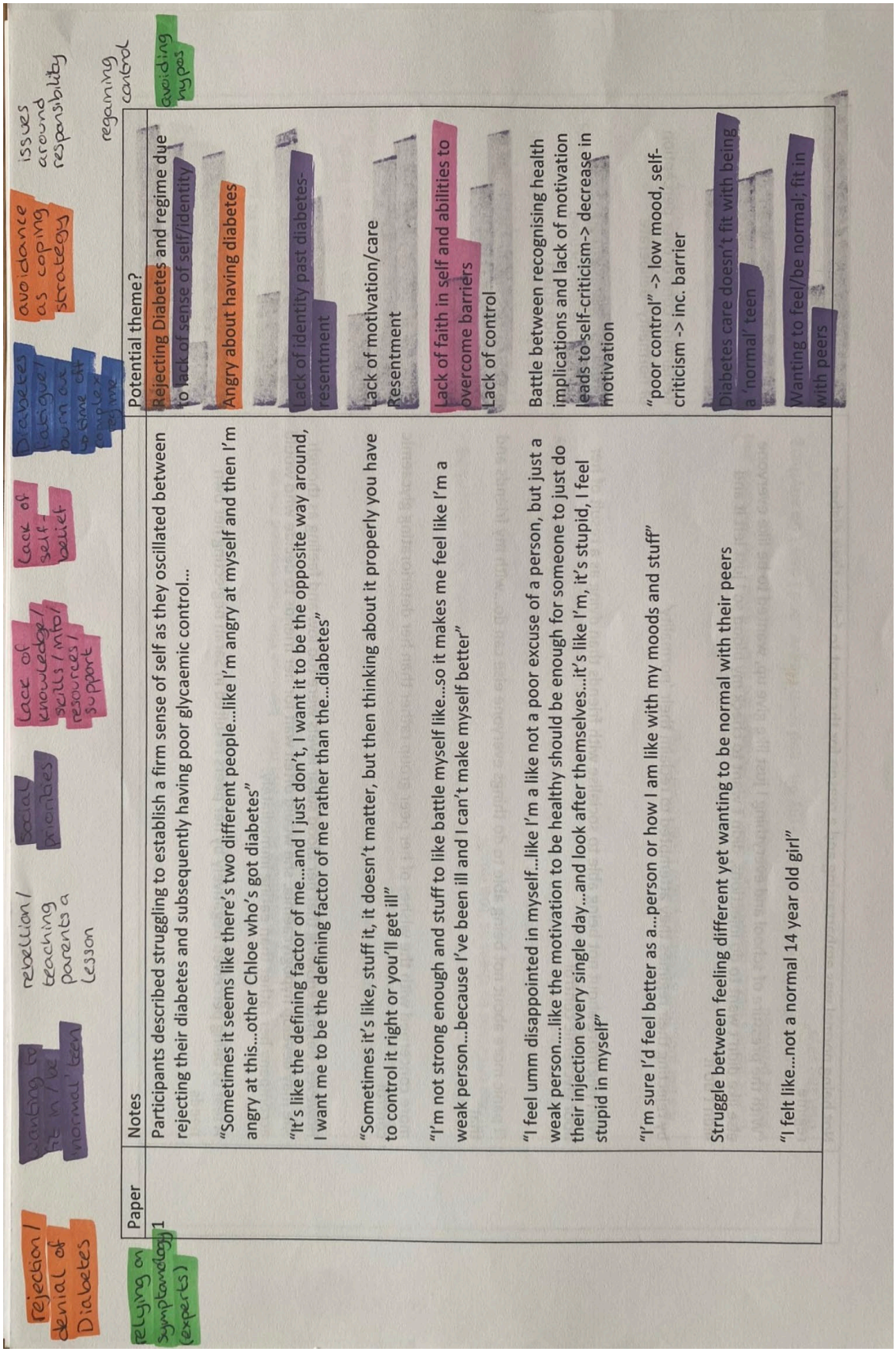
Ambivalence regarding the need for adherence resulted in non-adherence in the short-term. However, non-adherence was not sustainable in the long-term due to deteriorating glycaemic control and the resurfacing of associated feelings of guilt, thus resulting in a cyclical pattern of deteriorating and improving glycaemic control. Perhaps being ambivalent initially served as a buffer which protected participants from their self-critical thoughts. It is also important to consider whether the ambivalence served as a façade enabling participants to hide their difficult feelings from others. Unfortunately, regardless of the function of this ambivalence, it seems that it ultimately deepened the participants' intra-personal struggles with guilt and shame. Indeed, this indicates that if adolescents were better able to accept their diabetes, their glycaemic control and psychological wellbeing could improve. The oscillating model of glycaemic control captured in this theme is represented diagrammatically in Figure 1.

façade to hide internal struggle?

accepting diagnosis.

Discussion

This study aimed to explore adolescents' experience of living with DM1 and poor glycaemic control. The four superordinate themes indicated that participants struggled to develop a cohesive identity as they attempted to reject their diabetes and associated feelings



Paper	Notes	Potential theme?
1	Participants described struggling to establish a firm sense of self as they oscillated between rejecting their diabetes and subsequently having poor glycaemic control...	Rejecting Diabetes and regime due to lack of sense of self/identity
	"Sometimes it seems like there's two different people...like I'm angry at myself and then I'm angry at this...other Chloe who's got diabetes"	Angry about having diabetes
	"it's like the defining factor of me...and I just don't, I want it to be the opposite way around, I want me to be the defining factor of me rather than the...diabetes"	Lack of identity past diabetes-resentment
	"Sometimes it's like, stuff it, it doesn't matter, but then thinking about it properly you have to control it right or you'll get ill"	Lack of motivation/care Resentment
	"I'm not strong enough and stuff to like battle myself like...so it makes me feel like I'm a weak person...because I've been ill and I can't make myself better"	Lack of faith in self and abilities to overcome barriers Lack of control
	"I feel umm disappointed in myself...like I'm a like not a poor excuse of a person, but just a weak person.....like the motivation to be healthy should be enough for someone to just do their injection every single day...and look after themselves...it's like I'm, it's stupid, I feel stupid in myself"	Battle between recognising health implications and lack of motivation leads to self-criticism-> decrease in motivation
	"I'm sure I'd feel better as a...person or how I am like with my moods and stuff"	"poor control" -> low mood, self-criticism -> inc. barrier
	Struggle between feeling different yet wanting to be normal with their peers	Diabetes care doesn't fit with being a 'normal' teen
	"I felt like...not a normal 14 year old girl"	Wanting to feel/be normal; fit in with peers

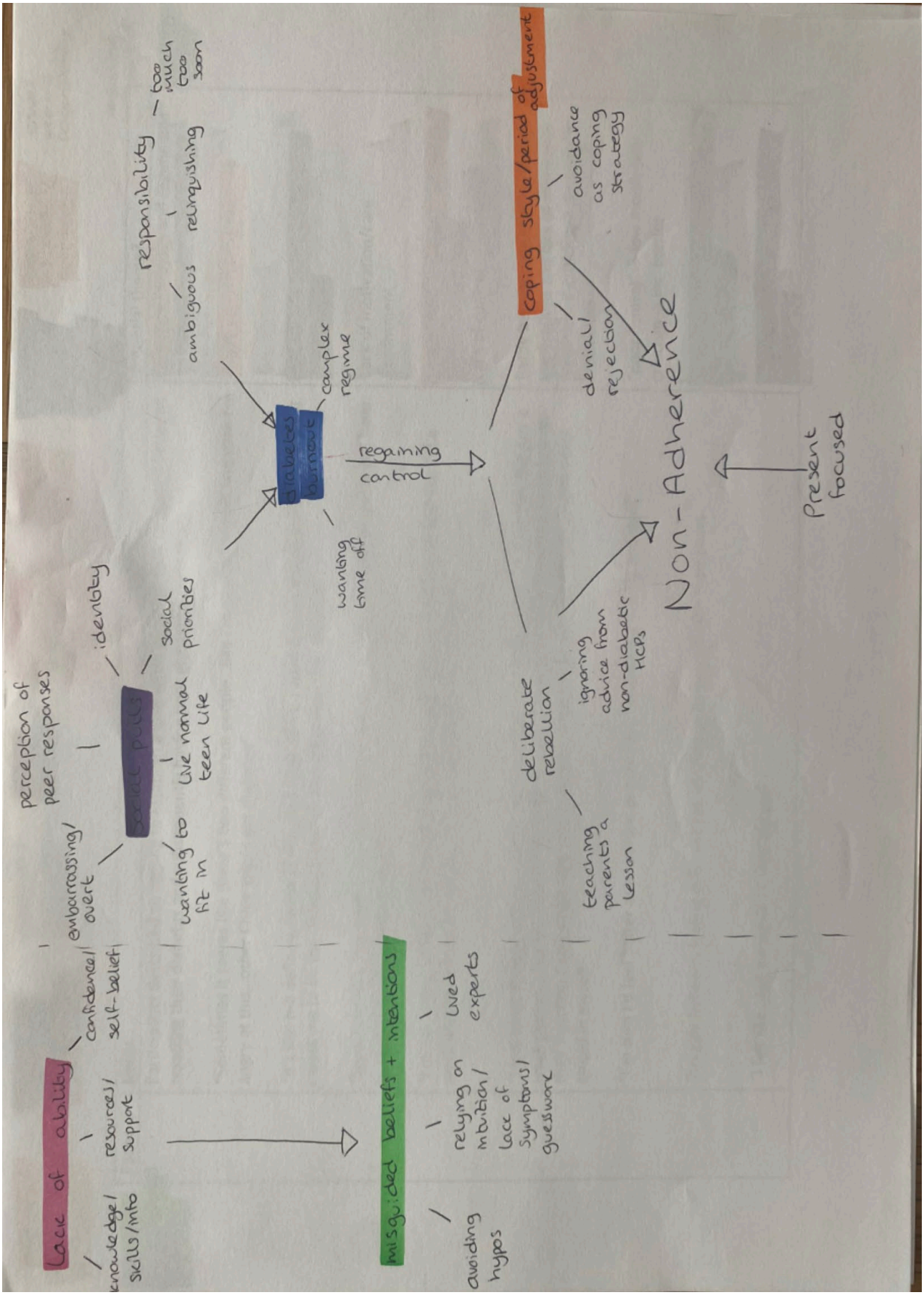
avoiding hypos

	Prioritised schoolwork and extracurricular activities over diabetes care, self-management interfered with their ability to keep up with peers Performing self-management was seen as a reminder of the condition and avoidance was a means of temporary escape "Like sometimes I'll skip out on checking my blood sugar. Or giving myself insulin because I just don't want it, like I don't want to have this, I don't want to have this at all. Sometimes I try to forget about it completely and not do it" Limitations in eating, especially in public and social settings, and imposed social limitations by their parents due to diabetes. For example, many were not allowed to sleep over at a friend's house. Anxiety about treating diabetes in public, especially in front of untrusted peers. They did not want to be exposed as 'sick' or 'different'. Many youth would decrease their insulin and increase their carbohydrates if they planned to go out for a social event: "That morning I'd lowered my insulin dose so that I didn't go low on the hike...and there wasn't really anything to kind of help if I got low on the hike...I sat down and checked my sugar and I was HI because I had kind of overcompensated" Some refused to wear insulin pumps or continuous glucose monitors because they could be seen and heard. Others would silence their alarms during the day- "I don't need, like, something bleeping during the day, like, drawing attention to me" Youth reported that T1D was a second full-time job, an added 'layer' that further complicated the already challenging experience of adolescence. The more 'layers', the more difficult it was to integrate diabetes into daily life.	Avoidance as escape from diagnosis Denial Avoidance of condition Resent condition Lots of restrictions/limitations leading to resentment Purposeful non-adherence by changing regime Avoiding hypo Lack of resources for hypo- prefer hyper? Value discreetness Fitting in with others/not drawing attention more important Deliberate and non-intentional non-adherence Accumulative stress -> less adherence Burnout/overwhelmed Integration and acceptance needed before adherence

