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Master of Research: *Design, Health & Care*

SELF-MANAGEMENT BEYOND THE SELF

*Participatory design practice
towards preferable diabetes
self-management principles*

MRes Research Project
Practice-based 9,549 word Thesis

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January 2019 - January 2020

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Abstract

This practice-based research project explored how participatory design practice can help discover the barriers and facilitators of digital self-management devices, to reveal preferable user-centred design principles for long term condition innovation. Participants with type 1 diabetes were recruited as a contextual vehicle for this inquiry, due to the symbiotic relationship that those who self-manage this condition have with their digital self-management devices: like a flash/continuous glucose monitor and/or an insulin pump.

Participatory design methods were adopted to conduct semi-structured interviews to understand the lived experience of using self-management devices, as well as an interactive situational mapping activity to discover relationships beyond each user - which resulted in a synthesised stakeholder relational map. Then a collaborative participatory workshop featuring generative activities; relational map validation and co-analysis, *what if* provocations and *provotype* generation, and *alternative now* contextual interventions - towards the co-creation of self-management design principles.

From situational and thematic analysis of the six interactive interviews conducted and a participatory workshop with three users, the following self-management principle findings emerged; *self-management relations go beyond a singular user and their devices*, *self-management trust needs to consider the holistic user experience* and *self-management education and experiential insight is key*. This research concluded by reflecting on how the participatory design process helped drive user-centred design innovation - which was evident in the principles delivered as they respond to participants suggesting that relations, trust and education beyond the end-user have not been fully considered within the design of current self-management products and services. Therefore, participatory design approaches can help develop preferable relationships to digital self-management practice for users with long-term conditions and consider how self-management support systems could be transformed, collaboratively with users, towards preferable futures.

Key Words:

Participatory Design (PD), Self-management, Type 1 diabetes (T1D), User, Device, Relationships

Acknowledgement

Firstly, I would like to thank all my research participants for being so open, honest and generous during their interactive interview sessions and contributions to the participatory workshop. In particular, I would also like to thank Diabetes Scotland and the *Type 1 Diabetes in Scotland* group organisers for their help in participant recruitment.

Furthermore, I would especially like to thank my MRes supervisors Madeline Smith and Dr Cara Broadley for their encouragement, support and guidance throughout this research project. Alongside the other academic research staff who have delivered the taught elements of the MRes programme, in particular I would like to thank Professor Lynn-Sayers McHattie and Dr Marianne McAra for their input during the MRes seasonal schools. I would also like to thank the Digital Health and Care Institute (DHI) for their studentship opportunity and NHS 24 for their User Research work experience and industry exposure alongside my studies.

As for my holistic learning experience over the past six years studying BDes (Hons) *Product Design*, MDes in *Design Innovation and Service Design* and now an MRes in *Design, Health & Care* at GSA - I would like to thank all the undergraduate and postgraduate staff throughout the Innovation School who have contributed to my development as a designer, reflective practitioner and now as a researcher. Lastly but not least, I would like to thank my fellow MRes students, and especially my full-time MRes partner Christopher Wild, for their companionship and support throughout.

Declaration

I declare that this submission of a practice-based 8,000-10,000 word thesis and portfolio of practice meets the regulations as stated in the course handbook in partial fulfilment for the degree of Master of Research (MRes) with DHI studentship. This submission is my own work and has not been submitted for any other academic award.



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December 2019

Presentation of Practice Statement

This practice-based 8,000-10,000 word thesis is submitted with a portfolio of practice. Both documents are to be read alongside each other as indicated to understand the involvement the practice had in this study. The relationship of practice will be further explained in the portfolio.

Throughout this thesis, when recommended that you read the portfolio of practice for additional contextual insight. You will be directed to the associated section using the key in Figure 1 through highlighted text and/or colour code that represents the chapter and section of the thesis, portfolio or appendix.

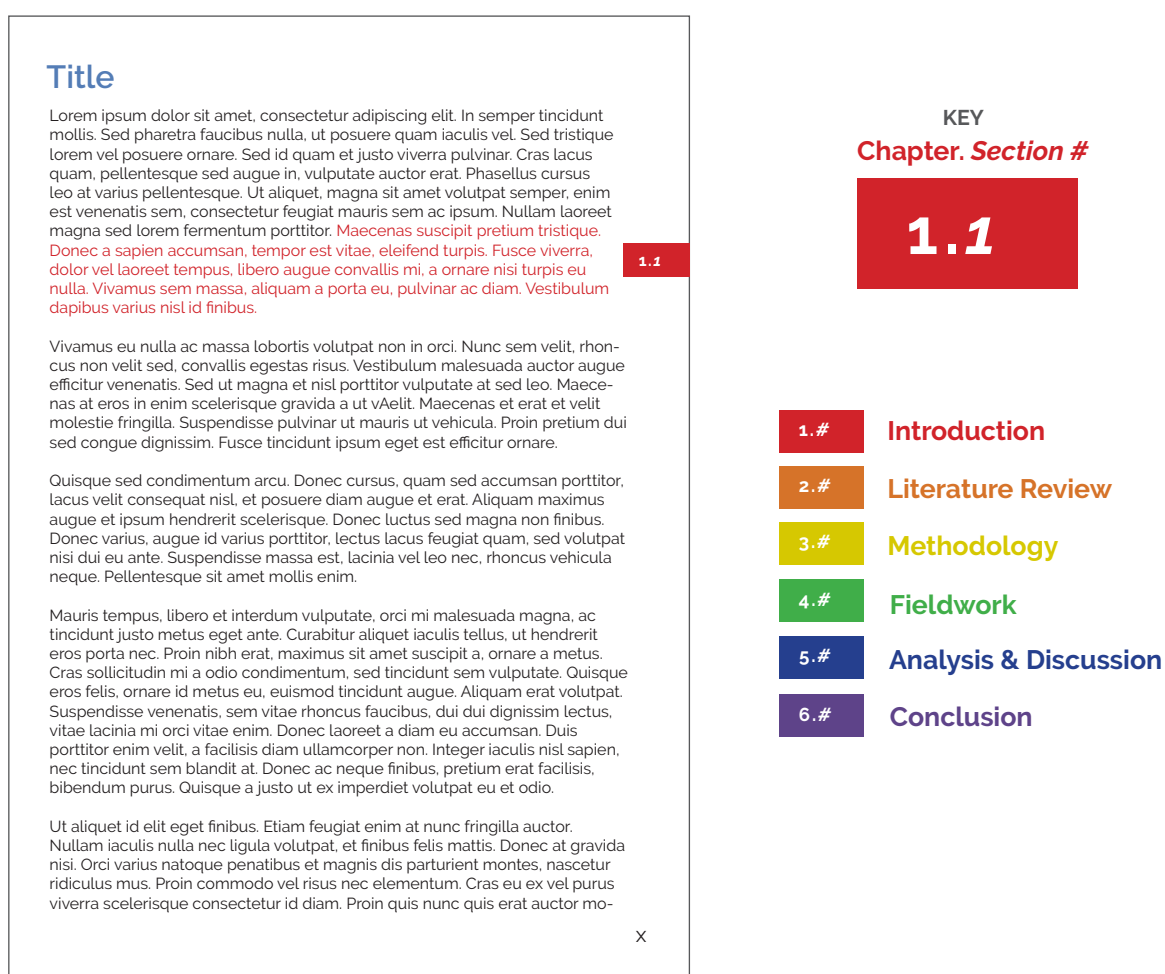


Figure 1: McIntosh, R. (2019) Graphic representation of how the thesis indicates to read a section of the portfolio of practice. Diagram. Source: authors own.

Preface: *Connected Community*

This MRes research project was inspired by my MDes Semester 2 *NHS 24: Alternative Now* live project proposal (McIntosh et al., 2018), the *Connected Community* initiative utilised condition-specific Internet of Things (IoT) health monitoring devices through new *Community Contributor* interface roles, to establish health-centred citizen communities towards an innovative pre-emptive care strategy to fulfil the Scottish Government's *2020 Vision* (2013: 3). This initiative was targeted towards frequent and *high intensity users* of NHS services, like those with long term conditions such as diabetes to prevent avoidable primary care admissions. Targeted citizens would be prescribed condition-specific IoT healthcare devices to provide consistent background condition tracking and localised responding. By accepting and consenting to using these connected monitoring devices, like blood glucose monitors for type 1 diabetes (Figure 2), *Connected Contributors* would have access to subscribed members health data through the AI-driven *Cloud Care* platform to monitor their condition-specific community remotely and react when pre-emptive intervention is recommended, before urgent or critical care is required, within home and community settings. This pre-emptive response could help citizens who would otherwise struggle to evaluate when to reach out for urgent or critical need. By anticipating and preventing these instances, NHS 24 and other NHS services can be better optimised.

Please read our groups newspaper that contextualises this MDes project outcome further:

<https://bit.ly/nhs24connectedcommunity>



Figure 2: McIntosh, R et al. (2018) Example of a diabetic *Connected Community* that share their health monitor data to a community contributor's monitoring device. Illustration. Source: authors own.

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Glossary of terms

Artificial pancreas is a human-made device that mimics the blood sugar function of a healthy pancreas through automating basal insulin delivery and alleviating some of the time and effort that goes into managing type 1 diabetes (JDRF, 2019). The most widely tested artificial pancreas is a *closed-loop insulin delivery system* that uses a CGM to measure blood sugar levels, and the result calculates how much insulin needs to be delivered by the insulin pump and the required dose is automatically delivered into the body, completing the cycle (ibid).

Blood glucose monitoring uses a portable *meter* device and disposable *test strips* that are used to measure how much glucose (a type of sugar) is in the blood (Diabetes UK, 2019). This method of glucose monitoring requires a finger prick of blood on a test strip that the device reads for a persons *blood glucose level*; people with diabetes should frequently test throughout the day (ibid).

Co-design is an act of collaborating *with*, instead of *for*, stakeholders as partners of the design development process to ensure the results meet their needs (Sanders and Stappers, 2008). "Co-design in a broader sense refers to the creativity of designers and people not trained in design working together" (ibid; 5).

Continuous glucose monitor (CGM) [or a Flash Glucose Monitor] is a small wearable device that is applied just under the skin to measure glucose levels continuously [or frequently when scanning a flash monitor] compared to the act of *finger-prick* blood glucose monitoring (Diabetes UK, 2019). The sensor sends reading data to a display device to provide real-time glucose level tracking that can help users make more informed decisions about how to self-manage their diabetes by alerting for high [hyperglycemia] or low [hypoglycemia] glucose levels (ibid).

Data as a general concept refers to the fact that some existing information or knowledge is represented or coded in some form suitable for better usage or processing (Diffen, 2019). Data is raw and unorganised facts that need to be processed and can be something simple and seemingly random and useless until it is organised, structured or presented to make them meaningful or useful as information which provides context for data (ibid).

Device is a *thing* or tool made or adapted for a particular purpose, especially a piece of mechanical or electronic equipment. Within healthcare contexts, a medical device is a manufactured product, instrument, apparatus, appliance, material or another article, whether used alone or in combination, together with any software necessary for its proper application to support diagnosis, prevention, monitoring, treatment or alleviation of disease (WHO, 2019).

Health monitoring [or remote health monitoring] is the process of using technology to monitor patients in non-clinical environments, such as in the home or community contexts. Such devices require a sensor which can measure specific physiological data and wirelessly communicate information to both the patient and healthcare professionals - remote monitoring is likely to become a core component of the preventive healthcare of the future (Edwards, 2018).

Insulin is a hormone made by the pancreas that allows the body to use sugar (glucose) from carbohydrates in the food that a person eats for energy or to store glucose for future use. Insulin helps regulates blood sugar levels from getting too high (hyperglycemia) or too low (hypoglycemia) and is also involved in the storage of fat (JDRF, 2019).

Insulin pump [therapy] is a small device attached to the body that continuously delivers amounts of rapid or short-acting insulin via a catheter placed under the skin and are seen as a better alternative to insulin injections as they reduce the need for multiple insulin jabs per day and give the user increased ability to control blood glucose levels (Diabetes UK, 2019). The user must change their insulin pump site frequently to ensure insulin is working correctly (ibid).

Intervention is the action or process of intervening directly or indirectly, through an orchestrated attempt by one or many people, to improve a person's health by preventing disease, by curing or reducing the severity or duration of existing disease (Smith et al., 2015). Interventions can be classified into two broad categories: preventive interventions are those that prevent the disease from occurring and thus reduce the incidence of disease, and therapeutic interventions are those that treat, mitigate, or postpone the effects of a person's disease or long term condition (ibid).

Internet of Things (IoT) is the interconnection via the internet of computing devices embedded in everyday objects, enabling them to send and receive data over a network without requiring human-to-human or human-to-computer interaction (Rouse, 2019). The definition of the Internet of Things has evolved due to the convergence of multiple technologies; artificial intelligence (AI), machine learning, edge analytics, automation, sensors and embedded systems to enable the Internet of Things (Hendricks, 2015).

Interoperability is the ability of computer systems or software to exchange and make use of information and to work with other products or systems, at present or in the future, in either implementation or access, without restrictions (Slater, 2012). Within healthcare contexts, interoperability is crucial because it ensures healthcare providers have the information that they need to provide adequate care (Forcare, 2017).

Long-term condition (LTC) [or chronic diseases] are conditions for which there is currently no cure, and which are managed with drugs and other treatment, for example; diabetes, chronic obstructive pulmonary disease, arthritis and hypertension. Transforming care for people with long term conditions, including support for self-management, requires comprehensive reform of health systems primarily geared to provide acute care (Eaton et al., 2015).

Participatory action research (PAR) is a qualitative research methodology characterised by the active participation of researchers and participants in the co-construction of knowledge and the promotion of self and critical awareness that leads to individual, collective, and social change (McIntyre, 2008: 5). PAR emphasizes collective inquiry and experimentation grounded in experience and society (ibid).

Participatory design (PD) is a qualitative research approach which focuses on processes and procedures of design, in which the future users of a design participate as co-designers in the development process (Velden & Mörtberg, 2014). Similar to PAR, PD is a value-centred design approach because of its commitment to the democratic and collective shaping of a better future (Robertson and Simonsen, 2013). "Participatory Design is about the direct involvement of people in the co-design of the information technologies they use" (ibid; 19).

Practice-based research is an original investigation undertaken to gain new knowledge partly through practice and the outcomes of that practice (Candy, 2006). There are two types of practice-related research: practice-based and practice-led: if a creative artefact is the basis of the contribution to knowledge, the research is practice-based, whereas if the research leads primarily to new understandings about practice, it is practice-led (ibid).

