ROSS MCINTOSH

Master of Research: *Design, Health & Care*

SELF-MANAGEMENT BEYOND THE SELF

Participatory design practice towards preferable diabetes self-management principles

MRes Research Project
Portfolio of Practice

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INNOVATION SCHOOL
THE GLASGOW SCHOOL OF ART

DIGITAL HEALTH & CARE INSTITUTE

Contents

Portfolio Guide

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.

KEY
Chapter. ***Section #***

1.1

1.#	Introduction
2.#	Literature Review
3.#	Methodology
4.#	Fieldwork
5.#	Analysis & Discussion
6.#	Conclusion

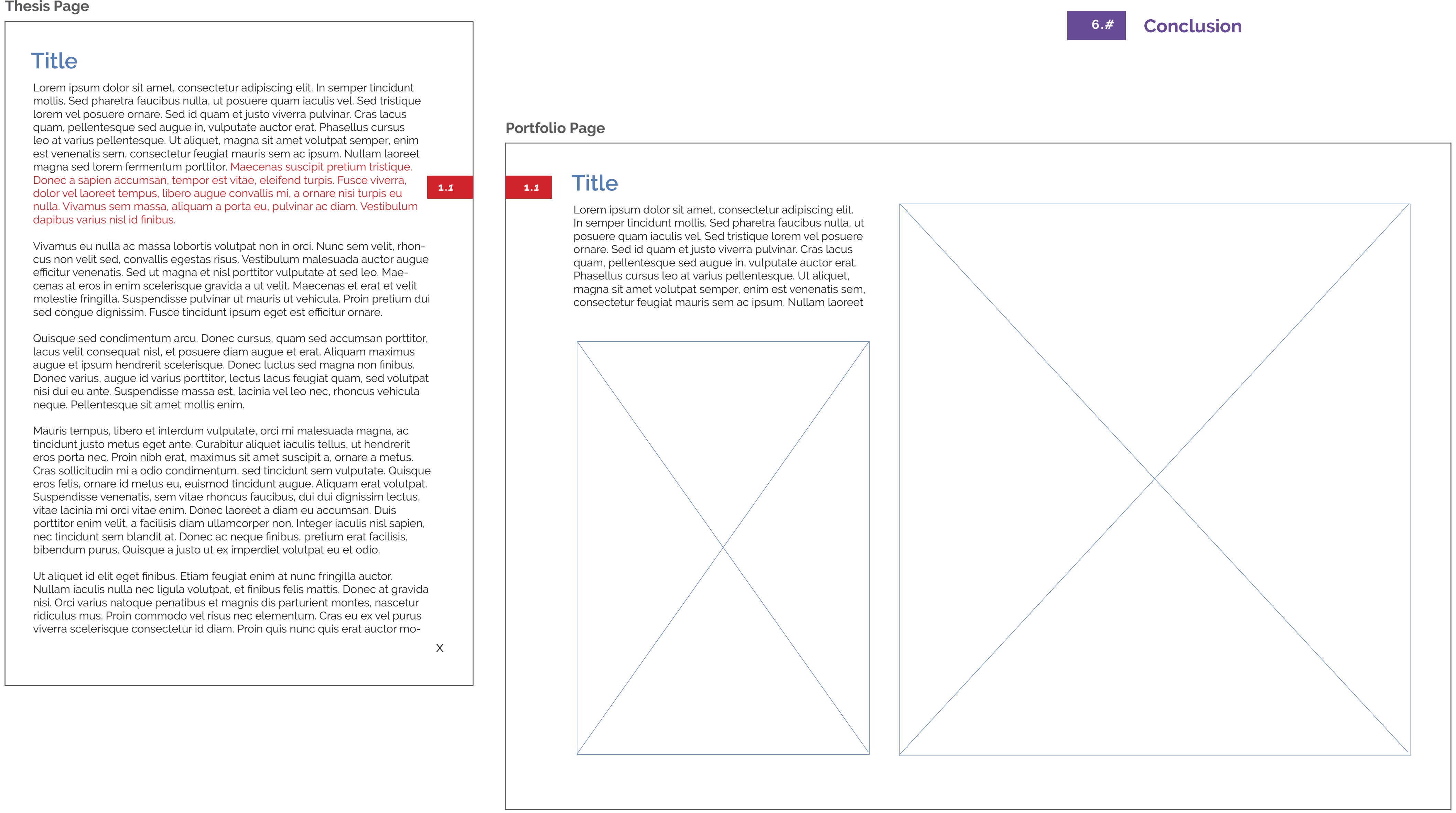
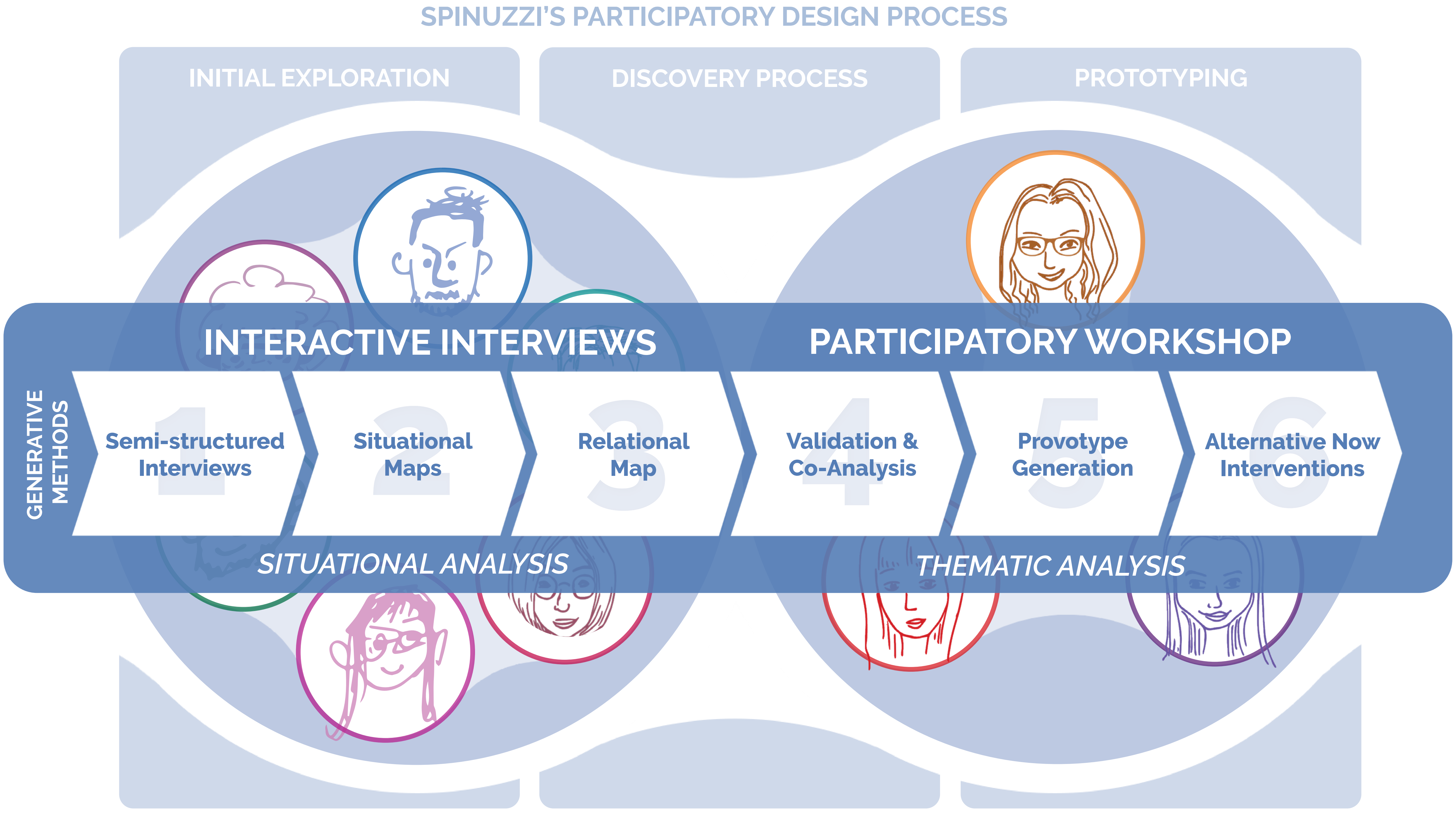


Figure 1: A graphic representation of how the thesis indicates a recommendation to read a section of the portfolio of practice through the key indicated

Practice Overview



SPINUZZI'S PARTICIPATORY DESIGN PROCESS

INITIAL EXPLORATION

DISCOVERY PROCESS

PROTOTYPING

INTERACTIVE INTERVIEWS

PARTICIPATORY WORKSHOP

GENERATIVE METHODS

1 Semi-structured Interviews

2 Situational Maps

3 Relational Map

4 Validation & Co-Analysis

5 Provotype Generation

6 Alternative Now Interventions

SITUATIONAL ANALYSIS

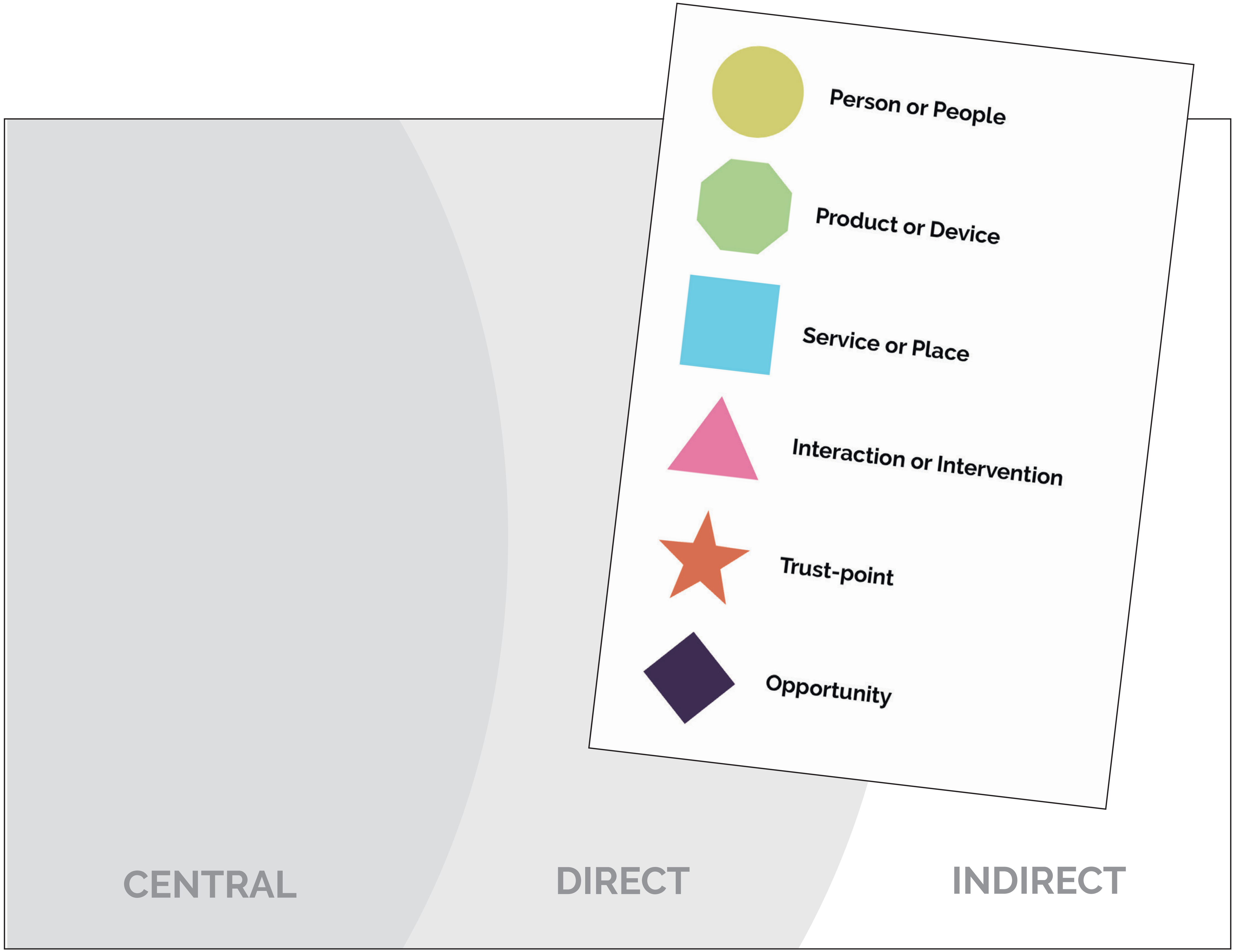
THEMATIC ANALYSIS

Spinuzzi, C. (2005) *The Methodology of Participatory Design*. Technical Communication (Washington), 52(2), pp 163–174.

4.1 Participant Interview Framework

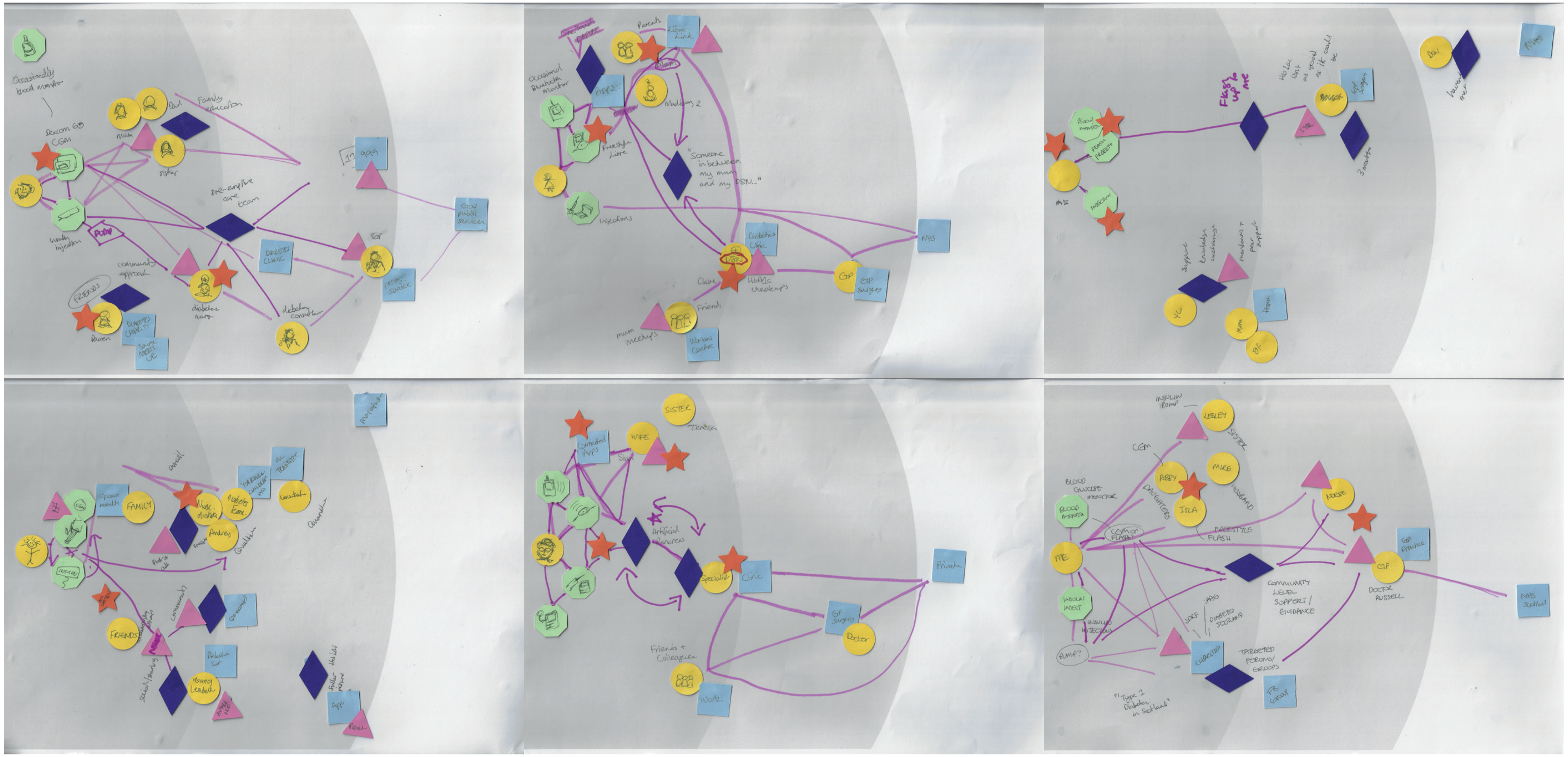
Part 1: ***Understanding you and your diabetes***	**Part 2:** ***Understanding your relationship with devices***	**Part 3:** ***Exploring your wider health network***
So tell me about yourself? Who? What? When? Where? Why?	*Back then, how was managing your Type 1 Diabetes through conventional methods ('finger prick' blood glucose monitors and insulin injections)? Could you give any examples of when this was difficult?*	*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?*
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?	*If I could ask, what diabetes complications have arose in the past? What has caused them? What would have prevented them?*	*So thinking about relationships, could we map your current connections? Who/what do you most trust? And could you explain your reasoning?*
Could you describe your journey till now? What has lead you to this point?	*So I understand you have a Continuous Glucose Monitor (CGM) and/or an Insulin Pump? Which devices do you have? When did you get these devices/first impressions? What was the process/journey to getting these devices? Did your expectations meet reality?*	*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?*
So what are you doing now? What was your motivation to do what you are doing currently?	*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?*	*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 own words, how would you define your diabetes? How would you describe it to people who are not experienced or knowledgeable of the condition?	*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?*	*In your opinion, what is the future of diabetes self-management? Artificial pancreas?*
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?	*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?*	*And lastly, could you describe a preferable future or world for diabetes?*

4.2 Participant Activity Toolkit



Participant Activity Toolkit

4.3 Participant Activity Outcomes



4.3 Participant Activity Outcomes

Interview Participant Personas:

Linda

LB

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

IG

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.

Jenny

JH

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

BS

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

TD

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

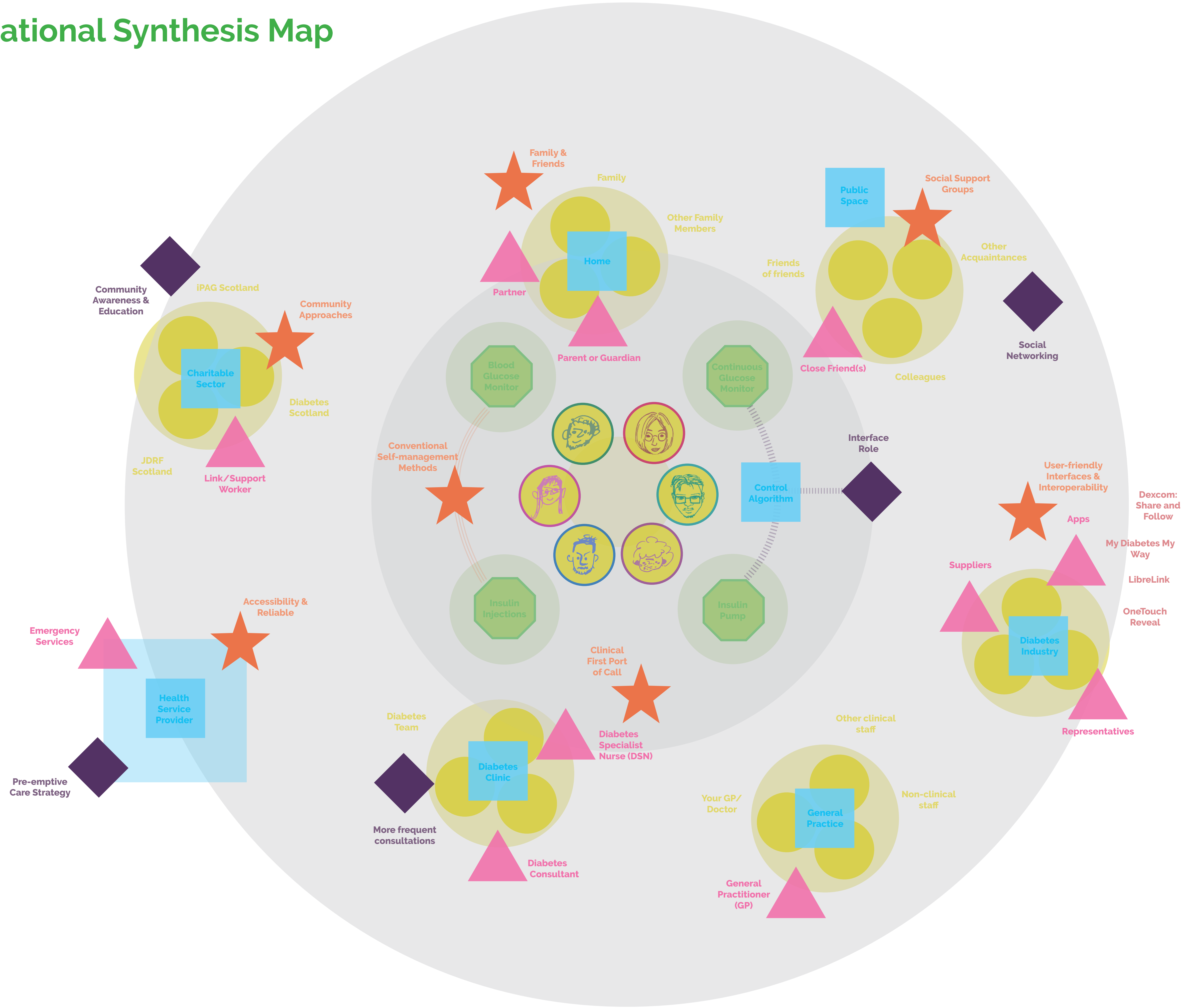
SM

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.

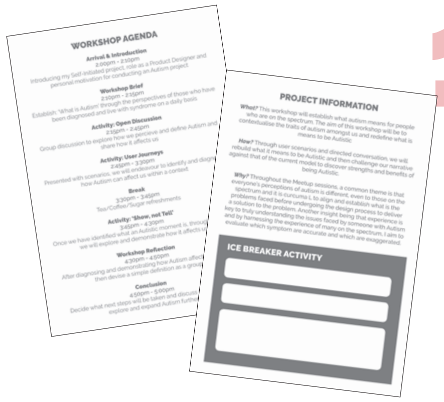
Since his incident, he sees his diabetes specialist nurse often to maintain good practice of his diabetes self management.

4.4 Relational Synthesis Map



4.5 Participatory Workshop Framework

1 Introduction, Consent & Icebreaker Discussion



WORKSHOP AGENDA

Arrival & Introduction
2:00pm - 2:10pm
Introducing my Self-Initiated project, role as a Product Designer and personal motivation for conducting an Autism project

Workshop Brief
2:10pm - 2:15pm
Establish: 'What is Autism' through the perspectives of those who have been diagnosed and live with syndrome on a daily basis

Activity: Open Discussion
2:15pm - 2:45pm
Group discussion to explore how we percieve and define Autism and share how it affects us

Activity: User Journeys
2:45pm - 3:30pm
Presented with scenarios, we will endeavour to identify and diagno
how Autism can affect us within a context

Break
3:30pm - 3:45pm
Tea/Coffee/Sugar refreshments

Activity: 'Show, not Tell'
3:45pm - 4:30pm
Once we have identified what an Autistic moment is, throug
we will explore and demonstrate how it affects u

Workshop Reflection
4:30pm - 4:50pm
After diagnosing and demonstrating how Autism affec
then devise a simple definition as a group

Conclusion
4:50pm - 5:00pm
Decide what next steps will be taken and discuss
explore and expand Autism furthe

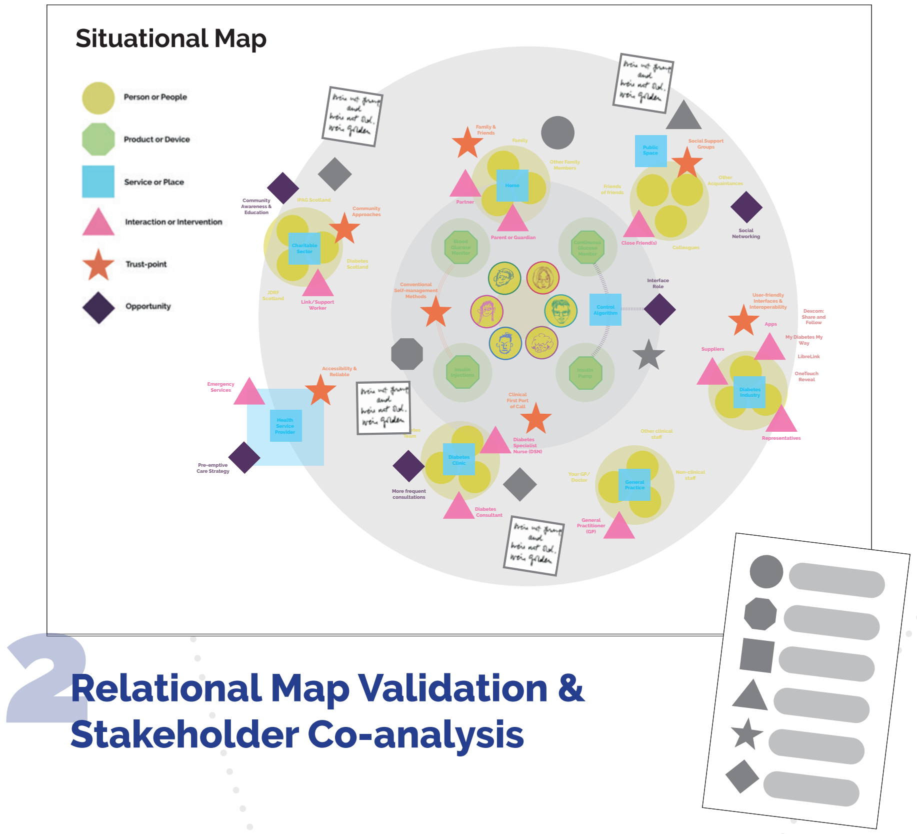
PROJECT INFORMATION

What? This workshop will establish what autism means for people who are on the spectrum. The aim of this workshop will be to contextualise the traits of autism amongst us and redefine what is means to be Autistic.