	Parents should be there as back-up when the teenager lacks decision-making competence. On the other hand, they should be ready to withdraw their support when the teenager is finally able to make independent decisions.	
5	Patients compared themselves with their friends, and when they saw themselves with some restrictions (such as eating no sweets) and feeling of losing organs, they experienced stress and lost their incentive to continue their daily treatment plan and self-care behaviours. Lack of confidence in their abilities or feelings of low self-efficacy in all participants was a major obstacle in their self-care activities. When an adolescent thinks that the illness is injustice and oppression, this can influence their motivation to perform self-care behaviours and control the disease. Patients have to hide their illness for fear of confrontation with others because the stigma associated with diabetes in rooted in the lack of information about the disease.	Restrictions/loss leading to dec. motivation Resentment towards condition and treatment Lack of confidence/self-belief Oppressed by Diabetes -> dec. motivation Stigma Wanting to feel normal; fitting in
6	"...I am bored now. Why can't I just die? It was the question that I was thinking every minute. Why did I become a diabetic? I'm only 14 years old. Why me, while there are so many people out there?" "Taking pills is not such a difficult thing. But the insulin represents a different dimension. It is a hard job to arrange it" They wanted to look good "...well, I do not like at all walking with a machine (glucometer) in my pocket" During the conversation, researchers noticed that adolescents lacked knowledge regarding diabetes management	Thoughts of 'why me?' may lead to resentment of diabetes and apathy about living -> dec. motivation Difficult/complex/painful treatment Social pressures to fit in, act normal, look normal Not normal to have to do this

	"I take it normally, I got used to sticking, at first it was bad, I did not even use it"	Pain as barrier Period of adjustment
	It is essential for them to differentiate the symptoms of hypo and hyperglycaemia	Intricacies of diabetes- which response for which symptoms
	"Usually, I get to feel it, then I eat something, so it goes back to normal, but then when it comes back it goes too high"	Getting balance right Relying on symptom intuition
	"I feel hungry, I take the Dx and then if it is low, I eat something. I've had hypoglycaemia"	Using treatment in response to eating, rather than planning ahead- then unpleasant hypo Complex regime
	"It's in physical exercises, I have a little difficulty, it's because I do not have a fixed activity, I do not play football, and I do not swim."	Expectation of exercise dependent on availability and enjoyment
	"The difficulty I have is with the money to buy food"	Resources- availability of food or money to buy food Non-deliberate
	"...practicing exercise and some days you are not willing to do so...it's difficult [not eating when others are]"	Difficult regime- sometimes lose motivation/interest – diabetes burnout? Difficult when everyone else is eating Not fitting in/ could be excluded

	In their eyes, appearing normal was more important than physical comfort or possible health risks.	
	In the face of demanding diabetes management tasks and the stress of T1DM, some of the adolescents expressed frustration and fatigue with their diabetes self-management tasks and a desire to forsake all of these requirements. "I need to be very honest to tell you that I really hate this disease. It's like a chain that I am trapped by"	Diabetes fatigue/ burnout
	These adolescents repeatedly mentioned that many difficulties they had encountered at school, such as limited food choices, the long walk to the health centre, and the inconvenience of bringing supplies to school each day, all of which hampered self-management.	Availability of resources to manage diabetes- non-deliberate
	Sometimes they chose to avoid performing required tasks although they knew it was not good for their health and safety.	Deliberate NA to avoid embarrassment in public/ wanting to appear normal/fit in
	For example, rather than checking blood glucose with a glucose meter, most participants used symptoms as the main or supplemental indicator to judge glucose levels. They thought they would be fine if they paid attention to their bodies, believing that such sensations were reliable indicators of their glucose levels. It was perceived as a way to earn freedom or gain control. "I haven't checked my sugar for a long time. I feel it's enough to sense my body. If my sugar is high, I'll feel uncomfortable. If it's low, I'll feel uncomfortable too. I'm not so stupid to be unaware of my discomfort." "So far I haven't read anything regarding diabetes on my own. My mom will teach me, and I feel that's enough"	Relying on intuition rather than blood glucose meter to judge need for treatment. Misguided information Reliance on parents to learn -> contributes to lack of knowledge


Lack of ability
knowledge/ skills/info
resources/ support
confidence/ self-belief
embarrassing/ overt
perception of peer responses
identity
social pulls
social priorities
wanting to fit in
live normal teen life
responsibility
ambiguous
relinquishing
too much too soon
diabetes burnout
complex regime
wanting time off
regaining control
coping style/period of adjustment
denial/ rejection
avoidance as coping strategy
Non-Adherence
present focused
deliberate rebellion
ignoring advice from non-diabetic HCPs
teaching parents a lesson
misguided beliefs + intentions
relying on intuition/ lack of symptoms/ guesswork
lived experts
avoiding hypos

Libre for 21 months

Researcher: Please describe your experiences, good or bad, of your child using the blood glucose monitoring device

YP2: Oh it's definitely good. Um, it's just so much easier than having to get out the finger-pricker and blood-tester every time you wanna, you know, test the blood. Erm, it's kind of, yeah, it's a lot quicker. Erm, it means that, I kind of know what my levels are doing, erm, pretty much all the time, whereas before it would be when I woke up and when I went to bed and then when I eat. Um, and it's helped, um, with my Lanctus injections, um, so I'm not hypo-ing during the night as much-from giving too much Lanctus. Cos, like it lets you see what you're doing like 8 hours I think it is, erm, between each scan. So, yeah.

Researcher: OK, and did you have any expectations when you started using the Libre and did these differ at all to your actual experiences?

YP2: Erm, I didn't really have many expectations- I thought it would hurt having it in a lot more, and I didn't think I'd be able to put it in myself, like I thought it would be something I'd have to go and have done. Erm, but it's just a lot easier, it doesn't hurt at all-unless you rip it out of course [laughs].

Researcher: And does that happen often?

YP2: Err...not often, um, but kind of sometimes it'll be too far round on my arm, erm, so like, the curve of my arm plus, like, you know, my clumsiness, don't exactly mix well [laughs] and I'll whack it and it'll rip off or, erm, or like I'll get dressed a bit too quickly and completely forget about it and it'll, like, tug it a bit, erm, but no it doesn't happen often.

Researcher: And does that cause problems when it does happen, in terms of replacing it?

YP2: Erm, usually it's fine if I've got another sensor at home, erm, but if like I'm waiting to pick up a prescription then it can be a bit of a pain and I'll have to, kind of wait, and just use my blood tester until I can get a new one to put on.

Researcher: Mmm. So, we've sort of touched on this, but what would you say has been helpful or unhelpful about using the device?

more data = knowledge + trends = more info = control

YP2: Erm, definitely like, being able to see, like, cos it gives you the graph that shows you what your levels are doing, rather than just, exactly what it is in the moment of time that you do a proper blood test. Erm, sometimes, when, like when I'm hypoing, erm, I'll scan it and it'll- and I'll do a blood test as well- but the blood test will be completely different to what it's said.

inaccuracy at extremes.

Researcher: OK-

YP2: -generally it's pretty much spot on, but when my levels are...quite high or quite low, that's when it can have a bit of erm...like, it might be, a bit different.

inaccuracy at extremes.

Researcher: Mmmm-

YP2: -yeah, and it's quick and easy, and not painless, especially compared to FP. [laughs].

convenient, easy

Researcher: Yeah, yeah. And, you mentioned there that when, perhaps it's at the extreme, so either very high or very low it seems a bit inaccurate, so- this might be a silly question-, but how do you know which one to trust, the device or the blood test?

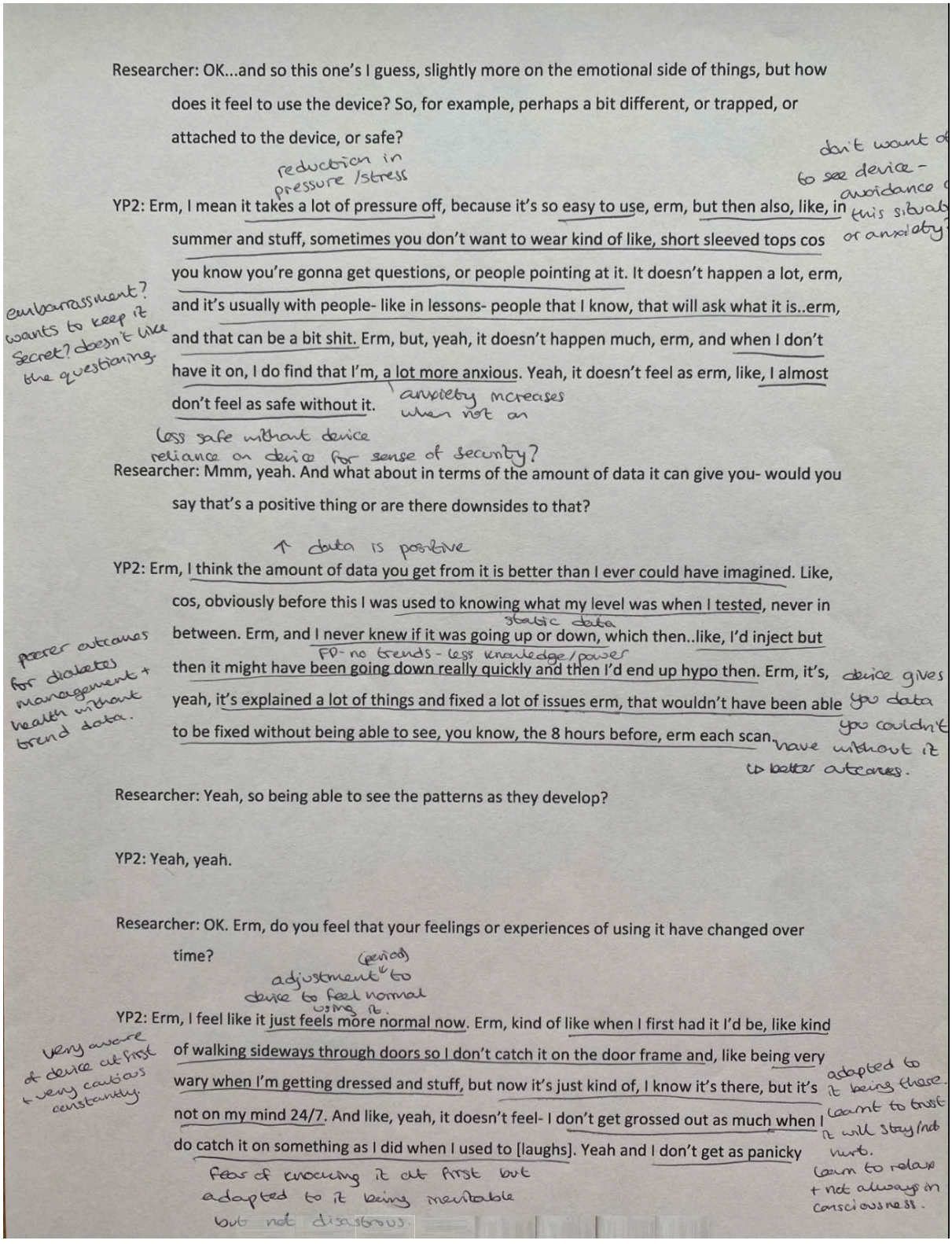
YP2: Oh, the blood tester, always, cos that's the actual blood whereas the Libre is, I can't remember what it is, but it's not your actual blood.

