SELF-MANAGEMENT BEYOND THE SELF

Participatory design practice towards preferable diabetes self-management principles

MRes Research Project
Portfolio of Practice

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This portfolio of practice is submitted with a practice-based 10,000 word thesis. Both documents are to be read alongside each other as indicated to fully understand the involvement the practice had in this study.

Throughout the thesis, when it is recommended that you read the portfolio of practice, you will be directed to the associated section using the key in Figure 1 through highlighted text and a colour code that represents the chapter and section of the thesis/portfolio.
Practice Overview

### Part 1: Understanding you and your diabetes

**So tell me about yourself?** Who? What? When? Where? Why?

**Could you describe your family?** What was your childhood like? What were your hobbies and interests? What did you want to be when you grew up?

**Could you describe your journey till now?** What has lead you to this point?

**So what are you doing now?** What was your motivation to do what you are doing currently?

**In your own words, how would you define your diabetes?** How would you describe it to people who are not experienced or knowledgeable of the condition?

**So could you tell me more about how you became diagnosed with Type 1 diabetes?** What age were you? What led to your diagnosis? How did you feel at the time?

### Part 2: Understanding your relationship with devices

**Back then, how was managing your Type 1 Diabetes through conventional methods (‘finger prick’ blood glucose monitors and insulin injections)?** Could you give any examples of when this was difficult?

**If I could ask, what diabetes complications have arose in the past?** What has caused them? What would have prevented them?

**Could you describe a typical day in a life with your devices?** How do you manage your devices? How do you feel physically, emotionally and mentally towards your devices?

**How transformational were these technologies compared to conventional diabetes management practices?** What are the advantages/benefits? How did this impact you... did it change your perception/behaviour/outlook towards diabetes?

**What is your relationship like with your CGM/Insulin Pump?** Do you trust these digital devices more than conventional? Why? What makes you trust these connected ‘things’ more than manual methods?

### Part 3: Exploring your wider health network

**Alongside your devices who/what else contributes to your diabetes management?** [Introduce stakeholder mapping tool] What role do they play in your diabetes management and why?

**So thinking about relationships, could we map your current connections?** Who/what do you most trust? And could you explain your reasoning?

**What do you think of your health network, does this map reflect reality?** Does everyone/everything meet your expectations/play their role in helping you manage your diabetes? (Pain-points) What could be improved and why?

**If you could create a new role in your network, what would this role do?** What would its purpose be? How would they connect to your devices/intervene preferably?

**In your opinion, what is the future of diabetes self-management?** Artificial pancreas?

**And lastly, could you describe a preferable future or world for diabetes?**
4.2 Participant Activity Toolkit

- Person or People
- Product or Device
- Service or Place
- Interaction or Intervention
- Trust-point
- Opportunity
4.2 Participant Activity Toolkit
4.3 Participant Activity Outcomes
Interview Participant Personas:

**Linda**

43 year old from Saltcoats, Ayrshire. Diagnosed with Type 1 diabetes when she was 8 years old.

She has managed her diabetes using a traditional blood glucose meter and insulin injections for 35 years but now wants to embrace technology to help manage her condition.

From self managing manually for years, she is seeking assistance with choosing which technology would be most helpful for her.

**Irene**

19 years old from Mount Florida, Glasgow. Diagnosed with Type 1 diabetes at aged 11 when she was in primary school.

She currently uses an insulin pump and a blood glucose monitor to manage her diabetes. She has also used a CGM in the past.

She has a close relationship with her diabetes team and is currently transitioning to the adult clinic.

**Jenny**

32 years old from Cadder in Glasgow. Diagnosed with Type 1 diabetes at aged 7.

She uses a Flash glucose monitor and insulin injections to manage her diabetes. Although as a busy single mum she has been interested in exploring the insulin pump for added assurance.

From missing some appointments recently, she feels like she isn’t coping with her diabetes as efficiently as she could.

**Brian**

25 years old from Dunblane, Stirling. Diagnosed with Type 1 diabetes at aged 5 when his mum insisted he should have his blood tested by a family doctor.

Over 20 years, he has managed his diabetes through a conventional blood glucose monitor and insulin injections... he also has a Freestyle Libre flash glucose monitor.

He does not have a diabetes specialist nurse but meets with his doctor instead.

**Tim**

37 years old from Bearsden in East Dunbartonshire. Diagnosed with Type 1 diabetes at aged 9.

From managing his diabetes recently with a CGM and insulin injections successfully, he is eager to try an insulin pump.

Although he feels confident in his ability to self manage, he believes an artificial pancreas could be more convenient for him with his fast paced lifestyle.

**Scott**

37 years old from Bearsden in East Dunbartonshire. Diagnosed with Type 1 diabetes at aged 9 after falling ill.

He currently uses a CGM and insulin injections to manage his diabetes. He has had his CGM taken away in the past due to misuse - he went 6 months without a sensor.

Since his incident, he sees his diabetes specialist nurse often to maintain good practice of his diabetes self management.

**20 years old from Livingstone, West Lothian. Diagnosed with Type 1 diabetes at aged 4 after falling ill.**

He currently uses a CGM and insulin injections to manage his diabetes. He has had his CGM taken away in the past due to misuse - he went 6 months without a sensor.

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Participatory Workshop Framework

1. Introduction, Consent & Icebreaker Discussion

2. Relational Map Validation & Stakeholder Co-analysis

3. What If Provocation & 'Provotype' Generator Canvas

4. Contextual Interventions and Principle Capture

5. Workshop Evaluation
Participatory Workshop Agenda
Blythswood House Boardroom, 9th November 2019, 2-4pm

Arrival & Introduction
2.00pm - 2.15pm
- Group welcome and introduction to the project.
- Complete participant consent forms.
- Icebreaker activity and initial exploration of diabetes self-management using prompt cards.

Activity 1: ‘Relational Map’ Validation and Co-analysis
2.15pm - 2.45pm
- Open discussion focusing on the self management engagement themes from personal experience.
- Introduction to relational map for group engagement with key themes and prioritising areas for co-creation.

Activity 2: Collaborative ‘Prototype’ Generation
2.45pm - 3.15pm
- Develop a ‘What if.’ scenario based on provocations to create a preferable ‘prototype’ concept.

Activity 3: ‘Alternative Now’ Interventions and Principles
3.15pm - 3.45pm
- Test concept using user journey examples to gauge how transformative and valuable our co-created intervention could be in context.
- Establish preferable self-management principles towards designing for users with long term conditions.

Reflection & Evaluation
3.45pm - 4.00pm
- Reflect and evaluate the effectiveness of the workshop together.
- Further questions and workshop conclusion.

Workshop Participant Personas:

Emma
- EM
- 33 year old from Gourock. Diagnosed with Type 1 diabetes when she was 29 years old following first pregnancy. She currently manages her diabetes using a Freestyle Libre flash monitor and an insulin pump system. Emma is currently pregnant with her second child and works as a college lecturer.

Anna
- AL
- 31 years old from West End, Glasgow. Has been diabetic for 24 years. She currently uses an insulin pump and CGM together to avoid hypos, she is one of 40 people in Scotland with this system. Anna is also currently pregnant and praises her devices to help her have a safe pregnancy and works in higher education.

Jean
- JC
- 59 years old from West End in Glasgow. Non-diabetic participant but mother to Anna and has monitored her daughters condition as a child and adolescent. Given her experience with using monitoring devices for 24 years and her close relationship with daughter and has a unique perspective.
Participatory Workshop Outcomes
Participatory Workshop Outcomes
Participatory Workshop Outcomes
4.7 Participatory Workshop Outcomes

Principle Pyramid

- Humanise the condition
- Emphasise to really understand
- Educate yourself and others
- Every request has a reason
- I am still ‘me’ - I am a person
- ‘new’ normal
- Educate yourself and others
- Beyond numbers
- Strength rather than weakness
- “I can’t” appreciate more positivity
- Consider user’s experience

“I can’t” appreciate more positivity

Strength rather than weakness

Every request has a reason

I am still ‘me’ - I am a person

‘new’ normal

Educate yourself and others

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‘new’ normal

Educate yourself and others
Follow up feedback:

"You are more than welcome Ross, we had an excellent afternoon. Thanks for being an fantastic facilitator and also showing great empathy, you gave the space to think, the opportunity to share and also to learn - exactly what the research process should look like. I’m really looking forward to seeing what you’re next steps are and wish you all the very best. Many thanks from mum and I,” - AL

"Hi Ross, no worries at all, it was a great day, I really enjoyed it! all the best with the rest of your research and write up, and I look forward to hearing how you get on. Happy to help, any time. Take care x x" - EM

< Please read transcript in Appendix E1 for full evaluation discussion
Situational Analysis Mapping

Scott

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Tim

37 years old from Bearsden in East Dunbartonshire. Diagnosed with Type 1 diabetes at aged 9.

From managing his diabetes recently with a CGM and insulin injections successfully, he is eager to try an insulin pump.