Pre-emptive care utilises actionable personal data as well as other holistic information about lifestyle to predict the risk of illness and complications to delay or prevent the onset of disease; these predictions are used as the basis for preventive actions and intervention (Kato and Kinoshita, 2017). This approach has the potential to strengthen individual motivation toward efforts to delay or prevent the onset of disease while reducing the cost of healthcare (ibid).

Relationships are considered social constructs in which two or more people or things are connected, or the state of being connected or working together (Luhmann, 2005). Effective self-management is reliant on strong relationships through understanding, acceptance, transparency, communication, respect and trust between people and things (ibid).

Self-management is considered the management of or by oneself; through taking of responsibility for one's behaviour and well-being. Within healthcare contexts, self-management practice is the care and encouragement provided to people with chronic conditions and their support networks to help them understand their central role in managing their health condition, make informed decisions about care, and engage in healthy behaviours (Kidd et al., 2015).

Type 1 diabetes occurs when a person's body attacks the pancreas cells that make insulin so they cannot produce any insulin at all. In contrast, type 2 diabetes occurs when a person cannot produce enough insulin for the pancreas to work effectively. Everyone needs insulin to live as it allows the glucose in the blood to enter a person's cells, if not, this can lead to complications of diabetes such as hypoglycaemia (hypo) when blood glucose drops too low or hyperglycaemia (hyper) when blood glucose rises too high (Diabetes UK, 2019).

User is a person who uses or operates something. Within healthcare contexts, a service *user* describes anyone who is a patient or user of a health-related service and includes not only present and past patients but also potential users of health services - that is, the general public (Hopkins et al., 1994: 203).

1. Introduction

1.1 Research Motivation, Rationale & Focus

This research follows on from the outcome of my NHS 24 Alternative Now live project (2018) [Appendix A1], which explored how the *Internet of Things* could help deliver Scottish Government's 2020 Vision for NHS Scotland - of an integrated healthcare system with a focus on "prevention, anticipation and supported self-management" (2013: 3). The *Connected Community* initiative utilised IoT connected condition-specific monitoring devices and new *Community Contributor* interface roles to better manage Scotland's target long-term health conditions and *high intensity users* towards an innovative pre-emptive care strategy. This research project aims to further explore the relational implications of digital self-management devices beyond the self, such as; trust, agency, responsibility and accountability of mismanagement out with the user, towards how participatory design practice can help discover preferable self-management design principles.

As we approach an increasingly connected future, with forecast projections of "up to 100 billion active IoT devices predicted by 2025" (Smith, 2017), approaches helping towards understanding and conceptualising this phenomenon will be imperative to accepting an IoT-prevalent future. IoT will inevitably have a disruptive impact upon the healthcare sector - with over 30% of the world's data currently related to health, but with only the capacity to analyse and use 3% of its potential, we are data rich but intelligence poor (Piai and Claps, 2013: 21). Although the imminent IoT revolution can provide intriguing opportunities to monitor long-term conditions and support self-management through the sensing and analytical capabilities these connected devices enable. This also poses many ethical considerations regarding how such personal and pervasive health data is used, stored and shared, especially with recent GDPR regulations enhancing citizen's rights to control their data. Development of this field has been highly contentious, due to threats to privacy and the growing "trust deficit" (Grayson et al., 2018) in healthcare towards patient-generated health data as well as the risk of monitoring device mismanagement. However, the interoperability of this data could provide insight to improve self-management and care coordination (Genes et al., 2018: 3). Hence, there are opportunities for design to intervene within these technological tensions and influence relationships towards preferable futures (Dunne and Raby, 2013: 4). This research utilises participatory design practice to explore the lived experience and relational impact of digital self-management devices and systems, to establish preferable design principles to support the estimated 47% of the adult population in Scotland with at least

one long term condition and growing according to the Scottish Health Survey (2016). If the Scottish Government's *2020 Vision* is to be achieved, its focus on prevention, anticipation and supported self-management could be transformational for those affected by long term conditions and beyond.

From prior work comparatively analysing the appropriateness of IoT monitoring for long term conditions [Appendix A2], this research focuses on type 1 diabetes as a contextual vehicle in this study due to the symbiotic relationship and experiential insight those who self-manage have with their flash/continuous glucose monitor (CGM) and/or insulin pump device. Due to end-users relationship dependency and frequency of interaction with these digital self-management devices, I engaged with participants living with type 1 diabetes for this research.

1.2 Research Question, Aims & Objectives

My central research question for this MRes project's research inquiry is:

How can participatory design practice help discover the barriers and facilitators of type 1 diabetes self-management beyond the self?

The following aims and objectives were set to respond to the research question through participatory design practice:

- To explore current practice for type 1 diabetes management and user's relationships with their devices. Through semi-structured interviews, I intend to discover the lived experience of participants self-management devices and how they affect relationships beyond the self.
- To frame the barriers of type 1 diabetes self-management beyond users and their devices. Through conducting situational stakeholder mapping with participants, I intend to define key relationships and facilitators for trust towards the development of a synthesised relational map.
- To co-create self-management design principles with a sample of participants with type 1 diabetes. Through a participatory workshop, I intend to facilitate a series of generative design activities towards the delivery of user needs and design principles for future digital health products and services.

2. Literature Review

2.1 Introduction

In this chapter, I will critically examine the movement from *reactive*, to *proactive* and potentially *preventive* healthcare models (Gillies et al., 1995: 15-18), and how these shifts are primarily driven by technological progression from analogue to digital self-management devices [Appendix B1]. Hence, this literature review explores the implications of these paradigm shifts through public, private and third sector reports, policy recommendations, academic journal papers and news reports to present a broad overview of current and future of self-management practice. Appendix B2 presents research *signals* that contextualise this scope further through insight mapping.

2.2 Historical Context: Reactive Paradigm

"The essential unit of medical practice is the occasion when, in the intimacy of the consulting room, a person who is ill, or who believes himself to be ill, seeks the advice of a doctor whom he trusts. This is a consultation and all else in medicine derives from it." (Spence, 1960: 273)

Within historical contexts, reactive healthcare involves reacting after an adverse disease, condition or symptom occurs (Gillies et al., 1995: 15). Like most health systems globally that were designed in the post-World War 2 era, this *fix and treat* approach is where problems tend to be easily diagnosed and treated with a *cure* (ibid). Given how deeply embedded this reactive system is within healthcare systems, acting beyond this paradigm encounters systematic barriers. This reactive paradigm is still the foundation for modern healthcare practice today.

2.2.1 Clinical roles, traditional settings and patient relationships

Reactive practice is highly reliant on the role of the healthcare professional (Delamothe, 1993: 218-29). Within traditional contexts of early health systems, clinical roles were defined and distinct from one another: from doctors, matrons to nurses, every role had a particular purpose and clear responsibilities, the clear differentiation between professional and patient has been the foundation for health practice (ibid). As per Spence (1960) considers, this clarity around role and hierarchy could be considered to develop trust from a patients perspective within the healthcare system. Alongside clinical roles, the practice of healthcare was conducted in traditional settings, such as hospitals and GP surgeries (Gillies et al., 1995: 16). This notion of a traditional setting played a part

in establishing a patient/professional hierarchy (McCormick, 1994: 390). The importance of *place* can be seen to play an important part in establishing trusting relationships between professional and patient as well as ensuring privacy and confidentiality within a clinical consultation space (ibid). Furthermore, since the inception of the NHS in 1948, public access to treatments and advancements in disease control have contributed to an increasingly ageing population (Kelly and Charlton, 1992: 223-224). With people living longer into elderly age, conditions become more complicated and complex to cure and are often co-morbid (ibid). Moreover, with population projections indicating a steady progression of those aged 65 and over (Kelly, 1992: 292-296), this results in an increased demand for services even though supplies are continually strained. Healthcare systems are struggling to cope with unprecedented change and increased demand whilst maintaining and sustaining trusting relationships with service users.

2.2.2 Emergence of self-management devices

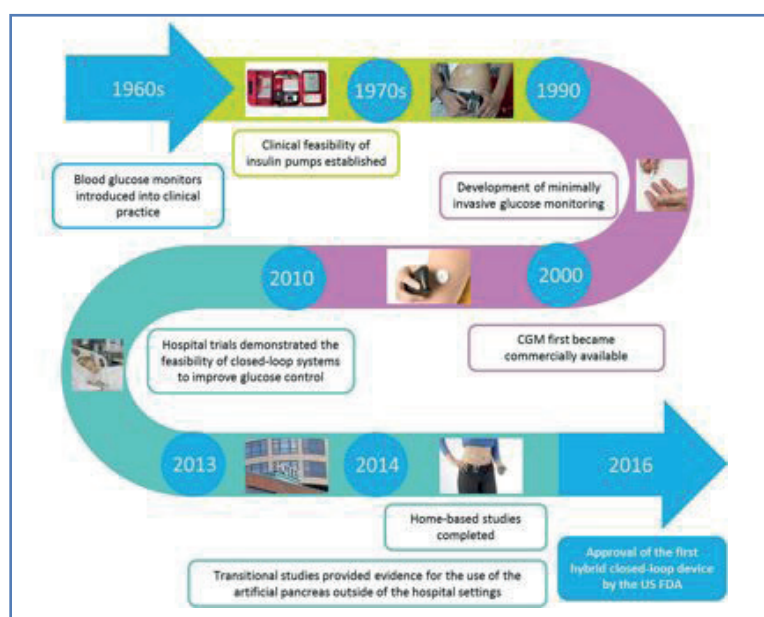


Figure 3: MedicineMatters, (2017) *Diabetes self-management device timeline from market inception until 21st century. Diagram. Source: MedicineMatters.*

As shown in Figure 3, self-management devices helped to bridge the gap between professional and patient by allowing clinical indications to be measured outside traditional settings, as well as a step towards proactive self-management. Notably, blood glucose monitoring for diabetes management emerged as one of the first self-management devices for consumers due to the frequency of measurements required (BDA, 1993). Through giving those living with diabetes the ability to control their blood glucose concentration by measuring glucose levels and injecting insulin when needed (ibid). Such practice has not only saved clinicians time but also money from avoiding critical/emergency treatment. The socio-material aspects of these devices

enabled exclusive human-technology relationships through mutuality, performativity and multidimensionality (Parmiggiani and Mikalsen, 2013) allowing material artefacts interacting within the health system. However, as technology progressed and evolved, such devices have become more culturally and economically accessible to the broader diabetic population (ibid).

2.3 Contemporary Context: Proactive Paradigm

In comparison to reactive, proactive healthcare involves reacting before an adverse disease, condition or symptom occurs (Gillies et al., 1995). This takes a more holistic view of a patient's care-taking into account: behavioural health, public health, and general wellness approaches (Krawiec et al., 2015). Grant (2015) considers that the patient takes an active role in maintaining their health autonomously alongside the healthcare provider. Proactive approaches are generally underfunded and reduced in status as healthcare resources and culture are still focused on more quantifiable reactive responses (Hixon, 2014). As such, true proactive care also requires a holistic understanding to predict condition depreciation in advance of problems occurring (ibid).

2.3.1 Age of self-management: Current practice for type 1 diabetes

With NHS Scotland spending almost £1.5bn per year on diabetes treatment, up to 80% of cases to primary care services are considered avoidable complications (Audit Scotland, 2017). Within the knowledge economy, there is increased importance towards self-care approaches (Krawiec et al., 2015). This movement has influenced the user experience (UX) and user interface (UI) design of health monitoring devices to be as easy to understand and usable as possible for self-care (ibid). Moreover, within diabetes management there has been recent progress towards continuous glucose monitoring (CGM) devices; like the Freestyle Libre flash monitoring system, that can measure blood glucose levels less invasively and more frequently than traditional finger pricking methods (Dias and Cunha, 2018: 8). Such innovations allow for more information to be captured beyond the recommended 4-10 readings (Diabetes UK, 2019) of conventional glucose monitoring practice and enable more proactive care through added data. Frequent data uploading can enable more in-depth and profound insights into a user's condition with the ability to learn more about patterns of symptom behaviour to understand why a person's condition is depreciating.

“[A proactive approach requires] commitment between a provider and a patient, where both parties take an active role in managing the patient's health to keep the patient healthy.” (Grant, 2015)

Hence, the ability to view contextual and comprehensive information about a long term condition is crucial for users to be able to act and intervene pre-emptively (Krawiec et al., 2015). Hence how these devices communicate and indicate potential anomaly detections and data discrepancies is vital to be able to alert users to problems in advance pro-actively (ibid). However, this approach relies on the patient's knowledge and literacy of the condition and self-management to be sufficient in recognise problems and act accordingly. Users may continue to mismanage their condition even with the added knowledge and insight that these monitoring devices can provide as the user controls interpretation and reaction to the monitor data.

2.3.2 Interoperability: Sharing health data

With innovations such as continuous glucose monitoring (CGM), the notion of sharing health data with others or interoperability between systems is the next evolution, "within five years, the majority of clinically relevant data will be collected outside of clinical settings" (Krawiec et al., 2015: 8). The prospect of connected healthcare opens up a new dimension of possibilities to these devices through new interactions and relationship opportunities that are instigated through things (ibid). The idea of connected things is a relatively recent phenomenon driven by the exponential popularity of the Internet of Things. Through advancements in networking technologies - the internet is more accessible and available than ever. It is ever more pervasive and ubiquitous in our lives, with up to 100 billion IoT devices predicted by 2020 (Smith, 2017), more things are becoming smart through their ability to connect to the internet. However it takes more than just networking abilities to make a thing smart: "it's a combination of services, trust, and ease of use that make a smart device a better choice for a consumer than a *dumb* one" (Schaefer, 2017). Hence these connected things are only smart if users know how to use them to meet their needs.

"Patient [3.0] are expected to take responsibility of own health and to be so-called 'active' patients using for instance diverse forms of technologies, that can enable them to be more informed and engaged in their own health."
(Gagnon and Chartier, 2013: 39)

With 19% of the Scottish population not yet attaining basic digital literacy skills (NES, 2018), the prospect of a *digital divide* due to increasing digitalisation means that up to 1 in 5 Scots would not be able to embrace digital fully (ibid). Notably, this attainment gap is strongly linked to age and household income - meaning that the most vulnerable citizens, like the elderly and those in poverty, are most at risk within a *digital first* approach to public services. With varied digital literacy and condition management competency, the ability to share health data with others could

be deemed safer for individuals that are not fully able to undertake self-care themselves (Dias et al., 2018: 8). Many smart health monitor brands have enabled the functionality to share data with others through their app and web interfaces. Once permitted, this allows users the ability to export health data information with consented others. Yet, such a feature is intended for non-clinical stakeholders such as family or close friends to access as this approach is not approved yet through the public health system's clinical governance. Sharing detailed condition data to friends and family members could be considered the most appropriate stakeholders to support an individual's self-management. Therefore, it is worth considering the role of the non-professional health networks and how this raises issues around responsibility, ethics and clinical governance.