discrepancy- believe FP- not total dependence/over-reliance on device

Researcher: Yeah. OK, and I guess, if there was that discrepancy between the blood test and the device, does that cause any mistrust towards the device or is it quite an in the moment thing, do you think?

YP2: Err, I'd say it's more in the moment thing. Like, when we had the, like, course for it, erm, they did say that, erm, it's, more- like, it's less accurate the more extreme your levels are. Erm, so I kind of have expected that anyway.

prepared for inaccuracy at extremes.



Researcher: OK...and so this one's I guess, slightly more on the emotional side of things, but how does it feel to use the device? So, for example, perhaps a bit different, or trapped, or attached to the device, or safe?

reduction in pressure / stress

don't want to see device - avoidance of this situation or anxiety?

YP2: Erm, I mean it takes a lot of pressure off, because it's so easy to use, erm, but then also, like, in summer and stuff, sometimes you don't want to wear kind of like, short sleeved tops cos you know you're gonna get questions, or people pointing at it. It doesn't happen a lot, erm, and it's usually with people- like in lessons- people that I know, that will ask what it is..erm, and that can be a bit shit. Erm, but, yeah, it doesn't happen much, erm, and when I don't have it on, I do find that I'm, a lot more anxious. Yeah, it doesn't feel as erm, like, I almost don't feel as safe without it.

embarrassment? wants to keep it secret? doesn't like the questioning.

anxiety increases when not on

less safe without device

reliance on device for sense of security?

Researcher: Mmm, yeah. And what about in terms of the amount of data it can give you- would you say that's a positive thing or are there downsides to that?

↑ data is positive

YP2: Erm, I think the amount of data you get from it is better than I ever could have imagined. Like, cos, obviously before this I was used to knowing what my level was when I tested, never in between. Erm, and I never knew if it was going up or down, which then..like, I'd inject but then it might have been going down really quickly and then I'd end up hypo then. Erm, it's, yeah, it's explained a lot of things and fixed a lot of issues erm, that wouldn't have been able to be fixed without being able to see, you know, the 8 hours before, erm each scan.

static data

FP- no trends - less knowledge / power

poorer outcomes for diabetes management + health without trend data.

device gives you data you couldn't have without it to better outcomes.

Researcher: Yeah, so being able to see the patterns as they develop?

YP2: Yeah, yeah.

Researcher: OK. Erm, do you feel that your feelings or experiences of using it have changed over time?

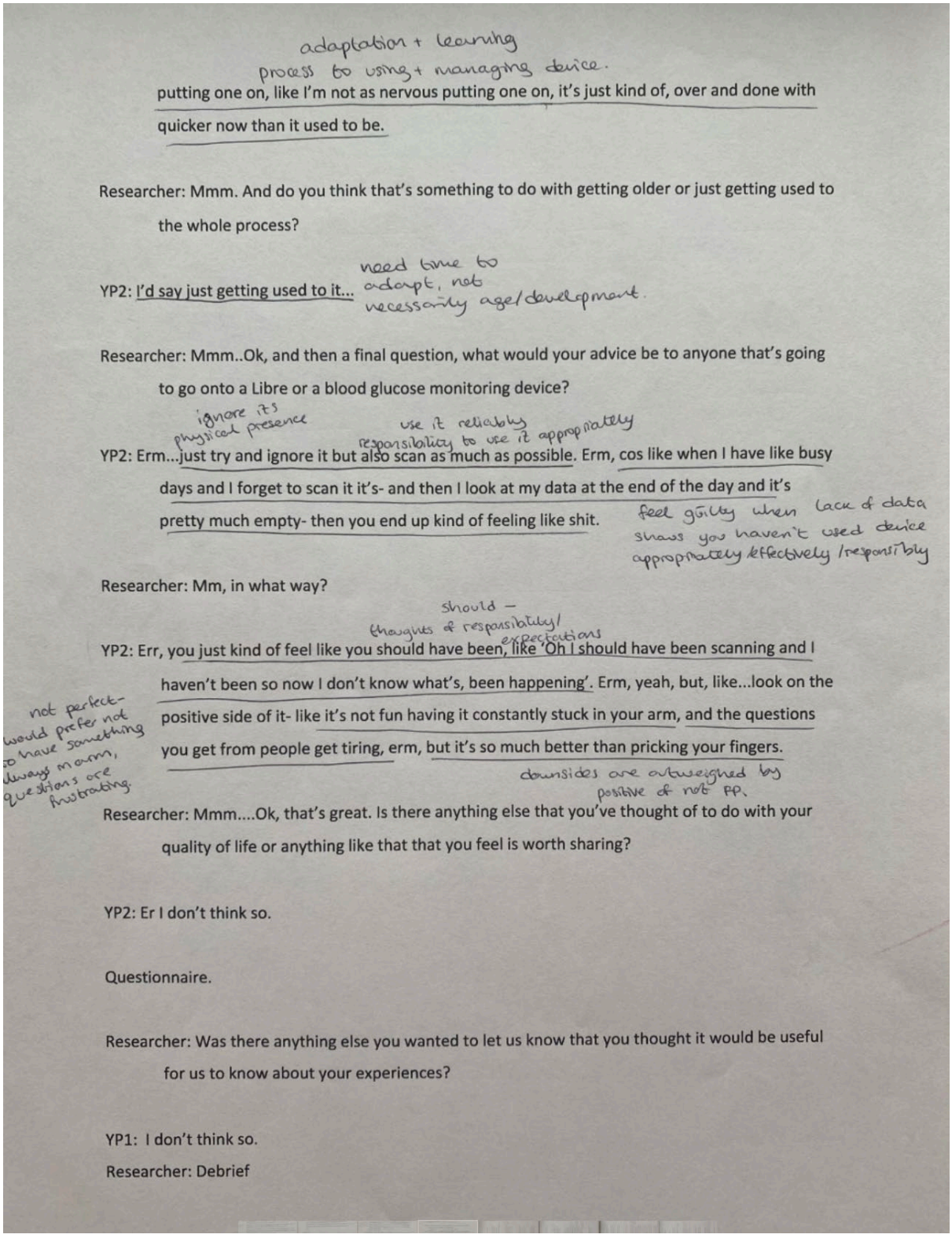
(period) adjustment to device to feel normal using it.

YP2: Erm, I feel like it just feels more normal now. Erm, kind of like when I first had it I'd be, like kind of walking sideways through doors so I don't catch it on the door frame and, like being very wary when I'm getting dressed and stuff, but now it's just kind of, I know it's there, but it's not on my mind 24/7. And like, yeah, it doesn't feel- I don't get grossed out as much when I do catch it on something as I did when I used to [laughs]. Yeah and I don't get as panicky

very aware of device at first + very cautious constantly.

adapted to it being there. Learnt to trust it will stay/not hurt. Learn to relax + not always in consciousness.

fear of knocking it at first but adapted to it being inevitable but not disastrous.



adaptation + learning process to using + managing device.

putting one on, like I'm not as nervous putting one on, it's just kind of, over and done with quicker now than it used to be.

Researcher: Mmm. And do you think that's something to do with getting older or just getting used to the whole process?

need time to adapt, not necessarily age/development.

YP2: I'd say just getting used to it...

Researcher: Mmm..Ok, and then a final question, what would your advice be to anyone that's going to go onto a Libre or a blood glucose monitoring device?

ignore its physical presence

use it reliably responsibility to use it appropriately

YP2: Erm...just try and ignore it but also scan as much as possible. Erm, cos like when I have like busy days and I forget to scan it it's- and then I look at my data at the end of the day and it's pretty much empty- then you end up kind of feeling like shit.

feel guilty when lack of data shows you haven't used device appropriately/effectively/responsibly

Researcher: Mm, in what way?

should – thoughts of responsibility/ expectations

YP2: Err, you just kind of feel like you should have been, like 'Oh I should have been scanning and I haven't been so now I don't know what's, been happening'. Erm, yeah, but, like...look on the positive side of it- like it's not fun having it constantly stuck in your arm, and the questions you get from people get tiring, erm, but it's so much better than pricking your fingers.

not perfect- would prefer not to have something always mean, questions are frustrating.

downsides are outweighed by positive of not FP.

Researcher: Mmm....Ok, that's great. Is there anything else that you've thought of to do with your quality of life or anything like that that you feel is worth sharing?

YP2: Er I don't think so.

Questionnaire.

Researcher: Was there anything else you wanted to let us know that you thought it would be useful for us to know about your experiences?

YP1: I don't think so.

Researcher: Debrief

G6 11 year old female, CGM for 2-2.5 years.

Researcher: Please can you describe your experiences, good or bad, of your child using a blood glucose monitoring device?

P5: In, in the main, we find it better than injections because we haven't got to do finger pricks all the time and consequently it's less invasive for [YP5]. Erm, we also, obviously, we can keep an eye on her ourselves on our phones which is extremely useful. I mean, [YP5]'s not always totally committed to, erm, dealing with it herself. She, she's 11 now and suddenly she's [incomprehensible] it's fair to say, and erm, well I, I think she takes the broad view that 'well they'll do it, why should I?'.