How? Through user scenarios and directed conversation, we will rebuild what it means to be Autistic and then challenge our narrative against that of the current model to discover strengths and benefits of being Autistic.

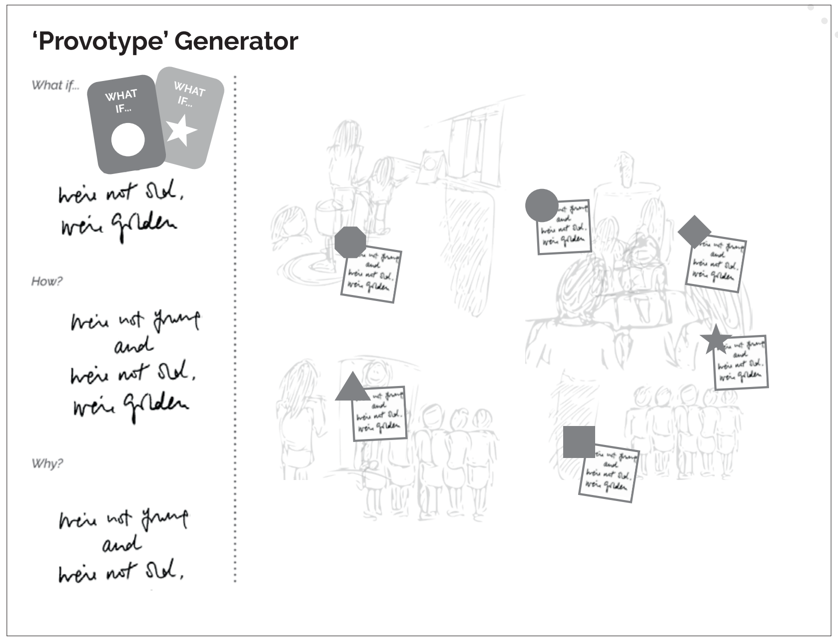
Why? Throughout the Meetup sessions, a common theme is that everyone's perceptions of autism is different, even to those on the spectrum and it is curcuma L to align and establish what is the problems faced before undergoing the design process to deliver a solution to the problem. Another insight being that experience is key to truly understanding the issues faced by someone with Autism and by harnessing the experience of many on the spectrum, I aim to evaluate which symptom are accurate and which are exaggerated.

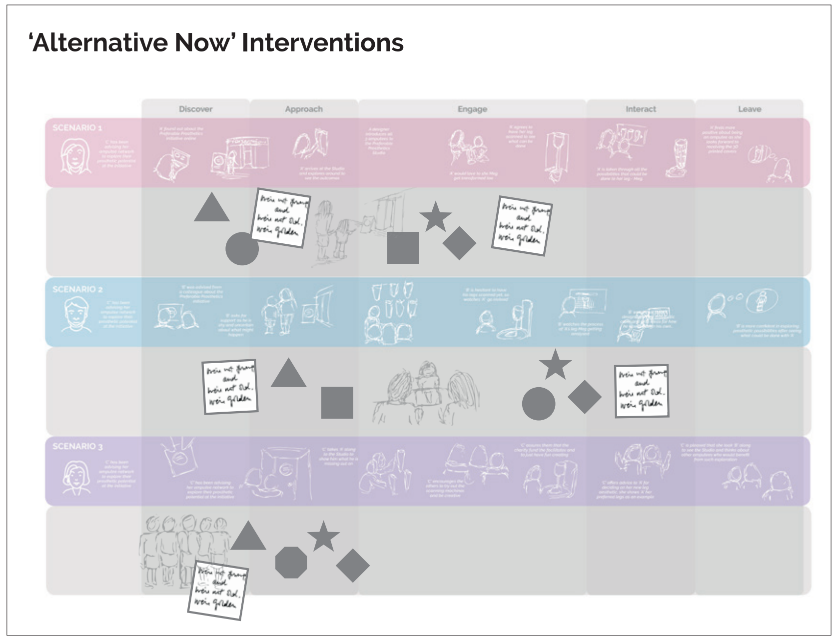
ICE BREAKER ACTIVITY



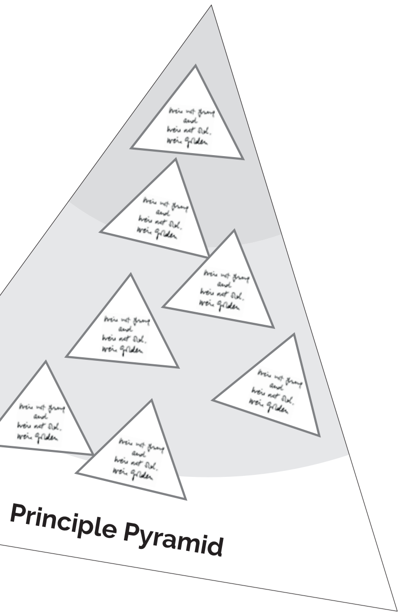
2 Relational Map Validation & Stakeholder Co-analysis

3 What If Provocation & 'Provotype' Generator Canvas

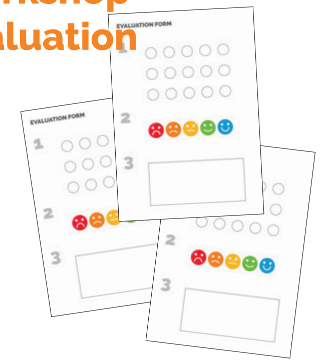




4 Contextual Interventions and Principle Capture



5 Workshop Evaluation



4.6 Participatory Workshop Preparation

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 'Provotype' Generation

2:45pm - 3:15pm

- 'What if...' generative activity using provocation cards to explore experience/ insight into self-management of diabetes.
- Develop a 'What if...' scenario based on provocations to create a preferable 'provotype' 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.

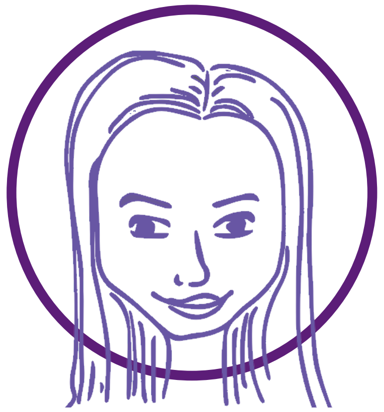
Anna

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.

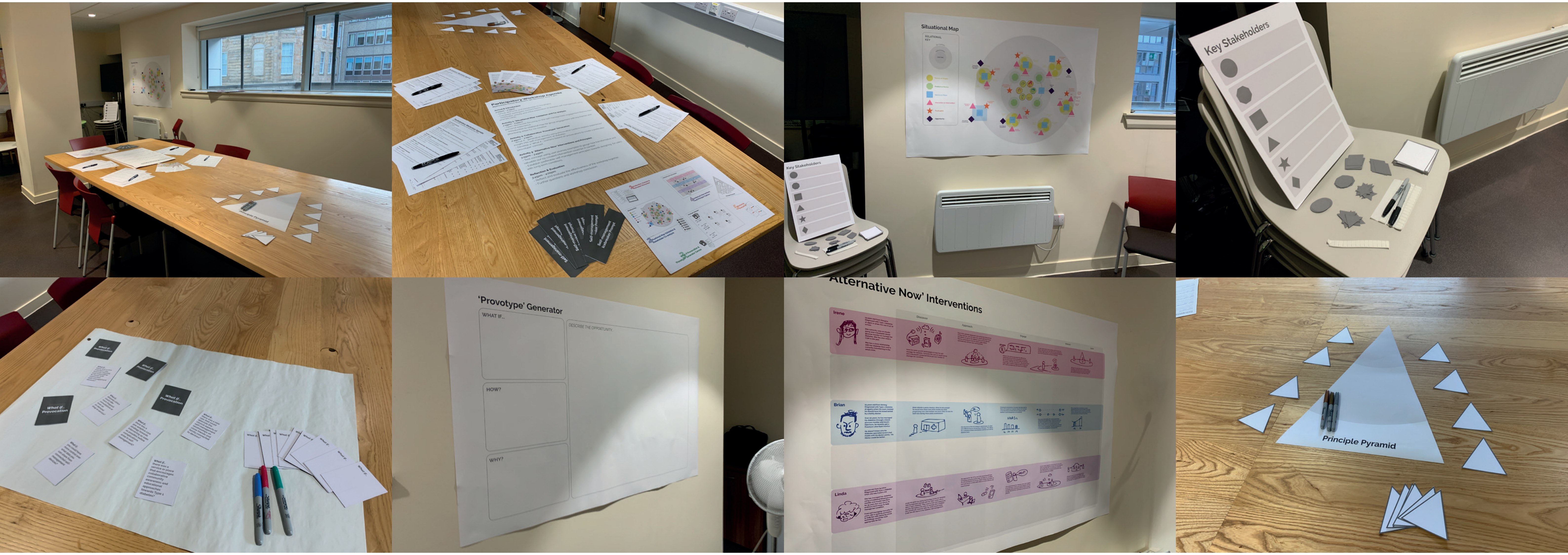
Jean

JC

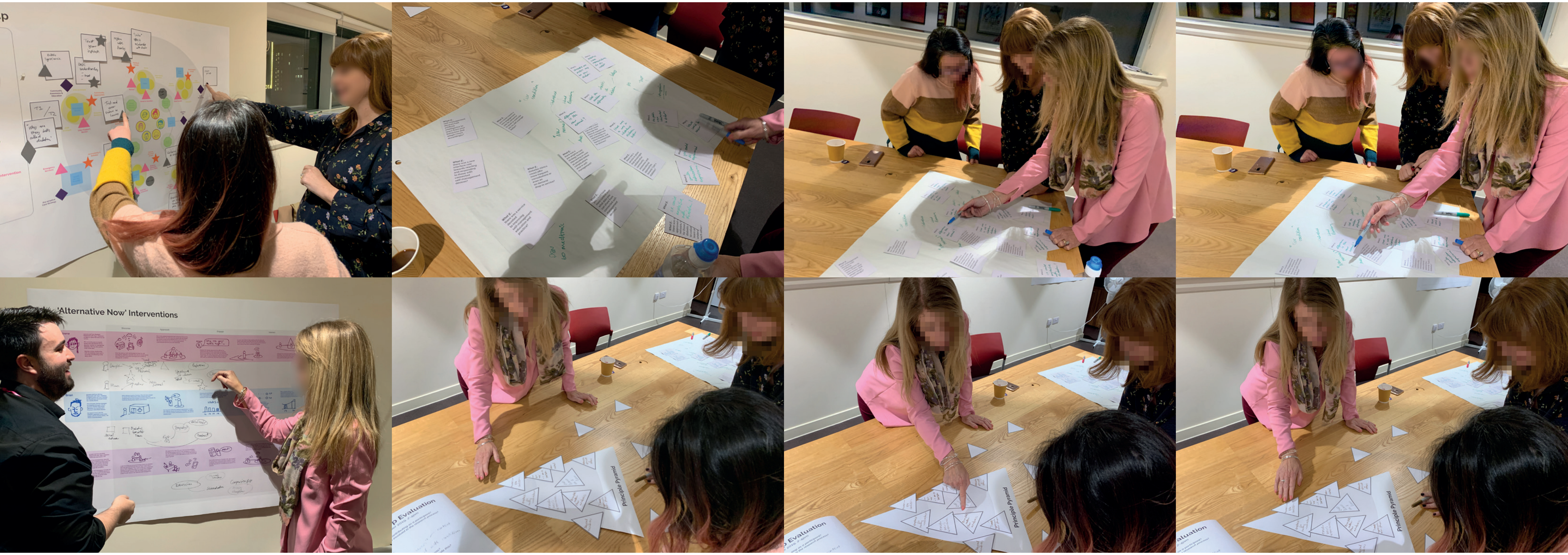


59 years old from West End in Glasgow. Non-diabetic participant but mother to Anna and has monitored her daughters condition as a child and adolescent. Given her experience with using monitoring devices for 24 years and her close relationship with daughter and has a unique perspective.

4.7 Participatory Workshop Outcomes



4.7 Participatory Workshop Outcomes



4.7 Participatory Workshop Outcomes

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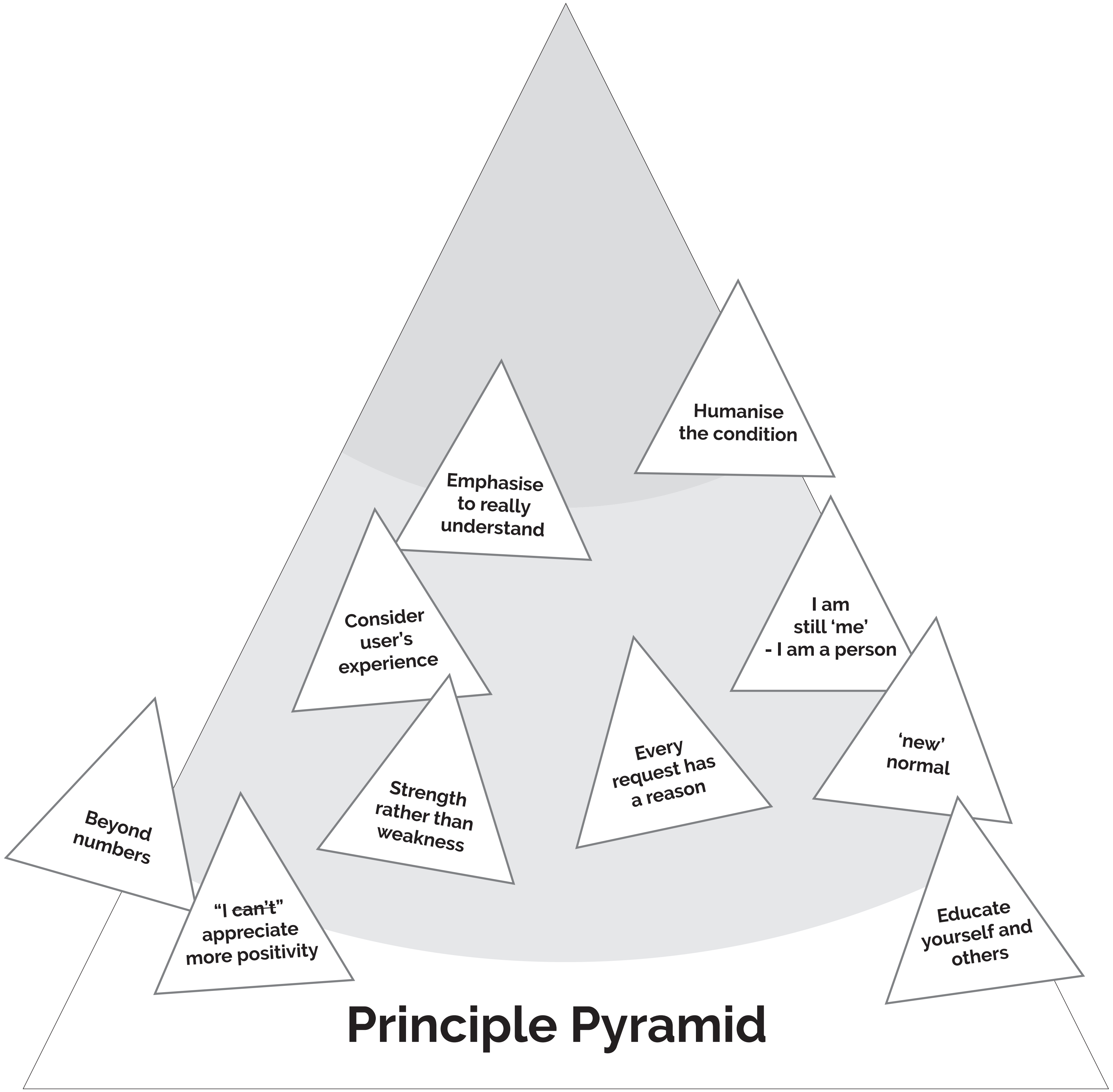
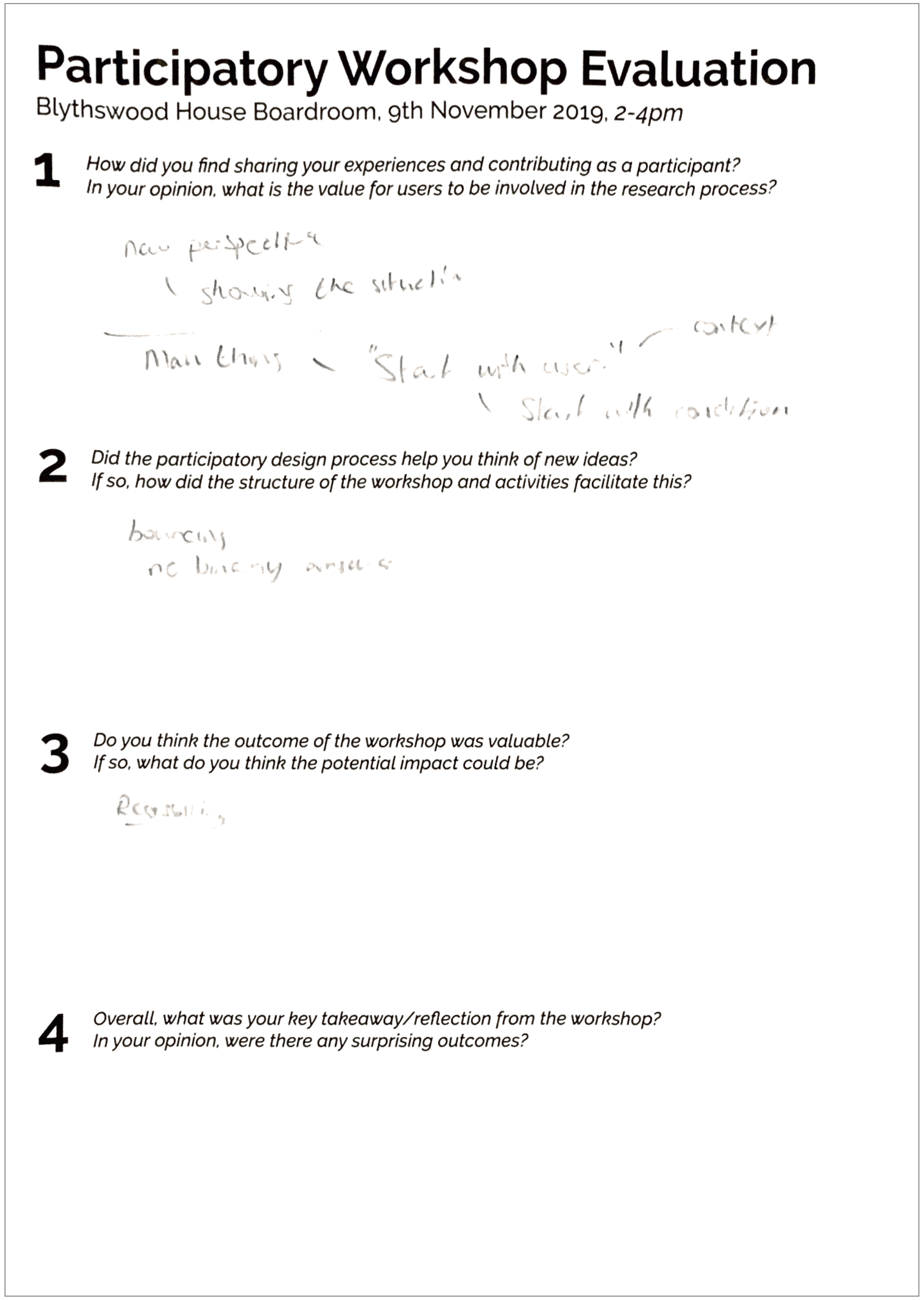


4.8 Participatory Workshop Evaluation



Participatory Workshop Evaluation

Blythswood House Boardroom, 9th November 2019, 2-4pm

1 *How did you find sharing your experiences and contributing as a participant?*
In your opinion, what is the value for users to be involved in the research process?

new perspective
\ showing the situation

Main things – "Start with user" – context
\ Start with condition

2 *Did the participatory design process help you think of new ideas?*
If so, how did the structure of the workshop and activities facilitate this?

bouncing
re bouncing answers

3 *Do you think the outcome of the workshop was valuable?*
If so, what do you think the potential impact could be?

[illegible]

4 *Overall, what was your key takeaway/reflection from the workshop?*
In your opinion, were there any surprising outcomes?

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

5.1 Situational Analysis Mapping

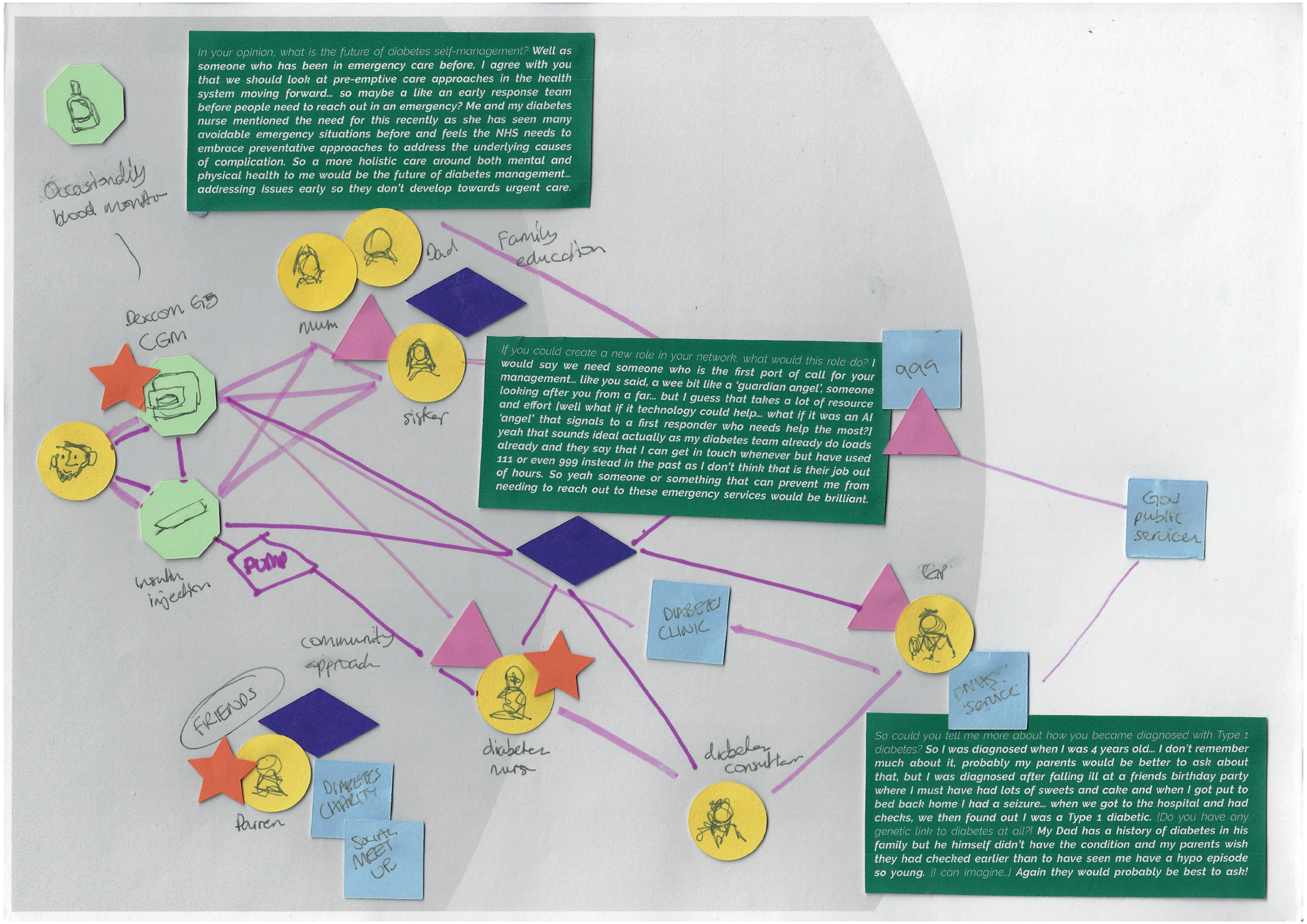
Scott

SM

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.