Although he feels confident in his ability to self manage, he believes an artificial pancreas could be more convenient for him with his fast paced lifestyle.
Irene
19 years old from Mount Florida, Glasgow. Diagnosed with Type 1 diabetes at aged 11 when she was in primary school.

She currently uses an insulin pump and a bluetooth blood glucose monitor to manage her diabetes. She has also used a CGM in the past.

She has a close relationship with her diabetes team and is currently transitioning to the adult clinic.
5.1 Situational Analysis Mapping

Brian
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- 32 years old from Cadder in Glasgow. Diagnosed with Type 1 diabetes at aged 7.

She uses a Flash glucose monitor and insulin injections to manage her diabetes. Although as a busy single mum she has been interested in exploring the insulin pump for added assurance. From missing some appointments recently, she feels like she isn't coping with her diabetes as efficiently as she could.

- 43 year old from Saltcoats, Ayrshire. Diagnosed with Type 1 diabetes when she was 8 years old.

She has managed her diabetes using a traditional blood glucose meter and insulin injections for 35 years but now wants to embrace technology to help manage her condition. From self managing manually for years, she is seeking assistance with choosing which technology would be most helpful for her.

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### Jenny

**JH**

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"You need someone there to actually motivate you to go. And I am okay because my Mum and Dad have forced me to do things... and for people who don’t really have supportive parents, ‘ooh do what you want...’ there is not going to be any motivation to push themselves" - IG

"Its very important to understand the condition well and at least have a base understanding of the biology/physiology as well as understanding what the device is doing, rather than just following the device alone, like that will just manage it for you." - TD

"If I knew what or who my DSN was and they got a live feed and they could kick me up the arse... that might be a good thing. But I wouldn't want it to be someone I was in a relationship with or a close family friend as I don’t want my relationship with them to be medical." - BS

"This is why I need help with all of this... its so hard to keep up with technology now a days! But I have a few friends who have one of those devices and her partner can see all the results which I think is fantastic!" - LB

"I cannot explain how confident the CGM makes me feel... I don’t walk around terrifed anymore! When my CGM got taken away from me, things started to slip as I didn’t have any safety net. At times like that I couldn’t even concentrate on managing myself, nevermind my diabetes." - SM

"LibreLink automatically uploads all my results and we have set it up so my mum can receive them in real time too... as a nurse she kept me and my dad right growing up, so the Freestyle Libre allows me to keep that connection even though I have my own life and family now." - JH

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5.2 Thematic Analysis Coding
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Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

1. Relational: Both diabetic participants pregnant at time of study and use an insulin pump as well as a CGM/Flash Glucose Monitor for their self management.

2. Education: Complications with Type 1 Diabetes diagnosis due to contextual situation, such as pregnancy and honeymoon etc.

3. Educational/Relation: Participant had multiple variations of insulin pumps and uses a CGM and pump that “speak to each other” to alert hypo’s before they happen. Also both diabetic participants are both educators.

4. Relational/Trust: “My mum was the pancreas” and tightly managed daughter growing up. New technology has been ‘absolute godsend’ towards self-management.

So I’m Emma. I was diagnosed just 5 years ago, aged 29. I started on injections and now on an insulin pump and the CGM. Popular choice! I’m I have gone through a pregnancy since being diagnosed and am also currently pregnant. ‘Oops’ Oh my god, so am I! I could not have predicted that at all... what are the chances!

So you were two years diagnosed? No actually I was just shy of my ‘discovery’ when I first fell pregnant and I was still on my honeymoon period. Absolute nightmare! So at one point I came off my insulin and I was still having hypo’s. I was only allowed to eat half meals, I was starving and hungry. It was horrible but this time because everything has levelled out... touch wood!

Good that’s what you want! Sorry I could not have guessed this... I know! What’s the chances?

Well my name is Anna. I have been an Insulin dependent diabetic since I was 16. I have been on a pump now for 7 years, different variations of pumps. Where I also lived in the Netherlands where the healthcare was private, where I had a nice suite of choices - where with the NHS it’s slightly different. I have a CGM and a pump, so they speak to each other - so I am blいけful (AIL signing, all dancing) and that is because I do not sense Hypoglycaemia at all. Right! So I can drop to 3.2 and still be chattering away, still lecturing and then I drop. [laugh a lecturer? I do Politics.] I’m an Accounts lecturer. Ohh, how funny! That was the other thing, educational mum!

I would be absolutely fine... all singing all dancing! Have you always been like that? Yeah well it’s the irony of being very tightly managed. So when I was diagnosed, my mum was the pancreas - and does it very well, so it’s one of those catch 22 - if you run high then you are blind, your legs come off and we all know the other things that happen. But it meant that my wee margin for error is a lot lower. So at 5.2, the rest of the human population are feeling a bit hungry and hungry, I am fine! So the effect of it is being able to use the CGM, so I get put on the waiting list for the first and it has been an absolute godsend]
5.2 Thematic Analysis Coding

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There is only 40% in Scotland. Really? So we had to go to court to get it. Well there was no pleading. It was just the funding was incredible, especially before the 2018 was on prescription. Especially in America to have them fight and the need for open source - it’s a PhD in itself but it’s amazing to hear the benefit of the technology! Well it’s right and day for me! For my work I travel and I don’t think I would feel confident to do what I do without it. I mean as well if you go to high then your pump will automatically correct it? It can start to do that, so that’s the next upgrade. If I am honest, I don’t need that at the moment. So it just alerts you when you are going low? It could, so you will hear it beep. Erm so what that does, is it’s got an algorithm that will feel my trajectory going south basically. And what it will do is cut the insulin off. So then I have no background insulin at all - so that will allow me to stabilise or come up a wee bit but sometimes you are just going down too quick. You know the game is a boogie. Then it should do that before a hypo. That’s great! So I know that maybe sometimes at 4.1 I need an Apple. That’s great! So I never get to that crisis point. Which is great. Very reassuring. Yeah so it’s really fantastic.

**Educational/Relational: “Only 40 people” with artificial pancreas like open loop systems for Type 1 diabetes in Scotland. Struggle to get technology initially but has helped build confidence as system means she “never gets to that crisis point”**

6 Relational: Mothers relationship with daughter’s self-management as she feels only people who are “parents of diabetic children will understand” and how she acted as the algorithm between blood glucose levels and insulin injection. Had to strictly monitor what daughter intakes and experience gave her an ‘instinct’ and ‘sense that you got to do something’. Also hierarchy between parent and consultant...

7 Trust/Relational: Interesting how participant likes that she needs to verify every action the pump wants to make as the technology doesn’t know the context, like eating in situ for example. Makes her reluctant to give over control to devices/connected system.

8 Educational/Relational: Again how context affects self-management algorithm and wider systems affect trust, like conflicting carbohydrate levels on food labels/restaurants and even medical advice from external sources.

But also to hear from your parents... and what we will discuss later is what this extra role and responsibility has an effect on being a mother to your child. Very very very difficult. You couldn’t.. the only people who will understand are parents of diabetic children themselves because you have a child who has to be aware, exact amounts, and you think how hard that would be. If they are sick. I mean I have had Anna want to have admissions, and then feeding her ice cream because she has insulin in her that needs to be managed. She was also. I have three children but Anna was the most active, which is hard again because you have got to plan. She couldn’t just go on a long walk. Even it was more than a full time job. It must be such a worry as well, because you would worry anyway about your children but I can’t even imagine like through the night and things like that.. Sneeze! And Anna has had hypoglycemia through the night too. You must never been able to relax. Terrible. Absolutely terrible. And my husband father was diabetic, so he passes the whole guilt that it was through him but very very very difficult. Anna and I have a very very close relationship and I think that’s why, because we had to be close. Open and honest. And would you say that the technology, especially with everything becoming a lot more connected... would you say you are a lot closer now with digital? Oh huh! And it was also horrific when you used to go to the hospital with Anna every three months and you had a diary. I don’t know if you are aware of that. And we had to fill it in 2 times a day. And the consultant would sit with you and I was very good at it. Which sometimes I thought, annoyed her slightly. And she would say why did you drop that and increase that... because that’s what you’re doing all the time. So my mum was basically doing what the algorithm was doing. Finding pathways and things. Yeah, 3 days and then move in. And sometimes it was just a feeling and a sense that you got to do something. But it was a huge huge pressure and you felt like you were being judged all the time. And see that sense. that’s something that artificial intelligence hasn’t caught up with yet - that kind of instinct.
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Educational/Relational: Situations and contexts that led to diagnosis of Type 1 diabetes. Lack of knowledge of who to turn to or where to go for help. Other factors like festive sessions, mental health, physical health, confusion/uncertainty affecting ability to reach out for diagnosis.

Trust/Relational: Prompts reveal trust issues with Flash/CGM technology as per previous interviews for its reliability and accuracy.

Relational/Educational: Again participants highlight functional and aesthetic issues related to devices. Interesting how participant ‘hacked’ CGM by using a ‘drip’ adhesive strip to keep device attached for longer. Notable that participants frustration to device ‘falling off’ led the user asking supplier “Have you ever had one of these on?” Implying that the CGM hasn’t been properly user tested/verified before production.