Researcher: [laughs] yeah-

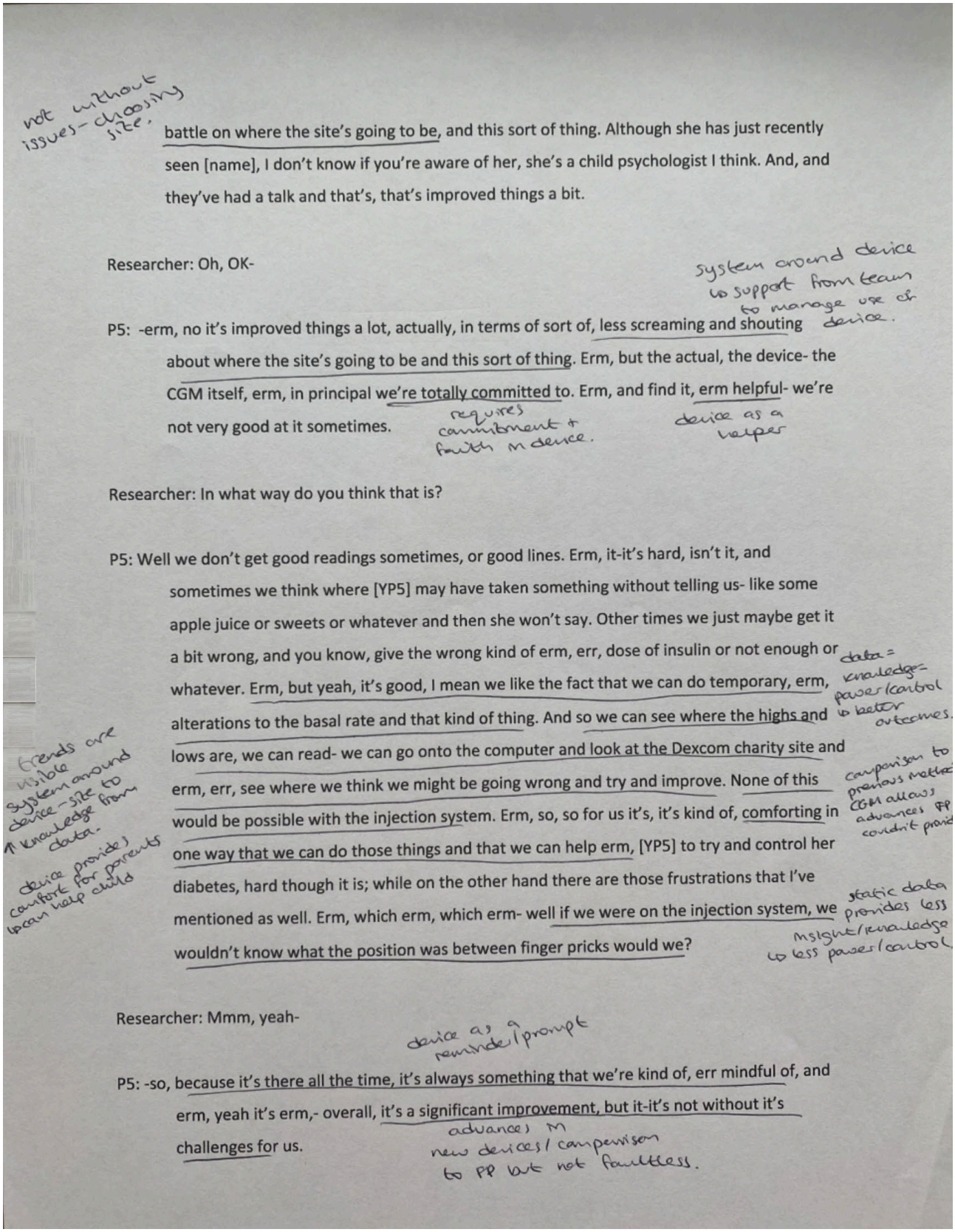
P5: -[laughs] which I suppose is understandable from an 11 year old, erm, but it-it's a bit frustrating for us at times when the alarm goes off and she doesn't take any notice of it at all, she'll just literally carry on to play on her computer game or, or sleep or whatever it is. She-she just- it's like a train going past the window, you eventually get used to it and you don't hear it. It's almost as if she just doesn't kind of, erm, think it's something that affects *her*...which is a bit, kind of, frustrating for us.

Researcher: Mmmm.

P5: But the, the actual monitoring itself, erm, in, in the main, we're pretty happy with it. The pumps, the erm sensors don't always last as long as they should, errr, we're not always quite sure why that is, whether it's because she doesn't rotate her sites enough which has been a problem, erm or whether that's because of a fault with the erm, with the unit itself. I don't know, but sometimes it would only last 3 or 4 days when they're supposed to last 10.

Researcher: Oh right, OK-

P5:- and we [reported this] to the diabetes team, and to Dexcom themselves, and I think they say well... they're, they're not really sure I don't think, erm, why that would be. Erm, so that's a bit trying at times cos she'd have to change it again more often and so on, and she'll have a



battle on where the site's going to be, and this sort of thing. Although she has just recently seen [name], I don't know if you're aware of her, she's a child psychologist I think. And, and they've had a talk and that's, that's improved things a bit.

Researcher: Oh, OK-

P5: -erm, no it's improved things a lot, actually, in terms of sort of, less screaming and shouting about where the site's going to be and this sort of thing. Erm, but the actual, the device- the CGM itself, erm, in principal we're totally committed to. Erm, and find it, erm helpful- we're not very good at it sometimes.

Researcher: In what way do you think that is?

P5: Well we don't get good readings sometimes, or good lines. Erm, it-it's hard, isn't it, and sometimes we think where [YP5] may have taken something without telling us- like some apple juice or sweets or whatever and then she won't say. Other times we just maybe get it a bit wrong, and you know, give the wrong kind of erm, err, dose of insulin or not enough or whatever. Erm, but yeah, it's good, I mean we like the fact that we can do temporary, erm, alterations to the basal rate and that kind of thing. And so we can see where the highs and lows are, we can read- we can go onto the computer and look at the Dexcom charity site and erm, err, see where we think we might be going wrong and try and improve. None of this would be possible with the injection system. Erm, so, so for us it's, it's kind of, comforting in one way that we can do those things and that we can help erm, [YP5] to try and control her diabetes, hard though it is; while on the other hand there are those frustrations that I've mentioned as well. Erm, which erm, which erm- well if we were on the injection system, we wouldn't know what the position was between finger pricks would we?

Researcher: Mmm, yeah-

P5: -so, because it's there all the time, it's always something that we're kind of, err mindful of, and erm, yeah it's erm,- overall, it's a significant improvement, but it-it's not without it's challenges for us.

Researcher: Mmm. I'm wondering, on the times when you feel that [YP5]'s sugars are out of line, do you find yourself checking the results more often at those times, or do you check-

overt indication of issue - proactive rather than passive readings

P5: -well the thing bleeps, you've got no choice really [laughs]. If you do corrections or there's some kind of up or down, erm, if it hasn't worked I mean it'll let you know quite quickly because of the alarms.

can help to refine Diabetes practice through instant notification of errors/ things to change

Researcher: OK, and what about times when perhaps- obviously this isn't happening right now, but perhaps when out with friends or out at school, are you aware that the machine's alarming for her? Do you get notifications?

P5: Yes.

Researcher: And how is that managed for you? Obviously not being with her to be able to intervene yourself, how does that work for you?

P5:Well, probably we'll-if it's in school time we'd probably expect- up until about just before they finished before Christmas I think it was, the school care plan, erm, was that they took responsibility. So, erm, it was the school was kind of in loco parentis if you like, and they had the care plan signed off by the diabetes team and we left it to them to deal with it. We didn't always agree with what they're doing and I think consequently, we had a further talk with the diabetes team and we've now agreed a different strategy, erm where, much of the responsibility has been returned to [YP5] herself, with the help as necessary to do her own treatment in the main. Certainly, unless there is a massive high over 13.9 when she has to do ketones, but as long as they're below 13.9 [YP5] will manage the condition herself by use of the pump and/or glucose as necessary. Erm, but I think the teachers do get involved and say 'come on [YP5], you know, you're thing's gone off, what are you going to do?', and they have this kind of friendly discussion about it and come to a decision about what will happen; hopefully [YP5] does. And when she goes to high school next, err, September (all being well), erm, she'll be better placed to manage the condition herself again. And as she gets older and being more mature, that's what we're looking for.

handing over of responsibility to school - trust in device system around device

YP taking on more responsibility as device less overwhelming for YP to do this?

device + its alarm serves as prompter for guardians system around device

The other part of your question which is regarding our interventions, as I say when she's in school, probably not much, erm, but erm, we do tend to send texts to her if she's with her

system around device allows parents to resume control if necessary when YP not with them

friends and say look, or we'll ring her, and we sort of come to an agreement by text messages as to what's gonna happen, erm, as necessary.

Researcher: OK, yeah, and it sounds like it's a big thing for the family to manage isn't it and-

P5: -Oh yeah, yeah, it's it's a massive- I wouldn't call it an intrusion on our lives but I suppose it's a massive challenge for us all to try and keep on top of it and it's obviously something [where] you can't have a day off, sort of thing. It's always there and in the uppermost of our thoughts where at mealtimes for example or if the machine and the alarm goes off.

alarm serves as constant reminder.

Researcher: Mm, there's kind of no getting away from it.

P5: -and what's the worst time is at night. Sometimes, you know, you might say it's our fault, and perhaps it is in some respect for getting it wrong, but we can be up 5,6 times a night, you know attending and pressing buttons on that blinking machine. [Laughs], you know, it's just, you can imagine can't you...it's not great to have broken sleep, but you know, we're committed to it as I say and one of us does it. Erm, and err, there's no alternative is there?

intrusion at night + impact on sleep to QoL.

Researcher: No, no-

P5: -the only alternative is to leave it and you risk her health. No one would knowingly just do that.

Researcher: No, and like you mentioned before, kind of, comparing it to the finger-pricks, have you noticed any difference since she's been on the device in terms of the night time, how you manage the night time situation?

P5: It's much more invasive with the finger-pricks isn't it? You haven't got a clue what's happening between the two finger-pricks. I mean, say you give her a finger-prick at, I dunno, 7/8pm when she went to bed, when do you do your next one? Do you wake her up to do it? Do you do it if she wakes up? Or do you leave it until morning? But *regardless*, between those points in time you've no idea what's happening. With the CGMS that's not the case.

although intrusive to night time routine, it takes away anxiety of knowing when to check etc.

Researcher: Yeah. So in some sense although there's more disturbances because the alarm's going off-

more covertly invasive

P5: -oh it's massive, massively more. I mean, with the finger-prick and the injections, I mean you know, I suppose, you know, as I say, you give her the-you do the finger-prick, you give her the injection or whatever or the glucose, and that's it isn't it and then, you might say 'Well I better check that in two hours time', erm, and I suppose you might do that, but that may mean awakening the child, erm, which I suppose isn't very nice; but with the CGMS though it just alarms and if you haven't got it right you know about it pretty quickly [laughs].