2.3.3 Web of care: Health stakeholder networks

As proactive care takes a more holistic approach to a person's needs, this extends beyond just interactions with health professionals (Halse et al., 2018). Hence within the context of a singular patient, there is a broad and comprehensive *web of care* of stakeholders who take responsibility for the care of that person (ibid). Therefore the current approach to sharing within close networks is not fully utilising the potential of full interoperability; through sharing data with broader patient and professional networks (ibid). To harness the power of proactive care, full open exchange of data interoperability is required to enable pre-emptive care intervention and better support for self-management. As contemporary approaches to sharing require users to actuate the sharing of data exchange - users may choose not to utilise or be aware of data sharing abilities of IoT connected health monitors and not be connected with their full health network which can lead to reactive practice within a proactive paradigm.

2.4 Theoretical Context: Preventative Paradigm

"An ounce of prevention is worth a pound [maybe a ton] of cure." (Hixon, 2014)

A preventative health approach focuses on practices that are designed to avert and avoid problems, through *predicting* anticipated disease, conditions or symptoms before it occurs in the first place (Clarke, 2011). Theoretically achieving this approach would require harnessing the full potential of data interoperability to gain rich insights into deeply personal and collective public health together. However, to go beyond the traditional patient/professional relationship paradigm needs investment in preventative practice - as Hixon (2014) implies investing in prevention infrastructure will be worth the potential savings in treatment costs from predicted problems.

Hence, innovations such as *my mHealth* apps, that focus improving education and insight towards self-management for long term conditions such as COPD, asthma, diabetes and heart disease, are already helping to reduce mismanagement and prevent primary care admissions.

2.4.1 Automatic uploading of data

Following on from the notion of a web of care is the prospect of automatic (also known as active or dynamic) uploading of data towards an *electronic health record* (EHR) for preventative purposes (Genes et al., 2018). Emerging technologies such as artificial intelligence (AI), *machine learning* and on-device *edge analytics* are enabling patient-generated health data to become clinically actionable and preventative (ibid). As such, if a patients health data could be directly shared or streamed towards a relevant clinician or specialist, then appropriate action could be made as soon as possible before a condition depreciates - this system would ensure clinical governance is upheld in an area that is exclusive to non-clinical stakeholders. This approach is especially important with regards to long term conditions like diabetes, where investment in IoT networking infrastructure could be justified for the potential savings in avoidable treatments (Kumar et al., 2016). This suggests that an ideal audience for automatic data uploading are current users who are prone to mismanagement of their long term condition, or notionally high intensity users of primary care services (Foster, 2018). Therefore, automatic uploading of data could allow new interactions and relationships to be established with IoT devices acting as a catalyst for prevention (Heintzman, 2016).

2.4.2 Privacy and ethical considerations

Although automatic uploading of data presents many benefits and opportunities for preventative practice, there are also many ethical challenges towards this approach; its impact on privacy and subsequent trust of health systems (Bietz et al., 2016). In particular, privacy has been a contentious topic to date with regards to how much data can be shared through the internet. From the exponential expansion of IoT infrastructure, this predicament will only progress as we advance into an ever more online and data-centric world (Wood et al., 2016). As such, measures were put in place by the European Union in 2018 to protect the digital data rights of its citizens through GDPR regulations that were designed to extend citizens access and control of their online *data footprint* (2018). However, such rigid restrictions can limit the opportunities that interoperability and automatic sharing could bring to health innovation (Genes et al., 2018). Furthermore, there is a

growing “trust deficit” (Grayson et al., 2018) in the healthcare industry from patients to share their data as well as clinicians apprehension towards the risk of monitoring device mismanagement. These social and governance challenges can prevent progression towards preventative practice due to the latent ethical considerations from current privacy and data sharing legislation.

2.4.3 Artificial pancreas: A preferable future?

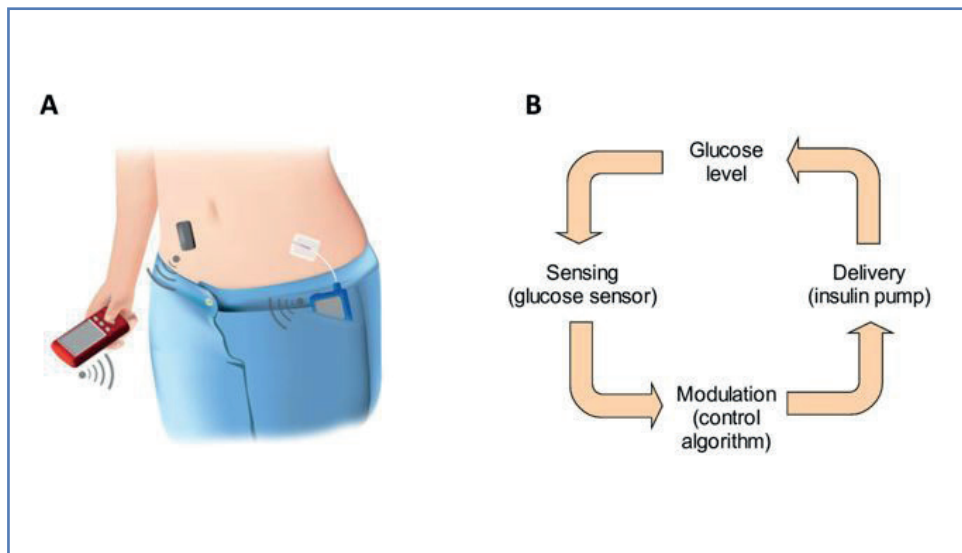


Figure 4: MedicineMatters, (2017) Artificial pancreas system utilises a continuous blood glucose monitor, an insulin pump, and a control algorithm to automatically manage blood-sugar levels. Diagram. Source: MedicineMatters

Such regulations have led some diabetes activists to *hack* their medical devices to unlock the preventative potential of their health data (Mann, 2016). The artificial pancreas system (Figure 4) replicates the role of a functioning pancreas by regulating insulin levels through measuring blood sugar using a continuous glucose monitor (CGM) and transmitting this information to a connected insulin pump that releases the required amount of insulin into the body automatically (Ragan, 2018). This open-source system evolved from the diabetes community's frustration towards medical device manufacturers and a desire to progress technology to meet the needs of people (Mann, 2016). Although there are now approved commercial products available, there are still thousands of people with type 1 diabetes who use this hacked open-source system for self-management (Black, 2018). Furthermore, the online open-source community has already shown significantly higher collective intelligence than conventional medical, economic, and regulatory institutions combined (Ragan, 2018). This shows a preference towards systems and services that are designed with people, not just for them. There are opportunities for design to influence these technological relationships towards preferable futures (Dunne and Raby, 2013: 4)

2.5 Practical Context: Participatory Design towards digital health and care

"Today's healthcare system is undergoing perceptible changes as the system is facing a paradigm shift due to demographic changes, technological developments, increasing complexity, organisational changes, and demands on user involvement [...] participatory design is used in healthcare, because the epistemological, cultural, methodological assumptions of participatory design collide with the traditionally well-established science tradition, language, culture and biomedical approach in health science." (Rothmann et al, 2016: 2)

Although research into participatory design practice has been reported in the relevant literature since 1970 (Kensing and Blomberg, 1998: 7), it remains topical in contexts where involvement of various stakeholders is required when designing a system (Schuler and Namioka, 1993: 14). Participatory design has become a well-established practice within healthcare, which is considered a complex and complicated process as many actors are involved (Mantzana et al., 2007: 16). Moreover, the inclusive and collective nature of participatory design methods can contribute towards higher power for patients and changes to clinical culture (Simonsen and Robertson, 2003: 2). This follows a paradigm shift in approach from "designing for the user" to "designing with the user" (Sanders and Stappers, 2008: 5). Participatory practice is built on the idea of an equal partnership that gives voice to those who are most impacted by design - the end-user (Qazi, 2018: 52). Therefore, end-users are treated as partners and "experts of their experiences" (Sanders, 2002: 8), rather than objects of design. As such, participatory design approaches acknowledge the critical and vital role played by end-users. Therefore these methods would be appropriate for the context of this study due to the focus on the end-user and their relationship with a monitoring device.

2.6 Summary

Given this context situated within emergent digital health and care discourse, there are gaps in the literature I have presented due to the speculative nature of this inquiry which suggests gaps in the scope of knowledge. However, the paradigm shifts discussed a broad overview of current practice for type 1 diabetes self-management and a trajectory towards relational considerations within theoretical and practical contexts. Therefore, this research will explore the lived experience of end-users and relational impact of digital self-management devices and systems through participatory design practice.

3. Methodology

3.1 Introduction

In this chapter, I set out my theoretical and methodological stance for this practice-based study and explain my practice as the researcher. This chapter will also critically examine the research methods selected and analytical framework for fieldwork engagement and data analysis.

3.2 Methodological Positioning

Given epistemological and theoretical perspectives of the researcher influence methodology (Creswell, 2009), as shown in Figure 5 - I outline my methodological positioning (Crotty, 1998: 4) of; epistemology, theoretical perspective, methodology and methods in depth in Appendix C1.

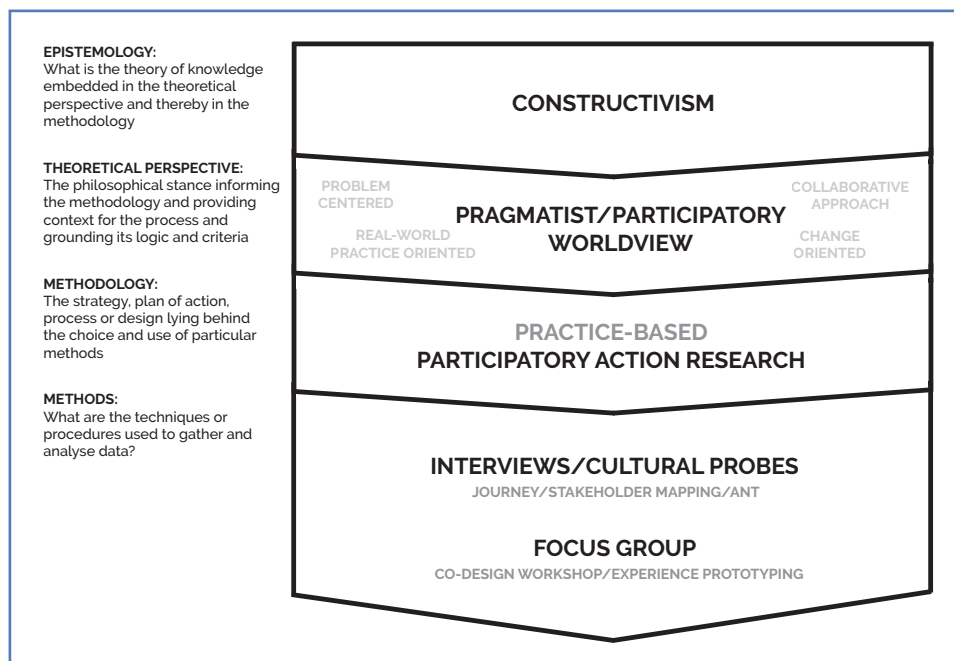


Figure 5: McIntosh, R. (2019) Theoretical positioning inspired by Crotty's research design elements in *The Foundation of Social Research* (1998, 4). Diagram. Source: SAGE publications

3.2.1 Participatory Design Practice

Following a "research through design" (Frayling, 1993; 14) approach towards my Participatory Action Research (PAR) methodology, I choose to take a more Participatory Design (PD) approach to PAR by exploring pragmatic perspectives of this research, inspired by product and service design disciplines, through participatory practice. PD is a form of action research and a socio-technical design approach to actively involve all stakeholders in the conception of systems and services to help ensure the designed result meets user needs (Sanders and Stappers, 2008).

Participatory Design emerged during the 1960s and 70s in Scandinavia from the civil and political movements rooted with trade unions, “to participate in collective action around shared interests and values” (Robertson and Simonsen, 2003; 2). PD asserts that end-users, who are most “affected by the research theme and the expected outcomes must be involved” (Sanders and William, 2001; 1) to develop truly user-centred products and services. PD refers to a complete co-creation process, “in ongoing, productive collaboration with, and supported by all relevant parties, with end-users playing a central role” (Pieters and Jansen, 2017: 9). PD practice has been used in many settings and various scales of co-designing with participants (Trischler et al., 2018: 75). Therefore, PD was chosen as my methodology for this research due to the collaborative nature of the engagement intended and focus on end-users.

3.2.2 Researcher's Role

Through a PD framework, the researcher's role can be considered complex and contradictory due to the participatory nature of this practice, the role of the researcher within PD becomes more of a *facilitator* and *enabler* within participatory contexts (Pieters and Jansen, 2017: 9). Therefore my role as the researcher will be to support participants to generate knowledge and insight into the experience of diabetes self-management through generative sessions (Visser et al., 2005: 123). Yet, in line with Creswell's view that participatory researchers cannot be separated from their tacit knowledge and interpretation (2009), underlines the requirement for reflexivity that acknowledges the researcher's attitudes and assumptions towards understanding participant roles (Bolton, 2009). My practice as a researcher will develop through “reflection-in-action” as defined by Schon (1991: 141) to continuously inform and guide the research further with participant engagement throughout the study.

3.3 Methods

For the Participatory Design methods within this study, research participants will be invited to take part in individual interactive interview sessions and then a collaborative participatory workshop to discover the barriers and facilitators of type 1 diabetes self-management beyond the self. These methods were chosen for their appropriateness within the participatory design process of; “initial exploration, discovery process and prototyping” (Spinuzzi, 2005). As such, through the interactive interview engagements, I intend to conduct an initial exploration through semi-structured interviews; a discovery process through situational and relational mapping; and prototype with participants during the participatory design workshop.