Thematic Analysis Coding

I didn’t use the insulin pump as an ideal reflection on the user either. Horrific!" I would say it looks a wee bit like a cassette player actually, especially where they are placed. People say to me: Is that the IP? I’ve had the same. They do and the cannula, I have heard so many stories of them leaking and disconnecting! And also the CGMs, although great, with the adhesive... They don’t stick! Watch this... This is what I have to do on my CGM. Ohh have you got like a band or something? Aye that is! That’s what you keep a drip on with! And see when I take this off, it will be my whole arm... Because it falls off it just comes off and I phoned Medtronic and said to the guy “Have you ever had any of these on?” And he was like “No madam, I don’t confirm or deny,” and I was just like “It has fallen off!” And I am not a particularly heavy person.

Sorry, just looking for trust. I have a real trust issue with my IBS. I don’t trust it at all! I have to double lock it almost everyday. Interesting as the previous name of this project used to be ‘trusting internet of things interoperability for long term conditions’, so for you to say that to me, is quite comforting. And like the artificial pancreas, how can you trust something to do something automatically, trusting technology... so it is all about relations.

Full transcript available to read transcript in Appendix E1
Thematic Analysis Coding

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13 Relational/Educational: This explores relations further, especially more intimate relationships and how you can introduce the device to partner as well as learn from one another and others to progress your self-management. Notably the importance of tacit knowledge from experiences by “meeting someone as a diabetic” is crucial.

14 Relational/Educational: Good placement of project scope as a discovery around “what do you think about [your self-management devices?]” and exploring relationships these devices create. Notably change in perspective as one gains more experience with devices, reflecting back to teenage years where it would have made her ‘different’. Possibly co-generational learning aspect?

15 Trust/Relational: Interesting insight as blood glucose monitor wasn’t considered as one of “two things I use” but is more trustworthy, especially closing statement with suggests a high margin of error between separate readings. Also notable is the idea that its an “added job” suggesting self-management could have been easier before the Libre Flash monitor?

16 Relational/Educational: No participants had seen a network map or visual representation of their diabetes management

But its that kind of experience actually, and another thing I heard was sleeping with one on! That you get used to one way of sleeping and then need to switch cannula site - so I think its so important to speak to users! Even when you think, I mean you obviously are both in relationships but someone who is in a newish relationship, you know what I mean... "he is going to lie on it...”, you know? And how do you introduce it... Exactly! I suppose as you say that, I was with my husband when we weren’t married at the time when I was diagnosed... So you both were learning about it together? I mean two of his best friends had Type 1 diabetes, so he already had background information... But I have never had to meet someone as a diabetic!

Yeah, ahh hah! I have never thought about that actually!

“which product or device is most crucial to effective diabetes self-management? What does this thing facilitate and why does it help you self-managed better?”. I find that a very difficult question to answer! Obviously the two things I use are my [device] and my pump... but going back to the trust thing, I trust my blood glucose monitor more than my [device]. Anytime I scan that I think “thats not right!” And I trust my blood glucose meter. So probably that one! Its actually an added job! I can do too high or too low and think thats not right! And then I check it and think sometimes it is right... where other times its telling me that I am low, like 1. whatever, when I am sitting at 6.2!
I would say online community, so social networking and stuff like that. Yeah I would agree with you - well that's where I found out about this! I was just going to say that I was going to say as this is self-management, which in itself implies it can be quite lonely... Is that true? Absolutely, so the idea of social... do you think that self-management could ever be social? I have to say, the majority of my wider group of friends are not great when it comes to my diabetes at all - and actually I find them quite offensive! Yeah! Umm... There are a couple who understand, like my sister and best friend and things like that but my wider group... no! You hear if you stop eating sweets and you will be fine. One of my friends, I remember I was rotating sites and I said, "guys, do you mind?" And they said to just go to the toilet. And I was like no! Thats dreadful! It really annoyed me. I was like I am not a junkie! Oh my god! Terrible! And I remember when it was coming up to my wedding, I made up some type bags and I was just going to leave a bag with certain different groups, and this one group were the no. I don't want the responsibility... Disgusting! And I was like, its a bag of sweets and juic... its nothing in it! And someone said, I will be getting up your dress and injecting... I was like "Don't ever inject me!" No! They didn't listen to anything I would say! They are both called 'diabetes' because I feel really sorry for type 2, as I would rather be type 1 than type 2. With type 2, if you think we are shooting in the dark right now, thats go no... I have to say I don't think I agree with you. I think if you were type 2, there are things you can do to try and combat it. Yeah and if I had that option I would love to do that! No, I don't mean that, you only have the option to be type 1 or type 2, I would always be type 1... pancreas is dead - just get in. If I had type 2 just now, it may be type 5 stone and you are cured - absolutely! I will lose 5 stone! But what I mean is if the only thing is to have type 1 or 2, with type 1 its black and white. I still don't know if I would agree... see if I could just pop a tablet everyday and that would be me... I would maybe choose that! Erm yeah, maybe. Remember when the consultant diagnosed Anna. She said I would rather be telling you she has got cancer... because we can cure cancer. But she was right! What a terrible thing to say! But she was right. I would say thats a bit defeatist as well. But you can know that Anna, she was telling me... Well you are either cured or you die of it... with type 2 you can manage it. And one thing I asked all interview participants is what would be the ideal outcome or future for diabetes - many people did say cure and many also sold better self-management because they were doing fine as is. You always say now, that you wouldn't want to be diabetic... Yeah its part of who you are. Have you heard of that? Absolutely. Its what makes you, you! She said she wouldn't know what to do. It doesn't bother me, it lets me know how my body works and exactly what anything will do...
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

Trust: Clear trust in diabetes consultant and team compared to other health professionals. Notably they treat diabetes patients more as an 'equal' and know their patients better. Interesting reflection later in discussion as to how they 'empower' patients.

Trust/Relational: Nice reflection on how much the diabetes consultant/team can affect their patients as participant remembered consultant from juvenile years.

Trust/Education: Knowing when to 'stop' and how much self-management can affect the everyday.

Trust: Participants don't trust their GP and hospital settings. Interesting anecdote about hospital experience post pregnancy.

Trust/Relational: Nice reflection on how much the diabetes consultant/team can affect their patients as participant remembered consultant from juvenile years.

I do not trust the GP! Thats what I say! And a hospital is the most dangerous place for me to be! Really? Actually see when your saying that!

One day I said to them, I am not taking this many units for my background tonight... but I said I am not asking for permission... I am telling you I am not taking it - you need to speak to a diabetes consultant! But they should have been, she manages this herself - everyday! Or should it be different? She only sees me 3 times a year! And one of the reasons for focusing on users for this project was that you are experts of your own experiences. Yeah! And as you do say you only see someone 3 times a year for 10 or 15 minutes... that no where near going to give you the context of what's going on. And like you said, hospitals are dangerous places to be, I agree with you having given birth and whatever but I just know if you are the same with your consultant and things like that? My consultants and doctors are like you know better than me! My consultant is top-class, he is great! My consultant, I would say, treats me as an equal - so he will say, "what do you think about this?" or he will use terms, the terminology is key... like "I am thinking about this, what about you?" or he will give me journals to read.
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

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Rebranding of type 1 and type 2 towards being more distinct. I think there is a lot of chat about that sort of thing... There is also a type 3 and 4 suggested recently... so maybe the numbering of the conditions isn't the best way? I think having them both called diabetes causes a lot of confusion for members of the public who don't have any personal interaction with it. But I don't see it changing anytime soon. No. Do you think that could change if users were to make a change and rebrand themselves? I don't know, what do you think Anna? I think its who gets to be called diabetic... this sounds really silly because with type 2, certainly when I was diagnosed, it was juvenile onset diabetes, type 1, and type 2 diabetes which are one under the age of 18! So and then there was the kind of weight related, but we were told there were no children with type 2 diabetes. Whereas there is now! And obviously there is older people diagnosed with type 1! It seems like that, but I don't think a type 2 diabetic is any less... erm... important? Yeah, important... there is different lifestyle choice that they have perhaps influenced them and things like that but they are still chronically unwell! I still think there is a genetic disposition with type 2 as well and sometimes it can't always be avoided. They are both health conditions but they are very very different! So different... but who gets to call themselves the diabetic then? Or maybe another term entirely, we could really go quite far here! Do you want to keep the diabetes, aye? I think I have kind of earned it!! For 24 years I don't know what she would do without it, but I think that's what's made Anna who she is.

Education: Discussion around 'rebranding' Type 1 and Type 2 diabetes as more distinct conditions due to common confusion even though they are both 'very very different!' Conflict over whether Type 1's or 2's would be able to call themselves 'diabetic'.

Trust/Education: Topical discussion around insulin use for non-diabetics to gain muscle. This practice has made insulin prices rise and trust in supplies/ers lessen. Interestingly confusion as to how extra insulin would affect a person with a fully working pancreas.