FP has less info but you can move on with less info whereas alarm will update you about attempts to control sugars.

Researcher: [Laughs] yeah, and this might sound like a strange question, but when the alarm goes off, does that bring about a thought or an emotion in you? Because I've noticed you've been using words like you're getting it wrong, and not doing the right thing, so do you feel a sense of guilt or shame when the alarm goes off, or is it panic over 'is she ok', or have you not really noticed what goes through your mind when the alarm goes off?

P5: Oh no, I certainly have [laughs]. Erm, no, shame, I,I,I don't think, no, I think that would be quite wrong, it would be- we don't feel ashamed because we're not good enough. I think we feel, we feel we're not good enough, but then who is? Err, and the Diabetes team assure us, they think we're doing quite well.

Researcher: Yeah, absolutely.

P5:I suppose it's all comparative isn't it? Erm, but no, no we're not ashamed, but I suppose...in the day time when it goes off, our emotion is 'Well why isn't [YP5] taking some notice of this, why isn't she more, why isn't she more involved with this? Why can't be positive towards what's going on? That's the emotion then, if you follow me. I think at night time, the first thing is 'Oh, no, not again' [laughs]. I mean, or you know, 'Oh, here we go again'. It's not an emotion of shame, it's probably an emotion of annoyance to be honest, or frustration, than shame or feelings of inadequacy.

overt alarm allows clear indication of YP's non-adherence which leads to frustration

alarm can bring feelings of anger + frustration.

Researcher: Yeah, yeah, OK. And also, what were your expectations when [YP5] started using the device and did these differ to your actual experiences?

P5: Erm, I don't think we knew. I mean, [name]- do you know [name from the Diabetes team]?

Researcher: A little, yeah.

P5: Yeah well I mean they explained to us what was going to happen, and we had a training session from Dexcom. Some lady came out and did a sort of, installation of the sensor thing, showed us how to do it, in a room with about 10 or 12 other people. And then we had a sort of session, a subsequent session from Dexcom on using the CGMS, and then the Diabetes team are always there for advice. They're superb, I can't speak highly enough of them. Erm, and err, did we know what was going to happen? Probably not. It was probably sold to us as a kind of 'This is better'. Erm, [YP5] didn't think so, initially [YP5] was- she's one of these children that doesn't sort of, she's quite resistant to change. She'll get used to one thing, and then if you give her something new, well that's a bad thing [laughs]. So we had that to overcome, to begin with, probably for 10 or 12 months maybe. She's had it for about two years now, something like that, or two and a half maybe, and she's certainly used to it now. But I- at the beginning, to answer your question, I think we just kind of had a bit of a trial and error feeling our way through it saying 'Well what does this mean and what do we have to do? Can we get better at it?' We're always keen to have new, kind of, devices or experiment, like this um, what you're doing now, for example.

training prior to conception

initial adaptation period for YP due to change

whole new learning process - device + its data + what to do with it.

Researcher: Yeah

P5: Always happy to help and try and get involved in the, in the kind of, research side of things. We've been to a couple of seminars as well in- from, err, what are they called, JDRF, try and support those as well. We just basically learn what we can, and at one of these JDRF sessions there was a chap there, and he was an airline pilot I think, and he stood up and spoke, and he said 'Well look, I've done degrees, and airline pilot, and goodness knows what, flying aircrafts and things blah blah blah, but do you know what, it's a lot easier than this'.

Researcher: [laughs] yeah.

P5: Because I think he was frightened like us, that to try and get that line to lie straight, is damn near impossible.

can became obsessive over visual cue - impossible.

Researcher: Yeah, yeah. And I guess it's whether there's an element of just acceptance of it's never going to be perfect, you know-

P5: -yes that's right. And it's kids-children, isn't it. You know, we've thought about this and that's how children's diabetes is. Erm, you know, it's hard, and they're growing, or they're excited or on holiday or whatever it is...

Researcher: Yeah, and it all impacts doesn't it?

P5: Or they want sweets because their friends have got sweets. We had an occasion, I don't know, a few months ago now, where [YP5] went to the shop and bought a load of sweets with money that she shouldn't have had, and err, it's totally irresponsible but that's a 10/11 year old [indecipherable] isn't it?

can see at YP's non- adherence behaviours n real-time + adjust accord

Researcher: Yeah, absolutely

P5: You know, it's just trying all the time to instil in her the need to be more responsible and take the thing seriously really.

Researcher: Yeah

P5: Or even take *any* knowledge of it at all [laughs], to be brutally frank.

Researcher: Yeah, yeah. OK, and then I guess this question is more on the emotional side as a parent, how does it feel to have your child using the device? So for example, does it make you feel more safe, or less safe, or more anxious, or less anxious?-

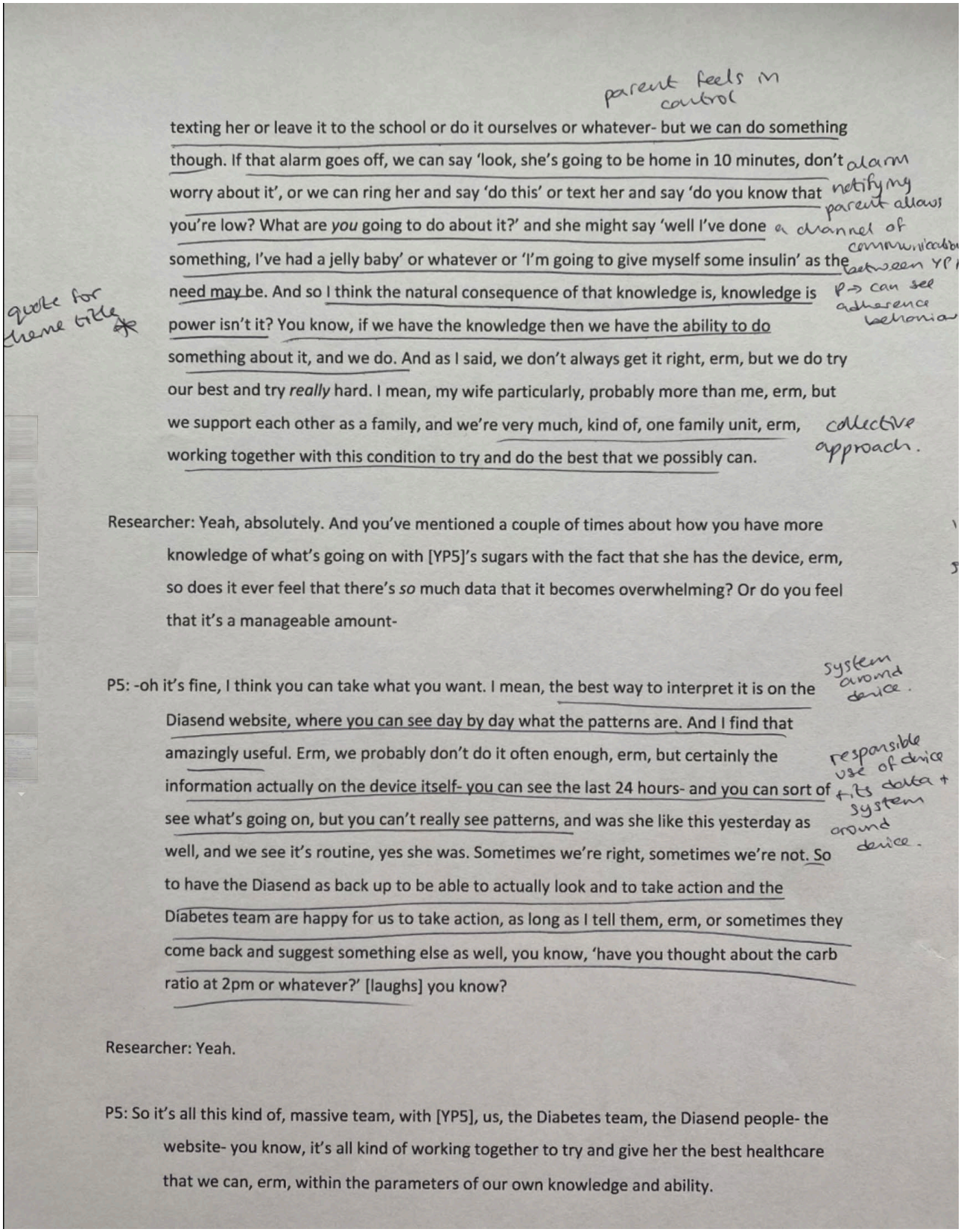
P5: -more safe.

parents feel safer with device.

Researcher: Ok, and in what way do you think that is?

P5: Well, as I've already explained to you, if you're using the injection you don't have any idea what's happening between those finger pricks, with the CGMS you know exactly what's happening, so it has to be better and then we can take any action as necessary, such as ringing her or

data = knowledge - power



texting her or leave it to the school or do it ourselves or whatever- but we can do something though. If that alarm goes off, we can say 'look, she's going to be home in 10 minutes, don't worry about it', or we can ring her and say 'do this' or text her and say 'do you know that you're low? What are *you* going to do about it?' and she might say 'well I've done something, I've had a jelly baby' or whatever or 'I'm going to give myself some insulin' as the need may be. And so I think the natural consequence of that knowledge is, knowledge is power isn't it? You know, if we have the knowledge then we have the ability to do something about it, and we do. And as I said, we don't always get it right, erm, but we do try our best and try *really* hard. I mean, my wife particularly, probably more than me, erm, but we support each other as a family, and we're very much, kind of, one family unit, erm, working together with this condition to try and do the best that we possibly can.

Researcher: Yeah, absolutely. And you've mentioned a couple of times about how you have more knowledge of what's going on with [YP5]'s sugars with the fact that she has the device, erm, so does it ever feel that there's *so* much data that it becomes overwhelming? Or do you feel that it's a manageable amount-

P5: -oh it's fine, I think you can take what you want. I mean, the best way to interpret it is on the Diasend website, where you can see day by day what the patterns are. And I find that amazingly useful. Erm, we probably don't do it often enough, erm, but certainly the information actually on the device itself- you can see the last 24 hours- and you can sort of see what's going on, but you can't really see patterns, and was she like this yesterday as well, and we see it's routine, yes she was. Sometimes we're right, sometimes we're not. So to have the Diasend as back up to be able to actually look and to take action and the Diabetes team are happy for us to take action, as long as I tell them, erm, or sometimes they come back and suggest something else as well, you know, 'have you thought about the carb ratio at 2pm or whatever?' [laughs] you know?

Researcher: Yeah.

P5: So it's all this kind of, massive team, with [YP5], us, the Diabetes team, the Diasend people- the website- you know, it's all kind of working together to try and give her the best healthcare that we can, erm, within the parameters of our own knowledge and ability.