3.3.1 Interactive Interviews

The interactive interview sessions are split between a semi-structured interview and interactive mapping activity with participants to last around 1 hour. The purpose of these semi-structured interviews will be an initial exploration of the experience of using self-management devices. A semi-structured interview question framework will be designed “to establish self-reflection on the part of the participants, which is then harvested during the generative sessions” (Visser et al., 2005; 123). I will design an interactive mapping activity to encourage a discovery process to define broader relationships of self-management with participants. This activity helps contextualise participant's experience of current self-management relationships and suggest preferable interactions between stakeholders. These interactive interviews are semi-structured to allow relative comparison between each other but still allow the participant to guide the conversation (Gray et al., 2007). Following these engagements, the semi-structured interviews will be transcribed and resulting in situational maps to understand which stakeholder interactions “make a difference” in these situations (Clarke, 2005; 86). A one-to-one and informal approach to these sessions will be designed to build trust between participants and myself, the researcher, to increase confidence towards the collaborative participatory workshop.

3.3.2 Participatory Workshop

The participatory workshop will last two to three hours and feature and seek to discover barriers and facilitators to self-management generatively and co-design a prototype intervention together towards preferable self-management design principles. At the start of the workshop, I will introduce myself as the researcher and conduct an icebreaker activity with participants to provoke the theme of self-management before commencing with the generative workshop activities. The first activity will be validation and co-analysis of the situational and relational mapping from the interactive interview analysis. Following this, I will facilitate participants through a *what if* generative exercise to explore possible scenarios towards earlier *pain-points* from previous participant interviews and facilitate participants towards generating a *provotype*, which is a provocative prototype and considered a “physical embodiment of a *what if* card” (McKenzie, 2015: 272). Hence provotyping can be thought of as a vehicle in the early exploratory phases of the design development process to provoke and engage stakeholders into imagining possible futures (Boer et al., 2012). This provotype will then be tested through *alternative now* (Dunne and Raby, 2013: 9) user journey scenarios to show the value of it in juxtaposition to each current

contextual reality. This engagement will conclude with self-management principle co-creation with participants to evaluate the impact of participatory design approaches collectively.

3.4 Analytical Framework

With regards to the analytical framework, I will deploy situational and thematic modes of analysis for this study. Situational analysis provides a supportive mode of analysis given the need to holistically interpret complex situations, involving both human and non-human stakeholders, within the initial exploration of self-management through visual situational maps with individual participants to support relationship discourse during interactive interviews (Clarke, 2005). In Clarke's method of situational mapping, the participant and researcher will lay out all stakeholders involved situation and provoke analysis of relations among them to explore: "Who and what are in this situation? Who and what matters in this situation? What elements 'make a difference' in this situation? What benefits or hinders each relation?" (Clarke, 2005: 86). These individual situational maps will be synthesised into a collective relational map of a self-management network for those with type 1 diabetes. Thematic analysis was chosen as a mode of analysis given its flexibility within different theoretical frameworks and the ability to provide a detailed account of complex qualitative data (Braun and Clarke, 2006). Braun and Clarke's six-stage thematic analysis process (2006, 77–101) will be deployed following the participatory workshop's generative activity sessions to reveal common themes across all fieldwork engagements and support collective self-management principles as findings from this research.

3.5 Ethics

Through PD practice, researchers have the responsibility to address the ethical issues that may emerge during fieldwork (Kelly, 2018). Given the potential vulnerability of the participants I seek for this study, with type 1 diabetes being a chronic and life-threatening condition; a full ethical assessment has been approved by the GSA Research Ethics committee before commencing with participant recruitment and fieldwork engagement [Appendix C2]. Within the ethical documentation, such as the Participant Consent Sheet and Consent Form [Appendix C2], participants were reminded thoroughly that this study is voluntary and that their identity will be anonymised throughout to encourage participant contribution. My ethical responsibility would be to ensure that prospective participants are appropriately informed about the study in conversation and give participants plenty of opportunities to ask questions before requesting ethical consent to

proceed with fieldwork engagement. Recruitment will take place indirectly to ensure participants are not coerced into participating in the study by the researcher.

3.6 Participant Recruitment

I will use an “intermediary” (Ssozi-Muyarura, Blake and Rivett, 2017: 91) to help identify suitable research participants based on their knowledge and experience working with people living with type 1 diabetes. Participants will be indirectly invited to take part in this research through a *call for participants* invitation [Appendix C2] that will be distributed by the intermediaries to their internal networks. This invite communicates the inclusion criteria through questions as a method for screening appropriate participants:

Would you like to participate in a research project that will explore preferable self-management principles towards influencing the design of future products and services for those with long term conditions?

Do you have experience of using self-management devices, such as; a blood glucose monitor, flash or continuous glucose monitor (CGM) and/or insulin pump for type 1 diabetes?

Are you over 18 years old and willing to attend an interview session and/or participatory design workshop at the Glasgow School of Art?

If participants answered yes to all these questions and indicated an interest in participating in this study, then they are invited to get in contact with the researcher. For the semi-structured interviews, I will seek the participation of six individuals, as over five participants in a user research study will show over 80% of the usability problems (Nielson and Landauer, 1993: 205). As such, six participants allowed for an equal sample of end-users for comparison between gender, age and ability dimensions (Flick, 2008). As participation is voluntary, I am willing to adjust the selection criteria to ensure I have the required sample size. Following the interactive interviews, I will conduct the participatory workshop with only three to four participants collectively.

3.7 Summary

In this chapter, I explained this study would deploy a Participatory Design approach to Participatory Action Research by exploring pragmatic perspectives of the research inquiry, inspired by product and service design disciplines, through participatory practice. The methods chosen for fieldwork were semi-structured interviews with an interactive activity and a participatory design workshop, towards situational and thematic modes of analysis for findings.

4. Fieldwork

4.1 Introduction

In this chapter, I describe the fieldwork practice that was conducted to inform the barriers and facilitators of self-management. As discussed in the Methodology chapter, fieldwork consists of interactive interviews and a participatory workshop with participants. Modes of analysis are conducted after each fieldwork intervention, as shown in Figure 6.

4.2 Participant Recruitment

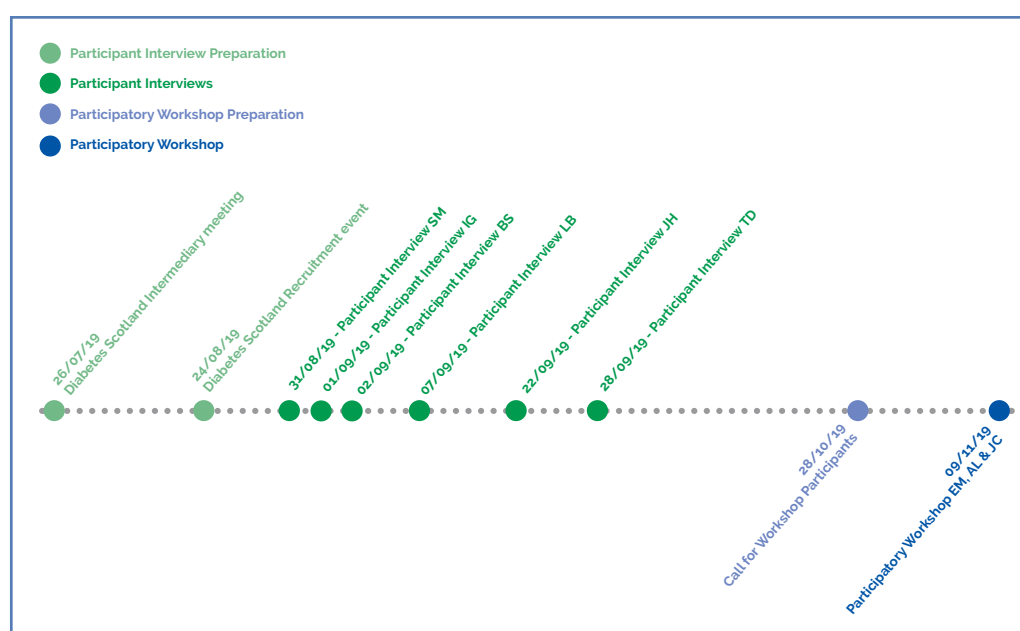


Figure 6: McIntosh, R. (2019) Timetable of participant recruitment and fieldwork engagements with participants. Diagram. Source: authors own.

For recruitment towards participant interviews, I approached an intermediary at Diabetes Scotland. During the meeting, the intermediary suggested that I target younger demographics for my research as this group are more likely to have experience with digital self-management devices, like insulin pumps and flash/continuous glucose monitors due to their eligibility criteria for funding and technological aptitude to use these devices to their full potential. From this engagement, I was informed of Diabetes Scotland's *Young, Fun and Type 1* event [Appendix D1] which one of their engagement initiatives for those living with type 1 diabetes between 16-30. We agreed to situated recruitment at this event and that I set up a *pop-up* engagement to recruit participants at this event (Figure 7). Interested delegates were invited to contact me when available for a semi-structured interview through the participant invite [Appendix D1].



Figure 7: McIntosh, R. (2019) Pop-up recruitment stall at Diabetes Scotland's *Young, Fun and Type 1* event. Image. Source: authors own.

Following initial interview participants from the *Young, Fun and Type 1* event, I adjusted my participant scope towards older demographics as they would provide different relational insights towards self-management devices. As such, I received further responses for interviews from Diabetes Scotland disseminating my interview invite through their internal networks indirectly. For the participatory workshop recruitment, it was recommended that I post a participant call indirectly on the iPAG (Insulin Pump Awareness Group) *Type 1 Diabetes in Scotland* private Facebook group. Subsequently, I was invited to join the private group instead to answer any post comments directly. Following the participant call post [Appendix D1], 3 participants contacted me directly to indicate interest in the participatory workshop, and I arranged for them to attend the event in Blythswood House's Boardroom between 2-4 pm on Saturday 9th November 2019.

4.3 Participant Engagement 1: Interactive Interviews

As outlined in the Methodology 3.6.1 chapter, these engagements were split between a semi-structured interview section (Figure 9) and an interactive stakeholder mapping activity with participants [Appendix D2]. Through engaging with 6 participants for interactive interviews, this approach should have identified over 80% of usability issues related to self-management (Nielson and Landauer, 1993: 205). Among the participants interviewed, these engagements lasted approximately 1 hour. Interview participants were anonymised with pseudonyms to create personas (Figure 8) in order to comply with GSA policy, as discussed in Chapter 3.4.

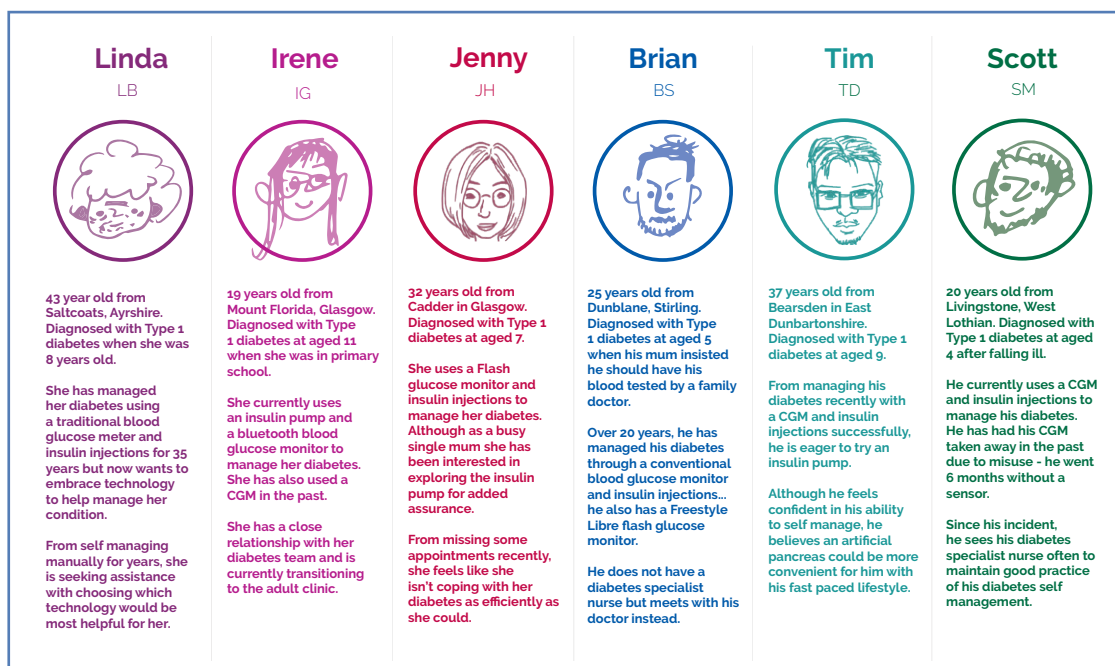


Figure 8: McIntosh, R. (2019) Interview Participant Personas. Diagram. Source: authors own.

4.3.1 Part 1: Semi-structured Interviews

As shown in Figure 9, the interactive interview framework was split into a semi-structured interview session discussing Part 1 and Part 2 to inquire into them and their diabetes and the relationship they have with self-management devices towards exploring their broader health network comprehensively through the interactive stakeholder mapping activity during Part 3. Due to the semi-structured approach to this question framework was flexible and adjusted in situ to guide conversations. From transcribing these interviews and thematic analysis, they revealed interesting initial insights around preferable self-management.