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



In your opinion, what is the future of diabetes self-management? **Well as someone who has been in emergency care before, I agree with you that we should look at pre-emptive care approaches in the health system moving forward... so maybe a like an early response team before people need to reach out in an emergency? Me and my diabetes nurse mentioned the need for this recently as she has seen many avoidable emergency situations before and feels the NHS needs to embrace preventative approaches to address the underlying causes of complication. So a more holistic care around both mental and physical health to me would be the future of diabetes management... addressing issues early so they don't develop towards urgent care.**

If you could create a new role in your network, what would this role do? **I would say we need someone who is the first port of call for your management... like you said, a wee bit like a 'guardian angel', someone looking after you from a far... but I guess that takes a lot of resource and effort [well what if it technology could help... what if it was an AI 'angel' that signals to a first responder who needs help the most?] yeah that sounds ideal actually as my diabetes team already do loads already and they say that I can get in touch whenever but have used 111 or even 999 instead in the past as I don't think that is their job out of hours. So yeah someone or something that can prevent me from needing to reach out to these emergency services would be brilliant.**

So could you tell me more about how you became diagnosed with Type 1 diabetes? **So I was diagnosed when I was 4 years old... I don't remember much about it, probably my parents would be better to ask about that, but I was diagnosed after falling ill at a friends birthday party where I must have had lots of sweets and cake and when I got put to bed back home I had a seizure... when we got to the hospital and had checks, we then found out I was a Type 1 diabetic.** *[Do you have any genetic link to diabetes at all?]* **My Dad has a history of diabetes in his family but he himself didn't have the condition and my parents wish they had checked earlier than to have seen me have a hypo episode so young.** *[I can imagine...]* **Again they would probably be best to ask!**

5.1 Situational Analysis Mapping

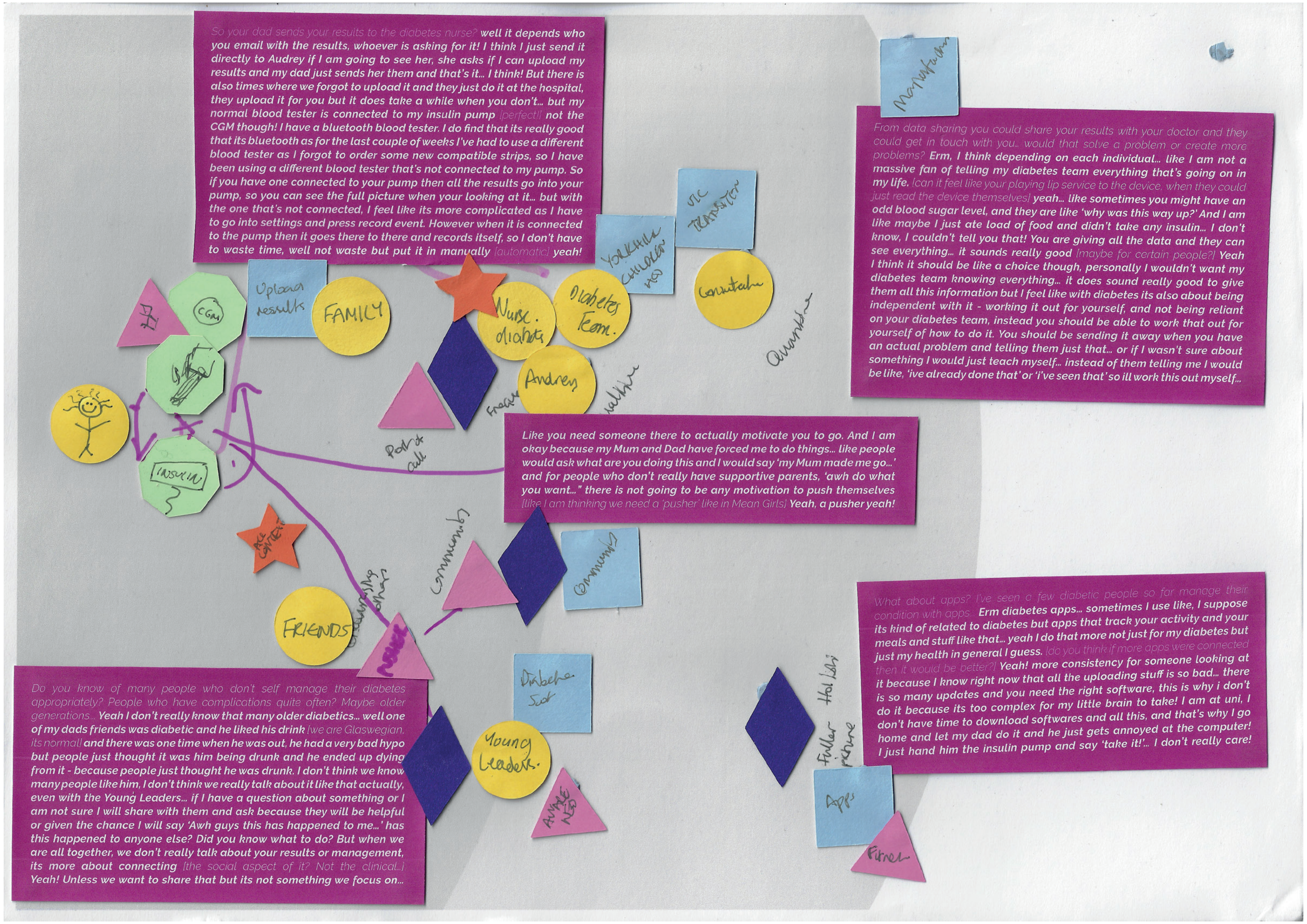
Irene

IG

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.



So your dad sends your results to the diabetes nurse? well it depends who you email with the results, whoever is asking for it! I think I just send it directly to Audrey if I am going to see her, she asks if I can upload my results and my dad just sends her them and that's it... I think! But there is also times where we forgot to upload it and they just do it at the hospital, they upload it for you but it does take a while when you don't... but my normal blood tester is connected to my insulin pump [perfect!] not the CGM though! I have a bluetooth blood tester. I do find that its really good that its bluetooth as for the last couple of weeks I've had to use a different blood tester as I forgot to order some new compatible strips, so I have been using a different blood tester that's not connected to my pump. So if you have one connected to your pump then all the results go into your pump, so you can see the full picture when your looking at it... but with the one that's not connected, I feel like its more complicated as I have to go into settings and press record event. However when it is connected to the pump then it goes there to there and records itself, so I don't have to waste time, well not waste but put it in manually [automatic] yeah!

From data sharing you could share your results with your doctor and they could get in touch with you... would that solve a problem or create more problems? Erm, I think depending on each individual... like I am not a massive fan of telling my diabetes team everything that's going on in my life. [can it feel like your playing lip service to the device, when they could just read the device themselves] yeah... like sometimes you might have an odd blood sugar level, and they are like 'why was this way up?' And I am like maybe I just ate load of food and didn't take any insulin... I don't know, I couldn't tell you that! You are giving all the data and they can see everything... it sounds really good [maybe for certain people?] Yeah I think it should be like a choice though, personally I wouldn't want my diabetes team knowing everything... it does sound really good to give them all this information but I feel like with diabetes its also about being independent with it - working it out for yourself, and not being reliant on your diabetes team, instead you should be able to work that out for yourself of how to do it. You should be sending it away when you have an actual problem and telling them just that... or if I wasn't sure about something I would just teach myself... instead of them telling me I would be like, 'ive already done that' or 'i've seen that' so ill work this out myself...

Like 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... like people would ask what are you doing this and I would say 'my Mum made me go...' and for people who don't really have supportive parents, 'awh do what you want..." there is not going to be any motivation to push themselves [like I am thinking we need a 'pusher' like in Mean Girls] Yeah, a pusher yeah!

What about apps? I've seen a few diabetic people so far manage their condition with apps... Erm diabetes apps... sometimes I use like, I suppose its kind of related to diabetes but apps that track your activity and your meals and stuff like that... yeah I do that more not just for my diabetes but just my health in general I guess. [do you think if more apps were connected then it would be better?] Yeah! more consistency for someone looking at it because I know right now that all the uploading stuff is so bad... there is so many updates and you need the right software, this is why i don't do it because its too complex for my little brain to take! I am at uni, I don't have time to download softwares and all this, and that's why I go home and let my dad do it and he just gets annoyed at the computer! I just hand him the insulin pump and say 'take it!'... I don't really care!

Do you know of many people who don't self manage their diabetes appropriately? People who have complications quite often? Maybe older generations... Yeah I don't really know that many older diabetics... well one of my dads friends was diabetic and he liked his drink [we are Glaswegian, its normal] and there was one time when he was out, he had a very bad hypo but people just thought it was him being drunk and he ended up dying from it - because people just thought he was drunk. I don't think we know many people like him, I don't think we really talk about it like that actually, even with the Young Leaders... if I have a question about something or I am not sure I will share with them and ask because they will be helpful or given the chance I will say 'Awh guys this has happened to me...' has this happened to anyone else? Did you know what to do? But when we are all together, we don't really talk about your results or management, its more about connecting [the social aspect of it? Not the clinical...] Yeah! Unless we want to share that but its not something we focus on...

Situational Analysis Mapping

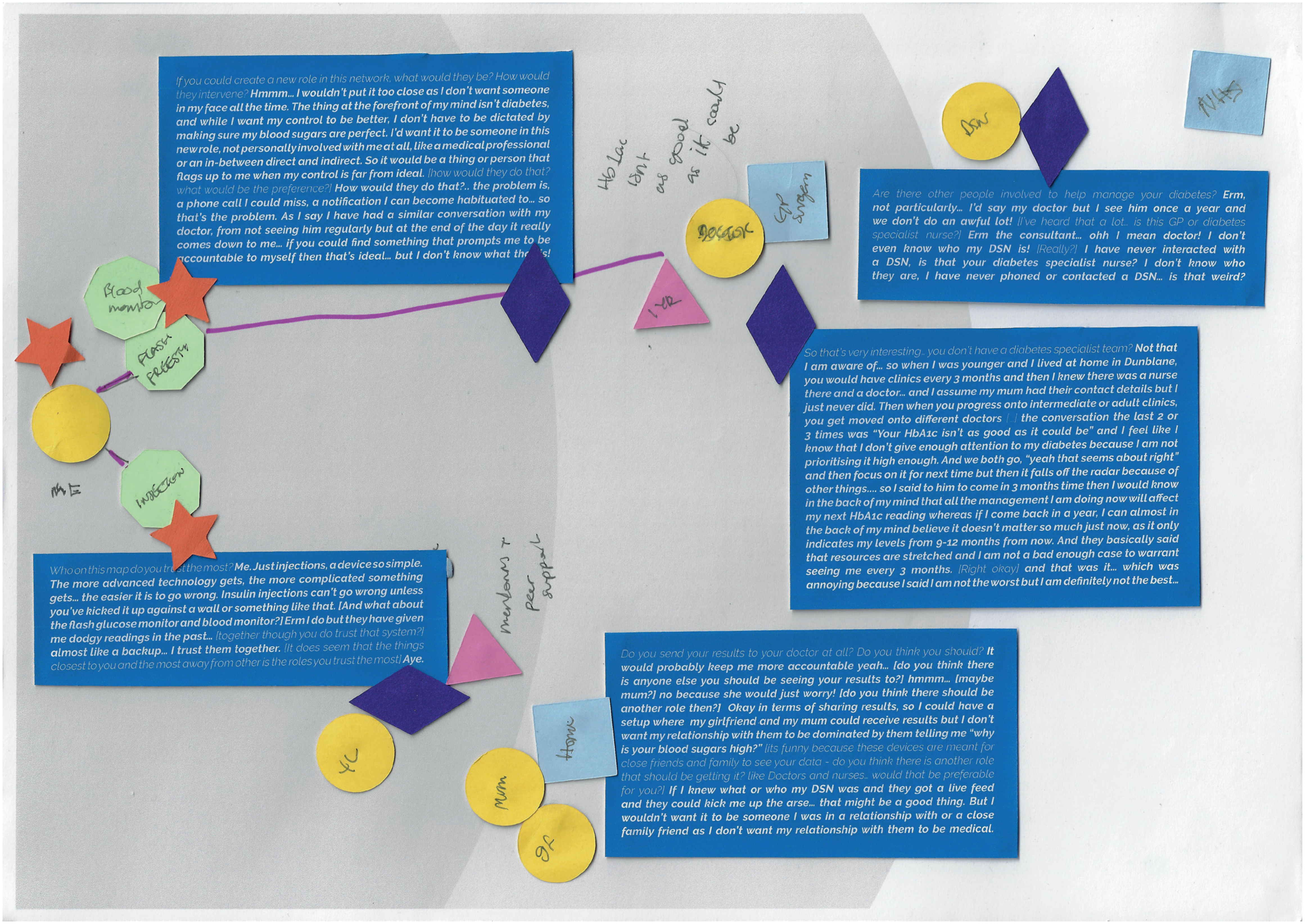
Brian

BS

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.



If you could create a new role in this network, what would they be? How would they intervene? ***Hmmm... I wouldn't put it too close as I don't want someone in my face all the time. The thing at the forefront of my mind isn't diabetes, and while I want my control to be better, I don't have to be dictated by making sure my blood sugars are perfect. I'd want it to be someone in this new role, not personally involved with me at all, like a medical professional or an in-between direct and indirect. So it would be a thing or person that flags up to me when my control is far from ideal.*** *[how would they do that? what would be the preference?]* ***How would they do that?.. the problem is, a phone call I could miss, a notification I can become habituated to... so that's the problem. As I say I have had a similar conversation with my doctor, from not seeing him regularly but at the end of the day it really comes down to me... if you could find something that prompts me to be accountable to myself then that's ideal... but I don't know what that is!***

Are there other people involved to help manage your diabetes? ***Erm, not particularly... I'd say my doctor but I see him once a year and we don't do an awful lot!*** *[I've heard that a lot... is this GP or diabetes specialist nurse?]* ***Erm the consultant... ohh I mean doctor! I don't even know who my DSN is!*** *[Really?]* ***I have never interacted with a DSN, is that your diabetes specialist nurse? I don't know who they are, I have never phoned or contacted a DSN... is that weird?***

So that's very interesting.. you don't have a diabetes specialist team? ***Not that I am aware of... so when I was younger and I lived at home in Dunblane, you would have clinics every 3 months and then I knew there was a nurse there and a doctor... and I assume my mum had their contact details but I just never did. Then when you progress onto intermediate or adult clinics, you get moved onto different doctors*** *[..]* ***the conversation the last 2 or 3 times was "Your HbA1c isn't as good as it could be" and I feel like I know that I don't give enough attention to my diabetes because I am not prioritising it high enough. And we both go, "yeah that seems about right" and then focus on it for next time but then it falls off the radar because of other things.... so I said to him to come in 3 months time then I would know in the back of my mind that all the management I am doing now will affect my next HbA1c reading whereas if I come back in a year, I can almost in the back of my mind believe it doesn't matter so much just now, as it only indicates my levels from 9-12 months from now. And they basically said that resources are stretched and I am not a bad enough case to warrant seeing me every 3 months.*** *[Right okay]* ***and that was it... which was annoying because I said I am not the worst but I am definitely not the best...***

Who on this map do you trust the most? ***Me. Just injections, a device so simple. The more advanced technology gets, the more complicated something gets... the easier it is to go wrong. Insulin injections can't go wrong unless you've kicked it up against a wall or something like that. [And what about the flash glucose monitor and blood monitor?] Erm I do but they have given me dodgy readings in the past...*** *[together though you do trust that system?]* ***almost like a backup... I trust them together.*** *[It does seem that the things closest to you and the most away from other is the roles you trust the most]* ***Aye.***

Do you send your results to your doctor at all? Do you think you should? ***It would probably keep me more accountable yeah... [do you think there is anyone else you should be seeing your results to?] hmmm... [maybe mum?] no because she would just worry! [do you think there should be another role then?] Okay in terms of sharing results, so I could have a setup where my girlfriend and my mum could receive results but I don't want my relationship with them to be dominated by them telling me "why is your blood sugars high?"*** *[its funny because these devices are meant for close friends and family to see your data - do you think there is another role that should be getting it? like Doctors and nurses.. would that be preferable for you?]* ***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.***

5.1 Situational Analysis Mapping

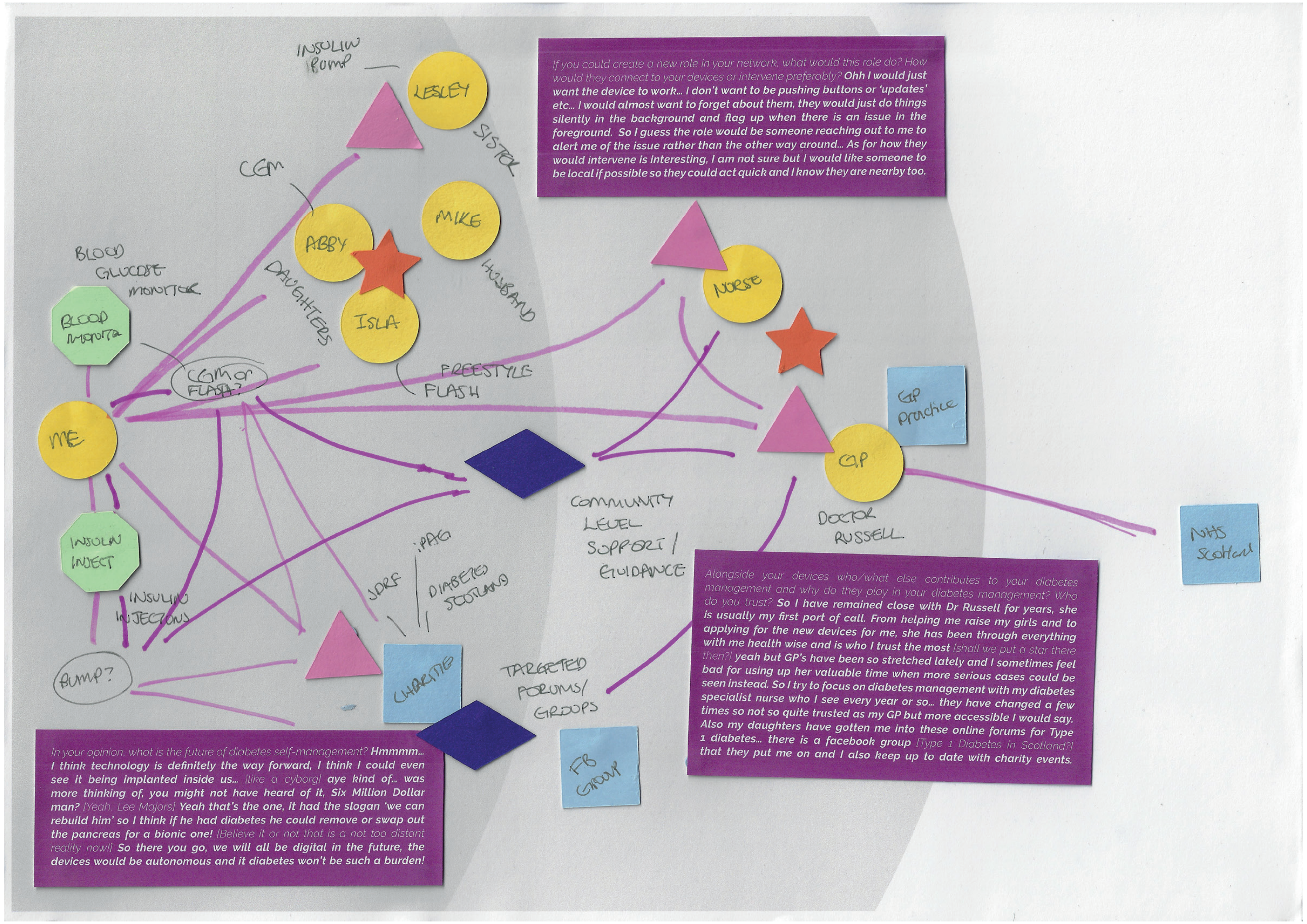
Linda

LB

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.



If you could create a new role in your network, what would this role do? How would they connect to your devices or intervene preferably? ***Ohh I would just want the device to work… I don't want to be pushing buttons or 'updates' etc… I would almost want to forget about them, they would just do things silently in the background and flag up when there is an issue in the foreground. So I guess the role would be someone reaching out to me to alert me of the issue rather than the other way around… As for how they would intervene is interesting, I am not sure but I would like someone to be local if possible so they could act quick and I know they are nearby too.***

Alongside your devices who/what else contributes to your diabetes management and why do they play in your diabetes management? Who do you trust? ***So I have remained close with Dr Russell for years, she is usually my first port of call. From helping me raise my girls and to applying for the new devices for me, she has been through everything with me health wise and is who I trust the most*** *[shall we put a star there then?]* ***yeah but GP's have been so stretched lately and I sometimes feel bad for using up her valuable time when more serious cases could be seen instead. So I try to focus on diabetes management with my diabetes specialist nurse who I see every year or so… they have changed a few times so not so quite trusted as my GP but more accessible I would say. Also my daughters have gotten me into these online forums for Type 1 diabetes… there is a facebook group*** *[Type 1 Diabetes in Scotland?]* ***that they put me on and I also keep up to date with charity events.***

In your opinion, what is the future of diabetes self-management? ***Hmmmm… I think technology is definitely the way forward, I think I could even see it being implanted inside us…*** *[like a cyborg]* ***aye kind of… was more thinking of, you might not have heard of it, Six Million Dollar man?*** *[Yeah, Lee Majors]* ***Yeah that's the one, it had the slogan 'we can rebuild him' so I think if he had diabetes he could remove or swap out the pancreas for a bionic one!*** *[Believe it or not that is a not too distant reality now!]* ***So there you go, we will all be digital in the future, the devices would be autonomous and it diabetes won't be such a burden!***

Situational Analysis Mapping

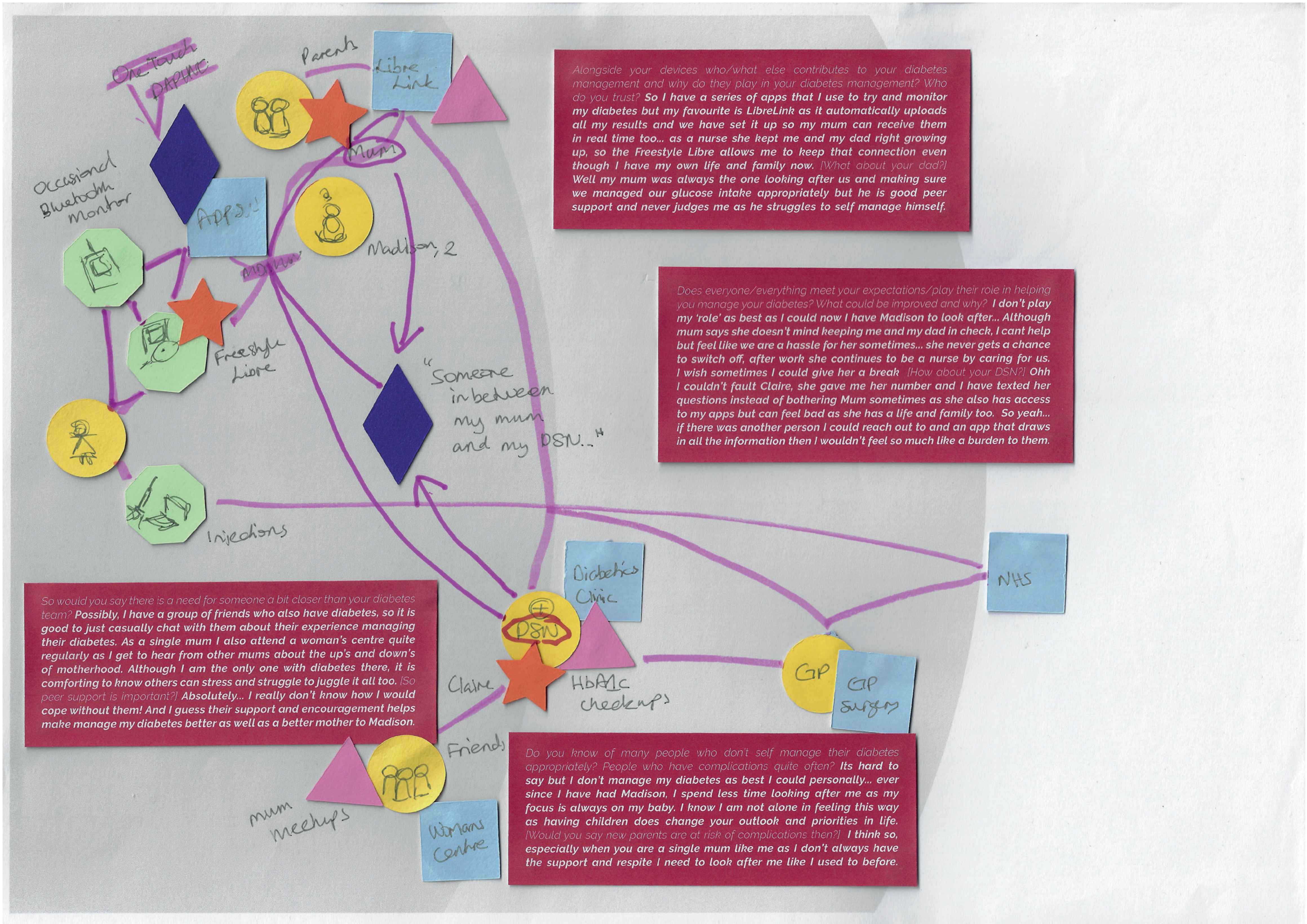
Jenny

JH

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.