Researcher: Yeah, yeah. And do you feel that her being on the device has had an impact on her quality of life in any way?

P5: No.

Researcher: No, things are pretty much the same?

P5: Well, that's such a strong one word answer isn't it? I don't think that, erm, she doesn't do anything that she wouldn't have done had she not contracted Diabetes. I think there's always kind of a way to sort of, prepare her for it and whether it's by, if she's doing sport, to sort of, knock back the insulin for a bit, or see patterns and act if she does, but we never sort of said to her 'you can't do this because of Diabetes'. In fact, I think that would be awful- I had a bit of an argument with the school, erm, I don't know, a while ago now, and they had a temporary teacher in, and he'd written the year end report, and he said that [YP5]'s Diabetes was holding her back. Well, I flew up there and said 'How dare you? It's up to you to ensure that kind of doesn't happen'. I think he was a young lad and he had just worded it poorly, to be honest.

allows her to be normal + live normal teen life.

Researcher: Yeah-

P5: -and so I was on that straight away. Because now I'm very conscious of the fact that she mustn't be disadvantaged because of her condition.

Researcher: Absolutely, yeah.

P5: In as much as that's possible.

Researcher: Yeah, yeah. OK, and then a final question for you- what would your advice be to any other parent whose child is considering or about to start using the device?

put faith in device

learning + development curve.

P5: Don't be frightened of it, give it a go, you'll get better at is as time goes on. Use Diasend to help you and use the Diabetes team to help you, and keep trying.

use system around device.

Researcher: Ok, thank you, that's lovely advice. Was there anything else that you wanted to add that perhaps we haven't touched on that you think would be useful for us to know?

tension at night - prior experience of how this was managed with PP.

P5: Erm, I don't think so. The main thing for us with it is the interruption at night that we find a bit trying really. And, it's um, -if there was a way- well, we plead actually, erm, from the bottom of our hearts, please, please can we have something that makes the alterations itself, for example if she's going low that it automatically stops the insulin? You know, and there's something, what's it called, the artificial pancreas. I suppose, we've been sort of promised- well not promised, that's a strong word- but we've been told about these things like artificial insulin and artificial pancreases and this has been going on for two or three years now and we don't seem to be moving forward as quickly as we would wish, or like. Erm, because if there was a device there that could sort of, take away some of the, sort of, human intervention if you like, and the device is talked to, so the pump and the CGMS interconnect by Bluetooth or whatever, then you can't seemingly- the stuff that is out there for sort of Bluetooth devices, it doesn't feel that it would be that hard. I know that's only me speaking as a non-medical person or a scientist or whatever, but that's how it seems to us, that it would be so much easier if there was some kind of automatism brought into it to, you know, not always require on us to have to do it ourselves- being lazy I suppose. But, if for example, I don't know, she was in- say she was in bed and then she went down to say, 3.5 or something, and you think 'well I need to stop the insulin for an hour' or whatever I'm gonna do, erm, and if the pump would suddenly, just do that...that would be where we would be coming from saying look 'this is really time that we kind of cracked on with this if funds and science allows' [laughs]. That's the sort of fantasy of perfection isn't it?

advances in tech are great but want/ expect more!

Researcher: Well it would be ideal because, like you say, the impact on the family and sleep routine is massive and so if we could try to reduce that then, of course, that would be absolutely ideal.

P5: Yeah, so I suppose that would be our kind of aim, our short term aim anyway.

Researcher: Yeah.

P5: I mean, you see these things on TV and in the paper about cures for Diabetes and all these things don't you, and you assume they're talking about Type 2- there's some that mention Type 1,

and reactivating pancreases and things and you know, I don't hold out much hope of that, but erm, you know, it's one of those things that our emotions can latch on to and we can think 'well maybe there is some light around the corner' you know? But yeah, I suppose for us, it is really the night times which are the most challenging.

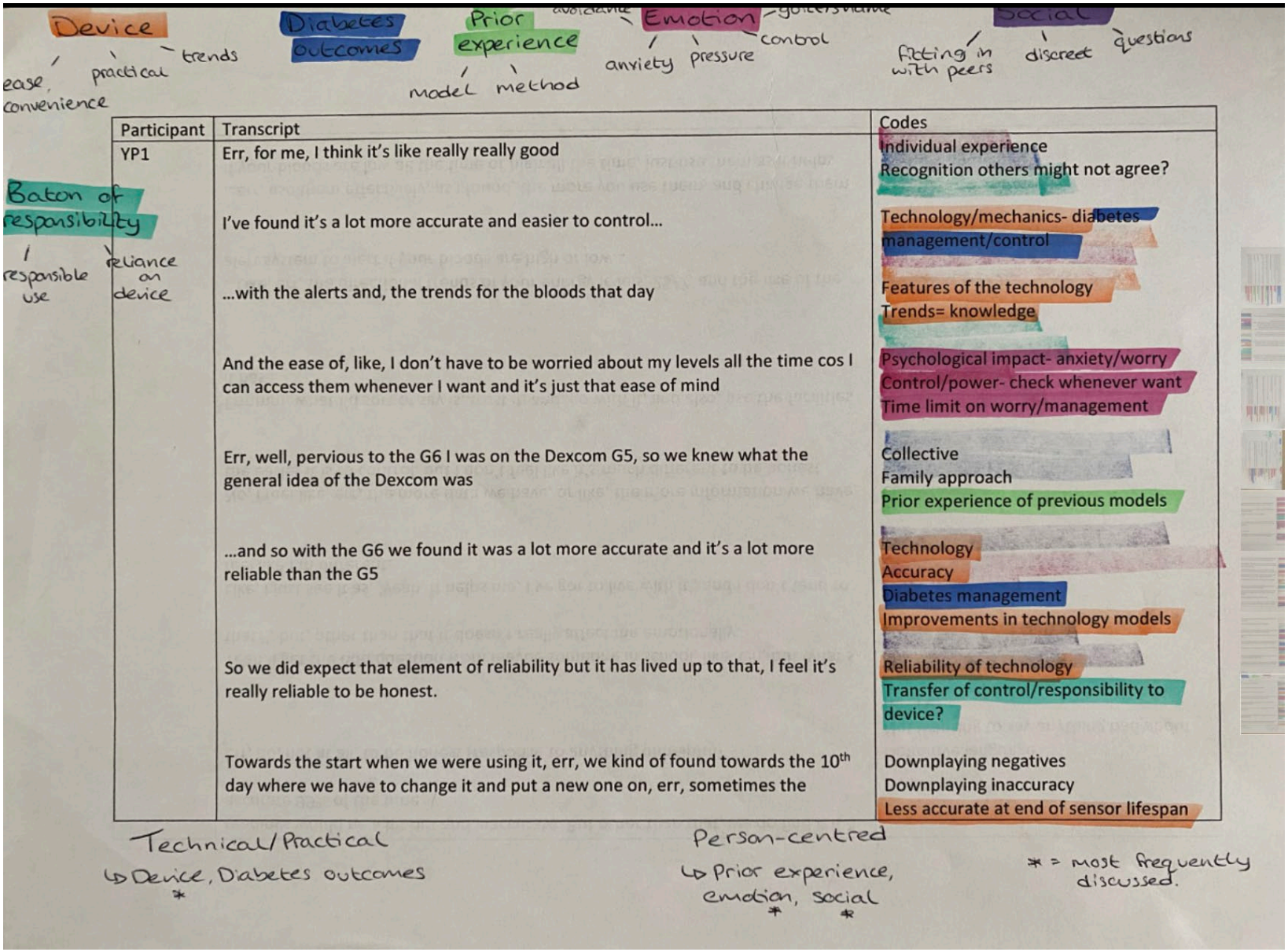
alarms at night are intrusive + invasive.

Researcher: Yeah, it does sound it, and like I say, it's a really difficult situation to manage, kind of, multiple times up in the night to sort that.

P5: Yeah, I mean, you must understand we get the odd night where we're not up at all and we say 'we had a good night last night' [laughs] cos we give her the right thing for tea or the right insulin or whatever or it wasn't too carb-heavy, you know, the meal, or she's in a good place herself and hasn't been growing or whatever. It's, it's- to an extent, is it a bit of luck sometimes, probably. But when it goes wrong it can be a bit of a, well, challenging, though there are other words [laughs].

when management isn't quite right alarms serve as a reminder + source of frustration.

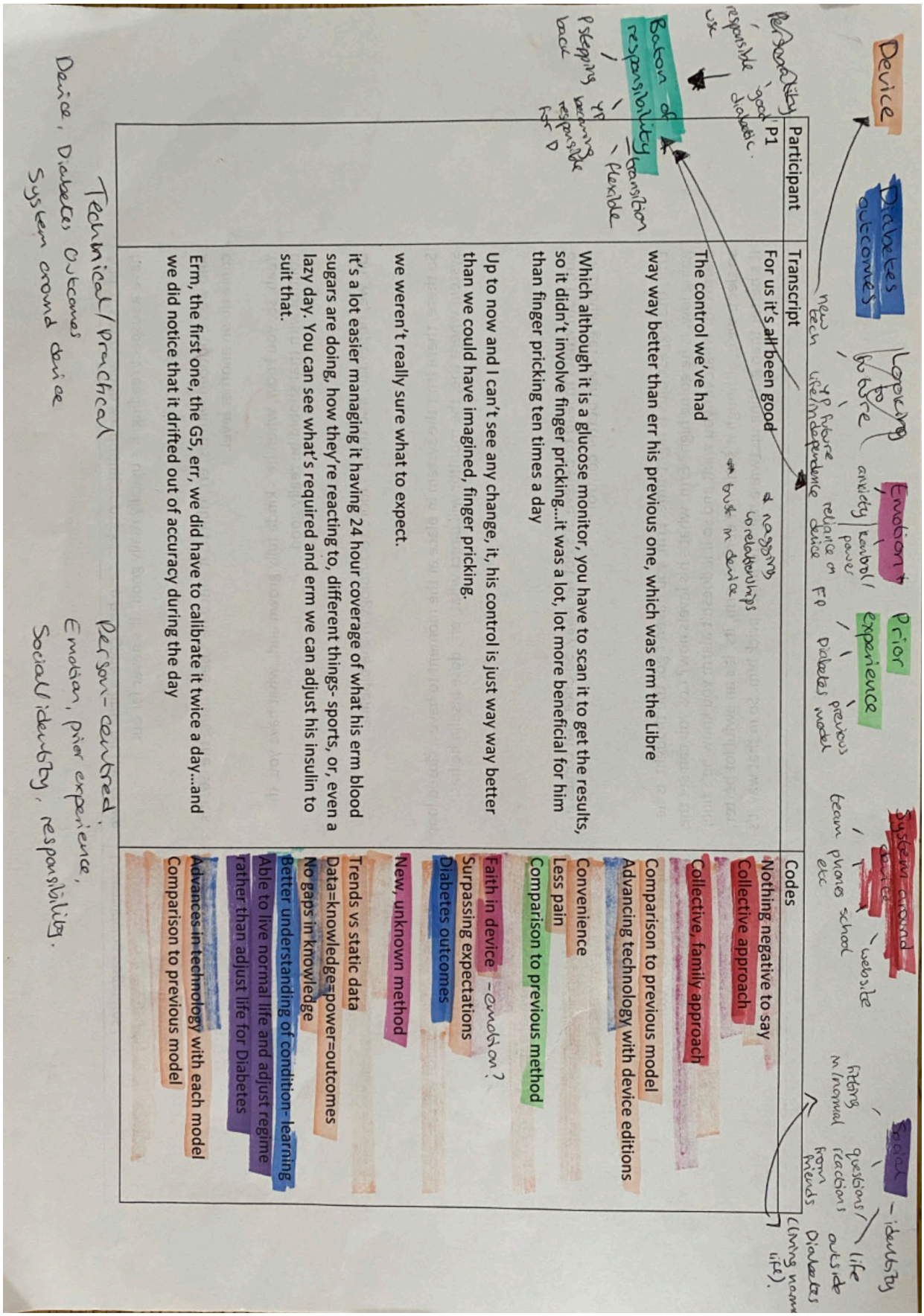
readings would be a bit out and inaccurate. But other than that, we do find it is accurate 99% of the time	
Err, no, not at all, to be honest (response to anything unhelpful)	Definitive language Not wanting to say anything bad about device?
Yeah, I get the odd question from maybe someone in school, like 'Oh, but what's that?', but, other than that it doesn't really affect me emotionally.	Curiosity/questions from peers Visible sign of diabetes
Like, I just see it as, 'yeah, it helps me, I've got to live with it', and I don't tend to feel like I'm different.	Device as helper No choice about Diabetes, lack of control Doesn't feel different from peers
No, I feel like, err, the more data we have, or like, the more information we have, the easier it is to control, but I don't feel like it's much different to be honest	Collective More data=knowledge=better control=better diabetes outcomes?
Ermmm, what I'd sort of say is..trust it, and, go with it, and also, use the facilities it has...	Put control in device Trust in device Use device responsibly Features of device
...Like, err, the directional trends of your energy levels, 25/7, and the use of the alert system to alert if your bloods are high or low...	Impact of trends vs. static data Control over how device is used Alerts for device to communicate
...err, use them effectively, as I found, the more you use them, and change them if your bloods are low all the time or high all the time, just use them as it helps	Use device responsibly Diabetes outcomes Device as helper