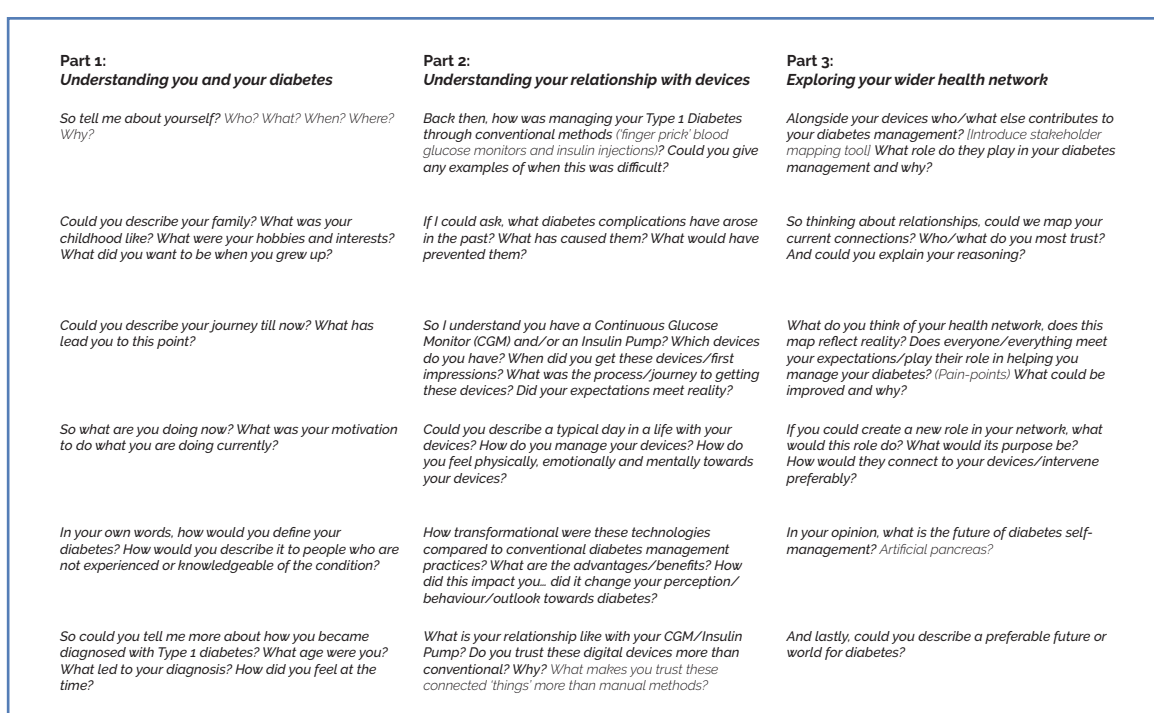
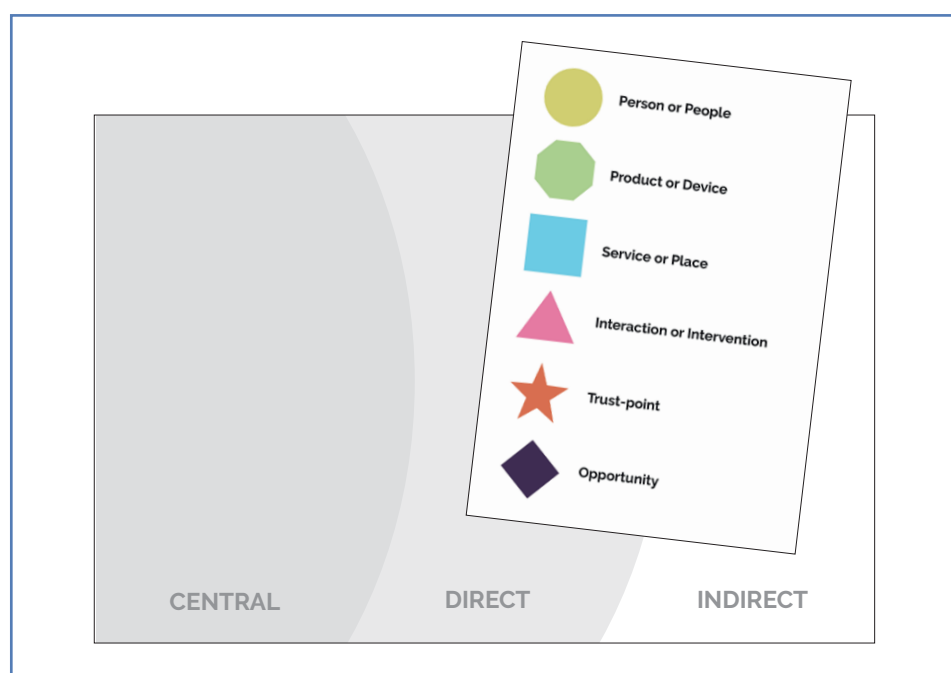


Figure 9: McIntosh, R. (2019) Participant Interview Framework. Diagram. Source: authors own.

Initial codes emerged from participants interview transcripts around the themes of *relations*, *education* and *trust* within contexts. These semi-structured interview sessions provided useful understanding and contextual scoping about how participants self-manage their diabetes and gave initial insight into user needs and preference towards the design and interaction of their devices and support networks.

4.3.2 Part 2: Situational Maps

The semi-structured interview was followed by an interactive stakeholder mapping activity to help contextualise Part 3 of the interview framework shown through a designed toolkit (Figure 10) to visualise situational maps with participants by scoping stakeholders between people, devices and services to provoke analysis of relations towards interactions, trust-points and opportunities within each of the participant's health network.



4.2

Figure 10: McIntosh, R. (2019) Stakeholder Mapping Activity toolkit. Illustration. Source: authors own.

During the interactive activities, it was noted that participants had generally never considered their self-management as a network before or the relationships between supporting stakeholders. This was interesting given participants responses during their interviews as most focused on other people/things/services rather than themselves when discussing their self-management. As such, this was a relatively new experience for participants and undertaking this activity alongside the researcher enabled a participatory element to these engagements. Figure 11 shows how these maps were co-produced in situ between participant and researcher to help understand and contextualise their situation during the interview engagement.

4.4 Participant Engagement 2: Participatory Workshop

4.5

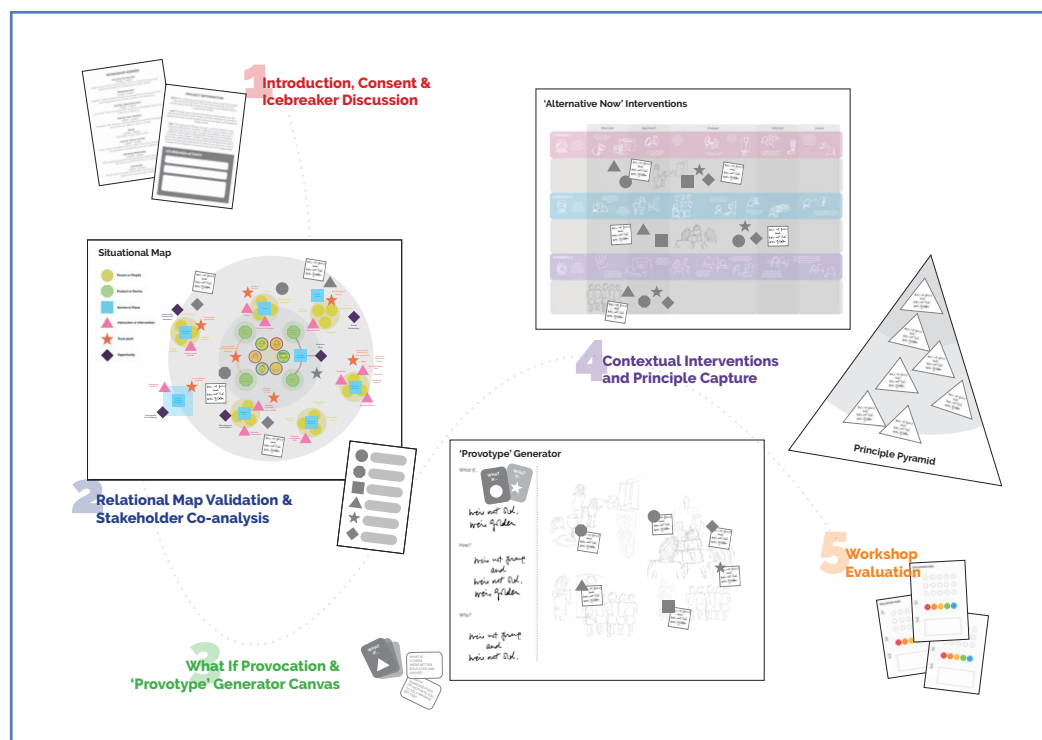


Figure 13: McIntosh, R. (2019) Participatory Workshop Framework planning. Diagram. Source: authors own.

As outlined in the Methodology 3.6.1 chapter, this participatory workshop featured three generative activities: Validation & Co-Analysis, Provotype Co-creation and an Intervention & Principle generation session (Figure 13) to explore preferable self-management principles with participants that have experience of using devices. I engaged with 3-4 participants for this workshop through a revised participant call invite [Appendix D3]. Participants were anonymised with personas (Figure 14) to comply with GSA ethics, as discussed in Chapter 3.4.

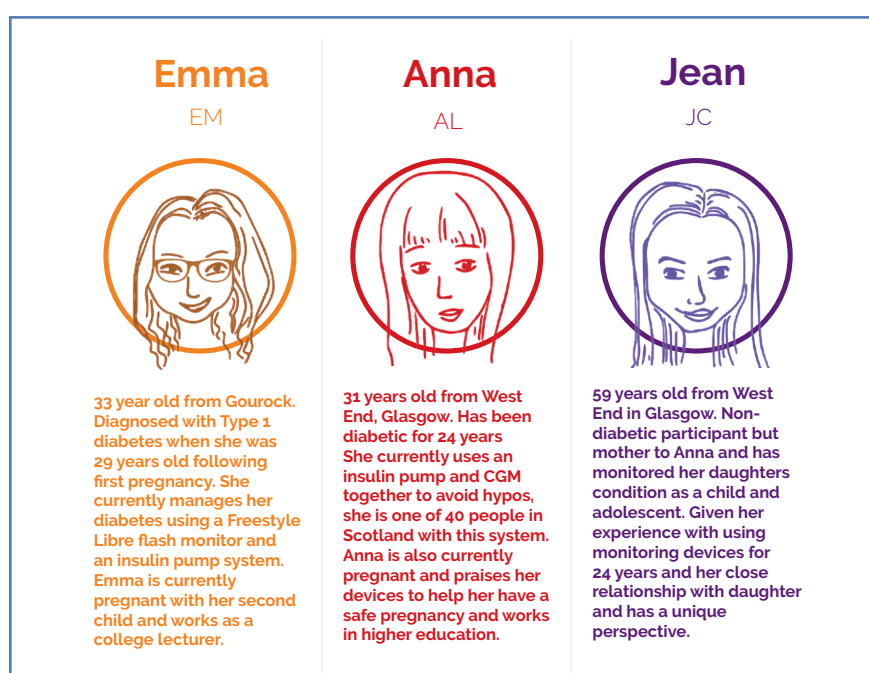


Figure 14: McIntosh, R. (2019) Participant personas from participatory workshop. Diagram. Source: authors own.

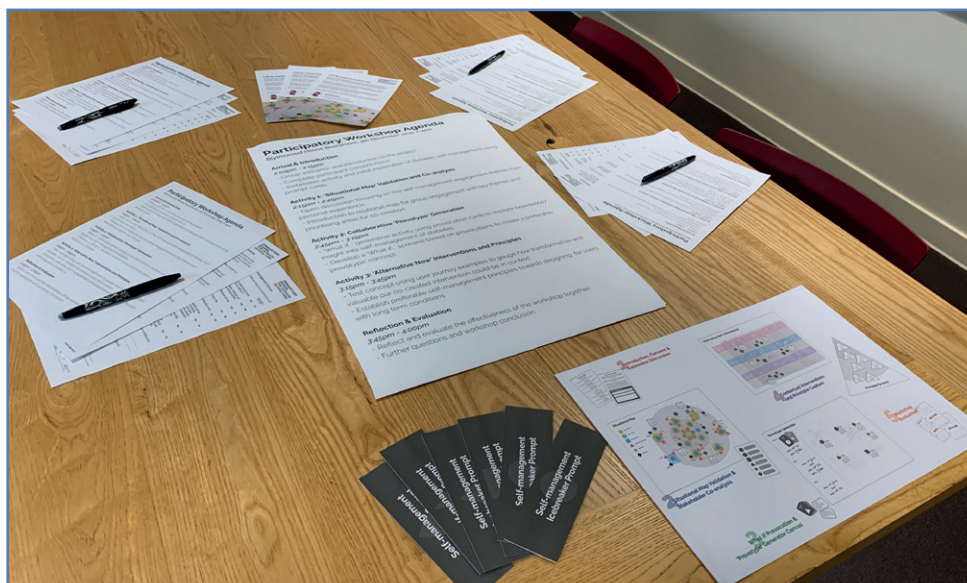


Figure 15: McIntosh, R. (2019) Participatory workshop introduction, consent and icebreaker discussion prompt activity. Image. Source: authors own.

4.4.1 Part 1: Validation and Co-analysis

Following the icebreaker activity to introduce and prompt discussion around the theme of self-management (Figure 15), I directed participants towards the first activity of validation and co-analysis of the situational map interpreted from my earlier fieldwork interviews. Like the other participants, they were unfamiliar with a stakeholder relational map for diabetes self-management. From facilitating participants through the map, stories emerged that delved into relationships further (Figure 16) and initial themes of *relations*, *education* and *trust* played a prominent role in many of these conversations as a problem between users and not only digital self-management devices but also other people illustrated within the relational map framework.



Figure 16: McIntosh, R. (2019) Relational Map Validation and Co-Analysis activity. Image. Source: authors own.

4.4.2 Part 2: Provotype Generation



4.7

Figure 17: McIntosh, R. (2019) *What If Provocation and Generation activity in situ*. Image. Source: authors own.

Following in-depth discussions inspired by the situational map, participants were invited to explore *what if* provocations that were derived from previous interview insights together. These *what if* provocations were used to inspire new conversations and ideas in situ with workshop participants. We developed our own *what if* possibilities around the prominent discussion themes of education and relational understanding between diabetic people, those they interact with directly like family, friends and clinical support as well *others* like the public (Figure 17) From these provocations, interesting ideas emerged such as diabetes as a “new normal” and positive notions of “our condition” rather individualistic perceptions (Figure 18).

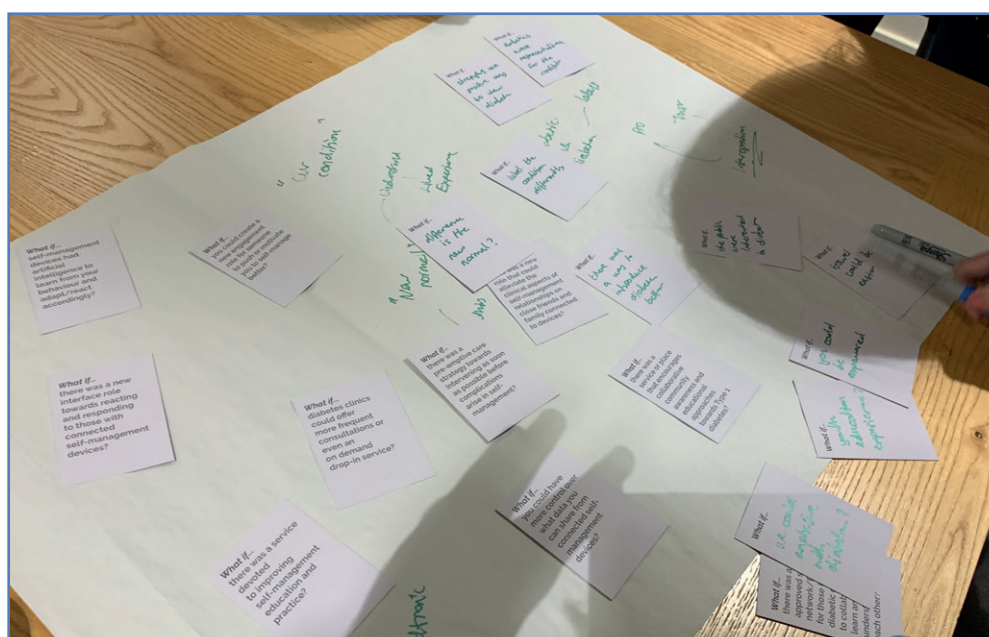


Figure 18: McIntosh, R. (2019) *What If Provocation and Generation activity result*. Image. Source: authors own.