Education: Interesting reflection regarding participant being told she 'couldn't do things' and mothers reflection on advice to get her daughter a job in close proximity and how that motivated her to travel the world.

Education: Discussion around 'rebranding' Type 1 and Type 2 diabetes as more distinct conditions due to common confusion even though they are both 'very very different!' Conflict over whether Type 1's or 2's would be able to call themselves 'diabetic'.

Because that is the real value for them, because that data becomes knowledgeable and power. But do you know from saying that as well, the interesting thing is 87 different graphs from my CGM right now, okay, when you go into the hospital the consultant will say to you, Steve will say "just a wee bit too much information here!" So you can tailor it to see this and that, nighttime patterns - that sort of thing! But its overwhelming! And it goes back to that, you can all day being a diabetic and forget to be a mother... My dad, when I was pregnant, I sold sunshine the Lifes and I was scanning all the time! I became obsessed with it! And your mental health... Thats understandable, isn't it? Uhh huh, well I actually got given the sensor and meter a week apart as I was so worked up and upset and stressed about things like type... I was up through the night, I don't feel the baby move! I have done something, like my bloods were too high yesterday... and they were like "you need to calm down"! How do you! You said you have suffered from anxiety as well. Yeah and it was my honeymoon period so everything was all over the place, and you are feel like score stories... like in the first 2 weeks, if your bloods are too high then your baby will have no arms! Yeah. I know... so I was like "I want my baby to have no arm! You must have been dreadfil, dreadful! It wasn't the best! But for the too much information, I completely agree with that... Its the kind of thing, like what do users actually need? Yeah... And what do you want as well though? There you go.
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

29 Relational: Interesting discussion on needs to lead to user preference. Participants understood that you can’t design for all diabetic users and how different a users needs are.

30 Education/Relational: Spinning off ‘too much information’ is the need for some people to have access to extra context. Notably the idea of levels of complexity emerged and how users can gradually learn how to use devices.

31 Education/Trust: Reflection from participants mother regarding pre-glucose meter testing with urine strips. Interesting story regarding the shade differentiation and how a ‘7’ could also be a ‘17’ which further indicates how poorly designed the system was for end users.

32 Trust: Discussion on learning and awareness at a ‘base’ level of self-management education. Interesting reflection from mother regarding mix-up of quick and long acting insulin that could have ‘killed’ her daughter and how this experience was a lesson to “never do it again!” However this was considered a ‘dreadful’ way to learn due to the guilt aspect of making a mistake and could easy affect behaviour and relationships.

It’s simple! Bye, its easy! I think it depends on who is using it... because some people. Want the extra information? Yeah, and some people might not understand the information thats given to them. Its often that it starts off complicated and the clever rings, and people in the know, excel... but if you start off simple and gradually get more complex...
Education: "you need to start off at the base and then add on layers of knowledge" to avoid overwhelming someone. Interesting reflection from the DAPHNE course of how participant miscalculated a ratio which could have lead to dangerous circumstances.

Education: Discussion regarding continual use of the menstrual pill to have control of participants period cycle. Interesting dynamic that stopping periods was "one less thing" and a way for her to take control of an aspect of her life. However from self-managing a condition like Type 1 diabetes, what does one need to sacrifice?

Has that ever all come up in the learning of diabetes? Or can you fail safely with someone? No. So how you learn though... I think it is though when you are first diagnosed. By trial and error, because you just learn what your rates are... when you start exercising! I know that I am very very sensitive to insulin, people laugh that I take a child's amount and I am affected by exercise... like you would be doing your 3 hours of Irish dancing but I also knew that most people are most insulin resistant in the morning, whereas I am at night. So in the morning I take hardly any carbs and I can still hypo but other people are the opposite. And there are a few wee things with my consultant where they are like 'you are the exact opposite of what a typical top 1 is!' But I only know that through trial and error. And she would do 'through the night, this is what your basal is... as soon as you wake up you are like down to 5.5!' Yeah it works for you and I am like... It works! So I think a lot of it is trial and error.

My interesting as you don't get taught these kind of things... Again as a personal thing! I made the conscious decision in my 20's, I ran the pill in for 10 years! You run what? My pill is... Back to basics! Yes, I didn't do it for 10 years because of the effect the period had on my blood sugars. For 20 years! Yeah, I was like 'not doing it!' Is that safe? It is fine. The gyroscopist said, "his hormones, you're fine" but for me it was because, at that point I was living by myself and building everything like that... it was one less thing. She had enough to cope with, aye! Its control for you as well actually. Yeah because, that shut off hormones has a massive effect on blood sugars... Aye! And obviously with that, you have cravings and things. Yeah! I feel to high to even be considering this... it affects the amount of exercise you are taking and what's in your body... so I just thought, I can't get rid of that but I can definitely get rid of my period. There you go! So its things like that when it would be interesting to see what decisions do people make because the type 1, if you are playing the game then type 1 diabetes is your priority. So what other things then do you... change? What do you have to sacrifice? Yeah. Or what do you balance it with? Diabetes is a balancing act! Absolutely but I just love the idea of learning that is coming out now... its something that I didn't fully consider before.

Education: "trial and error" approach to the question of whether participants could 'fail' safely when learning how to self-manage. Clearly this methodology is how people learn but no provision has been put in place to accommodate this style of learning.

Education: Discussion around life stages such as childhood, puberty, adolescence, pregnancy and its affect on a persons self-management. Notably the predictable aspects of pregnancy don't seem to be focused or targeted enough as priority for additional support compared to mental health and the ageing population.

Education: "you need to start off at the base and then add on layers of knowledge" to avoid overwhelming someone. Interesting reflection from the DAPHNE course of how participant miscalculated a ratio which could have lead to dangerous circumstances.

so when you are a kid between the age of 10 and 20, you learn something and see next Monday... 'hope? This you know? Totally! Before my insulin was to do this but now it does happen! Also on your honeymoon period. Yeah, yeah absolutely. You think you have it down and then the next month you are like back to the start! And with pregnancy as well... Well you are saying what's your priority but remember when my baby was wee, getting up during the night to feed him and thinking 'I am not well at all...' and it was down to the 5.0's. I was like 'I have a screaming baby that I need to feed, but I need to treat myself first because if I collapse... Uh huh! He is not going to get fed! So I had to lie him, my husband was working. In the middle of the bed while I am screaming... I am lying next to him while my blood sugar kicks in - It was horrible! And it is horrible feeling like you are putting yourself before your baby but logically you have to! That is your priority, absoulutely. Alongside this research, I have volunteered at NHS 24. So it came originally from the interventions side of things but the three main 'high intensity users' of their services are the women with small children, the elderly and those with mental health conditions. Oh my right okay! People who are unsure of their own condition or those who struggle to self-manage on their own. But we know and can anticipate that being a new mother will have challenges and it will be more difficult to look after yourself when your focus and energy is on your baby. Yeah your focus is on them but also your diabetes is up and down and so is your hormones all over the place... maybe breastfeeding and all that, and knowing to look after your baby you have to look after yourself.
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

these devices, living in the 21st century... that it should be different! But some of these things add extra pressure and trust issues into consideration. I think considering sixty years ago if someone said you are type 1, then you die... and then you have these big masses, you have seen the old needles! Being able to test once a day through urine. And the amount of blood needed for early monitors... Whereas now, "I’m... oh... I don’t even need to do an injection! It’s already in, so I just push a couple of buttons and that’s it. So, I have to say I think technology has moved on so much! Oh it’s amazing! It’s fantastic, although, obviously there is always things that could be better! Maybe not having type... but I think it’s amazing!

that’s what you didn’t tell him... Anna was on an adult regime. Which was illegal! It was illegal?! I had to get social work... So what should you have been on? It was illegal! So originally when I was first diagnosed... I would take two injections a day, so a long acting and a short acting “cocktail” for words of a better term. And a long acting at night. And you would take the long acting and short acting cocktail at nighttime. I then specifically because of the cow biscuits I said, is there a way in which I am hungry... I could have something to eat, and if I am not hungry... I don’t. And they were like, “Well no... that’s for adults.” So I went away to look on it. “What age were you?” I was 11. That’s very impressive! Compared to what most other 11 years olds do... And it was a basil bolus, and the consultant was like “there you go, smart Alec! But that’s six injections a day...” and I said it could be more! She said “yeah,” but does that mean I am really hungry for my dinner? I can eat more dinner? And not hungry for my snacks... and she said “yeah” exactly what it means. So we had to be trained up on that. That’s amazing! But it was illegal under 18. Or with special documentation. So she was the best controlled diabetic in Britain - because I knew exactly what I was doing with the needles, and I would still know the pump.

you don’t just have yourself to manage but someone else to look after too, that’s your child. you can’t have a full night sleep because your blood sugar. A constant worry! And one of the saddest things about it was that people didn’t understand, and even see to listen to myself... I think that sounds as if you are really exaggerating - but I wasn’t, that was the gospel truth! Because what I quite likened it to was that she could quite literally, die... at any moment! And it was a fact! And you as a mother probably felt that that weight on your shoulders... Mmm! I have met a few mothers with type 1 children and I have said to myself that I am so grateful that its me... and not my child! Because I don’t think that I could do it! Absolutely! And even Anna said that, she even made that decision a long time ago... she said “Mom, you will need to look to the boys for kids... because I am not doing it.” If I knew that it was definite that you would pass it on, which we don’t... But its something that my husband and I had a conversation about as well. Yip... and there is some people that don’t have children because of that! There is people who don’t for all sorts of reasons or health issues. Yeah but if really shouldn’t hold you back, it shouldn’t but it does in so many ways actually. Yip...