Participant	Transcript	Codes
YP1	Err, for me, I think it's like really really good	Individual experience Recognition others might not agree?
	I've found it's a lot more accurate and easier to control...	Technology/mechanics- diabetes management/control
	...with the alerts and, the trends for the bloods that day	Features of the technology Trends= knowledge
	And the ease of, like, I don't have to be worried about my levels all the time cos I can access them whenever I want and it's just that ease of mind	Psychological impact- anxiety/worry Control/power- check whenever want Time limit on worry/management
	Err, well, pervious to the G6 I was on the Dexcom G5, so we knew what the general idea of the Dexcom was	Collective Family approach Prior experience of previous models
	...and so with the G6 we found it was a lot more accurate and it's a lot more reliable than the G5	Technology Accuracy Diabetes management Improvements in technology models
	So we did expect that element of reliability but it has lived up to that, I feel it's really reliable to be honest.	Reliability of technology Transfer of control/responsibility to device?
	Towards the start when we were using it, err, we kind of found towards the 10th day where we have to change it and put a new one on, err, sometimes the	Downplaying negatives Downplaying inaccuracy Less accurate at end of sensor lifespan

it and it'll rip off or, erm, or like I'll get dressed a bit too quickly and completely forget about it and it'll, like, tug a bit, erm, but no it doesn't happen often.	Need to be more conscious of it at first
Erm, definitely like, being able to see, like, cos it gives you the graph that shows you what your levels are doing, rather than just, exactly what it is in the moment of time that you do a proper blood test.	Trends in data vs static data More data=knowledge + trends= more info and control
Erm, sometimes, when, like I'm hypo-ing, erm, I'll scan it and it'll- and I'll do a blood test as well- but the blood test will be completely different to what it's said.	Inaccuracy at extremes Not putting total faith/reliance in device
Generally it's pretty much spot on, but when my levels are...quite high or quite low, that's when it can have a bit of erm...like, it might be, a bit different.	Inaccuracy at extremes Downplaying negatives?
...and it's quick and easy, and not painful at all, unlike finger-pricking [laughs]	Convenient Easy Painless, especially compared to FP.
Oh, the blood tester, always, cos that's the actual blood whereas the Libre is, I can't remember what it is, but it's not your actual blood.	Discrepancy-believe FP Not over-reliance/dependence on device
Like, when we had the, like, course for it, erm, they did say that, erm, it's, more-like, it's less accurate the more extreme your levels are. Erm, so I kind of have expected that anyway.	Prepared for inaccuracy at extremes
I mean it takes a lot of pressure off, because it's so easy to use...	Reduction in pressure/stress Easy, convenient
...but then also, like, in summer and stuff, sometimes you don't want to wear kind of like, short sleeved tops cos you know you're gonna get questions, or people	Embarrassment? Wants to keep Diabetes/device secret? Doesn't like the questioning

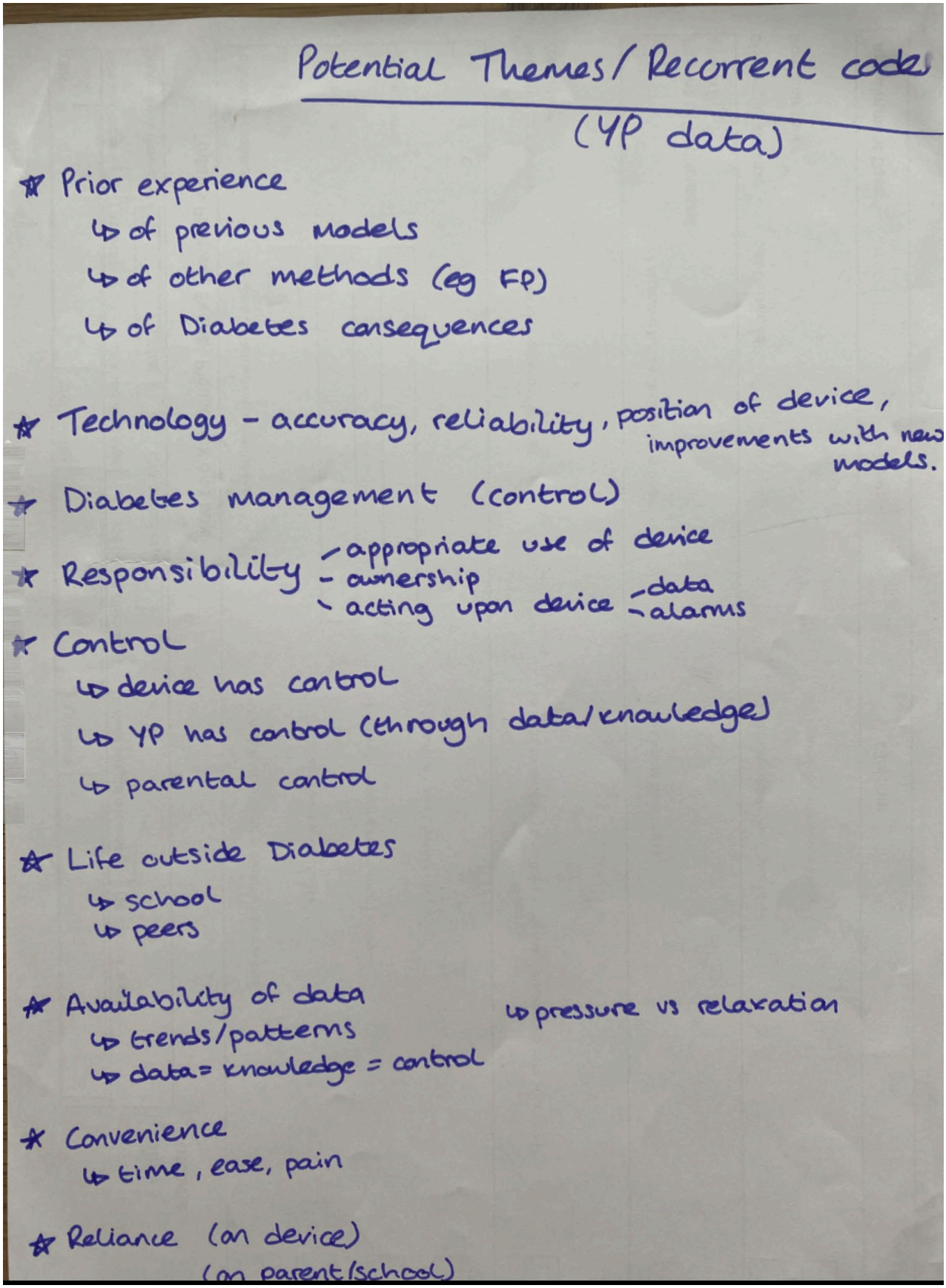
Yeah and I don't get as panicky putting one on, like I'm not as nervous putting one on, it's just kind of, over and done with quicker now than it used to be.	Fear of knocking it at first but adapted to it being inevitable but not disastrous Adaptation and learning process to using and managing device Skill development
I'd say just getting used to it...(response to whether adaptation is getting older or just getting used to whole process)	Need time to adapt, irrelevant of age/development
Erm...just try and ignore it but also scan as much as possible...	Ignore physical presence Use it reliably Responsibility with YP to use it appropriately
...erm, cos like when I have like busy days and I forget to scan it it's- and then I look at my data at the end of the day and it's pretty much empty- then you end up kind of feeling like shit.	Guilt when lack of data shows you haven't used device appropriately/effectively/responsibly No getting away from data and lack of data
Researcher: Mm, in what way?	
Err, you just kind of feel like you should have been, like 'Oh I should have been scanning and I haven't been so now I don't know what's, been happening'.	'Should'- thoughts of responsibility/expectations Lack of use=lack of data/knowledge/power