Alongside your devices who/what else contributes to your diabetes management and why do they play in your diabetes management? Who do you trust? ***So I have a series of apps that I use to try and monitor my diabetes but my favourite is LibreLink as it 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.*** *[What about your dad?]* ***Well my mum was always the one looking after us and making sure we managed our glucose intake appropriately but he is good peer support and never judges me as he struggles to self manage himself.***

Does everyone/everything meet your expectations/play their role in helping you manage your diabetes? What could be improved and why? ***I don't play my 'role' as best as I could now I have Madison to look after... Although mum says she doesn't mind keeping me and my dad in check, I cant help but feel like we are a hassle for her sometimes... she never gets a chance to switch off, after work she continues to be a nurse by caring for us. I wish sometimes I could give her a break*** *[How about your DSN?]* ***Ohh I couldn't fault Claire, she gave me her number and I have texted her questions instead of bothering Mum sometimes as she also has access to my apps but can feel bad as she has a life and family too. So yeah... if there was another person I could reach out to and an app that draws in all the information then I wouldn't feel so much like a burden to them.***

So would you say there is a need for someone a bit closer than your diabetes team? ***Possibly, I have a group of friends who also have diabetes, so it is good to just casually chat with them about their experience managing their diabetes. As a single mum I also attend a woman's centre quite regularly as I get to hear from other mums about the up's and down's of motherhood. Although I am the only one with diabetes there, it is comforting to know others can stress and struggle to juggle it all too.*** *[So peer support is important?]* ***Absolutely... I really don't know how I would cope without them! And I guess their support and encouragement helps make manage my diabetes better as well as a better mother to Madison.***

Do you know of many people who don't self manage their diabetes appropriately? People who have complications quite often? ***Its hard to say but I don't manage my diabetes as best I could personally... ever since I have had Madison, I spend less time looking after me as my focus is always on my baby. I know I am not alone in feeling this way as having children does change your outlook and priorities in life.*** *[Would you say new parents are at risk of complications then?]* ***I think so, especially when you are a single mum like me as I don't always have the support and respite I need to look after me like I used to before.***

5.1 Situational Analysis Mapping

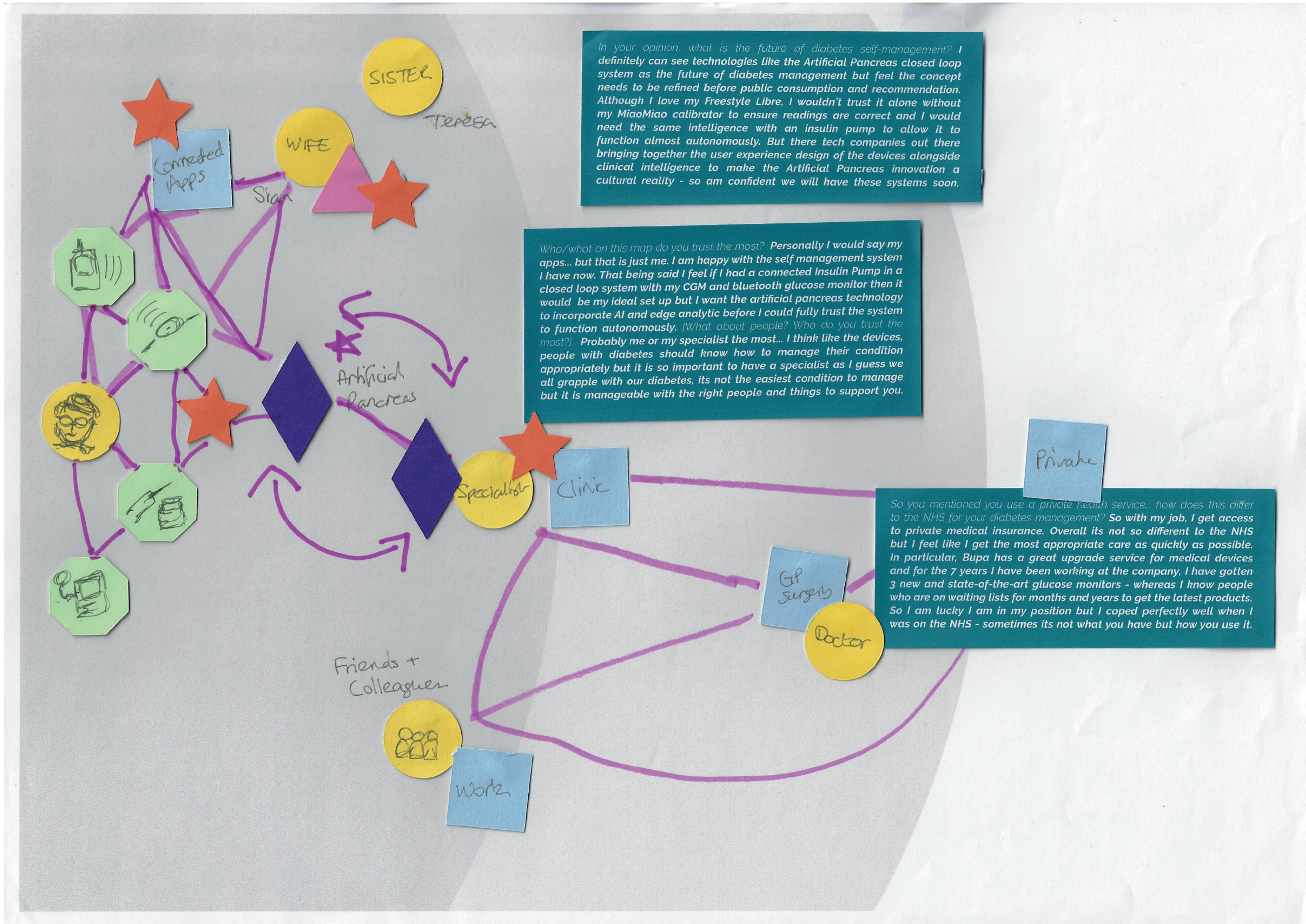
Tim

TD

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.



In your opinion, what is the future of diabetes self-management? ***I definitely can see technologies like the Artificial Pancreas closed loop system as the future of diabetes management but feel the concept needs to be refined before public consumption and recommendation. Although I love my Freestyle Libre, I wouldn't trust it alone without my MiaoMiao calibrator to ensure readings are correct and I would need the same intelligence with an insulin pump to allow it to function almost autonomously. But there tech companies out there bringing together the user experience design of the devices alongside clinical intelligence to make the Artificial Pancreas innovation a cultural reality - so am confident we will have these systems soon.***

Who/what on this map do you trust the most? ***Personally I would say my apps... but that is just me. I am happy with the self management system I have now. That being said I feel if I had a connected Insulin Pump in a closed loop system with my CGM and bluetooth glucose monitor then it would be my ideal set up but I want the artificial pancreas technology to incorporate AI and edge analytic before I could fully trust the system to function autonomously.*** *[What about people? Who do you trust the most?]* ***Probably me or my specialist the most... I think like the devices, people with diabetes should know how to manage their condition appropriately but it is so important to have a specialist as I guess we all grapple with our diabetes, its not the easiest condition to manage but it is manageable with the right people and things to support you.***

So you mentioned you use a private health service... how does this differ to the NHS for your diabetes management? ***So with my job, I get access to private medical insurance. Overall its not so different to the NHS but I feel like I get the most appropriate care as quickly as possible. In particular, Bupa has a great upgrade service for medical devices and for the 7 years I have been working at the company, I have gotten 3 new and state-of-the-art glucose monitors - whereas I know people who are on waiting lists for months and years to get the latest products. So I am lucky I am in my position but I coped perfectly well when I was on the NHS - sometimes its not what you have but how you use it.***

5.1 Situational Analysis Synthesis

“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, ‘awh do what you want…” there is not going to be any motivation to push themselves” - IG

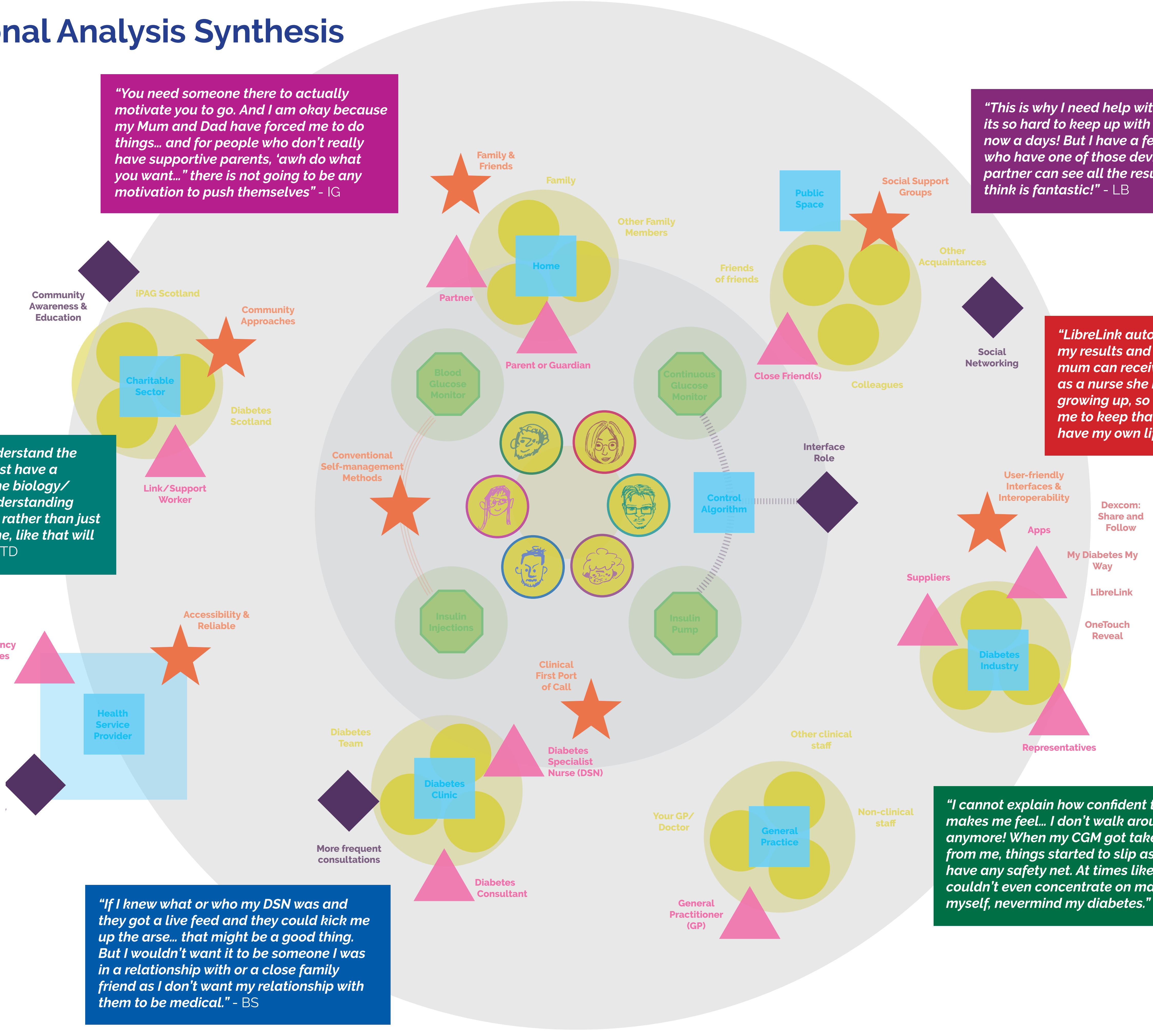
“This is why I need help with all of this… its so hard to keep up with technology now a days! But I have a few friends who have one of those devices and her partner can see all the results which I think is fantastic!” - LB

“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

“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

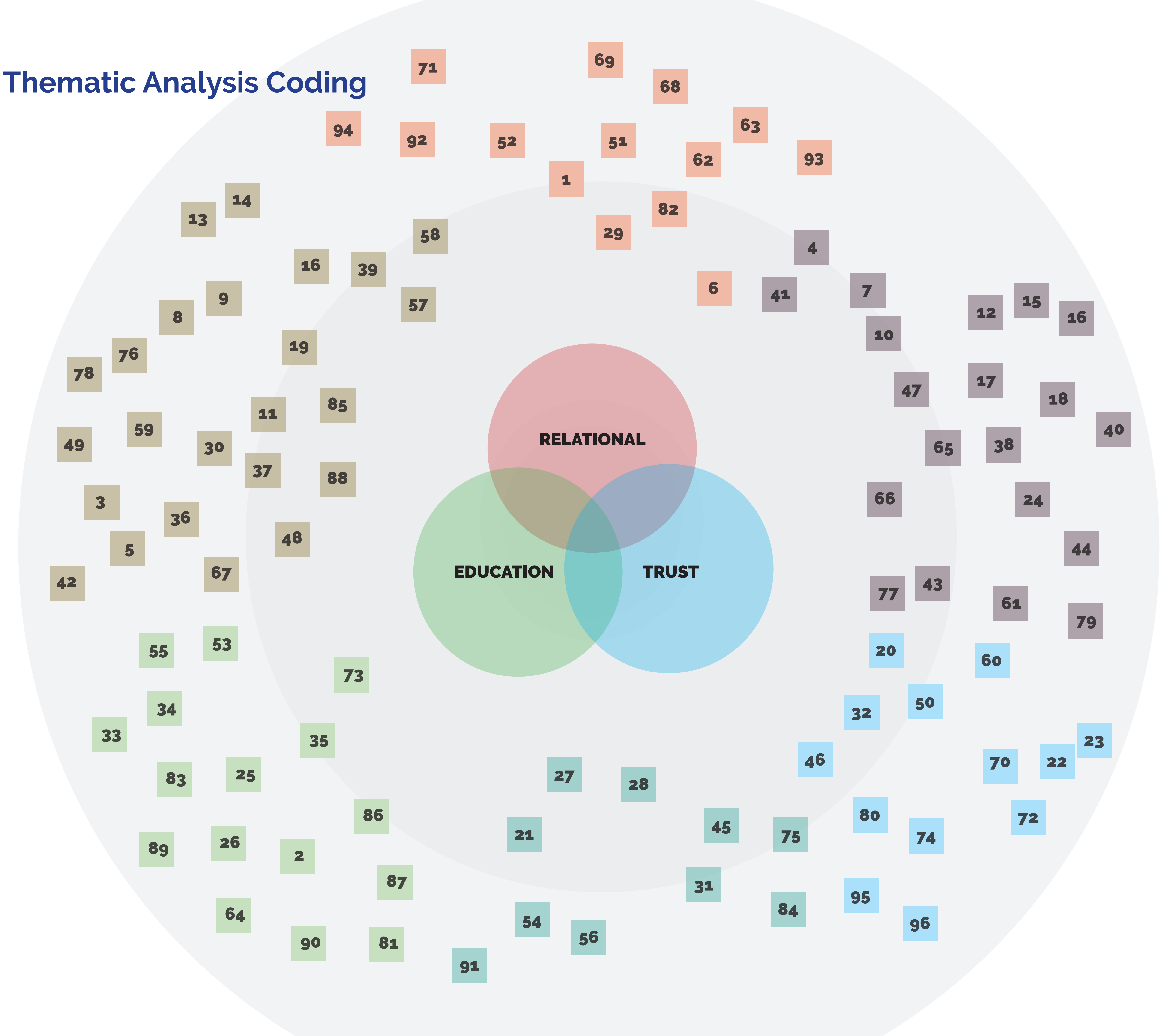
“I cannot explain how confident the CGM makes me feel… I don’t walk around terrified anymore! When my CGM got taken away from me, things started to slip as I didn’t have any safety net. At times like that I couldn’t even concentrate on managing myself, nevermind my diabetes.” - SM



KEY

- ● Person or People
- ⬣ Product or Device
- ■ Service or Place
- ▲ Interaction or Intervention
- ★ Trust-point
- ◆ Opportunity

5.2 Thematic Analysis Coding



5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

*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 libre. Popular choice! Erm I have gone through a pregnancy since being diagnosed and am also currently pregnant. *gasp* Oh my god, so am I! I could not have predicted that at all… what are the chances!*

***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.*

So you were two years diagnosed? No actually I was just shy of my 'diaversary' 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 hypos, I was only allowed to eat half meals, I was starving and hangry, 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 10. 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 bionic (All signing, all dancing) and that is because I do not sense Hypoglycaemia at all. Right! So I can drop to 1.2 and still be chanting away, still lecturing and then I drop. Your a lecturer? I do Politics. I'm an Accounts lecturer. Ohhh, how funny! That was the other thing, educational mums!

***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*

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 done 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 hangry, I am fine! So the offset of it is being able to use the CGM, so I got 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 libre 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 night 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, 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 boogey. Then it should do that before a hypo. That's great! So I know that maybe sometimes at 5.6, 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.

5 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 heirarchy between parent and consultant...

But also to hear from your pancreas... and what we will discuss later is what this extra role and responsibility has an affect 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 eat, exact amounts, and you think how hard that would be. If they are sick, I mean I have had Anna vomit and have diarrhoea, 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. Erm 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... [beep 37:00] Anna has had hypos through the night too. You must never been able to relax. Terrible, absolutely terrible. And my husbands father was diabetic, so he carries the whole guilt that it was through him but very very very difficult. Anna and I now 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 more closer now with digital. Uh 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 5 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 were 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.

continue onto the prompts, what about the one on trust? Ohh I've got it, you want to answer that one Anna? I think because your reliant on softer things that are not algorithms and a lot of these machines react to the now - they don't know if its cold outside, or hot. They don't know the context. So the context sometimes can be completely different or I think also, what you are doing next - so my blood sugar is very low when I am at work, I need fast acting, whatever you can get into yourself. Whereas when I am at home, I can take a wee step back and think right will I have my dinner early? That just stops me from going low afterwards, so its things like that where machines aren't just quite...

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.

continue onto the prompts, what about the one on trust? Ohh I've got it, you want to answer that one Anna? I think because your reliant on softer things that are not algorithms and a lot of these machines react to the now - they don't know if its cold outside, or hot. They don't know the context. So the context sometimes can be completely different or I think also, what you are doing next - so my blood sugar is very low when I am at work, I need fast acting, whatever you can get into yourself. Whereas when I am at home, I can take a wee step back and think right will I have my dinner early? That just stops me from going low afterwards, so its things like that where machines aren't just quite...

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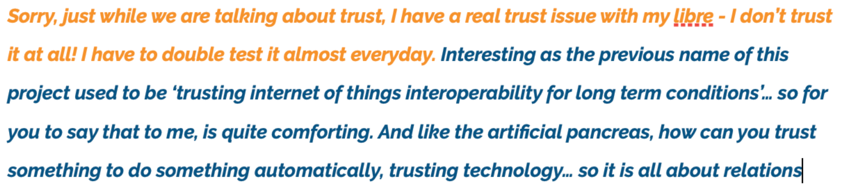
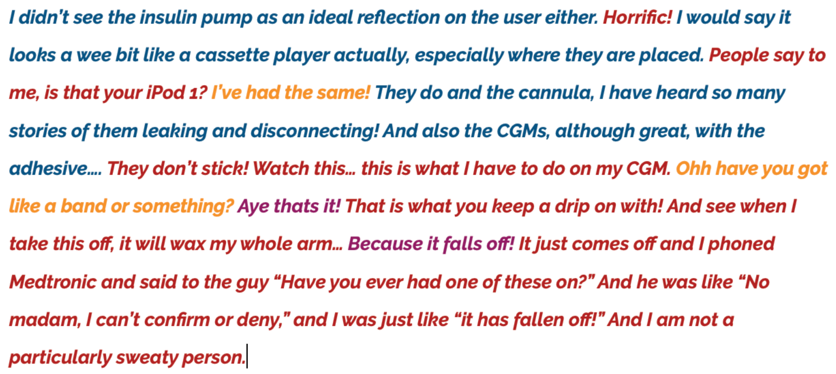
some hadn't even seen there DSN, which was surprising! And some never spoke to their doctor about their diabetes, so there was parts of their health that wasn't considered holistically. I think actually, what they do with kids versus adults, I am horrified when I hear someone has been diagnosed as an adult. We spoke to the GP and they said come back in a week… I couldn't actually get to my GP, I phoned the nurse and they couldn't see me, but I was so lethargic I didn't have the fight in me to argue and it got to New Years Eve… already my sight had started to go - I had gone all blurry. It was Christmas Day and I was like "I can't see the TV" and my mum was like "get your eyes tested" but I knew myself that it was diabetes. But I was so lethargic on New Years Eve, I remember being in Morrisons and I had the receipt and it was all Capri Sun's because I was craving fruit juice, apples and blue WKD's at the time. Erm thinking and having such a dry mouth, being very paranoid talking to people. I know doctors are going to be closed for two days and thought if I don't get to a doctor I am going off the Erskine Bridge… I can't do this! So I went to Lloyds and said please test me… I had been on Lloyds but obviously all their calculators are for Type 2 and I was very low… they said it was coming up high and tested it to see if it was working. They got a pharmacist and were like you need to get to a GP… I was like it was 10 to 5 on New Years Eve. So my GP then sent me to A+E and thats when I found out I was. So didn't know who to turn to. To be fair… I knew myself and that it was likely to be diabetes but I just didn't have the energy! I was so like I can't be bothered! That is so unusual at 29 though… very unusual! All my participants to date where diagnosed as children… I think the oldest diagnosis was about 12. It is unusual but when I was diagnosed a few months, my local hospital just had a introduction to diabetes course and somebody there who knew my mum had just been diagnosed at 40 and another guy at 50 odds… and it was type 1! Hmmm. Where you ill before? Did you have anything? Well I have suffered on/off for years with severe anxiety and depression - I was really really bad! I think the stress and that brought on shingles, and it was a really bad case of shingles, and I think it was it that brought on the symptoms. I had flu before, and it was a really awful flu! I think genetically I have a predisposition with my grandfather having type 1 diabetes, but I do think that was a trigger. Yeah! As to your immune system… If they knew what that trigger was they could cure you that. I would say its genetic. Well you are saying about genetics, I had no one in the history of my family with type 1 or type 2, so when it came out that I was diabetic, my mum was like WHAT?! But with the type 1 thing, you might not know because there has only been insulin available… Yeah. you are right, yeah! Its unfortunate, particularly with juvenile diabetes, these kids might have just been very very ill and going into DK and you know. I suppose at that time, there was a lot of illnesses and diseases that were…

9 *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 session, mental health, physical health, confusion/uncertainty affecting ability to reach out for diagnosis.*

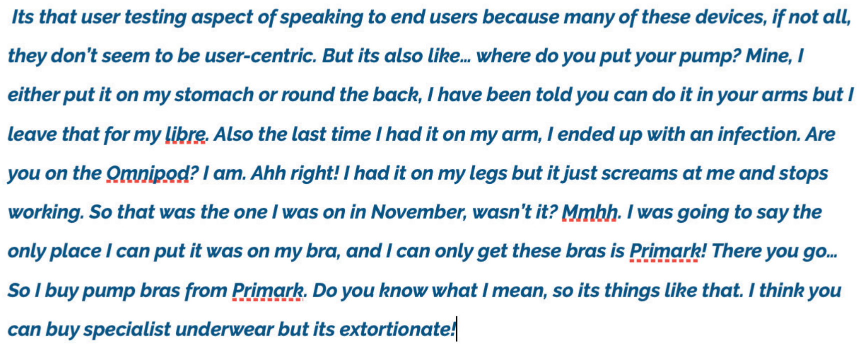
10 *Trust/Relational: Prompts reveal trust issues with Flash/CGM technology as per previous interviews for its reliability and accuracy.*


Sorry, just while we are talking about trust, I have a real trust issue with my libre - I don't trust it at all! I have to double test 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


I didn't see 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 your iPod 1? 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 thats it! That is what you keep a drip on with! And see when I take this off, it will wax my whole arm… Because it falls off! It just comes off and I phoned Medtronic and said to the guy "Have you ever had one of these on?" And he was like "No madam, I can't confirm or deny," and I was just like "it has fallen off!" And I am not a particularly sweaty person.