Relational/Education: Discussion around how carbohydrate counting affects relationship towards food and becomes numerical. Participants reflect on the strengths this can bring towards acknowledging what “hits off of your body”. However mother reflects on how that responsibility makes her feel ‘judged all the time’.

Relational/Education: The pressures of motherhood and diabetes. Frank discussions regarding how daughter could “die... at any moment!” And how this condition affected their decisions to have even children of their own.
very isolating experience, very very isolating and the only time you ever fell you could discuss it. In all aspects was with someone else who had a child through the same programme. Shared experience! Uh huh! And it can be quite lonely for that. Very lonely and quite frightening, and a huge responsibility on you. Like the responsibility aspect... and how much that changed your relationship. Uh huh! Because sometimes I felt as if I was Anna’s ‘jailer’ you know I felt as if I was like the bad cop. I was always...

**Relational/Trust:** ‘knowledge equals power’ that can also be ‘guise’. Notable from reflection on filling in dietary book for HbA1c which is ‘all total lies’ which shows interesting reflections on feeling ‘fantastic’ off regime, not putting on weight and not worrying about hypo. Also notable was the need to rebel and ‘push my extreme’ to understand limits which goes back to trial and error learning. Mother recommended that daughter rebelled early so complications don’t involve adult activities like alcohol or substance abuse.

**Relational/Education:** Discussion about rebellion between mother/daughter relationship and how that lead to daughter refusing to take insulin. Interesting reflections on feeling ‘fantastic’ off regime, not putting on weight and not worrying about hypo. This responsibility changed her relationship with daughter as she felt like her ‘jailer’

**Relational/Trust:** Reliance on pump to undertake a pregnancy with Type 1 diabetes. Shows how enabling such devices can be but also how they can turn people into ‘control-freaks’.

**Relational/Trust:** Mother reflects on how ‘isolating’ and ‘lonely’ experience was putting her underage daughter on basil bolus regime, she could only relate to others with shared experience of programme. This responsibility changed her relationship with daughter as she felt like her ‘jailer’

**Relational/Trust:** “how CONFIDENTLY never entertain the idea of pregnancy without my pump and my CGM! No chance! I have got to say though, I managed my first pregnancy without a pump... Hats off to you! I am too much of a control freak. There is not a chance I could do it! To nice to be able to do the small tweaks, rather than everything at a half unit.”

**Relational/Education:** Mother reflects on how ‘isolating’ and ‘lonely’ experience was putting her underage daughter on basil bolus regime, she could only relate to others with shared experience of programme. This responsibility changed her relationship with daughter as she felt like her ‘jailer’

Full transcript available to read transcript in Appendix E1
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

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And they said that doesn’t necessarily mean that you would be like that this time? No they said... Sorry Ross! No, not at all! They said there was more chance as I was having the baby with the same man, but if I had it with someone else then the chance would be less. They said a second time, there is more chance for it to happen later on and be less severe. My issue with that is that I don’t know how early it started. So when they say later on, how much later? Would that still be about the same? Well you are in every two weeks. But I was in every two weeks then before as well and the day before I had my diabetes appointment. And you were fine! But they don’t check you. Did they then pick it on the bloods? No, well... I went to the hospital the next day and said ‘Listen, I need to see someone... something’s just not right!” With drinking so much and my bloods were perfect. So the next day, I gave my breakfast, but I wasn’t hungry and I had to force myself to eat for the baby - then I really knew something wasn’t right. So I went up and took bloods. Shows you that you should always trust your instincts. Instincts, absolutely! I do know and it was the same with the diabetes. When I eventually got to hospital, I was like ‘oh’ but in a couple of hours I could have been in a coma.

My husband was working away, I was in a flat by myself - I thought it was my anxiety! Yeah, yeah! I was like, ‘frankly I can’t come to your new years party!’ So I am confident, I was in my honeymoon period, that my own insulin would have kicked in and I would have come through but the again... you just know! Trusting your instincts and making sure you have that understanding and knowledge of yourself.

45. Education/Trust: Anecdotal story about first pregnancy and being diabetic. Even though participant saw diabetes team one day before hospital, she couldn’t communicate situation to get to route of issue, preeclampsia, which lead to pregnancy 9 weeks early. If she could have trusted instincts and communicated concerns earlier then someone may have diagnosted her sooner and wouldn’t have lead to emergency.

46. Trust: Discussion about verbalising when something is ‘off’ and when do you ‘don’t feel right’. Notably this lead to notions of intelligence/ability playing into, as participants were ‘very educated people’ and discussion around the ‘person that can’t count’ and how they would be perceived in similar situations.

47. Relational/Trust: Discussion around admitting to mismanagement and and having the agency to make a change/ improve situation, especially as hierarchical notions of doctor/ patient still exist, even though self-management devices enable the person using them more knowledge and insight into their condition.

48. Education/Relational: Discussion around consultations and the importance for users to learn how to interpret data and patterns to make sense of their health. This further suggested the importance of trial and error learning.

Full transcript available to read transcript in Appendix E1

when you don’t think that of yourself, you can just know when something is off. Yeah, and it’s very hard to explain or communicate that to a doctor or other practitioners generally actually. With anything! Absolutely. Is the kind of thing that if you do go and see a doctor or consultant of any kind, they would be like, “so tell me what’s up with you?” Yeah! And sometimes thats often not so easy... It can be very hard to verbalise. If someone told me, “whats the matter?” I would be like, well, I don’t know. I just have a pain and I don’t feel right - I was drinking a lot of water and people would be like, ‘right, I think what worries me... Sorry I don’t mean to worry you! No no... I mean with the general population is that, blowing our trumpets here, but you are speaking to very educated people. Absolutely! So how do you find the person that can’t count? Someone that struggles with ratios for example... you know? I think the key problem with this kind of research in general, is that some people cant self-manage appropriately...

we could say goodbye to the face-to-face consultation actually. Yeah! See as well as a daily user, it’s important for you to be able to kind of the what you used to do when Anna was was, look at patterns and try and figure out what has changed... whether its your basal or bolus, rather than seeing your consultant in 6 months saying, ‘I hypo at 3 o’clock everyday, what do I do?’ I knew could you imagine? But thats where the education comes into it... because she educated me to deal with, I seen that aspect where people weren’t told what to do and they would only change their insulin once every three months - that is far too late! Whereas in the Management, they would say to my mum... just do it! ‘Just, what do you think? Let us know...’ and the proof was in the pudding. I was either going to be hypo, high or fine. Well thats it, its another trial and error... you try it, you put it up or down a bit and see whether it is enough or too much. Yeah! But there is so much discussion there...

see what you’re saying about like people that don’t know a ratio. I think if you didn’t know what you were doing, you maybe didn’t want to admit it? Yeah! You might not what to come to something like this... Or have the knowledge or understanding that its wrong... Or the agency! Absolutely. See to turn round to someone and say, ‘No, I actually don’t feel right... I was at the hospital yesterday and the doctor checked?’ Thats what my mum would say, I showed her a screenshot and said, ‘so you think I could have preeclampsia?’ And she was like ‘no you were at the doctors yesterday... everything there is normal!’ But I was like ‘nope!’ There is that hierarchy thing there as well, old school ‘you are the medic’ kind of thing. But with these devices a lot more agency comes to the user. Yeah! And a lot more knowledge comes to the user because you are the one generating the data, knowledge, Insight into your condition.
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

Do you know what I have seen is a massive improvement in DSM’s who have went for Medtronic. Oh hail! And they are silent hail! They are really good! I don’t know if it’s just the cohort from Medtronic who then... and that industry exposure. Yeah, I think what they do is they are treated as, they are not like the DSM and consultant, who are predominately women, are training them on devices... so they have been excellent and if I was looking at a service devoted to improving your self-management, “I think these people would be very key! Helping out with that... They are the ones who you interface with the most and in primary contact with.

And there’s a lady, the one that I have in mind is a lady called Heather Maxwell who is a DSM in [Sartanet] and she now works for Medtronic... she knows the condition inside out working with it for 20 years. I think she was a research practice nurse as well. And then has moved into Medtronic... so I think now she has more of a suite of things and gadgets that she can use... and its top of the range, so all that knowledge she can put into... She can narrow, and em utilise that knowledge in particular.

Whereas before for the NHS, she would be like, Ross, we could give you this super-duper gadget but you can’t be prescribed it, so we are going to start with... because my pump is optimised by my CGM. And I feel sorry for someone who has got a ‘dog’ and I am like its only doing half the work! Absolutely and its that kind of mindset, you need to fully utilise or harness the potential of their particular device... and you hit the nail on the head.