Device
Diabetes outcomes
Looking to future
Emotion
Prior experience
System around device
Social - identity
Participant
Transcript
Codes
P1
For us it's all been good
Nothing negative to say
Collective approach
Collective, family approach
The control we've had
Comparison to previous model
way way better than err his previous one, which was erm the Libre
Advancing technology with device editions
Which although it is a glucose monitor, you have to scan it to get the results, so it didn't involve finger pricking...it was a lot, lot more beneficial for him than finger pricking ten times a day
Convenience
Less pain
Comparison to previous method
Up to now and I can't see any change, it, his control is just way way better than we could have imagined, finger pricking.
Faith in device
Surpassing expectations
Diabetes outcomes
we weren't really sure what to expect.
New, unknown method
it's a lot easier managing it having 24 hour coverage of what his erm blood sugars are doing, how they're reacting to, different things- sports, or, even a lazy day. You can see what's required and erm we can adjust his insulin to suit that.
Trends vs static data
Data=knowledge=power=outcomes
No gaps in knowledge
Better understanding of condition- learning
Able to live normal life and adjust regime rather than adjust life for Diabetes
Erm, the first one, the G5, err, we did have to calibrate it twice a day...and we did notice that it drifted out of accuracy during the day
Advances in technology with each model
Comparison to previous model
Technical/practical
Person-centred,
Emotion, prior experience,
Social identity, responsibility.
Device, Diabetes outcomes
System around device

	yeah and this helps him with that to be honest. He doesn't have to worry about it either. It just, it goes to his phone or, or his watch, so he can just have a little check to make sure things are alright and he's, he's really good with that. And as they grow up, you've gotta, gotta step back as well haven't you?	Increased independence for YP Reduction in YP anxiety Responsible use/responsible YP Looking to the future Stepping back/reducing control/responsibility "good Diabetic" - is he good with it because of ease of use?
	I just can't wait for the next, kinda level one, the closed loop one where- although I've been told it's not 100% closed loop- it'll...if he starts going, down quickly it'll shut off insulin automatic and if he starts shooting up it'll increase his dose. So, the, err, medical side of that is, you know, it's really good.	Looking to future for further advances in technology Expectations from technology Diabetes outcomes
	I mean, since, we been diagnosed seven years now I think, and from, err, using the pen, for every meal, erm...and finger pricking, in between each meal and before every meal, it's come a long way in seven years even.	Comparison to previous method Improvements in QoL
	I know I'm kinda repeating myself, but it, it just makes everything so much easier and takes the stress out the day. Ummm, we have different programmes set up on his pump to reflect what's going on in his day, whether he's got PE in school, or football training. So we just go on a different programme and it just take all- well, not all the worry, but- it takes a lot of the concerns out of my head [laughs].	Ease, convenience Responsible use of device Allows teen to live normal teen life- QoL- adapt regime around life not life around Diabetes Can never remove all worry Device allows reduction in anxiety
	And, also knowing that, with his, good control, his HbA1c is really low, and that is, you know, beneficial, for long term isn't it?	Diabetes outcomes Looking to future-health

And, it's also, when we do finger prick in case he's gone a little bit low or we have a suspect reading, it's usually really good...it's never far out.		Downplaying negatives? If reading is out it's usually fairly accurate Unwavering faith in device
And we've noticed with his, err, HbA1c, it, since he's been using the G6, it's come down another level.		Diabetes outcomes
Yeah, so, you know, when he's kinda fully grown and...what have you, the control with that should be really good.		Looking to the future- YP taking over responsibility Diabetes outcomes
Oh, we, hopefully, and there's more technology in the pipeline.		Embracing technology and expecting more advancements
So there, there isn't the system in place at the moment to have a closed loop system where the, the monitor will direct what, err, dose insulin he has.		Looking to the future- device will take most responsibility/control YP as passive recipient Reliance on devices Want/expect even more from technology
But, from what I'm lead to believe, it's not far away. So once that comes in he should get even better control.		Hopeful for future advances in technology Room for improvements Diabetes outcomes
Erm, the biggest plus is night-time. Erm, you haven't got the thought, is he going low, is he going high? Erm, what's his levels now? Cos you can set the alarms for whatever you want and so if it doesn't alarm you know he's fine, so sleep-wise, although it's still not perfect, erm, its, it's an awful lot better. It's better than getting up twie a night to finger prick him. So in that way it's		Impact on sleep- QoL Worries about levels when YP sleeping Data=knowledge=reduced anxiety Control over device Room for improvement Family impact from device

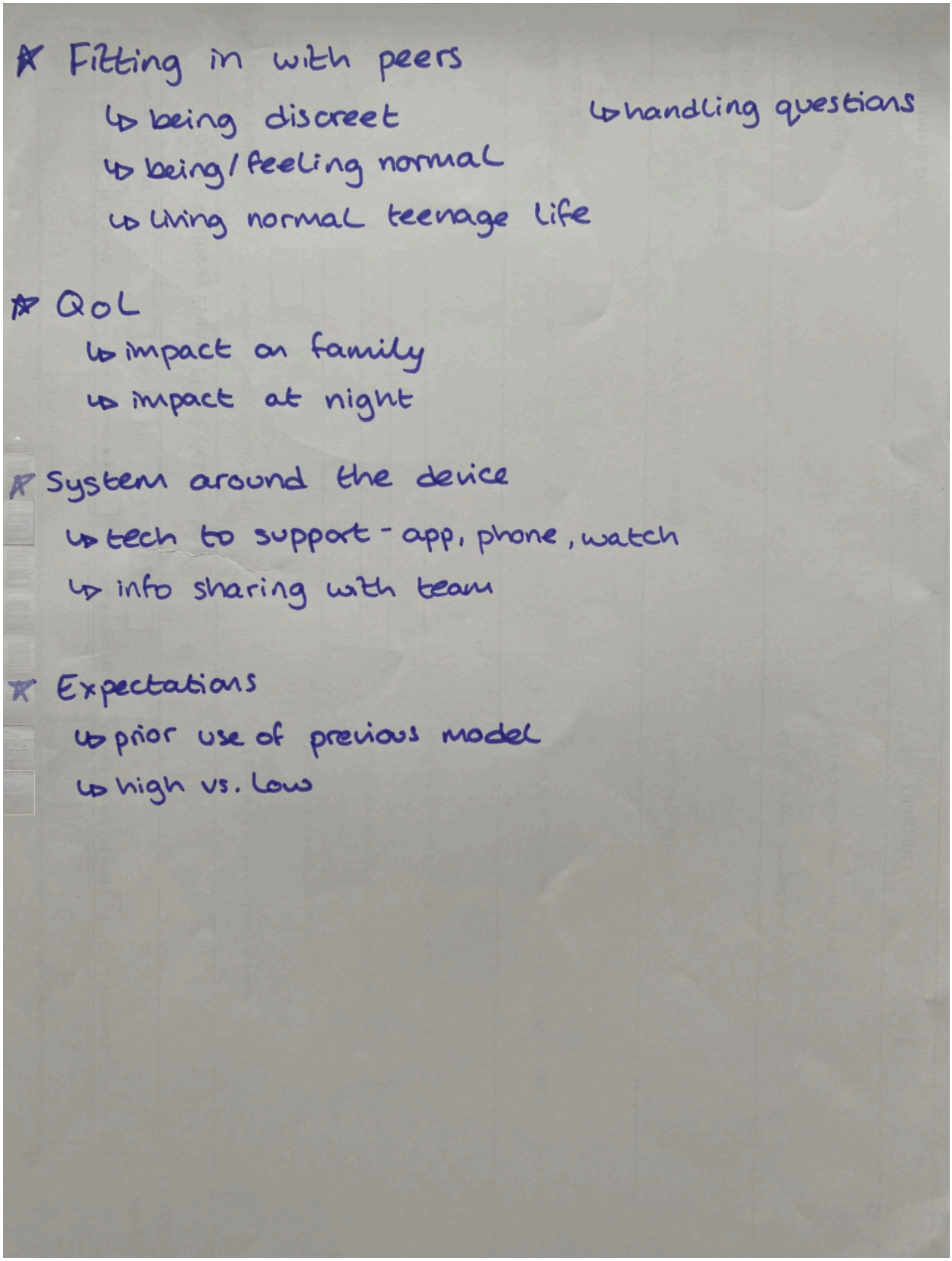
	Yeah, it must be so much better...whether they don't look at the bigger picture, I don't know, or you know, the extra consultations you might need, the admission, the long-term effects when they're older...they mustn't take that into account, that's all I can think of.	Implications of not having device on wider system/society/finance Effects of Diabetes without good control
P2	Yeah I've had a good experience really. It gives us peace of mind of how their levels are...you know, it's peace of mind more than anything.	Reduced anxiety Reassurance
	err, if I do ask her what her levels are she will tell me but she doesn't necessarily volunteer the information.	YP has control over information-sharing with parent(s)
	When she was first diagnosed I did, sort of, in the night I might have gone in and woken her up and done a blood test myself on her, you know, just to check up and make sure everything was sort of, OK.	Takes time to pass responsibility, particularly at night Comparison to previous method
	I think the only downside to it that we've found is, one time when [YP2] was getting out the car, she sort of caught it on the car and it ripped out of her arm.	Inconvenience of knocking sensor off arm Takes time to adapt to having it on your arm
	both my kids have found it a lot easier to use than the actual ordinary blood monitoring kits	Comparison to previous method Ease, convenience
	I just get on with it. I think, because I've lived with it for so many years with [YP2's brother]	Prior experience of Diabetes influencing experience of device?
	...maybe a little less anxious because [YP2] uses her phone and just, sort of, it's so much easier just getting her phone and just swiping that by it and she can see that, erm, what her level's doing and you know, she can see the patterns of what it's been doing and everything, so it, it is peace of mind as well.	System around device- making it easier Ease, convenience Patterns in data= knowledge vs static data Less anxiety due to data availability YP already use phones and like them! Reduced anxiety



Potential Themes / Recorrent codes

(YP data)

- Prior experience
  - ↳ of previous models
  - ↳ of other methods (eg FP)
  - ↳ of Diabetes consequences
- Technology - accuracy, reliability, position of device, improvements with new models.
- Diabetes management (control)
- Responsibility
  - appropriate use of device
  - ownership
  - acting upon device
    - data
    - alarms
- Control
  - ↳ device has control
  - ↳ YP has control (through data/knowledge)
  - ↳ parental control
- Life outside Diabetes
  - ↳ school
  - ↳ peers
- Availability of data
  - ↳ trends/patterns
  - ↳ data = knowledge = control
  - ↳ pressure vs relaxation
- Convenience
  - ↳ time, ease, pain
- Reliance (on device)
  (on parent/school)


Fitting in with peers
being discreet
handling questions
being/feeling normal
living normal teenage life
QoL
impact on family
impact at night
System around the device
tech to support - app, phone, watch
info sharing with team
Expectations
prior use of previous model
high vs. low

Statement of word count

Main documents

Thesis abstract	292
Literature review	
Abstract	191
Main text (excluding abstract, tables and references)	4498
Empirical paper	
Abstract	252
Main text (excluding abstract, tables and references)	4994
Contributions to theory and clinical practice	
Main text (excluding references)	4085
Total	**14, 312**

Appendices

Literature review	
Tables 1 & 2	494
Figures 1, 2 & 3	137
References	1792
Empirical paper	
Tables 1, 2, 3 & 4	311
References	849
Contributions to theory and clinical practice	
References	1272
Section of an Annotated Transcript	5496
Total	**10,351**