11 *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.*

12 *Relational/Trust: Again usability issues in relation to cannula site, sleeping and pump storage in mainstream bras/underwear highlights that the holistic experience of using these hasn't been fully considered within their design and application.*


Its that user testing aspect of speaking to end users because many of these devices, if not all, they don't seem to be user-centric. But its also like… where do you put your pump? Mine, I either put it on my stomach or round the back, I have been told you can do it in your arms but I leave that for my libre. Also the last time I had it on my arm, I ended up with an infection. Are you on the Omnipod? I am. Ahh right! I had it on my legs but it just screams at me and stops working. So that was the one I was on in November, wasn't it? Mmhh. I was going to say the only place I can put it was on my bra, and I can only get these bras is Primark! There you go… So I buy pump bras from Primark. Do you know what I mean, so its things like that. I think you can buy specialist underwear but its extortionate!

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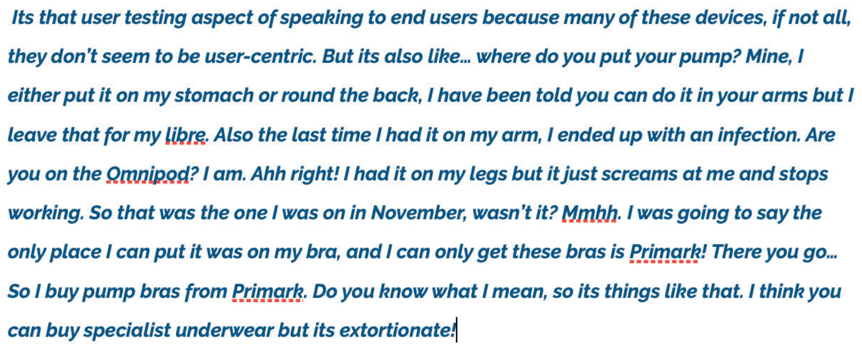

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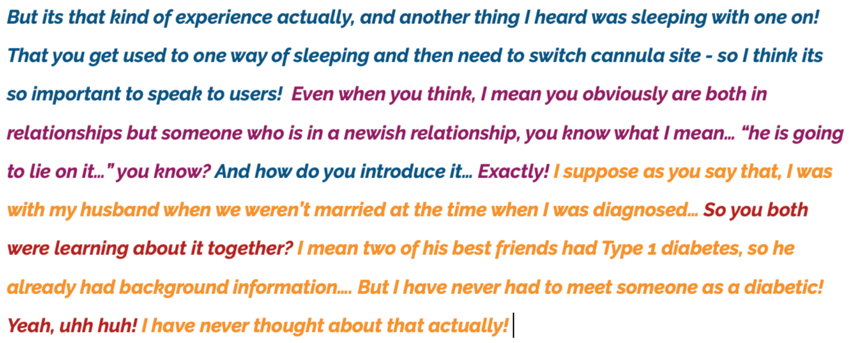
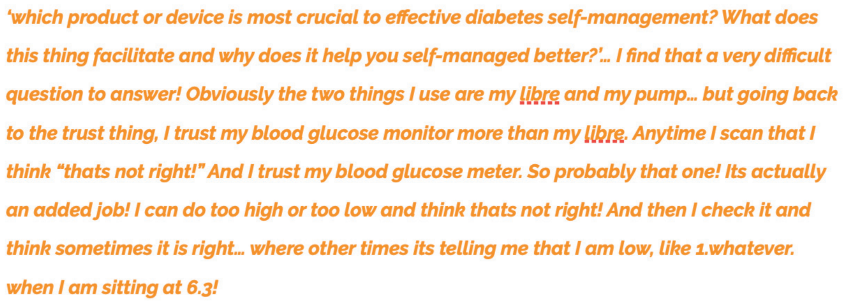
13 *Relational/Educational: This explores relations further, especially more intimate relationships and how you can introduce the device to partner as well as learn from one another and others to progress your self-management. Notably the importance of tacit knowledge from experiences by "meeting someone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



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, uhh huh! 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 libre and my pump… but going back to the trust thing, I trust my blood glucose monitor more than my libre. 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 6.3!

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*

Have any of you ever seen one of these before? Or a stakeholder map for your diabetes? Not for diabetes,

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I would say online community, so social networking and stuff like that. Yeah I would agree with you - well thats how 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.... isolating! 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! Ummhum! 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 gosh! Terrible! And I remember when it was coming up to my wedding, I made up wee hypo bags and I was just going to leave a bag with certain different groups, and this one group were like no, I don't want the responsibility... Disgusting! And I was like, its just a bag of sweeties and juice... its nothing in it! And someone said, I will be going up your dress and injecting... I was like "Don't ever inject me!" No! They didn't listen to anything I would say!

17 *Relational/Trust: Social networking arose early in discussion as a positive stakeholder. But negative reflections from friends and family who were ignorant to the condition.*

18 *Relational/Trust: Diabetes as a 'brand' was interesting insight into the everyday as it suggests there is marketing pull power towards certain products and services. Interesting experience from participants mother who had diabetic chocolate, which has aspartame - which has a laxative in large quantities.*

What annoys me is... and I don't know where this would go... is diabetes as a 'brand'. Right, okay so that would be more the diabetes industry. What do you mean by that? Erm you mean the split between Type 1 and Type 2? Ohh thats another thing! But the forcing of "this is for someone who has diabetes," remember when they used to do diabetic jam... and sweeties and stuff. And they could kill you! I remember I was in hospital. That one time in the toilet because it had laxative in it. When I was in for an operation, I had a diabetic bear and and my mum had some... when I came round, she was like "sorry I am in the toilet!" And "never again!" Actually when I was diagnosed, it was my diabetes nurse she was like "dont buy into this diabetic stuff, it doesn't have many carbs and has a laxative effect. So yeah I think the profiting from it, really drives me insane

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 lose 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. I 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 cure that Anna, she was telling me... Well you are either cured or you die of it... with type 1 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 said better self-management because they were doing fine as is. You always say now, that you wouldn't want to not 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...

19 *Educational/Relational: Interesting conflict between whether participants would rather be Type 1 or Type 2 diabetic that alludes to how difficult both conditions is to self-manage. Participants mother gave insightful reflection regarding that a consultant gathered her daughter had cancer, because it could be cured whereas her diabetes can't.*

20 *Trust: Confusion around food and notion of experiential learning "I dont think I have been diagnosed long enough to fully understand"*

foods is a prime example, to have a look at the nutritional value. I don't know about yourself but if you have ever gone on a diet and tried calorie counting? I don't understand as people say "this is carb free" but there is still calories in it. And I am like "I always just think in carbs..." all you think about and then when you have to think about calories as well. I have not but we will see later on if I need to! But what gets me as well is the protein. So protein has a massive effect on how much insulin... is that protein or fat? Its both because your protein will eventually break down to sugar, so I think just having a general awareness. I have to say I haven't reached that point of seeing how proteins affect my blood sugar... I don't think I have been diagnosed long enough to fully understand...

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another thing is knowing where to stop! Because you could sit with your libre every 5 minutes and I could sit with my CGM… there is a day that you are going to be 10 and its because thats whats going to happen.

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

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

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 dont 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.

23 *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.*

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

I dont know what kind of special training they get but they are a good team - they are phenomenal! They empower you as well. Even from a juvenile perspective as well… it was Dr Loudon from juvenile endocrinologist from the Monklands hospital and she was… amazing! Absolutely amazing! Its the kind of people who you remember so it is! Not it is, absolutely!

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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 1.5 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 dont have any personal interaction with it. But I dont see it changing anytime soon. No. Do you think that could change if users were to make a change and rebrand themselves? I dont 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 no one under the age of 50 had! 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 dont 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 dont know what she would do without it, but I think thats what's made Anna who she is

25 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'.

26 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.

she always strived to do better, better and better... because she felt as if... yeah people said I couldn't do things! It makes you more determined. I mean when Anna was diagnosed, they told me... get her a wee job in the co-up or chemist, locally, and then she will always be quite near you. And she has traveled the world! That was hard for me and her dad but you wouldn't have held her back.

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quite easily, even from your Facebook group for 'Type 1 Diabetes in Scotland,' people are selling this now. I have heard this... I can't! I have heard of people using it in gyms. These muscle guys... I dont understand how that works though. I can't get my head around it! I dont understand from a stimulant aspect of it but its the idea that people can sell something, and it just drives the price up! Yeah! And this is what people need to live... For building yeah, if you think of it... insulin is a woman of plenty - the more insulin you take, the more calories you require... so you can bulk up quite quickly. Some people can put on weight but other people can... Surely though, excuse me if I am being totally ignorant but I do not understand the whole concept of it! These people who are not diabetic, can just eat and bulk up anyway... because they produce their own insulin! No, its the hormone will impact 7 other hormones, so your fat cells become more receptive. So actually instead of you just taking the calories in, your fat cells are almost like grabbing it. Right! Because I was always told as well, as a type 1 diabetic its harder to lose weight as your body holds onto fat... the more insulin you take, the more fat you will end up having. Yeah, its because your cells are... How does that then work for them? Is that what they are looking for, they are looking for the fat? Yeah because they want to bulk up.. The more calories they can take. I still dont get it! I dont really get it either! It's like a steroid, I has the same kind of impact.

27 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.

28 Trust/Education: Interesting discussion leading from knowledge and how easy it is to become overwhelmed by data and 'too much information'. Notable inclusion of how this affects mental health and how too many voices can exercerbate existing worries, for example the pregnancy scare story

Because that is the real value for them, because that data becomes knowledge 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 sit all day being a diabetic and forget to be a mother... My dad, when I was pregnant, I self funded the Libre 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 hypos... I was up through the night, I dont 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 on my honeymoon period so everything was all over the place, and you are fed like scare stories... like in the first 12 weeks, if your bloods are too high then your baby will have no arms! Yeah, I know... So I was like I dont want my baby to have no arms! You must have been dreadful, 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...

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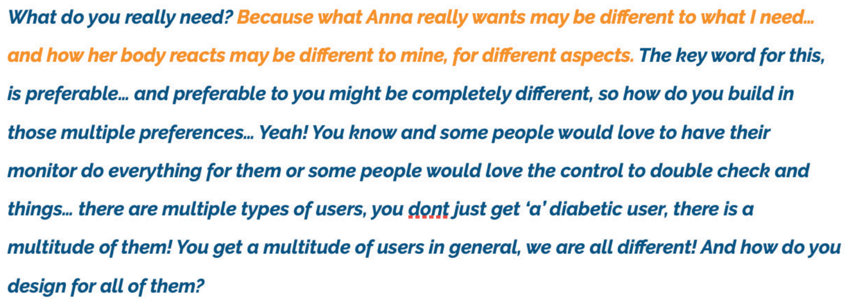
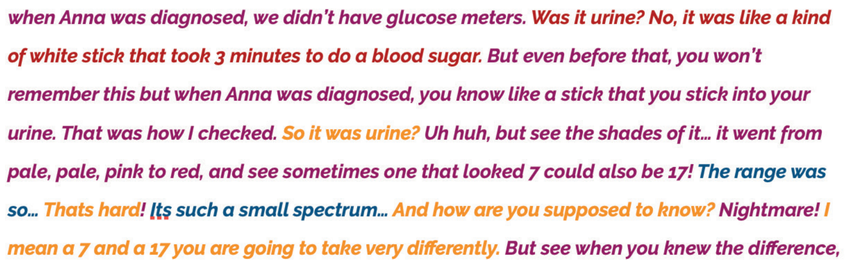


What do you really need? Because what Anna really wants may be different to what I need… and how her body reacts may be different to mine, for different aspects. The key word for this, is preferable… and preferable to you might be completely different, so how do you build in those multiple preferences… Yeah! You know and some people would love to have their monitor do everything for them or some people would love the control to double check and things… there are multiple types of users, you dont just get 'a' diabetic user, there is a multitude of them! You get a multitude of users in general, we are all different! And how do you design for all of them?

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.*

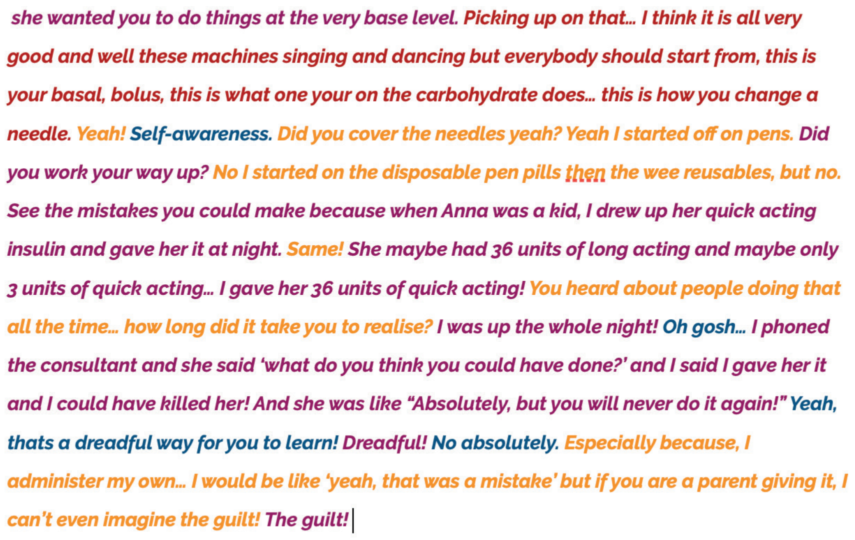
its simple! Aye, its easy! I think it depends on who is using it…. because some people. Want the extra information? Yeah, and some people might not understand the information thats given to them. Its often that it starts off complicated and the clever clogs, and people in the know, excel… but if you start off simple and gradually get more complex…



when Anna was diagnosed, we didn't have glucose meters. Was it urine? No, it was like a kind of white stick that took 3 minutes to do a blood sugar. But even before that, you won't remember this but when Anna was diagnosed, you know like a stick that you stick into your urine. That was how I checked. So it was urine? Uh huh, but see the shades of it… it went from pale, pale, pink to red, and see sometimes one that looked 7 could also be 17! The range was so… Thats hard! Its such a small spectrum… And how are you supposed to know? Nightmare! I mean a 7 and a 17 you are going to take very differently. But see when you knew the difference,

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.*



she wanted you to do things at the very base level. Picking up on that… I think it is all very good and well these machines singing and dancing but everybody should start from, this is your basal, bolus, this is what one your on the carbohydrate does… this is how you change a needle. Yeah! Self-awareness. Did you cover the needles yeah? Yeah I started off on pens. Did you work your way up? No I started on the disposable pen pills then the wee reusables, but no. See the mistakes you could make because when Anna was a kid, I drew up her quick acting insulin and gave her it at night. Same! She maybe had 36 units of long acting and maybe only 3 units of quick acting… I gave her 36 units of quick acting! You heard about people doing that all the time… how long did it take you to realise? I was up the whole night! Oh gosh… I phoned the consultant and she said 'what do you think you could have done?' and I said I gave her it and I could have killed her! And she was like "Absolutely, but you will never do it again!" Yeah, thats a dreadful way for you to learn! Dreadful! No absolutely. Especially because, I administer my own… I would be like 'yeah, that was a mistake' but if you are a parent giving it, I can't even imagine the guilt! The guilt!

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as you say, you need to start off at the base and then add on layers of knowledge… but if you overwhelm someone. With too much information aspect of it. The reliance of the machine, and again it goes back to this trust… if you are constantly relying on a machine, how do you know? I have to say, I couldn't even tell you what my ratios are just now, because it is all in my pump. So if my consultant says, what are your ratios…. I would be like 'hold on!' So see if this fails and I had to go back to a pen, I would be like… 'I dont know how much to give myself!' Yeah, so I do rely on it too much! But at least you know the sizes behind the ratio, you would get to it. Give yourself an hour and you would be like 'right, okay'. Even more so because of the job you do, you know numbers! No that is something, when I did my DAPHNE course, I was always lucky that I could work with numbers. You are numerical! But there is so many people that aren't! There was someone on our DAPHNE course and she was supposed to… on the last day she was given a box of celebrations and was told to work out how many there are per sweet. She was like 'per sweet' and worked out 4 when actually she should have given herself 10! And we were like how did you? And she said 'awh, I didn't get it!' How dangerous is that?!

33 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.

34 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.

Has that ever at all came up in the learning of diabetes? Or can you fail safely with someone? No. Its how you learn though… No I think it is though when you are first diagnosed, its like 'trial and error,' because you dont know 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 know 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 be like 'through the night, this is what your basal is… as soon as you wake up you are like down to 5%?' Yeah it works for you!And I am like… 'it works!' So I think a lot of it is trial and error.

Its interesting as you don't get taught those kind of things…. Again its a personal thing! I made the conscious decision in my 20s, I ran the pill in for 10 years! You ran what? My pill in… Back to back? Yes, I didn't have a period for 10 years because of the effect the period had on my blood sugars. For 10 years?! Yeah, I was like 'not doing it!' Is that safe?! Its fine. The gynecologist said, "its 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 sugar… huge! And obviously with that, you have cravings and things. Yup! I feel to high to even be considering this… It affects the amount of exercise you are taking and whats 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 hadn't fully considered before.

35 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?

36 Education/Relations: 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.

so when you are a kid between the age of 10 and 20, you learn something and see next Monday… 'nope!' Thats, you know? Totally! Before my insulin used to do this but now it does he-haw! 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 whats your priority but I remember when my baby was wee, getting up during the night to feed him and thinking 'I am not well at all…' and I was down in the 2'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 he is 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, absolutely. Alongside this research, I have volunteered at NHS 24. So it come 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. Ohh right okay! People who are unaware 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.

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you don't just have yourself to manage but someone else to look after too, thats 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 weighs on your shoulders... Mmmh! 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 'Mum, 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 it really shouldn't hold you back, it shouldn't but it does in so many way actually. Yup.

37 Relations/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.

38 Relations/Trust: Discussion on the impact of modern devices compared to previous practice and how 'amazing' participants consider technology while also acknowledging that it "could be better"

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 100 years ago if someone said you are type 1, then you die... and then you have these big massive, 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, its 'cho, cho'.... I don't even need to do an injection! It's already in, so I just push a couple of buttons and that is me. So I have to say I think technology has moved us on so much! Oh its amazing! Its fantastic, although... obviously there is always things that could be better! Maybe not having type 1... but I think its amazing!

these types of things. And you never forget them! Never... and you know what, if I was in Tesco and I had to just pick something... jobs done. But it was things like that where you were so regimented... And thats not so long ago. No, no but what I would say is that means is that you are acutely aware of every single little thing that hits off of your body... But I have to say that the guy that I am talking about that doesn't consider his, so it can go the other way as well! I have to say the relationship that you then start to have... it becomes quite medical. It does yeah, yeah! I was thinking Jean, what do you think of that kind of thing? How was it to be sort of mother and... I felt as if I was judged all the time... I definitely did feel that with the consultant. Oh a huh! She would sit with the diary and I actually used to feel... I didn't know why, but I would always be lower than her. And now I know thats you sort of deflecting to the person so it is... do you understand? Uh huh, and my body language. Erm, and I was very fortunate because I had mine to a tee

39 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 make her feel 'judged all the time"

40 Relational/Trust: Discussion of previous regime opened discussion on 'illegal' practice. Interesting distinction on what's for adults and children and also how intellect/ability plays into this anecdote as a "smart Alec" who was the "best controlled diabetic in Britain"

thats 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 if 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 up on it... What age were you? I was 11. Thats 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 thats six injections a day...' and I said it could be more! She said 'yeah...' but does that mean if I am really hungry for my dinner, I can eat more dinner? And not hungry for my snacks... and she said yeah thats exactly what it means. So we had to be trained up on that. Thats 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

5.2 Thematic Analysis Coding

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very isolating experience, very very isolating and the only time you ever felt 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. Its the responsibility aspect… and how much that changed your relationship. Uh huh! Because sometimes I felt as if I was Anna's 'jailor,' you know I felt as if I was like the bad cop. I was always…

41 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 'jailor'

42 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. 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.

rebelled a wee bit as well. Now you are all grown up, what did you think? No, I did! I just decided 'fuck it' I am not taking my insulin! From what I have heard, that is really really normal! Absolutely. But sadly what people don't tell you is when you stop taking your insulin, for a while you feel fantastic! You feel great! Really? Elation, euphoric kind of thing? You feel great, your blood sugars are high but not too high… Yeah because I was still taking background. Right okay! And remember I knew a lot about it, I could play the game. I suppose as well if you were excellent at managing, you could use your background to try and lower it. So, also you are 18 and you are not putting on any weight… you can do what you like! Well I have heard that as well aye! So its things like that where, nowadays you see young women with like 'diabelemia' and things like that. But that wasn't the case with me, but it certainly was like… A bonus? A bonus as well, but also I felt brilliant, I didn't worry about going hypo. I felt absolutely brilliant then I can't remember what happened… but I just got too high and went completely… I mean you were 18! Yup. That must have been terrifying for you! Mmh Hmm! But it was one of those things were actually it kind of had to happen! Because I had to push my extreme. To know yourself and your limits? Yeah but also to know there is a reason why everybody is doing this for you… at 18 you just think that your mum is just nagging you about how low your blood sugar is. So if you never experienced it, you would have never truly understood it? What they say is they like them to rebel really early. Maybe about 13-14… because the longer that you don't rebel, when you do it will be even more spectacular! I mean if your 18 and out drinking as well… its an added worry! And how many 18 year olds would turn down drink? I wasn't really that bothered about drinking I must say. But I was bothered about being out and having a nice wee handbag… but it had to have my blood kit in it! She was very very bright, so you always tried to be a couple of steps above her! A bit of a smart arse!

knowledge equals power, sometimes it can be your guise. Because you could go into the hospital at 18 and talk about your HbA1c and you could fill in your book… which is all total lies! I feel that when they get your HbA1c and say… 'na!' No, I would sit and fight with them and say thats wrong! Then they would say… 'yes, it is!' Nowadays you can say I am the actual doctor… But you need to do that early on, because you are given two options… either you are dead or you do what you are told! Can you trust yourself with that responsibility? Yeah, yeah! Because that brings in another element to trust

43 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 respect/trust between patient and consultant as the test will show truth behind background glucose management for past 3 months. However this was disputed later as "either you are dead or you do what you are told" Implying this relationship should be strengthened to enable trust in the truth.