Educational/Relational: Discussion around DSM’s going to work for a medical device manufacturer (Medtronic) enabled others to be better and more knowledgeable at their practice but also contribute their own experience towards devices. This was suggested as she was advised her old device was “only doing half the work!” Which means that these insights can impact on future devices.

Trust: Discussion today regarding users who don’t self-manage appropriately. From sharing anecdotal story from previous interviewee suggested that learning about self-management requires users to go “up the swanny” as a ‘reset’ moment to gain perspective.

Relational: Interesting notions of how a third party could intervene/interact with users, liking it towards motivation, influence people but not to ‘try and lecture’ them. Also connotation towards the mother was revealing as she said “you can see them as a number” suggesting that this medical relationship can overpower interpersonal mother and child relationship.

Relational: People with lived experience “understand in a way that nobody else can really” as participants mention others false/misleading perceptions towards the condition. Discussion leads onto close relatives that just dont grasp the condition and are lead by public preconceptions about diabetes rather than differentiation between Type 1 & 2.

“what if you could create a new engagement role for someone to push or motivate you?” Its a little bit like the mum role... If you could have that aspect of it? It would depend on how they motivate you! Or whether they direct and lecture you... Thats the thing, ‘how’ would they interact with you? How would they notify you... because from a prospective user of this, you don’t want to be nagged/ Kind of influence you... And mothers don’t want to do that either... Hmmmm! You want to have a good relationship with your child and to not be so ‘medical’ Yeah and if so, how could someone could do that on your behalf? How would that look like and how would they interact? You can see them as a number, you know... whatever your blood in! Absolutely, the kind of thing you would ask is ‘why is your blood sugar high?’ Especially with these devices becoming more connected... I could link to someone more clinically aware or knowledgeable instead of a close family member...

learn and interact with each other... I have to say I love that Facebook group because its people that understand and you can chat to... they can understand in a way that nobody else can really understand! Yeah! It’s the lived experience aspect of it. And I said my husband has two best friends who have diabetes but he will often be like, ‘your high again today’ or ‘low again’ towards a hype and suggests to just calm down high this week? Thats not going to work! And then he gets annoyed when I hype again!” because I am trying to have control. Yeah! Or alas, sorry but, so my mother-in-law will say things like, ‘but your not very well managed,’ like no Anna... the fact that I hype means I am so well managed - so you know its the things like that! I mean because I always say to people... he even had doctors say, ‘the last time I saw you, you have had a hype!” And I am like ‘ah haah, yes!’ What I know! I say to them, actually under Diabetes if you are well controlled you should have a hype a week. You should? On average, so why should I not? Absolutely! And Anna’s mother-in-law is a dietician... So we stayed with my mother-in-law for a few days and as soon as we moved out, she kept telling people. She is diabetic and takes sugar in her [unintelligible]”. Yes, I take two teaspoons of sugar... there is 4g of carbs in each, I boils for that and it is okay! But to her “Oh, its too much...” We had a debate, yeah! its the mismanagement aspect that lingers over things... No. its mental things! So we went to Portugal on holiday two weeks ago, and it was the debate around the breakfast table was the ‘no-added sugar Jaffa’ which was sending me like mega high because there is raisins in it! Ooh really!” I might as well actually just eat sugar! The debate was, can a dietician... thats something that really annoys me!
## 5.2 Thematic Analysis Coding

| 53 | Educational: Debate about nomenclature; ‘I have diabetes’ or ‘I am a diabetic’ as this term has derogatory connotations and we asked how the condition could be labeled in a positivistic way instead. |
| 54 | Education/Trust: Fake news and media press exacerbate false knowledge and lead to public misconception regarding the condition. However participant claims that ‘kind of news sells’ suggesting that people are only interested in stories that negatively impact diabetes. |
| 55 | Education/Trust: Fake news and media press exacerbate false knowledge and lead to public misconception regarding the condition. However participant claims that ‘kind of news sells’ suggesting that people are only interested in stories that negatively impact diabetes. |
| 56 | Education/Trust: Notions of positivistic views/perceptions towards diabetes, especially around destigmatisation of the condition through making diabetes a way of life. However interesting reflection that certain people “are not going to tell you what their weakness is” but strength to open up to tackle stigma suggests that it is empowering and a way to try and educate people through experience as a way to “break it down and help people understand.” |

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**Steve Redgrave, for example, I can remember sitting up watching it. Think it was his fifth Olympic and he had some kind of flash monitor on. Is he diabetic? Type 1. ** protests, I didn’t realise that! And my dad and I stayed up and watched him. *That’s amazing!* The strengths aspect of it. Amazing! It doesn’t have to limit you... The strongest man in that boat. Why? Because he knew exactly what he has to put into his body. Absolutely, and from what I have encountered many do excel in sports... and a strength is that they know their body better inside out. *It’s funny as well*...*as you were saying about marathons and I know a couple of people who run marathons...* and they are like in the first hour this will happen... and I am going to go high or low or whatever, then I have this stash for this and hydrate here. Like that is amazing! Absolutely. But that will be another trial and error learning though. But that is how I learned that in particular, it was from the failures and complications that he developed coping strategies. And he is learning about his condition, rather than just looking at it like ‘This is my diabetes’. So more this is how I run a marathon. Yeah! And that’s the really positive... and at the end of this, not only am I going to have all this knowledge about my condition but 26 miles completed! |
Relational/Educational: Notions of peer support arose as “your circle will treat a hypo at some point” and educating those close is essential for such events. Interestingly, children’s perceptions of diabetes were discussed and how early childhood experiences can shape future outlooks. It is suggested that educational campaigns should include positive portrayals of diabetes to change perceptions and reduce stigma. The role of family and peer support in managing diabetes was highlighted, with participants discussing the importance of sharing experiences and seeking support from others who understand the challenges. The concept of ‘visibility’ came into play as others see these devices, which can sometimes cause curiosity or confusion towards Type 1 diabetes.

Trust: Further discussion on issues with wearing devices, particularly during travel through airports, was a safety issue and caused problems for participants. Due to the security of airports, these devices and carrying insulin can be seen as risks, with interesting anecdotes from participants regarding experiences from security guards and needing to use the “Dr card” or other methods to overcome issues. The conversation arose to what if someone wasn’t as educated… how would those types of negative experiences affect them? And how would they approach overcoming issues?

Thematic Analysis Coding

57 Education/Relational: Notions of peer support arose as “your circle will treat a hypo at some point” and educating those close is essential for such events. Interestingly, children’s perceptions of diabetes were discussed and how early childhood experiences can shape future outlooks. It is suggested that educational campaigns should include positive portrayals of diabetes to change perceptions and reduce stigma. The role of family and peer support in managing diabetes was highlighted, with participants discussing the importance of sharing experiences and seeking support from others who understand the challenges. The concept of ‘visibility’ came into play as others see these devices, which can sometimes cause curiosity or confusion towards Type 1 diabetes.

58 Education/Relational: Discussion around a ‘new normal’ for diabetes and promoting diabetes through lived experience to change mindsets. Nationally positive campaigns arose that looked at new perspectives rather than a “poor wee thing sitting with their blood machine.” This suggests a more positive campaign would not only improve users’ perceptions but that of others.

59 Relational/Educational: Clothing and diabetes devices are not fully considered, especially one participant describing putting hers on her sunhat while wearing a bikini at the poolside and needing to put it in a bra while describing an acquaintance who said he kept his in his pocket. “It is just bloody annoying and falls out all the time!” Suggesting that manufacturers haven’t considered the wider lifestyle of users. Also the notion of ‘visibility’ came into play as others see these devices, which can cause curiosity or confusion towards Type 1 diabetes.

60 Trust: Further discussion on issues with wearing devices, particularly during travel through airports, was a safety issue and caused problems for participants. Due to the security of airports, these devices and carrying insulin can be seen as risks, with interesting anecdotes from participants regarding experiences from security guards and needing to use the “Dr card” or other methods to overcome issues. The conversation arose to what if someone wasn’t as educated… how would those types of negative experiences affect them? And how would they approach overcoming issues?

What if we could create a new normal for diabetes? How would you do that? It would be through promoting diabetes through a lived experience perspective! It’s something that clinicians haven’t ever done! But there was a campaign years ago, that was good and it was really quite hard hitting! And there was one that was a couple… the girl was all shy and ten like misfit macho, and they went having a conversation and there was a blood machine and she said ‘give me a mess bag and I can go all night!’ Maybe we could be looking this up now… but yeah! But to a young person that was quite hip and out there… in your face! What if you could change mindsets about diabetes? So that kind of mindset… Uh huh! Rather than a poor wee thing sitting with their blood machine... I mean they are vibrant and out there! Seriously.
Relational: Anecdote around pre-diagnosis encounter and how important it is for others to be “interested” and to listen. This encounter lead to the eventual diagnosis of her own daughter. However this story suggests that others can be interested in this subject even with no prior knowledge/relation to the condition. Also discussion on symptoms that lead to diagnosis suggests that we could all be on a diabetic spectrum and relate to the condition in some way.