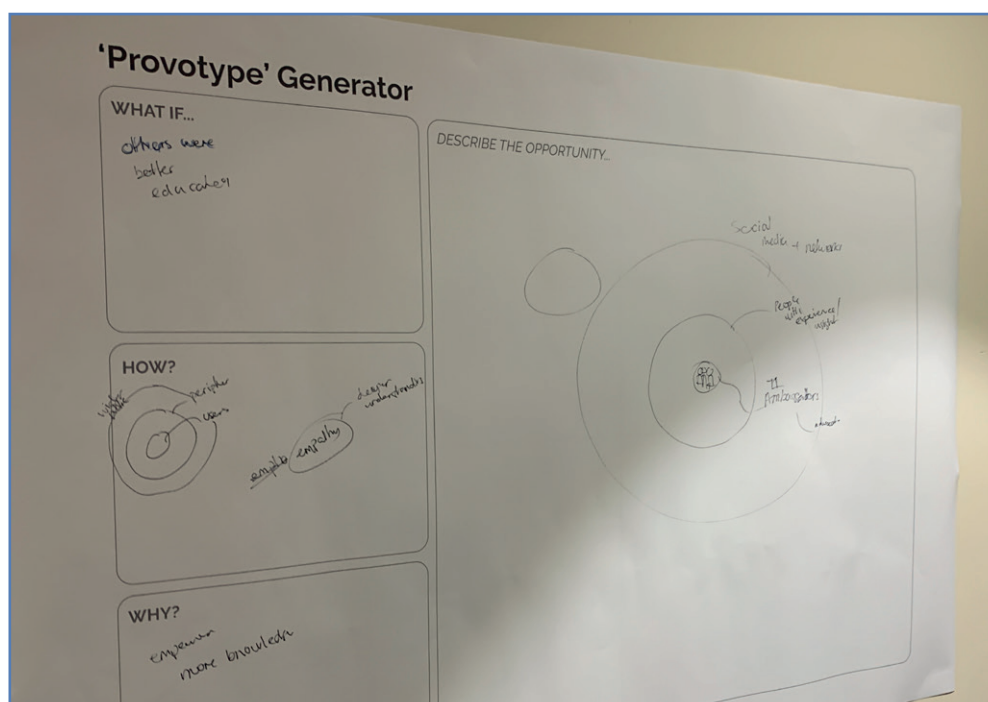


Figure 19: McIntosh, R. (2019) *Provotype Generator outcome*. Image. Source: authors own.

Notably, these ideas require others to gain insight into the *self* experience of living with diabetes. Participants highlighted the importance of education and socially knowing someone with the condition as the best way to understand and more importantly empathise with diabetes. From capturing all these ideas as *what if* scenarios together, participants selected “what if others were better educated?” for the provotype generator canvas (Figure 19). Like the situational map, ecologically there were different levels of others, from those with type 1 diabetes who self-manage too, other people they interact with directly like family and their diabetes team and others in terms of the wider public. Together participants created a provotype that saw those with lived experience of diabetes become ambassadors for the condition to holistically educate others into the realities of self-management and inspire positive outlooks for those with type 1 diabetes.

4.4.3 Part 3: Alternative Now Interventions

Through the assembled user journey scenarios based from participant interviews that explored complex relational situations, we tested our provotype contextually as interventions within these situations to discover *alternative now* scenarios we could refine our provotype further and explore the concept from different perspectives. This activity sought to help participants to think and empathise from new viewpoints by considering all stakeholders in each scenario and how the provotype intervention could change the situation for those involved (Figure 20).

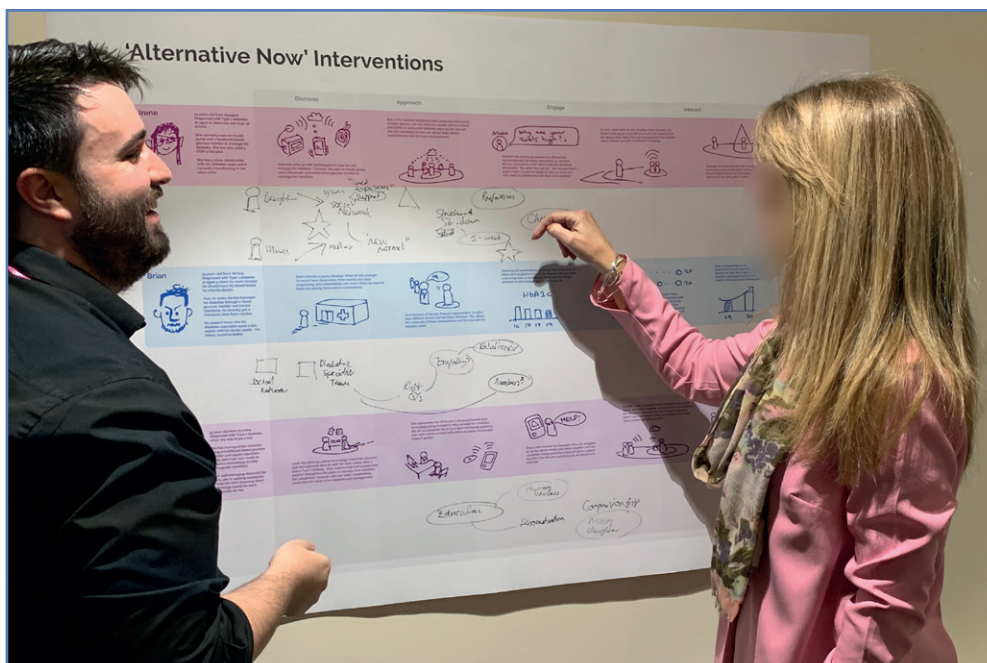


Figure 20: McIntosh, R. (2019) *Alternative Now* situations in situ. Image. Source: authors own.

After this activity, I asked participants to reflect on the workshop activities holistically to consider principles for those interested in user needs for long term condition management design; such as government, health boards, the digital health and care community, self-management device manufacturers and user experience designers. Following prompt questions, participants began to construct principles that consolidated their workshop experience together. Notably notions of “humanising the condition” and “empathy to deeply understanding” were prominent as discussions revolved around the idea of a “new normal” for those with diabetes. These were then arranged on the Principle Pyramid tool as a way of participants to structure hierarchy (Figure 21).

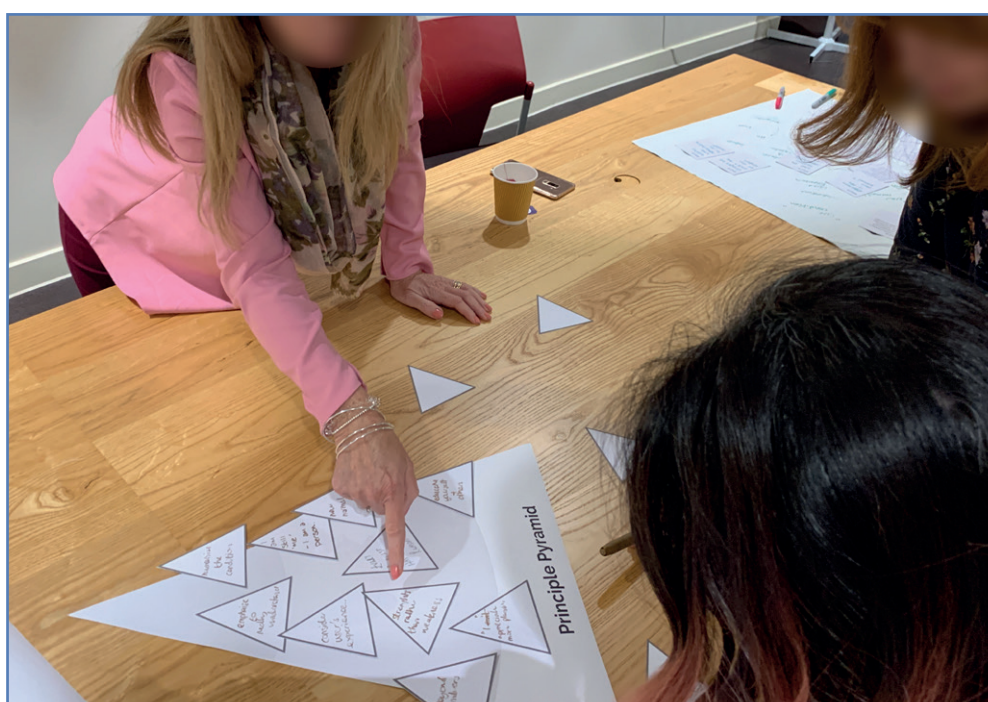


Figure 21: McIntosh, R. (2019) *Principle Pyramid* activity in situ. Image. Source: authors own.

This allowed participants to prioritise which needs are most relevant and valuable for them (Figure 22). These principles followed the flow of the workshop discussion narrative around establishing better relationships to better understand and empathise between people, and it was suggested that this could be achieved by improved education and knowledge by consulting end-users directly to discover the needs and preferences of those who self-manage.

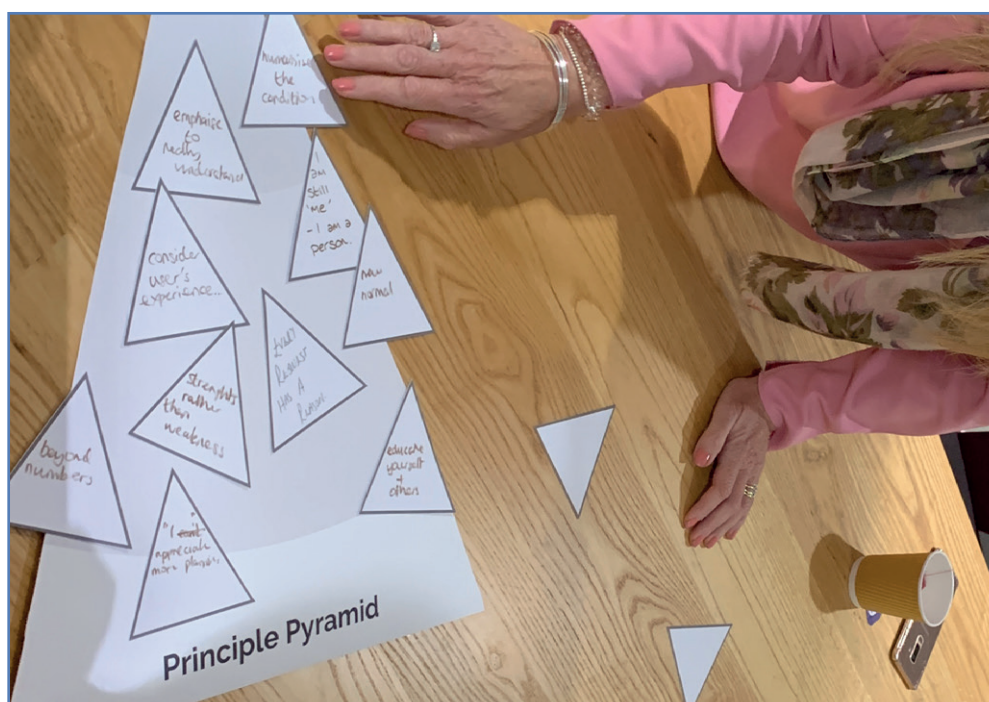


Figure 22: McIntosh, R. (2019) *Principle Pyramid* activity results. Image. Source: authors own.

Once all activities were complete, I conducted an evaluation and feedback session with participants at the end of the workshop [Appendix D3]. Overall participants reflected that the design process helped them to think in new ways and that they enjoyed the experience. Participants felt happy to continue discussion beyond the time allocated for the workshop and the additional time allowing for stronger relationships and trust between participants and researcher as shown from participant feedback; “gave the space to think, the opportunity to share and also to learn” (ibid). This feedback also demonstrates the added value of design-led engagements.

4.5 Summary

In this chapter, I reflected on fieldwork practice conducted: interactive interviews with six individual participants and a generative participatory workshop with three collective participants as well as modes of analysis conducted after each fieldwork intervention. In the following chapter, I will provide a more detailed account of the collective analysis and synthesised finding that emerged from both fieldwork stages towards a summative conclusion.

5. Analysis & Discussion

5.1 Introduction

In this chapter, I analyse the data collected through my fieldwork participatory design practice to discover the barriers and facilitators of type 1 diabetes self-management beyond the self. As discussed in the previous chapters, this analytical framework consists of Situational Analysis of the individual situational mapping and synthesised relational map to support a Thematic Analysis of the participatory workshop elements to reveal themes and finding/principle outputs (Figure 23).