44 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'.

how I 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! Its nice to be able to do the small tweaks, rather than everything at a half unit

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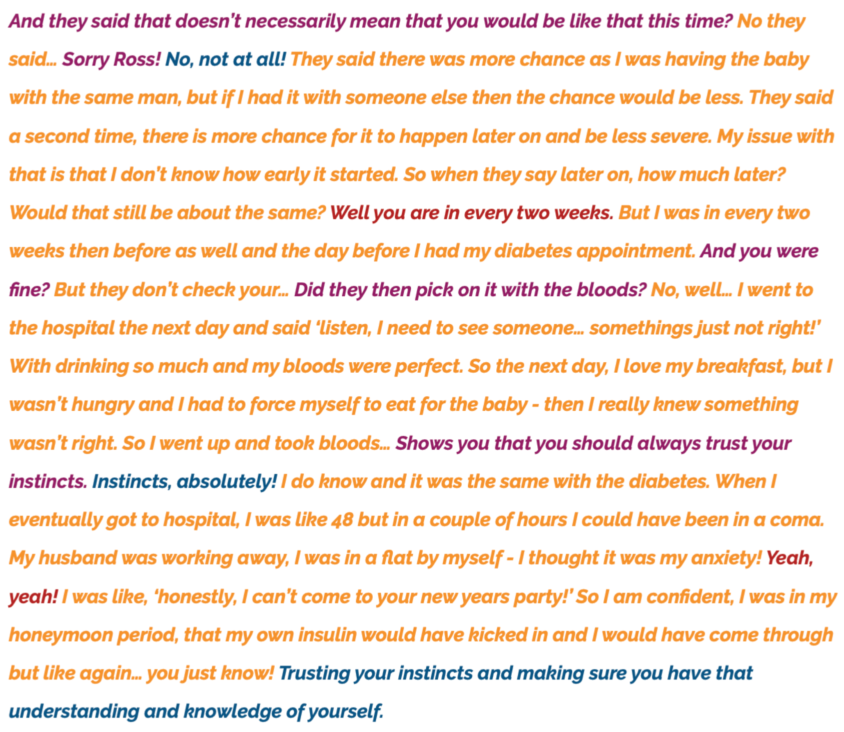
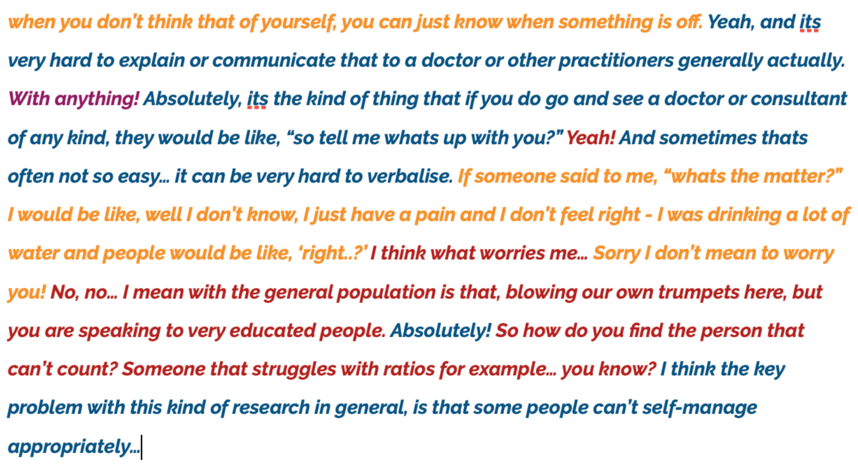


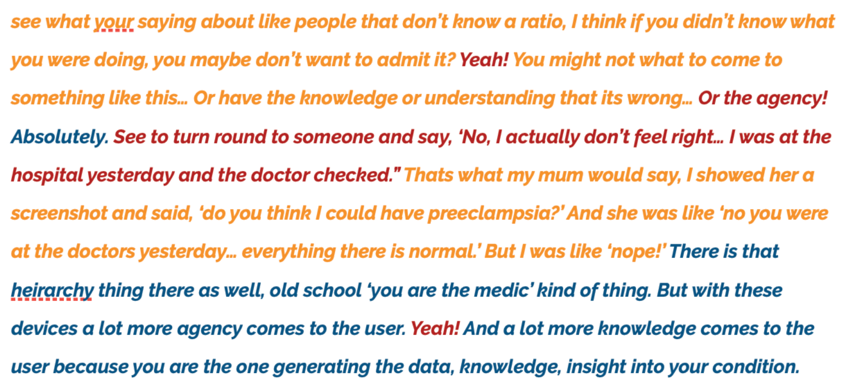
And they said that doesn't necessarily mean that you would be like that this time? No they said… Sorry Ross! No, not at all! They said there was more chance as I was having the baby with the same man, but if I had it with someone else then the chance would be less. They said a second time, there is more 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 your… Did they then pick on it with the bloods? No, well… I went to the hospital the next day and said 'listen, I need to see someone… somethings just not right!' With drinking so much and my bloods were perfect. So the next day, I love 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 48 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, 'honestly, 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 like 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 diagnosed her sooner and wouldn't have lead to emergency.*

***46** Trust: Discussion about verbalising when something is 'off' and when do you 'dont 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.*



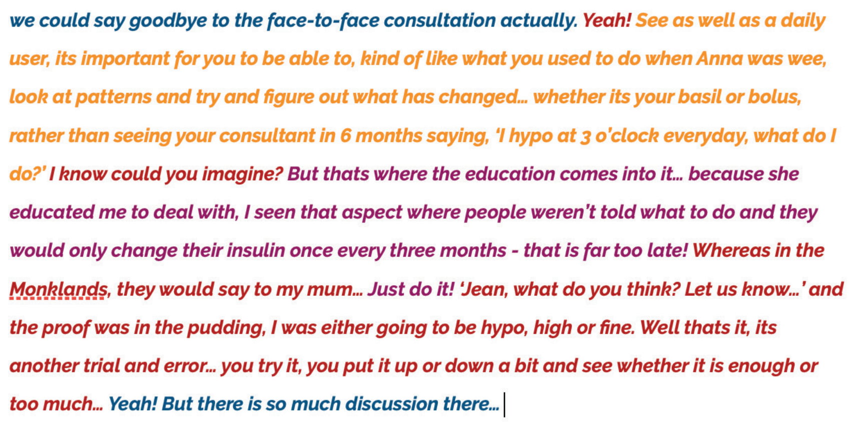
when you don't think that of yourself, you can just know when something is off. Yeah, and its very hard to explain or communicate that to a doctor or other practitioners generally actually. With anything! Absolutely, its the kind of thing that if you do go and see a doctor or consultant of any kind, they would be like, "so tell me whats up with you?" Yeah! And sometimes thats often not so easy… it can be very hard to verbalise. If someone said to 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 own 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 can't self-manage appropriately…



see what your saying about like people that don't know a ratio, I think if you didn't know what you were doing, you maybe don'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, 'do 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 heirarchy 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.

***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.*



we could say goodbye to the face-to-face consultation actually. Yeah! See as well as a daily user, its important for you to be able to, kind of like what you used to do when Anna was wee, look at patterns and try and figure out what has changed… whether its your basil or bolus, rather than seeing your consultant in 6 months saying, 'I hypo at 3 o'clock everyday, what do I do?' I know 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 Monklands, they would say to my mum… Just do it! 'Jean, 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…

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Do you know what I have seen is a massive improvement in DSN's who have went to work for Medtronic. Uh huh! And they are shit hot! They are really good! I don't know if its 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 DSN 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 those 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 is a lady, the one that I have in mind is a lady called Heather Maxwell who is a DSN in Gartnavel 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 erm 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 '640g' 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

49 *Educational/Relational: Discussion around DSN's going to work for a medical device manufacturer (Medtronic) enabled others to be better and more knowledgable 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.*

50 *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.*

thats exactly where the problem lies! Mmh Hmm! Or why this is even a discussion today, because people sometimes don't manage it appropriately. Sometimes it's out of their control, whether that be exercising or going out for the night kind of thing. Absolutely! I interviewed one guy who dabbled with drugs before. Right okay! And how did that impact him? Mainly his family were very very close to him and he got into the wrong crowd in particular… so he was 19 and started party drugs that eventually spiralled until he got his Libre taken off him… Did they right! Because he was misusing it essentially… I guess from our discussions, it was a bit like his lesson learned sort of thing - trail and error. As it really made him value the worth and impact of the technology. Yeah, yeah! No but I think its that mismanagement that people often do. I think you need to do it in a way - I mean I would never speak to a young person and say, 'go and give your six months up the swanny' but I think its one of those reset moments… you remind yourself that this is a chronic condition, you know this is where we are! Absolutely! I

'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 try 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… Mhh hmm! 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 is! 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 knowledgable instead of a close family member

51 *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.*

52 *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.*

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! 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 hypo and suggests to just run high this week? Thats not going to work! And then he gets annoyed when I hypo again? It's because I am trying to have control. Yeah! Or also, sorry but, so my mother-in-law will say things like, 'but your not very well managed,' like no Anne… the fact that I hypo means I am so well managed - so you know so its things like that! I mean because I always say to people… Ive even had doctors say, 'the last time I saw you, have you had a hypo?' And I am like 'uh huh, yes!' What I know! I say to them, actually under DAPHNE if you are well controlled you should have 2 hypos 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 Weetabix?' Yes, I take two teaspoons of sugar… there is 5g of carbs in each, I bolus for it and that 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 Alpen' which was sending me like mega high because there is raisins in it! Ohh really? I might as well actually just eat sugar! The debate was, can a diabetic… thats something that really annoys me!

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'A diabetic?' I have diabetes. Ohh you see I disagree with you there, I do refer to myself as a diabetic. I will but I can do that… Is it when someone else says it? It's the kind of sticker, you are a 'diabetic.' The labelling aspect of it? Yeah! Uhh huh! I did a previous project with autism which was a similar debate… do I have autism or am I autistic? Yeah! Uh huh! Its the spectrum aspect of it. Its similar to a lot of things! Yeah! And one of the things for that project is we removed the word 'autism' to embrace a more "we are all on the spectrum" approach it. Right! Yeah, yeah. It was a more inclusive aspect of it… Which is nicer then isn't it! Its a lot more approachable and doesn't have as much negative connotation because with these conditions you always think of the worst. Yeah! So maybe if you could create your own label, already creating our own now… 'what if you could label the condition differently?' That was something that came up from the earlier discussion as well. I know, I just don't know where I would start! Thats a big one! I think the only one with that would be the difference between type 1 and type 2… thats the only one that I could say. Personally, I am fine to be labeled as a diabetic. Oh no, I just don't want it used as a derogatory term. 'What if diabetes could be seen in a positivistic way?'

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.*

Do you know what I mean and I have comments from friends who waste their life on calorific diets… like 'if I eat purple this week I am going to be a size 8,' well good love, great! Shut up… I have one lady who tells me how allergic to carbohydrates she is because of her genetic predisposition, because if you trace back to where she was in a cave… I was like, 'Did you pay someone for that?' And she is like… 'Yes, I paid £500 for someone to tell me that' - bullshit! You know… stay away from Holland and Barrett, get a grip and eat your carbohydrates… you know, its those things! Its a strength in particular, and that aspect is not seen. Uh huh! Its a positive aspect! To show the positives… I have to say, I have never heard diabetes spoken about positively… never ever! Even the daily mail headlines this week… Oh yeah! Owhhh! Thats one to stay away from for sure… but its hard to not look sometimes. Horrendous! And people tell me about it, 'have you read the daily mail this week?' Great, but you also learn that all people of colour are coming to steal your meds and all that… erm but its quite startling! But then, that kind of news sells… you know. Yeah!

Steve Redgrave for example, I can remember sitting up watching, I think it was his fifth Olympic and he had some kind of flash monitor on. Is he diabetic? Type 1. Awh I didn't realise that! And my dad and I stayed up and watched him. Thats 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. Its 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 snack for this and hydrate here. Like that is amazing! Absolutely… But that will be another trial and error learning though. But that is how he 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', its more this is how I run a marathon. Yeah! And thats 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!

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."*

I really like the positive perspective of this… because I don't think its something that often gets talked about enough. And actually, I find it in my work as well. So when I am lecturing to students, they call me Iron Man because its blue and lights up! Thats the transhuman aspect coming in! I say to people, even in high level meetings in government… 'I beep.' If I beep like this, that biscuit is mine… nobody touch it! And it allows me to be quite tongue in cheek. I mean I work with a lot of students who have a lot of unseen disabilities, mental health that they are dealing with… I work with very very talented students, very very intelligent but that group of the population are not going to tell you what their weakness is… but if I stand up in the first lecture and say 'FYI, I beep. I eat. And this is me!' I think its great to be so open about it because I do think there is stigma around this and a lot of things, and thats a way to break it down and help people understand! But also things like students when they go into an exam, I say go and see Student Support services, so that allows me and my Segway into, if you need student support services then this is what to use… and I had to use that as a student. So its things like that where it allows me to do my job better. And you also like to try and educate people don't you… Yeah! Anna and my son, I have two sons and they were always very inclusive from a very very early age. Yeah! And Anna will show, I have a grandson, and he will say, 'let me see your beep beep machine.' Awh! You know what I mean? Its funny because with my wee boy I would say whats this and he would say 'mummy's pod. Awh great! And then id say whats in the pod… and he would say 'insulin'. Good! And sometimes if I am swiping, I will ask him to scan me but the issue is when I am hypo, I treat them with cartons of juice… and he would be like 'mummy share…' and I would be like 'I can't share!' And it ends in a tantrum. Hypo juice! I have to say 'I will get you something else…' But its that kind of thing of meeting or knowing a diabetic or people with diabetes that gives you that real life experience and insight into the condition. If people listen! That could be a possibility… 'what if we get people to listen or engage in a positive way?

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Maybe, what if strengths were a positive way to view diabetes? What if diabetics or people with diabetes were representatives for the condition? I think peer... Peer support! Yeah, peer support and not just for the immediate type 1... your circle will treat a hypo at some point. I have got to say, I wasn't well during the summer, nothing diabetes related but he said that 'mummy isn't well' and came in with a carton of juice for me. Awh! God love you! Thats the kind of stories that change perspectives... and you can tell he is going to have such a different outlook! Yeah! Absolutely and for him thats going to be 'normal.' So I have a friend who says I don't want you injecting in front of my daughter, but this is normal for me. Lose that friend! Yeah, we don't see each other... but at the time, I was like 'this is normal for me, this is my new normal!' But I think thats great for kids to see things like that! I don't know if this is your experience, but with kids as soon as you show them what your doing... Fascinated! They do not judge you! And I am like you got to make a wee hole and there is the blood... Everything is so curious to them! Yeah, and its great! I mean you might need to tell them every single time you see them but they take it on... Its a process isn't it. Yeah! And sometimes obviously for the pump I need to give myself an injection... and I would be like, 'remember needles are dangerous, you should only get this at your doctors' or whatever... but for my wee boy this is just normal!

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 was discussed and how early education can lead to a 'new normal' and changed outlooks in the future.

58 *Education/Relational:*
Discussion around a 'new normal' for diabetes and promoting diabetes through lived experience to change mindsets. Notionally 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.

What if we could create a new normal for diabetes? Mmhhmm! Yeah! So it is looking at things in a positivist way, so how would you do that? It would be through promoting diabetes through a lived experience perspective? Its something that clinicians won't ever do! Yeah! 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 all sexy and him like mister macho, and they were having a conversation and there was a blood machine and she said 'give me a mars bar and I can go all night!' Haha! I definitely will be looking this up now... but yeah! But to a young person that was quite hip and out there... in your face! Yeah! 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! Sexual!

wearing a bikini, I am mean like when I first went on my pump and my machine and everything... I was like 'oh god!' How long have you been on your pump? 6 years now but all different types of pump. So you have always been an adult on a pump? Always, always... erm so I can remember going on holiday and being like 'where the hell do I put all this?' And all the old wee ladies around the pool are like, I mean their necks are breaking looking on. Thinking whats that? And erm, I bought a big sun hat and clipped my pump... haha! And this wee lady walking past saying 'that is going to end in tears'... and it was just things like that where it was the clothing aspect. And when I was at university, one of the lecturers was male, American and on a pump and he was like, 'can I ask where you put it?' And I was like, "I wear a bra" and he was like, "Dammit, I knew I should have bought one." He had his in his pocket and said, "It is just bloody annoying and falls out all the time!" Erm so its about things like that! I mean I don't want a special range of diabetic clothing... absolutely not! But its the understanding that people are going to see it, it will light up... I mean I don't have the same kind of 'visibility' as you do because I have got the omnipod... its just stuck on and my device looks like a phone. But I do have people coming up and asking about my libre. I have had people on holiday asking, 'sorry is that a stop smoking device?' Yeah! Is it like a wee button? Uh huh! And I was like no, actually I'm a diabetic... and they were like 'ohh right, okay!' And I would much rather people came up and could laugh about it and get information.

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 and "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 traveling 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 anecdote from participant regarding experience from security guards and needing to use the "Dr card" but conversation arose to what if someone wasn't as educated... how would those types of negative experience affect them? And how would they approach overcoming issues?

airports are really bad, I have had all out fights with people... See when I go anywhere, I forget I shouldn't be going through anything magnetic. I mean my wee boy had an MRI last year and I was like glasses and rings off, ready to go and Steven was like... your pump! And I was, 'Awh, shit! Hold on a minute!' Yeah, and I find that... I am in airports all the time, in different countries... so I have had it translated into Mandarin and all the rest of it... just saying, can't go through it but Glasgow Airport is the worst! Really? Glasgow Airport is the worst... he said to me, "Ive had seven diabetics through here today wae all that gan!" And I was like, "Very good." So let me through! And he was like, first name... mmmmh! And that where... I shouldn't do it but thats when I use the 'Dr' card. Right okay! Because my passport says Dr on it... they don't need to know that I am an Ethicist and I couldn't mend you. So why does that matter if you have Dr on your passport? Because they show you more respect... its ridiculous! Its terrible you have to do that! I am like I am a Dr, and they are like 'owh, ohh... sorry!' And I am thinking, its just back to what we are saying right now... I am not a Dr but I'm an accountant. Honestly its as if you know more about something, a medical condition that you have... but virtually the degree! Its that thing of heirarchy starting to standardise sort of thing. Its terrible though! But its the only time I have ever pulled it in my life! I mean what if I didn't say that? What if you didn't have those kind of qualifications? I mean you get ushered into a wee room and they pat you down and all the rest of it. And then they are kind of scared to touch it, and I am like, 'its totally fine, on you go! You wanted to see it...' Look at it! So I just took off my top... and there you go! If it was a bomb, it would have gone off a long time ago! And we would not have been having this kind of conversation... so its things like that, where I wrote to the airport and it was actually the chap who is head of security in Manchester... his son is type 1, so he changed it and you will see the sunflower landyards that everybody wears... so for a wee while every airport that I went to, I would take a selfie with my landyard and put it up. I mean I have been in Heathrow, great! And then, Dusseldorf... no you need to do XYZ. Imagine you were a different type of person though... imagine you were an insecure teenager, traveling alone or... And you have to go through that ordeal! You wouldn't get on a plane! Yeah you wouldn't want to do it again. You wouldn't even get on the plane! Possibly if they were standardised... I think a big part of that issue is that there is so many devices for medical conditions like diabetes, and there is so many different generations of them... it just seems like there is so much in this kind of space! Yeah. That it can't actually be... maybe if there was an Apple iPhone equivalent of the insulin pump kind of thing... However, only if everybody used it! Exactly.

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Although saying that, I have very stupidly changed the batteries of the omnipod thats running out and it deactivated my pod! Ohh no! And I went to redo it and changed my handbag the previous day with a bit of insulin and I phoned and managed to get insulin from a pharmacy nearby, I went in and used my last pod. I normally have two and thought, 'this is a disaster!' And I managed, we were in Glasgow and I got hold of the Boots in Central Station… the woman was awful! Oh no! She said, "the fridge has failed and I can't give you anything." I said, "if your fridge has failed, the insulin in it is good for 30 days, so can I still get it?' And she said, it has been 'quarantined' or whatever. I said is there anyway, because otherwise I have nothing! I will need to go home… I knew I would be alright for maybe the next day or a night, I was like I want to have cocktails…. You want to enjoy yourself! One night in Glasgow, we don't ever do it without a babysitter for the wee one. Erm, she said right okay and went through all these questions with me. Like, 'what date were you diagnosed? What is this? And What is that?' Interogation! She asked if I could see your pump, and I was like yeah! Oh my god! I was like… can I come behind the counter? Because otherwise I am flashing my pants to the whole of Central Station! Ohh! And she was like right… here it is! I can show you my meter… But what could she have told from that? I think she thought I was lying! I said, I am not being funny but I am dressed up, in a dress… here with my husband, do I look like I am going to a gym or going to do something dodgy with it?! You can see from my records I am diabetic, I have all the diabetic gear… I am the one telling you what kind of insulin I need! Then eventually she said, here is a thing… But what if you could prove you are diabetic, other than doing all that? Yeah! Although the thing is, I always think its pretty easy… especially to a pharmacist who really should be like, I am diabetic and by giving her certain words and information… Okay, she know uh huh! Like no randomer on the street should know this! But instead having to actually lift everything and be like… 'what more do you want me to do?' So even in Glasgow, pharmacies! Pharamacies, who else do you go to in those situations? In Glasgow, you are taking about away but… But especially out of hours, thats when these problems sort of arise most. Yeah, its just one of those things about travel… Yeah travel as well!

61 *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).*

62 *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.*

In particular I liked the strengths and looking at diabetes in a positive way, to introduce diabetes better… To who? That was when you were saying. The general public? Yeah, to the wider public or 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 this one - I don't think anyone would be interested apart from someone close to them. Aye! I can't see a random, like if it was me before I was diagnosed, I would be like 'thats interesting, but…' Thats when we were talking about representatives. Yeah! You could brand yourself as a diabetic more differently, I just know from Diabetes Scotland thats who I was originally working with to get interviews. Ohh! They do consider they consider their young volunteers as 'Young Leaders.' Yeah! Ambassadors? Absolutely, so thats how they represent diabetes… not just yourself but a whole community!

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people who may not be able to speak up for themselves or manage their diabetes. Do you know when you are speaking about people, if they are interested or not interested. Because I remember, and I think you will remember this too. In Asda, do you know how they had pharmacies? And an acquaintance, she wasn't a friend, an acquaintance of mine had two carrier bags with the cross, boots right. And I said 'dear god, whats wrong… whose dead?' And she said Its terrible and my wee daughter has been diagnosed with diabetes. Was this after Anna's diagnosis? 6 weeks before! So I stood and I spoke to her, and was genuinely interested! And when I came away, she phoned me and 'said how did you get my phone number?' She said, 'it didn't matter… I wanted to thank you!' I said 'what for…' For listening? And she said 'because you were interested… and you didn't make me feel as though I was just rambling or… you were just interested!' And 6 weeks later Anna was diagnosed. Thats funny isn't it! Very strange. Very very strange! Did you get in touch with her after that? I told her, uh huh! Maybe because we were saying about how late some can be diagnosed, it could be more about awareness. Yeah! Mmmh! More publicly… not to be too influenced by the autism project, but maybe we are all a little bit on the diabetic spectrum? No, actually that conversation so helped me because I asked her, 'how did she know? What was it that brought it to your attention?' And she said that her wee girl had a toy tea set, and that she was getting up at night and filling the little cups with water to drink… and that was what I noticed with Anna! Yeah, I can remember my dad had said to us, because we didn't really have fizzy drinks, but he was like do you want a fizzy drink or an ice cream… and I can genuinely remember panicking, saying 'I need both!' And then the night, because my mum worked in a nursing home and had taken a urine sample, because you had a bit of an inkling didn't you! And the night that you tested it and everything, my dad came into the room and said 'would you like a glass of water?' Now we were never allowed, you know how someone takes a glass of water to bed and things like that… we were never allowed that! Uh huh! And he said, 'if you need to go up to the bathroom tonight, don't worry or if you need anymore water or anything…' and I could remember thinking, 'thats a bit weird, is it not?' Had that not been one of your symptoms? I was peeing all the time, it was a really warm summer though! It was the summer holidays… Right! So it maybe didn't feel that unusual? I was diagnosed very early though… Not right away, no! My blood sugar was only 18 was diagnosed. But you had that instinct? Aye, she was a wee, id like to say well built but you were a wee fatty! And literally the weight just dropped… Really? I went down to 4 stone… Skeletal! And then she just wanted to lie about all the time! And drinking all the time… Classic symptoms. And then I knew! But you were thirsty when you were drinking! Like drinking while thirsty… I remember one night I drank like 3 pints of water and 2 pints of juice and thinking 'I am still thirsty!' But thinking I can't drink anymore or im going to be sick! Yeah! I am so full but I can't and that was the worst, that thirst that just wouldn't go away! And I was peeing, I remember I was up 8 or 9 times during the night… but sometimes being so desperate and not even making it! Like, 'whats wrong with me!' It was like every 15 minutes at work, and my bosses were like 'youre at it!' And I felt like I was peeing more than I was drinking… thinking 'this isn't right!' Or thrush is another… sorry Ross! Your alright! But thats another symptom but Anna didn't have that. I was just drinking but it was the panic of when you were drinking, thinking 'I need another drink!' Yeah! It was constant!