Educational: Notions of diabetes spectrum explored further through empathy. Interesting suggestions like if diabetic people could get non diabetic people to experience a hypo to help them understand. Furthermore to simply it down to the pancreas, like in “Think Like A Pancreas” to objectify rather than subjectify. Also tools to help communicate these experiences better as current numerical system can be confusing and unrelatable.

Relational/Trust: Again issues with wearing devices and the conflict that comes with ‘proving’ you are diabetic. Notionally this anecdote with a pharmacist is a prime example and the barriers that some diabetic people have towards obtaining insulin. Interestingly the concept of proving your diabetes was popular even though from the story it seemed obvious. Also the notion of “who else do you go to in the those situations?” Suggested their needs to be more options for people needing help or knowing who to turn to... especially in circumstances like out of hours (NHS 24).

Relational: Idea of showing a more human and relatable side to diabetes was met with controversy towards who audience would be. It was suggested that the wider public would be target and people with Type 1 diabetes would become brand ‘ambassadors’ for the condition to not just represent themselves but the community.

By placing them in the robotic script, it meant that they could empathise with others. "Think like a" shares these type of empathy. People with Type 1 diabetes would become brand ‘ambassadors’ for the condition to not just represent themselves but the community.

In particular I liked the strengths and looking at diabetes in a positive way. To introduce diabetes better, to gain empathy. "Think like a" with the public to focus on a particular demographic to get them into diabetes, possibly children who would grow up with a different perspective?” I have got to say, see one - I don’t think anyone would be interested apart from someone close to them. But it’s not a reaction, like if it was me before I was diagnosed, I would be like "Hey!" interesting! But "Thank you when talking about representatives. Yeah... you could brand yourself as a diabetic more differently. Just to hear from Diabetes Scotland who I was I was originally working with to get interviews. Ohh! They do consider themselves their young volunteers as "Young Leaders" "Ambassadors" Absolutely, so that they represent diabetes...not just yourself but a whole community.
Educational/Relational: Focus on “what if we could educate the public better and empower people with Type 1 diabetes?” Discussion about public role models and ambassadors like the participants themselves as proponents of change. Notionally the situational map came into play with the Type 1 ambassadors at the centre, with those seminal to self-management like family, close friends and diabetes clinic at the periphery to educate and inform the wider public about the reality of being Type 1 and inspire positivity towards the condition.

Relational/Trust: Interesting family dynamics from participants when discussing shared experiences with one another. Firstly the opportunity to share openly was praised as an intervention in itself. Jean said: “Because I never Anna speak like this…” which suggests opportunity to innovate. Also discussed close family relationships with differences between participants from “I asked how do you treat a hypo… he couldn’t tell me. Asked what should he do if I collapse… he couldn’t tell me! That more than worried me, that really annoyed me. I was like, I have been diabetic for a whole year, and you are my dad! He doesn’t understand it.”

Relational/Trust: Notions of empathy from interesting idea of a partner pump yo-yo to understand the physical, mental and emotional experience of using a pump to other design interventions that inspire empathy.

Relational/Trust: Interesting insight from participant, “I feel there is a lot of type 1 diabetes that don’t understand” suggesting that education should be targeted further towards those with the condition instead of DAPHNE programme as misconceptions/confusion still arise.

Relational/Trust: True understanding of the problem with diabetes, the functionality of the pancreas. Interesting insight from participant, “I feel there is a lot of type 1 diabetes that don’t understand” suggesting that education should be targeted further towards those with the condition instead of DAPHNE programme as misconceptions/confusion still arise.

Idea of the community aspect, quite important or meaningful to know that other people are in the same position or had had similar experiences. Yeah! Yeah! That’s at least what I can understand from the conversation. Uh huh! A lot of reassurance and shared understanding from these experiences, it must make you feel better about yourself and your self-management! Yeah! I think so. Connecting to people. I think knowing what the stimulus is for something like the you saying… some people can tell you the symptoms of a condition but when it starts to just be important! And the impact of it too, whether that’s sleep or stress. Or heat! Time of the month. Everything! I think it’s quite nice to listen and tell you two girls speaking! Absolutely, I feel the same exact… this feels like an intervention in itself to bring you together. Because I never Anna speaking like this…, and your mum and dad would probably say the same about you! Probably me, and its really because I have never lived at home with it… Mmmmm! So when I was diagnosed, obviously I was in hospital for a day, my husband was away… not my husband then and I stayed with my mum for a week or two. But my mum has a ‘basic’ understanding but even now, I would test twice and she would, “What is it? What is it?” It’s very clear now, Mmmmm my mum has never been in the same situation as what you have been in. Which might be terrifying for your mum because if all else failed right now, I could go into hypoglycaemia and she would be able to work injections. Like a few months ago, my dad said he was going to do a ‘try old at work’ course and asked, ‘dad, what would you do if I was hypoglycaemic’ he was like, ‘Ermm…’ he asked how do you treat a hypo, he couldn’t tell me. Asked what should he do if I collapse… he couldn’t tell me! And that more than worried me, that really annoyed me. I was like, I have been diabetic for a whole year, and you are my dad! He doesn’t understand it.”

I think as well the empathy aspect of it, I think why is it has come up is that I’m a new way of people to understand a lot deeper… Mmmmm! You know I really understand this stuff, it’s not used in Diabetes care when someone was on a pump, their partner would wear a yo-yo. Right? So it was, the whole of the yo-yo and a bit of stuff, and every day they would have to put the type on them and understand where do you put your yo-yo? From an empathy perspective that’s brilliant to understand the experience of using a pump everyday! But how good is that? I mean I think, it’s not about being expressive, cheap but effective. It cost nothing… maybe, you know. But the experience it gave the partner would have been valuable. It was nothing to do with button pressing, nothing complicated. Just physical. And emotional! Like you going to your bed, where do you put it? It helps somebody else feel what you feel. I mean, I don’t mean when we do a project with RNH, then do we give them all that allowing glasses to experience what it like to be visually impaired. And wearing them for a minute, even just the cutaneous, was amazing! But it was terrifying! Terrifying but you could empathise with them and respect it! I went from poor them to you are fucking amazing! Yeah! I could barely walk a short distance without panicking… I could imagine! And also last year I was working with amputees for my Masters thesis, and I interviewed a charity founder who was a quadriplegic amputee. What? She contracted syphilis and was left with two stumps for hands, and I was absolutely amazed with what she could do! It made me want to tape my hands to see if she could emulate it… Uh huh! But I had such admiration for her!
5.2 Thematic Analysis Coding

I think what we mean by the empathy aspect of it, I think why it has come up is that it’s a new way of people to understand a lot deeper. *Mum*? You know a really good thing they used to do in *Mum* was when someone was on a pump, their partner would wear a yo-yo. Right? So it would be, so the ball of the yo-yo and a bit of string, and every 2 days they would have to put the tape on them and understand where do you put your yo-yo? From an empathy perspective that brilliant to understand the experience of using a pump everyday. But how good is that? I love that... doesn’t have to be expensive, cheap but effective. It cost nothing... maybe 50p. But the experience it gave the partner would have been so valuable. It was nothing to do with button pressing, nothing complicated. Just physical. And emotional. Like your going to your bed, where do you put it? It helps somebody else feel, what you feel. (The same when we worked on a project with RBH, and they gave us sight altering glasses to experience what it’s like to be visually impaired. And wearing them for 5 minutes, even just the cataracts, was amazing!) But it was terrifying! Terrifying but you could empathise with them and respect it. It went from your them to you are fucking amazing too! I could barely walk a short distance without panic... I couldn’t imagine. And also last year I was working with empathy for my Masters thesis, and I interviewed a charity founder who was a quadruple amputee. Wow! She contracted syphilis and was left with two stump for hands... and I was absolutely amazed with what she could do! It made me want to tape my hands to see if I could emulate it. *Uhh ha*! But I had so much admiration for her!

71 Relational: Interesting notions of how a third party could intervene/interact with users, liking it towards motivation, influence people but not to “try and lecture” them. Also connotation towards the mother was revealing as she said “you can see them as a number” suggesting that this medical relationship can overpower interpersonal mother and child relationship.

72 Trust: Notion of ‘silence’ who gets data notifications is an interesting prospect towards device data sharing as it puts control in users grasp rather than “all or nothing.” But how could preferencing be set and agreeable between people, especially close relationships?
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

73 Educational/Relational: Notions of mutual communities of support suggesting clinical knowledge and practical insight from an insiders perspective to demystify common confusion towards a ‘new normal’.

74 Trust: Idea of regular check-in between mother and daughter to reduce strain on their relationship yet allowing a mechanism for knowledge exchange. Dynamics of this concept were dubious, such as the possibility of a weekly ‘fight’, but structure was agreed as a positive intervention between both as it set boundaries for each.