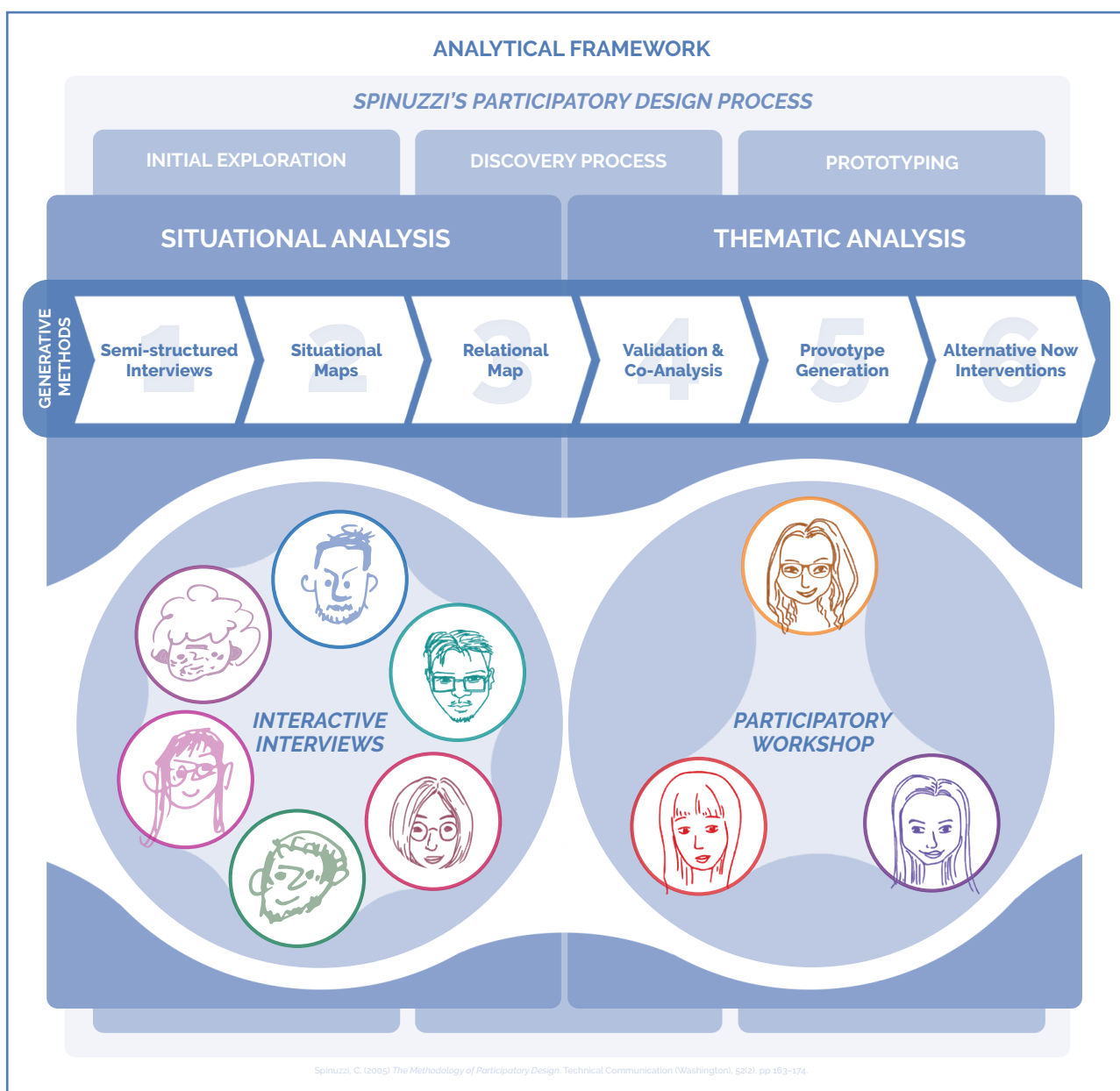


Figure 23: McIntosh, R. (2019) Analytical framework relation between situational and thematic modes of analysis. Illustration. Source: authors own.

5.2 Situational Analysis: Interactive Interviews

To analyse the Interactive Interview components, I deployed Situational Analysis as a supportive method in understanding the scope of self-management contexts through analysis of participant transcripts [Appendix E1] alongside visual mapping to support flexible and holistic interpretations of complex situations [Appendix E2]. This was achieved through Situational Maps constructed from participants mapping outcomes, where we laid out the significant human and non-human stakeholders within their self-management visually and overlaid discursive elements from transcripts to provoke analysis of relations among them (Figure 24).

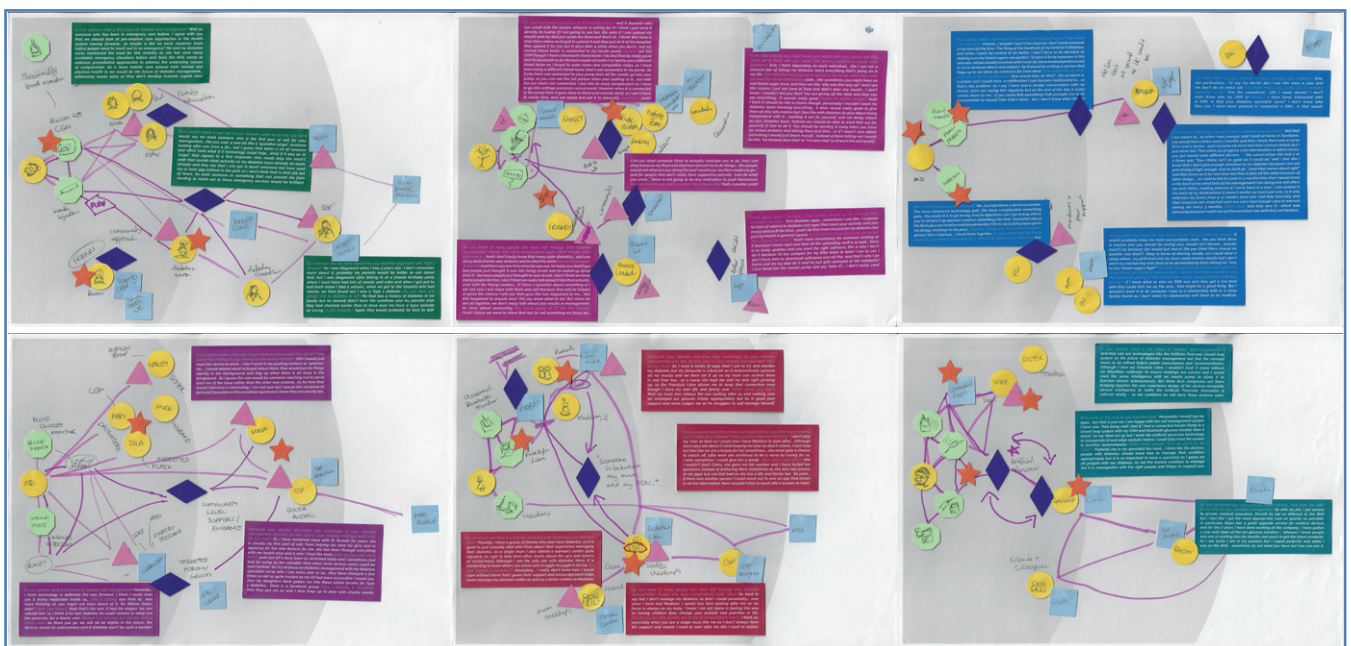


Figure 24: McIntosh, R. (2019) Participant Stakeholder Situational Map Outcomes with key discursive quotes. Diagram. Source: authors own.

This approach allowed an open but structured framework to be shared collaboratively between participants and researcher to maximise participation and situational insight. Through engaging with 6 participants for interactive interviews, this approach should identify a majority of usability issues related to self-management to provide a holistic overview. From centring users and their devices, I interpreted common relational hierarchy from anecdotal discussions with all participants to construct this Relational Map and overlaid participants transcripts visually to support discourse analysis and highlighted themes from participant interviews collectively. The data from these Situational Maps were then synthesised into a holistic Relational Map to collectively visualise broader networks of type 1 diabetes self-management device users and their wider health network stakeholders involved in self-management practice (Figure 25).

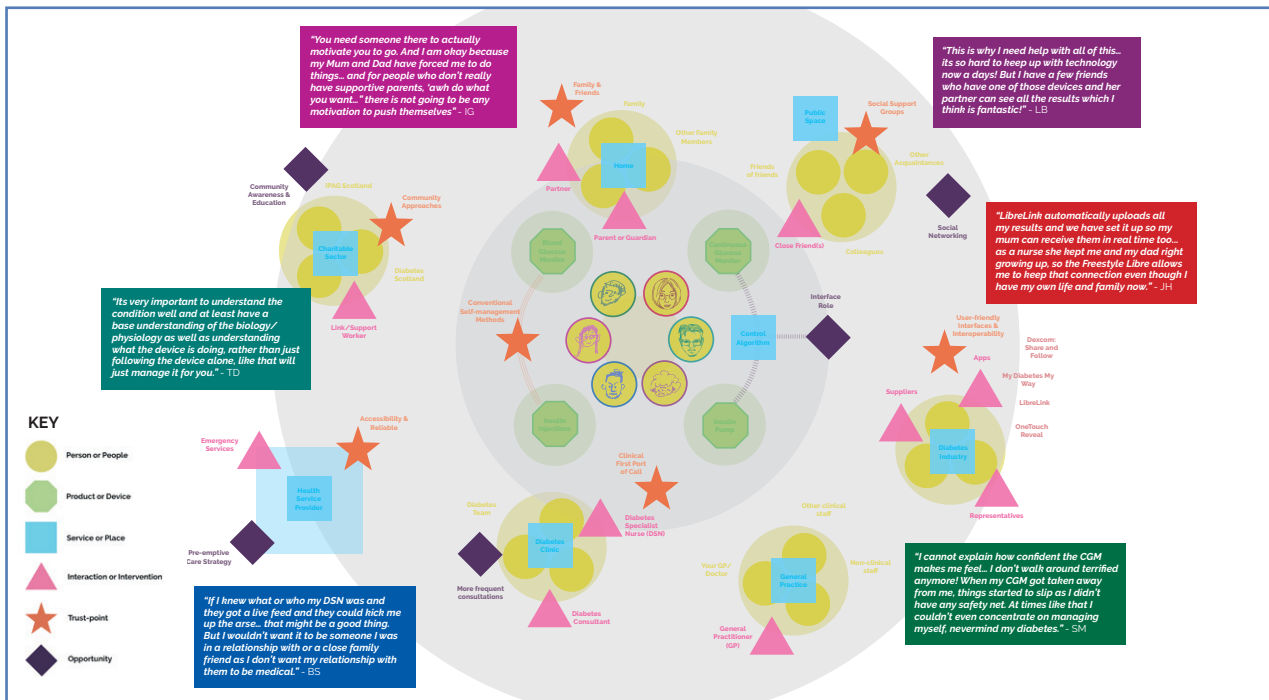


Figure 25: McIntosh, R. (2019) Synthesised Relational Map outcome with supporting quotes from interview participants. Diagram. Source: authors own.

From the situational analysis of the relational map around barriers and facilitators to self-management, it was notable that almost all participants who had used a digital device trusted their manual counterpart more than digital. This was owing to multiple reasons but primarily due to functional issues with digital devices, such as weak adhesives on their wearable CGM or the insulin pump cannula not fitting properly, like Linda who just wanted “the device to work”. Moreover, participants trusted their traditional peripherals only if they trust themselves to manage their diabetes. This echoes Scott who described the effect having his CGM taken away from him after mismanagement, whereas Brian signals users should be aware of how the device functions. This suggests there were relational issues between participants and their self-management devices that were partly due to inadequate user design consideration and diabetes education.

“I honestly 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!” - Scott

“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.” - Linda

“I think as well its a big talking point of technology, 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.” - Brian

Furthermore, from the situational analysis, it was notable that from my sample that there was not an agreed first port of call for their diabetes management. Most participants would approach their diabetes specialist nurse (DSN) or other members of their diabetes team, but some (like Brian) had confusion around this idea as they had not even met their DSN. Moreover, participants had varying relationships within their DSN, from participants who could casually text them to others who struggled to see the same contact for every clinic appointment. This uncertainty of this clinical role foreshadowed further responsibility left to family members and non-clinical stakeholders instead. In particular, parents and partners played a significant and often vital role in self-management across all participants sampled. Hence it could be interpreted that participants would benefit from a new role, as Jenny describes below, to alleviate the responsibility of clinical and non-clinical first port of call. This also further suggests how self-management goes beyond the singular self and affects others illustrated on the relational map.

"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?" - Brian

"Well just as I have said, it would be good if there was someone inbetween my mum and my DSN... I trust them the most to help me manage my diabetes but don't want to be another 'patient' in their already busy lives. So yeah, if someones responsibility was to be like a 'diabetes Mum'! [Interesting... how would a diabetes Mum act like? What would their job description be?] I guess like my mum... but someone else! They would check my app levels and get in touch when needed [And what would this role borrow from your DSN?] Erm... I guess that clinical specialism, there is things Claire is much better than than my Mum because she deals with diabetes everyday... like making sense of my app results!" - Jenny

Moreover, most participants defined a preferable interface role involving someone whose responsibility would be to push and motivate people to be all they can be. Interestingly this was not only from a clinical perspective but also a social and cultural one as well citing the importance of peer support and the development of a community of shared values and experience. Although the focus for self-management is to learn from clinically trusted sources, it was notable that participants learned more from engaging with others who have lived experience of self-managing the condition. However, this social/community aspect is not sufficiently considered towards a person's self-management. This discrepancy is further suggested as participants could not decide

how to interact or intervene preferably within a social/community context could be a focus for future research beyond this study.

"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." - Irene

"[In your opinion, how would they intervene preferably?] That's an interesting question... well it differs from person to person, I feel I manage my diabetes well with my devices but it always gives me comfort to know my specialist gets sent data too... they haven't intervened yet per se but I wouldn't mind if he did reach out or call me if needed, but am sure others would prefer other means of communication or alert - I guess that would be an interesting output of your research!" - Tim

Beyond these themes, this situational analysis enhanced my contextual understanding of how participants self-manage their condition and provided an initial insight into user needs and aspirations towards the design and interaction of their devices and support networks. The relational and situational mapping highlighted trust-points were common among the stakeholders closest to the central context of the situational map. As such, the closer a role or thing can be to the user, the more opportunity for trust can be established. Also, the more devices and connections were used together, the greater trust in the system as Brian alludes to below. This also suggests why stakeholders who were farther away and less frequently engaged were less trusted relationships. However, participants found more opportunities with closer stakeholders due to their existing interactions and trust with users, even though discussions highlighted that high-level and systematic change could have a more significant impact, especially using device data to anticipate and prevent situations that could lead to further complications was considered a positive application for connected devices.