63 *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.*

64 *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 numberical system can be confusing and unrelatable.*

By putting them in the autistic spectrum, it meant that they could empathise with others… Mmmh. Yeah! Once you get that bridge in, that introduction, 'what if you could empathise with the public or wider population, they could empathise better towards being diabetic?' Mmmh! We have one last 'what if' card here… Do you know what I think? Its about the hypo situation, so erm a colleague of mine was hypoglycaemic, you know she hadn't had something to eat and her blood sugar was low and everything… and her blood sugar was probably about 4, so I gave her orange juice and she said, 'is that what you mean when you say your blood is low?' And then she was like, 'Ohh that was horrible!' Erm, so there is a kind of empathy within that… What like a non-diabetic? Yeah. Right okay! I mean, I am not saying that everybody should feel a hypo but even now my husband will laugh and say he is having a 'hypo' and go and have a glass of orange juice. Especially when we were saying about that understanding but empathy is interesting… so for this project I used these engagement tools to get people to 'code' their autistic traits visually together whether they were autistic or not. But it was the idea of this colour of green was representative of anxiety and the intensity of the colour showed how anxious they were… Ohh! Awhhh! But it showed their condition holistically with others and allowed empathetic conversations to arise with non-autistic people. I mean for the last 'what if' card… Yeah, I think people will understand, like what you are saying like you need your breakfast in the morning, you will have things that you know… Exactly! You are almost showing your strengths as well. But that is such a wonderful idea, sorry! I think it could be quite useful for this too… For anything! So originally thats why I took away the autism… you could do that with anything! Like people you said with depression, anxiety… I have suffered with terrible anxiety. And its a very very difficult thing to talk about, its very very difficult to talk about it. But see if somebody had said, well here is a set of colours just to…. Make it a bit easier? You wouldn't need to verbalise it! You know what I mean? Well actually that is where the numbers come in, with these devices but how can you show that, as you as a person rather than a number! I think any person now, in this kind of age of so much data… like people are so fixated on their steps, 20000 or 10000 whatever! So they are monitoring an aspect of their life everyday. And a lot of people with these watches… Yeah! Uh huh! So its kind of saying, thats the way I say it to my students, that I also monitor my steps as they impact on my blood sugar. And peoples apps on their phone when they are diabetic is things like 'MyFitnessPal' or 'Apple Health'… everything comes together. So yeah, its not as alien. And when you talk about diabetes being a disease to diabetes being a condition, is that I am being a pancreas. And their is a book, 'Think like a pancreas' as well. Its in my 'to buy' list on Amazon, and it has been for a few years! Its good! There is a new one coming out next year, so I am holding off for that. Uh huh! I think thats what I say to people is actually. I am just being an organ that I don't have (working)

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previous participants to do initially was for them to 'draw' or show me a pancreas. Ohh! I mean one of the first thing I asked is 'what is diabetes?' And only around half said the key word, 'pancreas,' its the problem with diabetes but many went on to list the affects of the problem rather than the root of the issue… your pancreas doesn't function properly. I mean a lot of people will say, 'my pancreas doesn't work,' when actually its only a bit of your pancreas that doesn't work! Yeah, yeah! Absolutely! And my mother would be like, 'yeah, yeah… your pancreas is no good!' And I am like, 'its half good…' Its alright! I mean it doesn't do the bit I want it to do… But I really love that empathy idea, its something I haven't seen at all in this! Can I through a wee spanner in the works? Go ahead! We are talking about empathising and having people understand diabetes. I feel there is a lot of type 1 diabetics that don't understand… Themselves? Uh huh! Yeah! I know diabetics that would say… 'I can't eat that, im diabetic…' And I then I go 'Are you type 1… hmm!' Okay, and people that, and its fine to not carb count if thats not what your going to do… But I like the mismanaging idea, there will always be people that mismanage… And not even people that don't manage, if thats not what you want to do then thats fine… its your condition! You can manage or mismanage it, whatever… but its that belief, like I know type 1 diabetics that say they can't have chocolate! And then tell other people, 'I am diabetic, I can't have chocolate!' Uh huh! Then you meet people and they say, 'Oh you are diabetic… you can't have chocolate!' Yes, I can! Yeah, where is the quality street! Absolutely! Its kind of like a… Its a mixture of two things, the empathy idea but also the 'true' understanding? Mmmh! And I think its hard because sometimes I go to my consultant and DSN and things have changed… so even if I am testing my background insulin, then I say 'carb free lunch' and then I they say 'actually its better to fast now!' Or then you say, is this the limit… then actually they say the limit for hypo has changed. Which I was like 'no, its not!' I am sorry but I am hypo when my blood sugar is. You can't tell me when you have suddenly decided… I must say, I was always under the impression it was 4, then DAPHNE was 3.5, then I go on the pump and it is 4 again! I am like… 'right!' But then, it depends as well when you feel it. Well I don't feel it but I know if I am below 4, it needs to be treated pretty quickly. So this beeps now at 4.2 to say, 'Right Ash, you are on the way down… go and do something!' But I think 3.5, oh… I don't know! I mean sometimes I can get to, like my libre will say I am 3.whatever… and I will go thats not right! It happened today - I tested and then it said I was 3.3, like okay… didn't feel that one! Then other times I feel a bit low when I am 4.3!

65 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 diabetics that dont understand" suggesting that education should be targeted further toward those with the condition instead of DAPHNE programme as misconceptions/ confusion still arise

66 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! the CGM.

idea of the community aspect, its quite important or reassuring to know that other people are in the same position or have had similar experiences. Yeah! Mhhh! Thats at least what I am understanding from the conversation. Uh huh! A lot of resonance and shared understanding from these experiences… it must make you feel better about your self and your self-management! Yeah, I think so. Connecting to people. I think knowing what the stimulus is for something, like your saying… some people can tell you the symptoms of a condition but where it starts is just as important! And the impact of it too, whether thats sleep or stress. Or heat! Yeah! Time of the month. Everything! I think its quite nice to sit and listen to you two girls speaking! Absolutely, I feel the exact same… this feels like an intervention in itself to bring you together. Because I never hear Anna speaking like this… and your mum and dad would probably say the same about you! Probably not, and its mainly because I have never lived at home with it… Mmmmh! So when I was diagnosed, obviously I was in hospital for 5 days, 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 my blood and she would go, 'What is it? What is it?!' Like calm down… Mmmh! 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, like I could go to sleep just now and she would be able to work injections. Like a few months ago, my dad said he was going to do a 'first aid at work' course and asked, 'dad, what would you do if I was hypo?' He was like, 'Erm…' Hmmm. 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! And that more than worried me, that really annoyed me! I was like, I have been diabetic for 4 and a half years… and you are my dad! He doesn't fully understand it then. Mmmmh! My mum would be like, 'Right, I know how to test your blood… give you lucozade.' And I think to interview him in this similar situation, he may not understand what your going through from his own perspective. He might see it as thats your mums job. Or a personal thing!

Because thats what I had with my mum and now what I have got with Simon. Its things like, I can't physically put my CGM on my arm. Why can't you put it on youself? Because its a clunky thing to put on… And the area. Yeah, but you usually wear it on your belly. But I have been going to a wee anti-natal swimming class and I can't be submerged in the water for that long. So I have been putting it on my arm and thinking, well Simon could help me do it! So its things like that where, it becomes both our responsibility. Its nice that its not just me that has to worry about it. Its… 'Joint-management?' Yeah, I was going to say… I suppose we take care of different parts of it. But I think that was really nice as well because Simon has seen Anna warts and all. Yeah! True love. And I think thats a big thing because quite frankly if it was one of my sons that had a diabetic girlfriend… i'd say, 'pff… walk away!' I hope you wouldn't say that now! Uh huh, I absolutely would! Would you?! Absolutely I would! Completely, I know… I think its because you know Sean and Barry, and my brothers would take it on as their own personal… 'Crusade' if you like! Uh huh! But Simon has seen Anna warts and all, his mum is a dietician so she is well aware of the situation and to me it demonstrates how much he really really loves her. Ahh thats so lovely! I wasn't expecting this kind of chat… Me neither! Its very deep! It is true but I think when you are looking at other relationships, whether it be mother and child or husband and wife… Its that situation map! Uh huh! Its the DSN, family… Its whose condition is it? I think its a much much better world nowadays for everything. Yeah I would agree with you. Equality, race… these things should have been out the water years ago! Do you know what I mean? Yeah! And its education, thats all it is, education! I definitely do think its how could we educate better…

67 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 centre, with those seminal to self-management, like family, close friends and diabetes clinic at the periperphy to educate and inform the wider public about the reality of being Type 1 and inspire positivity towards the condition.

68 Relational: 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.

I think as well the empathy aspect of it, I think why it has came up is that its a new way of people to understand a lot deeper. Mmmh! You know a really good thing they used to do in Ninewells 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 3 days they would have to put the tape on them and understand where do you put your yo-yo? From an empathy perspective thats 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 50 pence. 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… Its the same when we done a project with RNIB, and they gave us sight altering glasses to experience what its like to be visually impaired. And wearing them for 5 minutes, even just the cataracts, was amazing! Bet it was terrifying! Terrifying but you could empathise with them and respect! It went from poor them to you are fucking amazing! Yeah! I could barely walk a short distance without panicing… 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 quadruple amputee. Wow! She contracted sepsis 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 my hands to see if I could emulate it… Uh huh! But I had so much admiration for her!

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69 *Relational: 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.*

70 *Trust: Discussion around the 'softer' periphery of provotype and insight that those who contribute to self-management can bring. Interesting story regarding mothers instinct that daughter was hypo before operation, her gut instinct may have saved her daughters life (and even changed protocols)*

I think the way it could be quite easily done is that you have social media and networks as the wider periphery, then this group who know, or are affected by diabetes... maybe people who have experience? Mmmh! And I think that is a resource that is just not used! I think there is now a 'mums of type 1' facebook group... but I think we concentrate on the individual, and we call them an individual, but actually they are part of a family or group - I mean we are habitual beings, and communal beings as well! What we have for dinner affects... Yeah yeah! So I do think its looking at the 'softer' periphery. Absolutely and I think that is going to be an outcome of this in general - the periphery. That self-management is more than the self... Yeah, your knowledge base to exploit there is huge! Exactly! I am quite glad as that does prove that the earlier work... See if I hypo, so I dont sense hypos but my mum probably has a better hypo awareness than I have... of me! Yeah! Because she will know that I do that funny wee thing... like your husband will know. He woke me up the other night, saying you are breathing funny and I tested fine... so I must have just been snoring! So thats something of your technology that he doesn't know. Its their experience of you kind of thing, it shows how much they understand... I put the word 'insight' there, but they really deeply understand you! Uh huh! If you know someone inside out. But that can be like parents really, trust your gut! If the doctors say just test them 4 times day but actually just get them to do 6, you know its things like that where the knowledge is so key! See when you spoke about that thing, the sliding scale. Do you know what that is? When you are on... Its like being on a pump actually. Sorry, I never really knew that. The background insulin and glucose in the other. So they get you to a point, where say you are 5... then they can operate. Right okay. They can balance you out. So they had a protocol for that across Britain, when you got to 5... keep going to the theatre to operate, you could be on the table for 10 hours even because they are on this scale. So when Anna was a wee girl, she was having an operation and they said to me whether I wanted to go down with her. And I said 'uh huh.' And I went right into theatre with her and they were just about ready to go and I said, 'I am really really sorry but I cant give you permission.' It was before they were about to put me under. And they said, 'why not?' And I said because she is hypo! And they said, 'thats ridiculous, she is on a sliding scale... thats not possible,' I said... 'I am really sorry but unless you test her blood... I can't.' And let me see. And she was hypo! But they had to give me pure sugar as they vein just went. Oh gosh! So how did you know? She just did. So in Britain, they had to change the protocol... and what they said is they didn't factor in adrenaline. Ahh! And its the extra context, I was going to say beyond medical, but you just understand a lot more... it gives you that instinct. Thank goodness you went down with her! Yeah, yeah! The anesthtcist was really upset... Because she said she would have killed her! Really? Thats terrifying!

But where would our provotype intervene? What could it change for an alternative now? Mmmh! She probably doesn't really know any other type 1's... on all these gadgets I would say. Absolutely!

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 preference be set and agreeable between people, especially close relationships?*

sure, maybe not on the one she uses but with technology maybe it would be useful if you could silence who can see them. The texts to your mum? Yeah! Because I read there that she is going back to her blood glucose meter, but really if she could put onto a Libre or whatever... she would be getting that graph that would be useful for her! But if she could silence it so her mum is not getting all they alerts. So its the preference idea! Also you get to choose who gets your data? Yeah, rather all or nothing! Exactly! So choice of data receiver

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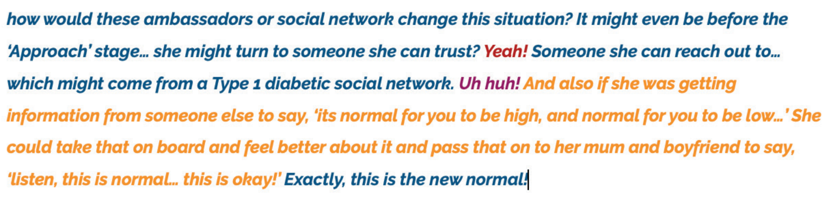
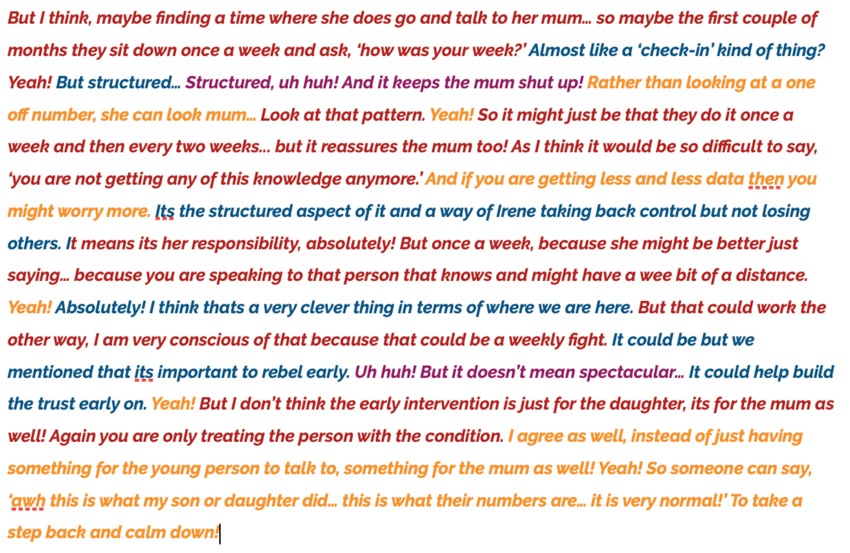


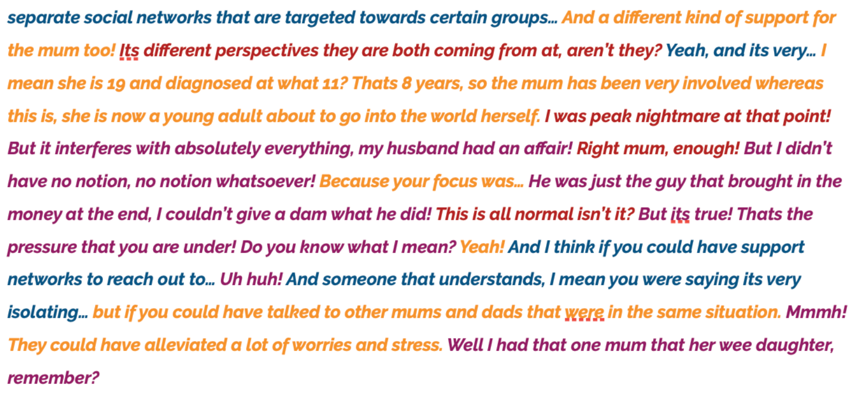
how would these ambassadors or social network change this situation? It might even be before the 'Approach' stage… she might turn to someone she can trust? Yeah! Someone she can reach out to… which might come from a Type 1 diabetic social network. Uh huh! And also if she was getting information from someone else to say, 'its normal for you to be high, and normal for you to be low…' She could take that on board and feel better about it and pass that on to her mum and boyfriend to say, 'listen, this is normal… this is okay!' Exactly, this is the new normal!

__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.



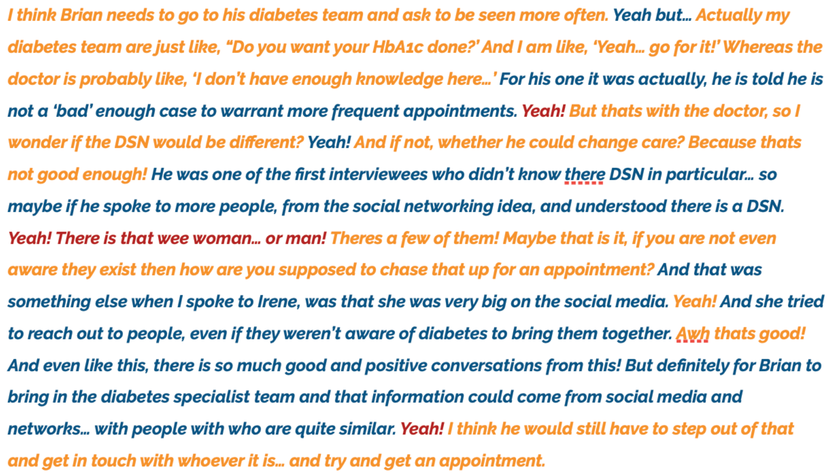
But I think, maybe finding a time where she does go and talk to her mum… so maybe the first couple of months they sit down once a week and ask, 'how was your week?' Almost like a 'check-in' kind of thing? Yeah! But structured… Structured, uh huh! And it keeps the mum shut up! Rather than looking at a one off number, she can look mum… Look at that pattern. Yeah! So it might just be that they do it once a week and then every two weeks… but it reassures the mum too! As I think it would be so difficult to say, 'you are not getting any of this knowledge anymore.' And if you are getting less and less data then you might worry more. Its the structured aspect of it and a way of Irene taking back control but not losing others. It means its her responsibility, absolutely! But once a week, because she might be better just saying… because you are speaking to that person that knows and might have a wee bit of a distance. Yeah! Absolutely! I think thats a very clever thing in terms of where we are here. But that could work the other way, I am very conscious of that because that could be a weekly fight. It could be but we mentioned that its important to rebel early. Uh huh! But it doesn't mean spectacular… It could help build the trust early on. Yeah! But I don't think the early intervention is just for the daughter, its for the mum as well! Again you are only treating the person with the condition. I agree as well, instead of just having something for the young person to talk to, something for the mum as well! Yeah! So someone can say, 'awh this is what my son or daughter did… this is what their numbers are… it is very normal!' To take a step back and calm down!



separate social networks that are targeted towards certain groups… And a different kind of support for the mum too! Its different perspectives they are both coming from at, aren't they? Yeah, and its very… I mean she is 19 and diagnosed at what 11? Thats 8 years, so the mum has been very involved whereas this is, she is now a young adult about to go into the world herself. I was peak nightmare at that point! But it interferes with absolutely everything, my husband had an affair! Right mum, enough! But I didn't have no notion, no notion whatsoever! Because your focus was… He was just the guy that brought in the money at the end, I couldn't give a dam what he did! This is all normal isn't it? But its true! Thats the pressure that you are under! Do you know what I mean? Yeah! And I think if you could have support networks to reach out to… Uh huh! And someone that understands, I mean you were saying its very isolating… but if you could have talked to other mums and dads that were in the same situation. Mmmh! They could have alleviated a lot of worries and stress. Well I had that one mum that her wee daughter, remember?

__75__ Trust/Educational: Idea of seperate social networks towards targeted subgroups of the Type 1 diabetic community, such as parents with diabetic kids and teenage diabetics, to reach out to 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.



I think Brian needs to go to his diabetes team and ask to be seen more often. Yeah but… Actually my diabetes team are just like, "Do you want your HbA1c done?' And I am like, 'Yeah… go for it!' Whereas the doctor is probably like, 'I don't have enough knowledge here…' For his one it was actually, he is told he is not a 'bad' enough case to warrant more frequent appointments. Yeah! But thats with the doctor, so I wonder if the DSN would be different? Yeah! And if not, whether he could change care? Because thats not good enough! He was one of the first interviewees who didn't know there DSN in particular… so maybe if he spoke to more people, from the social networking idea, and understood there is a DSN. Yeah! There is that wee woman… or man! Theres a few of them! Maybe that is it, if you are not even aware they exist then how are you supposed to chase that up for an appointment? And that was something else when I spoke to Irene, was that she was very big on the social media. Yeah! And she tried to reach out to people, even if they weren't aware of diabetes to bring them together. Awh thats good! And even like this, there is so much good and positive conversations from this! But definitely for Brian to bring in the diabetes specialist team and that information could come from social media and networks… with people with who are quite similar. Yeah! I think he would still have to step out of that and get in touch with whoever it is… and try and get an appointment.

5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

He said, 'He is not the worst, but definitely not the best neither.' And I think there is a kind of tendency, see instead of asking like, 'how are you managing to do okay?' And then they say, 'I am testing 17 times a day…' But sometimes that comes out that you are being too hard on yourself, it can actually… And thats where I went wrong. What you mean testing a lot? No, Anna's HbA1c was 5.2. That means nothing to me because I use the new way. Well 5.2, I would be 5.2… That means if they did an HbA1c, they wouldn't know she was diabetic. What they told me is that 'you are wonderful, absolutely fantastic…' no, I was too controlling! Do you get what I mean? Mmmh! But only by a fear. So what they are doing is just looking at a number! See if she was hypo all the time, that would make sense… but if you weren't then. But only by a fear, because her grandfather was blind and had no legs. So can you understand that? Yeah! You look at it from a different perspective… Its like everything else though, hindsight is a great thing isn't it? But I do think thats whats happening here, is that his doctor is thinking, 'here is my 70 type 1 diabetic patients, you are sitting in the medium.' So your fine? 'You look healthy, absolutely fine…' he needs to come in at least twice a year! They are focusing on the numbers too much! Its that, 'I have worse patients' kind of thing. And what Brian is saying is that he is not the worst but not the best either. I do think he needs support from somewhere else, the diabetes specialist nurse that can say, 'Come on in and we will do your HbA1c… I will help you get it better' and when he sees results in 3 months time then he will be spurred on! Because there are some DSN's who would go above and beyond. Absolutely! Mine do, I can see mine anytime I want! I have heard of people who text their DSN. Awh! But its the kind of thing if he only sees his doctor once per year for his diabetes… I mean its different doctors! Yeah! So there isn't really a continuity or a route to empathy there. Or a relationship is there? So you could fit it there, building a relationship, that he trusts. Yeah! And that changes the whole situation. Yeah yeah! Because it becomes much more regular and then when he sees results in his HbA1c, he will be better self-managed…

77 *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.*

78 *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 wont be able to learn and understand how to use device as intended.*

See by the sounds of that as well, it sounds like every time she puts a new sensor on that her daughters need to help her. Yes, it was! So, really she needs training! Yeah! She needs education. Yeah! I know but maybe she is using it in that way so that maybe she sees her daughters as well, no? Thats interesting… I didn't think of that at the time. There you go! Yeah! Because she is obviously missing her sister, I mean it depends if whether she was on social media or not but something like that would maybe help. Yeah! Because she did look up forums, thats what he daughters got her into. Got into what sorry? Forums online so she could speak to people. Ahh right okay! And it was from Diabetes Scotland. But again the missing daughter aspect… Maybe she wants to replace the company of the sister? Yeah! It was the closeness of her sister, as when they grew up she mentioned how they shared a blood glucose monitor between them, so they used to care for one another with the strips and things like that. Can imagine trying to keep track of each daughter? Can you imagine being the mother? Thats probably why! She mentioned that when their mother past away, they had to keep very very close… but then one got a job away in Australia. Ahhh… Australia but yeah! Thats probably it, its probably a companionship issue! Its that companionship for sure. Wait, is it that she was extremely lucky, or you know, that was a fortunate thing of that very unfortunate event. Yeah! We are both type 1… But then there could still be a chance that she genuinely doesn't know how it works. That was the key thing there, I think from better education and demonstrations she could have… Yeah! But she just went to her GP and was recommended a Freestyle Libre, without even having the right phone… she said she originally had an iPhone 5 and it only worked with iPhone 6s and above. Well thats funny because I had to do an online course after having it, from self-funding when I was pregnant, I had to do an online course to get the prescription… and I dont know if you are the same, oh you dont use the Libre anymore, but then we had to go to a theatre in the hospital and listen to a GP saying, 'if you dont use this, and if you dont use it properly… this is all the complications of diabetes.' And we were like, 'we know this… please just give us the sensors!' Horrible! I know! And from that, if we are focusing on numbers, up to 90% of people with long term conditions like COPD can misuse their device. Mmmh! Ohh! Really? But I also think, see the education… we all work in education and you can't teach everybody the same! Exactly! True. And not everybody wants to learn either!