75 Trust/Educational: Idea of separate social networks towards targeted subgroups of the Type 1 diabetic community, such as parents with diabetic kids and teenage diabetics, to reach out for peer support. Interestingly Jeans notion of it ‘interferes with absolutely everything’ lead to her husband having an affair when she had ‘no notion whatsoever’ suggests the strain self-management can have on people ‘very isolating’ and their relationships with others. Discussion around how helpful it would have been for support networks of ‘someone that understands’ suggests help doesn’t need to be clinical.

76 Education/Relational: Problem around who to turn to and not knowing who is available to support you. Importance of social network/knowledge to advise and guide towards better practice/insight. Unanimously Brian was suggested to reach out to a DSN.
Relational/Trust: Issues with suppliers with one participant shocked that insulin supplier is known for office supplies and other participant complaining about level of customer service over the phone. Suggests these services need reviewed and overhauled to become more user centric. Also notions of privatisation affect trust and outsourcing reliance in these supplies.

Relational: People with lived experience “understand in a way that nobody else can really” as participants mention others’ false/misleading perceptions towards the condition. Discussion leads onto close relatives that just don’t grasp the condition and are lead by public preconceptions about diabetes rather than differentiation between Type 1 & 2.

Relational/Trust: Discussion about how hard people who self-manage can be on themselves, especially with numbers (m/mol & HbA1c etc). In contrast to Brian, Jean provides interesting reflection on being “too controlling” that her daughter would not register as a diabetic for HbA1c. Also interesting reflection from Anna regarding the GP “here is my 70 type 1 diabetic patients, you are sitting in the medium… So your fine?” suggesting for those roles the quality of consultation is lacking.

Relational/Educational: Discussion about Linda’s journey suggests companionship issues after losing mother and sister co-management relationship. Uncertainty regarding inability to work Libre flash monitoring system but notions of “you can’t teach everybody the same” suggests that some won’t be able to learn and understand how to use device as intended.

Relational/Trust: Issues with suppliers with one participant shocked that insulin supplier is known for office supplies and other participant complaining about level of customer service over the phone. Suggests these services need reviewed and overhauled to become more user centric. Also notions of privatisation affect trust and outsourcing reliance in these supplies.
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

81 Education: Learning from user behaviour like this example regarding replacement pumps which suggests a few service tweaks would eliminate the issue, so if companies were to ask users what there needs were they could tailor there service towards them better.

82 Educational/Trust: Multitasking towards self-management and the everyday. Participants are numerically able to calculate things while undertaking day to day activities without impact. This suggests talent/skill that often goes unnoticed and undervalued.

83 Education: Negative considerations towards those with Type 1, referring to ‘can’t’ rather than ‘can’ and focusing on weaknesses/limitations, it affects those with condition - some aspiration to prove wrong but others can see these as degrading/demotivating.

84 Educational/Trust: Multi-tasking. Like even from the numbers you were throwing out today, I have learned so much from your guys today! And I don’t think I will look at certain foods again without considering carbohydrate grams... I think you have so much strength! Yeah, but my mum can predict that an high chance and what effect that’s going to have in 3 days. Ah, that’s better than anyone because sometimes its not the immediate low of the blood sugar... it’s like a days later you are hypo! I have got to say, I am really lucky because when I run, its like half an hour to 45 minutes, I know that for my breakfast, whatever my pump tells me. I take half and switch off my background when I am running - and that levels me out. Great! But I think if I did any extended exercise or ever went back to spin... I don’t know what I’d do! I would take no insulin and see what happens! Even and what you’re saying about multitasking, I was creating a road today and testing my blood sugar at the same time... like yeah yeah! In meetings we will quite often just adjust my pump and people are like, “Sorry we will stop” and I am like “no... keep going”! I don’t think the fact that you can do that “how much am I losing? 2-4 right.” Although, I have got to say that I have gotten really lazy and started asking online! I am like... “Ah, I can’t do 17 divided by six, multiply by 14, and add on... once I have weighted it and she tells me... I am getting so lazy... even just counting!”
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

85 Educational/Relational: New normal' notion and reference to normal changes, for example life changes after having children and is an even bigger change when you have diabetes as well. Which suggests empathy can be used as a way to look past condition.

86 Educational: Test your perception of ‘normal’ and meet more people that are diverse and different to broaden your perspective. Through doing so you will see similarities as well as differences between you and them and also learn your stance/position better within the ‘normal’ spectrum.

87 Education: Participatory methodology/approach was not a new experience for participants but design led process was, “I think that’s how you get things done!”

88 Educational/Relational: Participants suggested that products/services not considered the end user experience or feedback, that clinically the focus is on the condition more than the person who lives with the condition. “We know the condition but I think we don’t know enough about the person with the condition” and also that users are all different. “You could have 3 days, eat the exact same thing and take the exact same insulin, and everyday, every single blood reading will be different.”

89 Educational/Relational: ‘New normal’ notion and reference to normal that changes, for example life changes after having children and is an even bigger change when you have diabetes as well. Which suggests empathy can be used as a way to look past condition.

90 Educational: Test your perception of ‘normal’ and meet more people that are diverse and different to broaden your perspective. Through doing so you will see similarities as well as differences between you and them and also learn your stance/position better within the ‘normal’ spectrum.

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5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

89 Education: Participatory approach inspire new perspectives around ideas discussed as conflict/controversy between participants led to real moments of insight and opportunities for design intervention. Furthermore, participants realised there was no right or binary answer and each view was valid.

90 Education: Participants saw value in prototype, from an early stage concept and design direction participants approached user journeys well and could problem solve. Interesting reflection: “It’s reassuring to think that these types of conversations happen. Again, it’s not just the condition, you know…” suggesting that the person gets ignored/forgotten when considering people with long term conditions.

91 Education/Trust: Participants believed this approach to thinking was valuable but admitted it would take time for change to be implemented. Suggestion that trust will be an interesting topic for self-management as health devices become ‘smarter’ and potentially less control for user while more data for others.

92 Relational: Participants surprised how much they enjoyed workshop and possible new connection from Anna and Emma as they were both in education and pregnant. Also Anna and Jean discussed diabetes like never before during the workshop.

And lastly, what was your key takeaway or reflection? And was there any surprising outcomes? I am surprised I have enjoyed it. I must say, I am not, I was really looking forward to it… and I didn’t know what to expect though to be fair I did make the invite vague for that reason. Yeah, I didn’t think I wouldn’t enjoy it but I have actually really enjoyed it. I was going to give you out the agenda, which is more formal practice, but I didn’t want to scare you away with ‘prosthetics’ and such… Mmm! But I did want to try and make the workshop about thinking differently… because people don’t always think of ‘ohh what if there was a new role here...’ So something a wee bit different. I feel very positive after the workshop. I am pleased to [pick that I feel very positive as well]. And [name] has inspired me to find out what happens to find out what happens when I go to a spin class… Yeah, I am really glad you guys have met now! Yeah it’s great, it’s really good! Mmm! Any type pregnancy women. I am like… But the chances of that happening were... Any!
5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

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93 Relational: Discussion around the negative aspect of social networking and having so much information available through the internet - how easy it is to be overwhelmed with too much (false) information or too connected with others can make life worse. This suggests that such a social network should be managed and approved by third party to ensure it meets purpose and intentions.

94 Relational: Notions of balancing self-management and living your life, with some people being consumed/encompassed by the condition that it is hard to see different perspectives until you are "just a type 1 diabetic... and there is a lot of them who just, thats all they do!" This suggests lack of ambition or motivation to see past condition and something where social media/community approaches could benefit these users.

95 Trust: Pitching previous project for feedback and participants were concerned with being monitored "all the time" and scary "somebody having access to everything" However suggested that for certain users, like Linda, this concept could be preferable.

96 Trust: Criticism over giving data consent to an 'interface role' as trust and rapport needs to be built in order for this to be ethically viable. However, participants suggested if it was more clear and transparent then it would be potentially a credible concept.

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So would someone be monitoring your devices all the time? That was the key issue with this... when we were talking about ethics. Yeah! Pressure. Big brother is watching you! Also from a kind of what’s the worst I am looking for, staffing perspective? Oh no it was an artificial intelligence and cloud based system that would just notify the community contributor when needed... So someone would phone and check or? Yeah. Or a prompt on your phone to say... I think you are going to go live. This was just to show how design can intervene but this was the start or inspiration for this project. The idea of that kind of across me was big! Suddenly having access to everything. But for some certain people... it may be their preference - Lindy for example from the user journey? Yeah! She didn’t know how to use the device... originally it was conceived for type 2 and a lot older people who struggle to use their self-management devices... but also younger people to alleviate the stress on their parental relationships. Perhaps think there is certain sections of the community where that would be very useful. Or maybe times in your life, like if you do have a baby... sleep deprived and dizzy have the time. The target audience was people who misuse, or overserve, well there is not a proper serving or term for it but ‘high intensity users’ of NHS services are mothers with young children... The elderly! And those with mental health conditions, so if you can target them, you can target them. Yeah!"