Nightmare! Right, so okay PECOS is a system that administrators would use to order paper clips, office supplies! Okay so we got an email out NHS Glasgow saying, 'You now need to order your pump supplies on PECOS.' Okay… On what? Rather than doing what? What would you normally? Medtronic, you get to speak to a person and say, 'Hi Ross, I need this… my battery is running a wee bit low' - 'Ohh no problem, I will pop in extra batteries in your order.' Humans… right! So, I was horrified…. they sent out this pack. One it presumes that everybody has access to a computer with internet. And knows how to work it! Yeah, postcode lottery and a certain section of the population now can't do it. That would be me! 25% of the Scottish population are 'digitally illiterate.' Uh huh! Really? I would say I was! That surprises me. That goes across many things, from not being able to send an emails… which I know in particular because I have to send my mums! But it's those little things where this mismanagement becomes a reality. Correct! Especially when Scotland is pushing to be one of the first ever 'digital nations' by 2025, by speeding up the transition to digital services… who gets left behind? But what they also wanted, so the demonstration they gave you… they sent out slides and it told you how to order paper clips! Okay, so what this did… if I was 19, if I was Irene right now… id be like see - the doctor is describing my insulin like a paper clip… and I dont need a freaking paper clip! And the fact of that supplier… its like getting your medicine from Staples. Aye! Correct, its absolutely horrendous! So the message it sent to me, is that your ordering basic office supplies… Get your insulin from Amazon next! Aye, absolutely! And it doesn't give you feedback, so I go in and the only reason I can use it as my secretary can use it! And I am like, 'Hey Maxine, can you show me how to use this?'

79 *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.*

80 *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.*

and I am having to explain everything on the phone, nightmare! When they could just take it directly from your device! And see if I wasn't so proactive in phoning them or confident to talk to them… see if I was an older person who doesn't want to speak to somebody, I would think 'do you know what, I would go a couple of weeks without a sensor!' You would, yeah! Until my prescription catches up… lets just not bother, its not worth it! But sometimes I phone up and they could not be more helpful - brilliant!

5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

Erm I would say when it comes to your Abbott's and Medtronic's is understanding that the person you are talking to is managing their condition. Daily, on their own! Yeah, and actually, reading out the instructions… it doesn't help! So Medtronic, for example… if I get a crack in my pump, which I usually do every 6 weeks because… Every 6 weeks?! Mine does! I had heard… No they are really really bad! So you phone up and they say, 'you need to disconnect and hand the pump over to the courier.' And I always say, I can't because when I set up a new pump, I basically have to sit with both the menus and transfer the settings one by one, like for like. Marry up your settings! So I say this to them, please can you give me the poly pocket bag and I will send it back at the post office… you will have it in a week - but I can't give it to the courier. They say, 'we can't give you a new pump now.' Yeah, what do you do then? Do you take pictures of settings or write it down? No, I just refuse to give them it. Okay! Point blank, refuse. Its a fight, and its a fight I am having every 6 weeks! But what I would like them to know is that there is a reason that I am asking for something. Yeah! That I am not just being a pain in the arse! No, totally… not doing this to cause a fuss. But in a way thats quite good for you as you were thinking, well if I was in that situation would I need to photograph… and Anna is saying just say 'naw!' And thats probably what I would do, if thats not an option to take pictures and go through it when I get it. So I would say that every request has a reason. I just put 'consider the users experience.'

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 *Relational: Consider users as a person rather than just a number or condition. Humanise services for the people who use them.*

Yeah! I am still me, I am a person! I think that is more for friends and things. And I am a person to companies. Where would you want to put those on the pyramid? I think quite high up… 'I am still a person.' Rather than just a number. Mmmh! So maybe a principle would be, 'dont numericise?' or… consider beyond numbers? I think using numbers as guidance. What number are we talking about here? HbA1c. Oh I meant when you phone a company, I am not a number… Just patient number 5? But yeah, I think… I agree with the HbA1c. So what I would say you are describing is 'humanising' the condition. Uh huh!

In terms of labelling that was something else. Yeah! I think taking away 'can't'… like 'you can't,' I think its more, I would need to think about it a wee bit more but saying 'I can't' do something is really bloody frustrating! Yeah! And it you could push it totally the other way… in response to 'can't' I have done a lot of things that I probably have pushed myself too far. Absolutely! I have to say I not experienced that to the same extent as you, as you have had that for a much longer time than me and gone through a longer period of growing up with that. But the one that gets me is when people say, 'you can't eat that!' Yeah, yeah! So if I am sitting saying I wasn't going to eat a piece of cake, but now I am just to prove you wrong! Get tucked in! And I think thats fundamental that you are proving them wrong! Yeah! Yeah! I think you may be acting out of character and acting more… 'bolshie' than you normally would be. Yeah because you get angry. Because you are trying to prove something! Like, you are not a dietician… even if you are that doesn't mean that you know everything! But you have no idea of what I am or am not allowed… And what your capabilities is as well. Like you dont know what I have to deal with in order to eat something, so dont tell me what I can and can't eat! Absolutely. Sorry! I got a bit carried away… But I would take away the 'can't' to understand it is more about that this takes more thought… Consideration? And planning!

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

84 *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.*

multitask… Like even from the numbers you were throwing out today, I have learned so much from your guys today! And I dont think I will look at certain foods again without considering carbohydrate grams… I think you have so much strengths! Yeah, but my mum can predict that an irish dance and what effect thats going to have in 3 days. Mmmh! Better than anyone because sometimes its not the immediate low of the blood sugar… its like 2 days later you are hypo! I have got to say, I am really lucky because when I run, its like half an hour to 40 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! Erm and what you're saying about multitasking, I was crossing a road today and testing my blood sugar at the same time… like yeah yeah! In meetings I will quite often just adjust my pump and people are like, 'sorry we will stop' and I am like 'no, no… keep going.' I can listen! Or the fact that you can do that 'how much am I eating, 7, 6 right…' Although, I have got to say that I have gotten really lazy and started asking Alexa! I am like… 'Alexa… I can't do 17 divided by 100, multiples by 14, and add on…' once I have weighed it and she tells me. I am getting so lazy… even just counting!

5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

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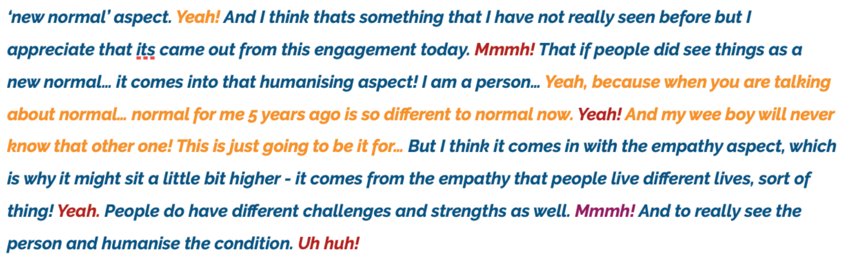
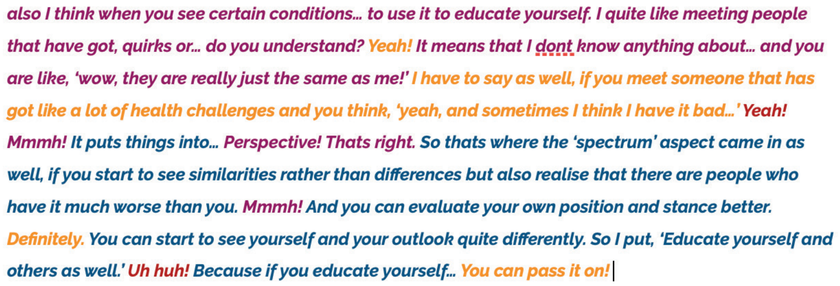


'new normal' aspect. Yeah! And I think thats something that I have not really seen before but I appreciate that its came out from this engagement today. Mmmh! That if people did see things as a new normal… it comes into that humanising aspect! I am a person… Yeah, because when you are talking about normal… normal for me 5 years ago is so different to normal now. Yeah! And my wee boy will never know that other one! This is just going to be it for… But I think it comes in with the empathy aspect, which is why it might sit a little bit higher - it comes from the empathy that people live different lives, sort of thing! Yeah. People do have different challenges and strengths as well. Mmmh! And to really see the person and humanise the condition. Uh huh!

85 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.

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.

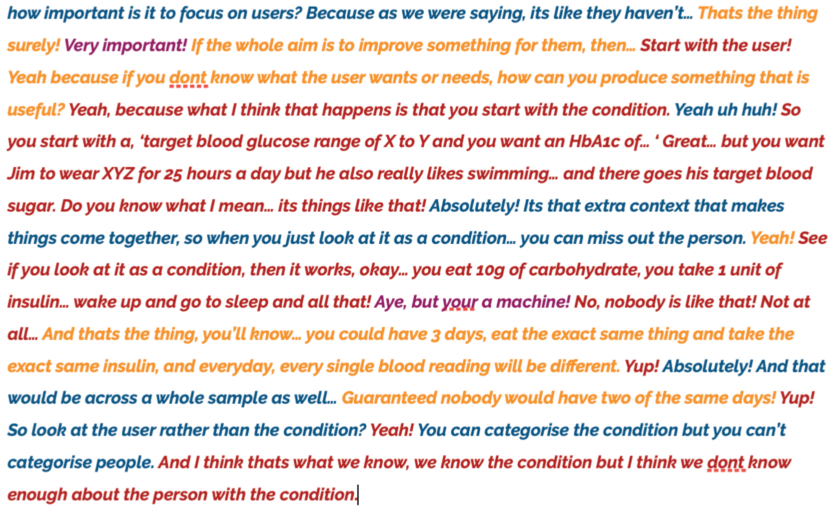


also I think when you see certain conditions… to use it to educate yourself. I quite like meeting people that have got, quirks or… do you understand? Yeah! It means that I dont know anything about… and you are like, 'wow, they are really just the same as me!' I have to say as well, if you meet someone that has got like a lot of health challenges and you think, 'yeah, and sometimes I think I have it bad…' Yeah! Mmmh! It puts things into… Perspective! Thats right. So thats where the 'spectrum' aspect came in as well, if you start to see similarities rather than differences but also realise that there are people who have it much worse than you. Mmmh! And you can evaluate your own position and stance better. Definitely. You can start to see yourself and your outlook quite differently. So I put, 'Educate yourself and others as well.' Uh huh! Because if you educate yourself… You can pass it on!

a new experience to share? Erm, I wouldn't say to share my experiences… but to share them in this environment yeah! Uh huh! And looking at it from a design or research perspective… Definitely new for me! Yeah, I guess for me it is new to focus on it, I suppose. I mean, I have had conversations with other type 1 diabetics but they… And showing it as well. Yeah, yeah! I mean hands up, I have never spent a three hour workshop… you know! So that has been a new thing for me! But I think thats how you get things done!

87 Education: Participatory methodology/approach was not a new experience for participants but design led process was, "i think thats 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 dont 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."



how important is it to focus on users? Because as we were saying, its like they haven't… Thats the thing surely! Very important! If the whole aim is to improve something for them, then… Start with the user! Yeah because if you dont know what the user wants or needs, how can you produce something that is useful? Yeah, because what I think that happens is that you start with the condition. Yeah uh huh! So you start with a, 'target blood glucose range of X to Y and you want an HbA1c of… ' Great… but you want Jim to wear XYZ for 25 hours a day but he also really likes swimming… and there goes his target blood sugar. Do you know what I mean… its things like that! Absolutely! Its that extra context that makes things come together, so when you just look at it as a condition… you can miss out the person. Yeah! See if you look at it as a condition, then it works, okay… you eat 10g of carbohydrate, you take 1 unit of insulin… wake up and go to sleep and all that! Aye, but your a machine! No, nobody is like that! Not at all… And thats the thing, you'll know… 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. Yup! Absolutely! And that would be across a whole sample as well… Guaranteed nobody would have two of the same days! Yup! So look at the user rather than the condition? Yeah! You can categorise the condition but you can't categorise people. And I think thats what we know, we know the condition but I think we dont know enough about the person with the condition.

5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

Full transcript available to read transcript in Appendix E1

So bouncing ideas around or? Yup! Yeah because I think, you know if Anna said something then it triggered something with myself… Yeah! Even the controversy when one of your disagrees… that is how you design because thats the interesting bit as to why you disagree… Mmmh! That conflict leads to true insight… Yeah there is no binary answer to it! Yeah! Exactly! And not everyone is the same! There you go, no binary answer! Yeah!

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 provotype, from an early stage concept and design direction participants approached user journeys well and could problem solve. Interesting reflection: "its reassuring to think that these types of conversations happen. Again, its not just the condition, you know…" suggesting that the person gets ignored/forgotten when considering people with long term conditions.*

outcome of this workshop was valuable? Even with making a provotype, very early stage concept… did it make you think differently? Absolutely! To then go onto user journeys to see how it could intervene… Do you think you would go away thinking a wee bit more about this? Definitely! I think its reassuring to think that these types of conversations happen. Again, its not just the condition, you know…

Do you think it could inspire change… in others? Absolutely! Its how you project it… Communicate it! Yeah. And how you implement it? Yeah. And I think it would take some time. Yeah. Everything does! Absolutely, but I think it will be small changes that will inspire big changes later on. Mmmh! But I can definitely see in the next few years you will see these devices become a lot more problematic as your control of them gets taken away.

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… well 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 'provotyping' and such… Mmmh! But I did want to try and make the workshop about thinking differently… because people dont 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 here that, I feel very positive as well! And Anna 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 its great, its really good! Mmmh! Any type 1 pregnant women, I am like… But the chances of that happening were. Ano!

5.2 Thematic Analysis Coding

Participants: Ross, Emma, Anna, Jean

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But you have to be careful as a lot of these social media groups are for people to either moan. Which type 1 is a moaner. Mmmh! Which when we are taking about social networking groups, I am so glad Mum that you are not part of a social networking group! Oh really? Like when my mum was managing my diabetes because it was like Mumsnet! Oh right! Everybody has got an opinion. Like they will talk about 'organic' avocados as being much superior… oh and the chinese herbalist has been telling me I can grow my own pancreas! And that was the way I was… No I dont think you've been like that but i think what it does is, when you are learning the basic facts of something… you dont need so many thousands of sources. And voices at once. Its the kind of DSN… And build your way up. Absolutely! When she was diagnosed, I had a week… like 40 hours of a consultant and me. Really? Thats so full on. It was in the hospital. Thats why I wasn't allowed anything for weeks, weeks and weeks because they built it up week by week. One week was exercise, then next alcohol, then snacks… A whole week 9-5! Intense course. Aye! Textbooks… Textbooks, homework… the lot! But then I think if you added that… because what you automatically would have done is google it! Yeah! And go on facebook… I mean when I was diagnosed, I was getting articles from friends saying, 'have you tried this cure?' Like, 'If you have this special cabbage' Owhh! Do not send me that stuff! My granny is like that! Aye 'my granda had it, lost his feet and died at 40…' delete! Dont send me these! Not a very good perspective but there was also a care order on us for a month. What does that mean? It meant, when I went the following week with my wee diary… if I had made so many mistakes they would have taken her into care. Social services. Really? I dont know if that happens now? I hope it doesn't! But you can understand that… because if you didn't know what you were doing. And it was for every child, didn't matter who you were, doesn't matter if it was a consultants child that was diagnosed for the care order… its a safety net! But could you imagine the pressure that put you under? Absolutely! Just more worry and stress! So I think there is a happy medium about the social networking.

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.*

my heart always thinks, when you see on the facebook page, someone will come on, 'my wee boy has just been diagnosed this morning with type 1 diabetes…' Get off your phone! Go and get sleep! Mmmh! Gain some perspective. And dont be asking Jimmy, who doesn't leave his computer, sitting… Waiting for someone like you. He is just a type 1 diabetic, he lives and breathes… and there is a lot of them who just, thats all they do! All they do is be diabetic. And you are like… 'Argh!' Go and try and have a wee bit of a life! You will probably enjoy it… Uh huh! And you are more than just your condition. Yeah! And I think you guys are living proof of that! So I think its a happy medium… which is hard to do!

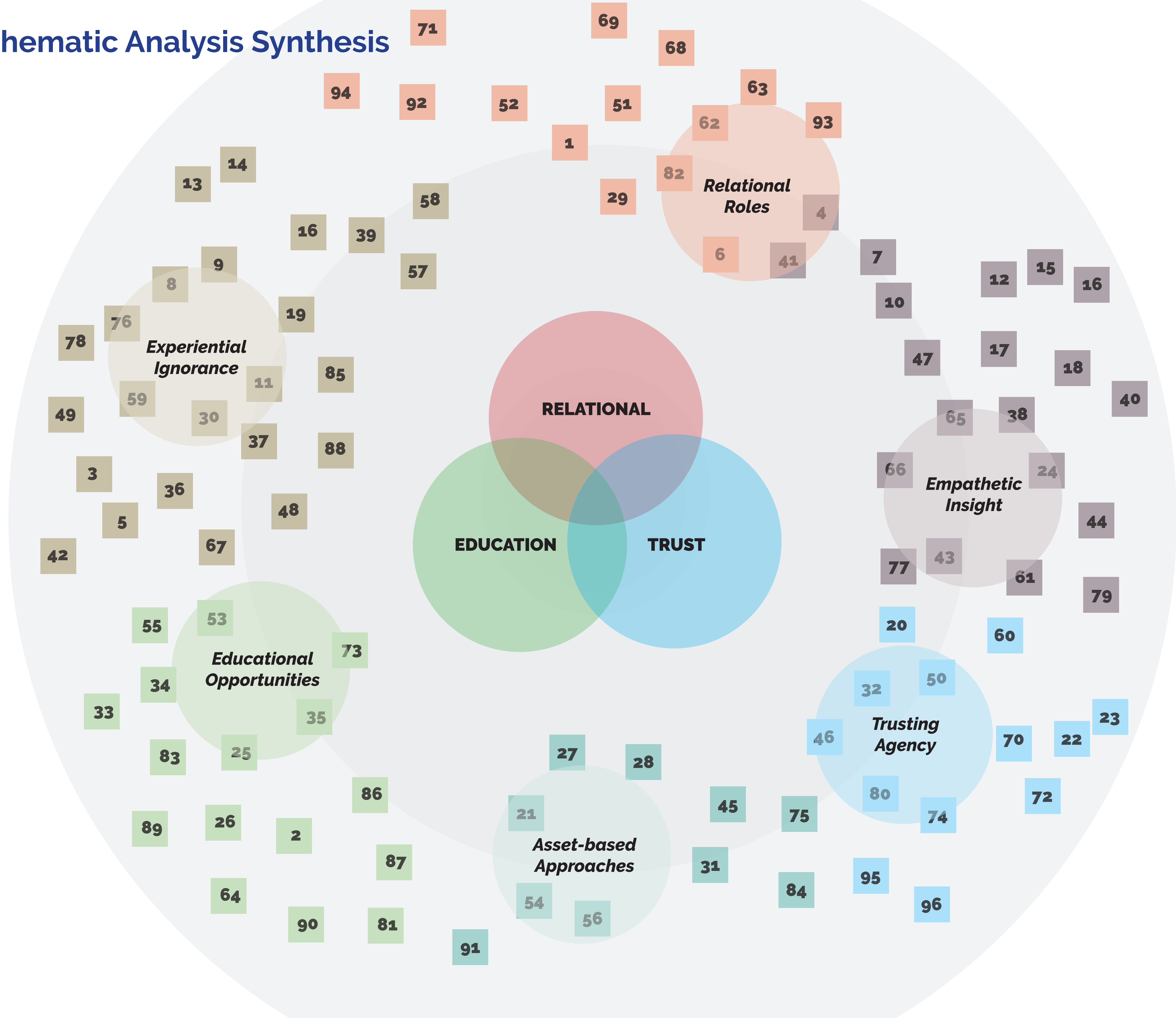
So would someone be monitoring your devices all the time? That was the key issue with this… when we were talking about ethics. Yeah! Pressure… Big brother is watching you! Also from a kind of, what's the word I am looking for… staffing perspective? Ohh so it was an artificial intelligence and cloud based 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 low. 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 scares me a wee bit! Somebody having access to everything. But for some certain people… it may be their preference - Linda for example from the user journeys! 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. Mmmh! I think there is certain sections of the community where that would be very very useful. Or maybe times in your life, like if you do just have a baby… sleep deprived and dont have the time… The target audience was people who misuse, or overuse… well there is not a proper phrasing 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. Yeah!

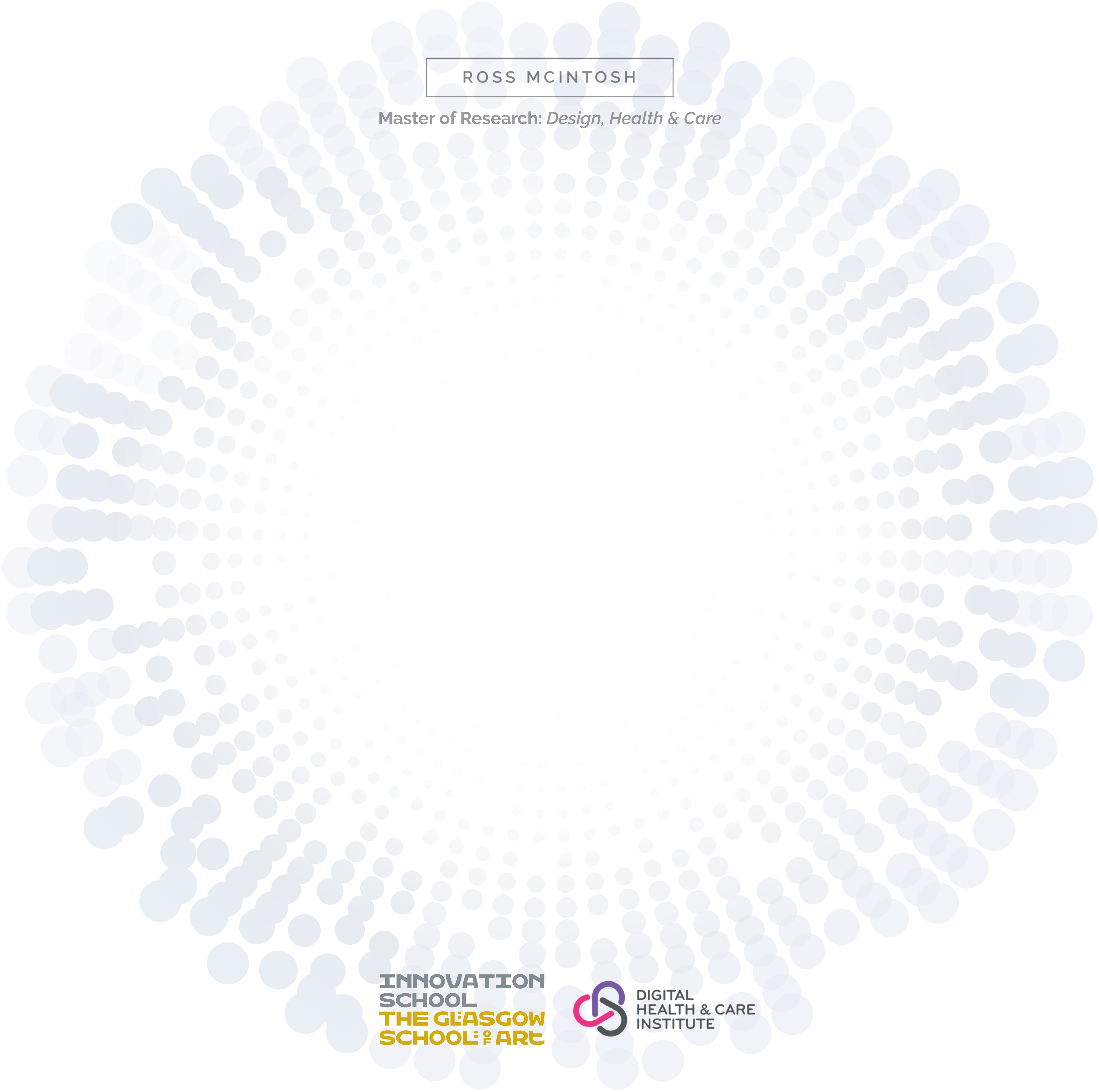
95 *Trust: Pitching previous project for feedback and participants were concerned with being monitored "all the time" and scary "somebody having access to everything" However suggested that for certain users, like Linda, this concept could be preferable.*

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.*

'what if you could give consent to your data…' but it centred around a preemptive care strategy and enabling prevention… Because I am very much, and I have said to my consultant… 'take all my data! As you wish'… but more in retrospect, if that makes sense! So when I am at a clinic appointment and he says, 'Oh thats quite interesting' this or that… but I feel then he is explained to me why he is using it and why it is interesting. What it will be used for… And I have agreed what it will be used for! So I think you need to be very clear, particularly to Irene… And your mum!

5.2 Thematic Analysis Synthesis





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