"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 [...] [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." - Brian

"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? [...] 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." - Linda

"I feel like I've always been close to my diabetes team and they know me and like especially my first nurse Gavin, I would like my results to go to someone your closest to, not like I'm going to send these to my consultant who doesn't like know me... if you know what I mean. They don't know much about me or what I do... like the course I am doing or daily routines are, exercises I do, food diary or how I lead my lifestyle - they don't know any of that! So that's why I wouldn't want them to have my data as they would look at it objectively... like 'your blood sugar is high here' when they don't know the context" - Irene

This situational analysis affirms that users of self-management devices have a broader network that are affected by their long term condition and that all stakeholders play a role in a person's self-management either directly or indirectly. Of these relations, analogue self-management devices were more trusted by participants due to their functional reliability and clinical accuracy over their digital counterparts - this differed from my contextual review into digital health and care, with many users divided between using both analogue and digital devices for their self-management. In the next phase of analysis, I sought to explore the repercussions of these mixed approaches. Notably, clinical relationships are stronger for those in a person's Diabetes Specialist team and consultants that are seen predominately as first-port of call for diabetes-related issues and thus are more trustworthy. However, such reliance on DSN's was not deemed effective or efficient for all participants sampled. For future analysis, I intended to focus on the implications of clinical reliance. Non-clinical relationships appeared to have a more substantial impact among family and close friends due to the frequency and proximity of these relationships, in particular with parents and partners, sharing significant responsibility for a person's self-management. However, this discovery indicated this additional responsibility affects of relational dynamics. Therefore, for future analysis, I wanted to explore these non-clinical relationships further. As such, an initial code framework of *relational*, *trust* and *education* emerged as prominent overarching themes to explore through further fieldwork.

5.3 Thematic Analysis: Participatory Workshop

To analyse the Participatory Workshop, I deployed Thematic Analysis as a method for identifying, analysing and reporting patterns towards themes in workshop transcript data [\[Appendix E3\]](#). This was achieved through Braun and Clarke's six-stage process of; "familiarising yourself with your data, generating initial codes, searching for themes, reviewing themes, defining and naming towards reporting and outputs" (2006). This mode of analysis was used as it can provide rich and detailed data, and within a participatory theoretical framework allows for limited interpretative power compared to earlier Situational Analysis, to further test my initial findings.

To familiarise myself with the data, I transcribed and coded the audio transcription of the 3.5-hour workshop to test within the theming of participatory workshop data alongside the overarching central focus generated from the previous Situational Analysis. Although this was complex to analyse due to the rich experiential accounts of self-management barriers and facilitators given, I mapped these Thematic Analysis codes to search for themes (Figure 26)

5.2

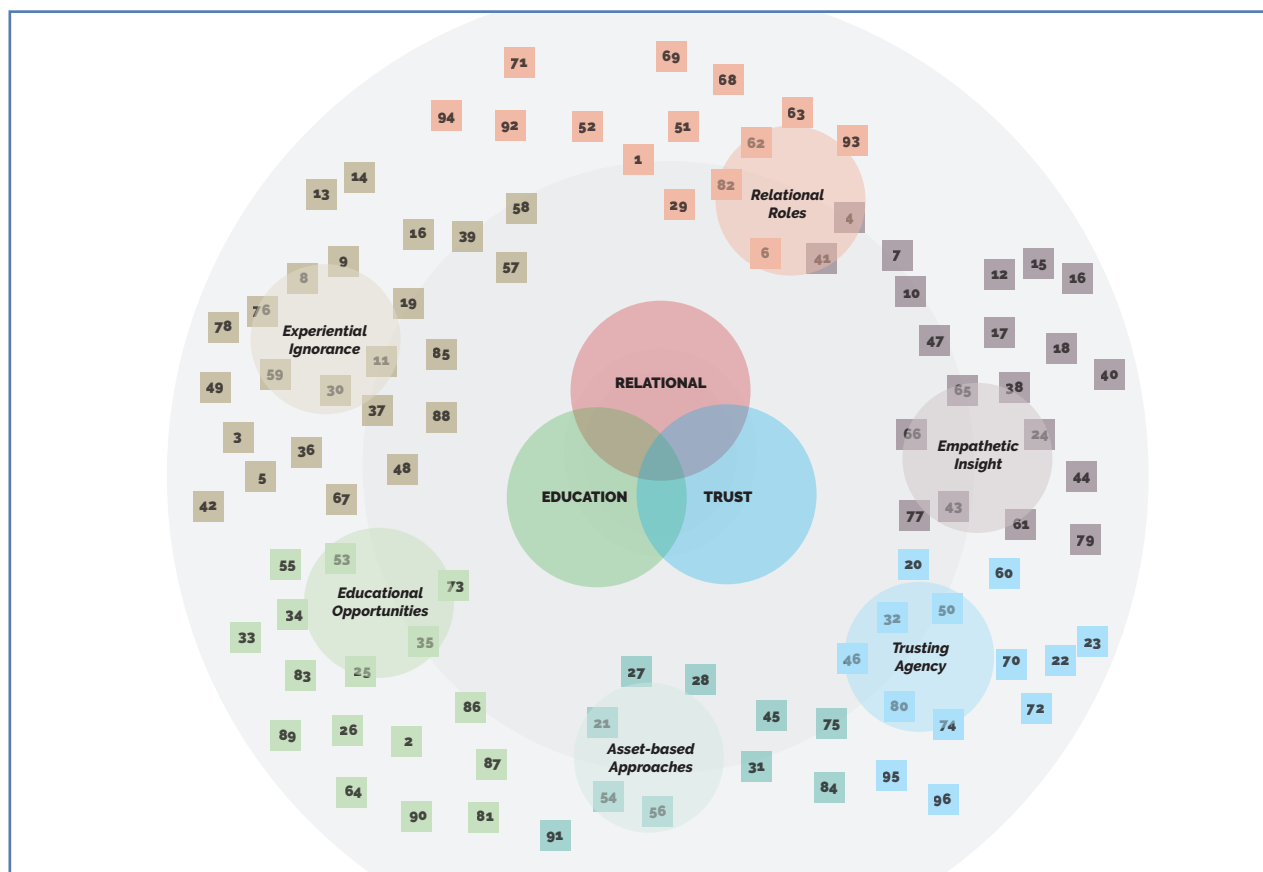


Figure 26: McIntosh, R. (2019) Thematic Analysis visual mapping to search for themes from coding data. Diagram. Source: authors own.

Theme A: Relational Roles

Due to the relational nature of this workshop inquiry with Anna and Jean being mother and daughter, discussion around relational roles was intriguing - not only from Anna introducing Jean as not only her mother but her “pancreas” [Code 4] but also to gain insight into Jean’s perspective as a parent, especially when Jean considered herself as Anna’s “jailor” [Code 41] instead of her mother due to the effects and strains that her diabetes management regime placed on their family relationship. Notably, Jean described this feeling as something only “parents of diabetic children will understand,” [Code 6] suggesting that this responsibility gave her a unique insight to her daughters self-management. This aspect is also apparent when she describes her “instinct” and “sense that you got to do something” [ibid]. This signals that diabetes self-management can profoundly affect non-clinical relationship roles. Although this dependency has resulted in increased intuition, it can also place strain on personal dynamics with family and friends.

Theme B: *Experiential Ignorance*

Participants also were poignant to highlight functional issues related to self-management devices. Notably, Anna hacked her CGM due to her frustration with the device “falling off”, led her to ask the supplier “have you ever had one of these on?” [Code 11]. This implies that device design has not fully considered the user experience and pain-points for end-users. This was also echoed by Emma suggesting that her Flash monitor was an “added job” as she sometimes struggled to trust the device readings, as convenient as the technology can be for users, it can also produce a high margin of error which requires cross-checking with a blood glucose meter - these errors could be fatal if managed incorrectly. It was suggested that digital devices give users “too much information” [Code 30] which can be overwhelming/confusing for some, which also can lead to mismanagement - but could also be helpful for those with the ability to gain knowledge from data. The notion of “visibility” [Code 59] and diabetic identity was raised regarding these devices and how their aesthetics and semantics can impact the user. The idea of levels of complexity emerged and how users can gradually learn how to use devices - as such, mixing these analogue and digital technologies poses challenges. However, user needs and experiences should be taken into account to mitigate these issues and reveal potential.

Theme C: *Trusting Agency*

Discussion flowed onto knowing when something is “off” and when you “don’t feel right” [Code 46] while self-managing. Notably, this leads to notions of users ability to self-manage their condition as all the participants considered themselves capable. As such, there was disparity towards some people’s capability to undertake self-management appropriately. Discussion on learning and awareness at a “base level” [Code 32] of self-management education to ensure the importance for users to know how to interpret data and patterns to make sense of their health. However, from all fieldwork engagements, participants have mentioned situations when you can and can not trust one’s self to self-manage. Interesting insights from participants regarding “trial and error” learning, with Jean reflecting on an accidental mix up that could have “killed” her daughter and how this experience was a lesson to “never do it again!” [ibid]. However, this was considered a “dreadful” way to learn due to the guilt aspect and could easily affect behaviour and relationships. That being said, within every self-management journey, participants agreed that users have to have a “reset” [Code 50] moment to gain perspective and grasp that diabetes is a chronic condition that can be life-threatening if not managed properly - but it is a manageable condition. As such, trust plays a role towards users own control over their self-management, devices and support network.

Theme D: *Asset-based Approaches*

From the further conversation of negative connotations towards diabetes came notions of aspirations, especially around de-stigmatisation of the condition through making diabetes a “way of life” and a “new normal” [Code 56]. However, an interesting consideration from Emma was that certain people “are not going to tell you what their weakness is” but the 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.” This was particularly applicable to both diabetic participants as they disagreed on nomenclature between; “I have diabetes” or “I am diabetic” [Code 54]. As such, asset-based approaches to user engagement enabled participants to learn and exchange new perspectives.

Theme E: *Empathetic Insight*

Throughout the workshop, the importance of others with shared experience was notable - not only generally, like the *Type 1 Diabetics in Scotland* Facebook group that the participants meet through; but also for specific subsets of users and stakeholders, like those who are pregnant with type 1 diabetes, to socialise and build communities of mutual support and understanding. Although social groups currently exist for people with diabetes to converse, there is not currently many opportunities or support to help people socialise and form friend/kinships to support their self-management together. This resonated with the idea that “there are a lot of type 1 diabetics that don't understand” [Code 65]. In particular, the workshop itself became an empathetic intervention with Jean stating “I never hear Anna speak like this...” [Code 66]. This suggests opportunities for empathetic engagement and insight between self-management stakeholders.

Theme F: *Educational Opportunities*

Throughout the participatory workshop, opportunities for education arose as transformative interventions across almost all self-management barriers. Particularly with regards to public perception and knowledge of the condition as confusion and stereotyping between type 1 and type 2 were prevalent within discussion [Code 53]. However, it was signalled that this ignorance did not affect those who had direct experience with someone with the condition as participants frequently referenced “others” [Code 67] and it was agreed among participants that the best way to understand the condition was to know a person with diabetes. This highlighted the need for social and experiential learning to combat condition mismanagement as it alluded that reliance on primary care can be caused by isolation while self-managing.

5.4 Findings: Self-Management Principles

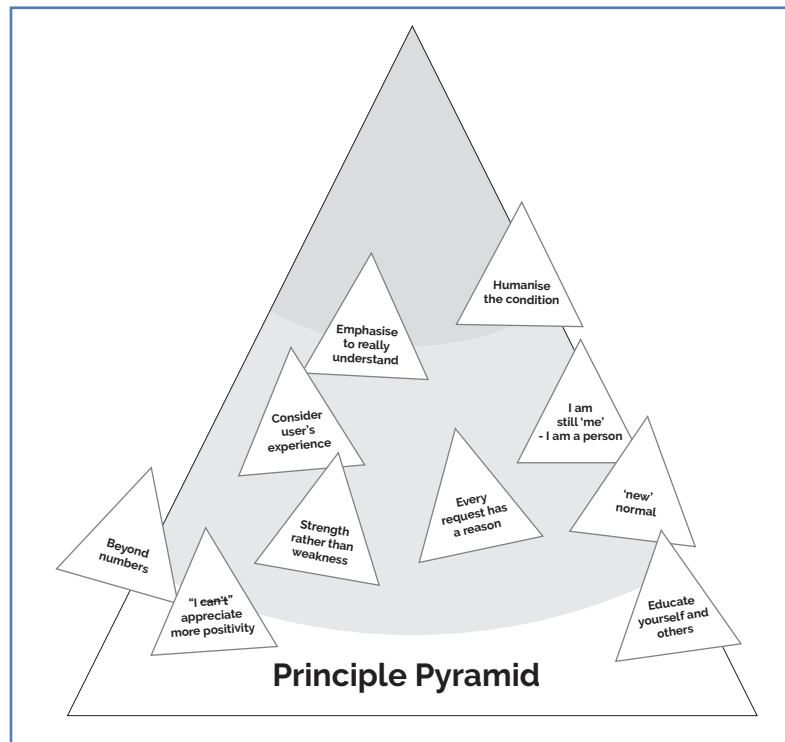


Figure 27: McIntosh, R. (2019) Illustration of the Principle Pyramid activity outcome from the Participatory Workshop. Diagram. Source: authors own.

Following the situational and thematic analysis of the fieldwork undertaken to discover the barriers and facilitators of type 1 diabetes self-management beyond the self, I synthesised the collective findings across both the interactive interviews and participatory workshop engagements, taking into account participants suggestions from the Principle Pyramid output (Figure 27), to reveal preferable self-management principles across my participant sample;

Finding 1: Self-management relations go beyond a singular user and their devices

A key finding from this participatory design practice was that a user's self-management goes beyond the singular self and affects other stakeholders directly and indirectly. The focus of this research was more relational and explored the barriers and facilitators of preferable self-management relationships. This was examined through the situational and relational mapping from the interactive interviews as well as co-validated during the participatory workshop. Notably, all research participants across both samples had not considered their self-management of type 1 diabetes beyond crucial stakeholders actively involved but considered these engagements insightful as looking beyond their periphery revealed opportunities for innovation within a user's broader network. From *what if* provotyping and *alternative now* user journey mapping, came positive notions of "our condition" rather individualistic perceptions as well as principles towards a

“new normal” (Figure 27). Through exploring self-management relationships from micro and macro perspectives, participants’ situational outlook of their condition changed as well as their role and agency as a user to influence change and encourage new connections.

Finding 2: *Self-management trust needs to consider the holistic user experience*

From investigating user’s relationships with their digital self-management devices, most participants raised concerns towards the functionality of their devices and how their accuracy impacted trust within these products and systems. Participants questioned if manufacturers had considered the lived experience of these devices with users as problems were common in day-to-day contexts, and some could have been fatal. These issues also affected trust and relationships with those who are integral to self-management, as users are “beyond numbers” with the importance of “humanising the condition” (Figure 27). Therefore, participants generally preferred their traditional devices over newer technology as they could trust these systems more. Affirming that digital self-management devices should be designed around these user needs and holistic experience to build trust and relationships towards connected systems.

Finding 3: *Self-management education and experiential insight is key*

Throughout this research, educational opportunities continually arose from participants towards self-management barriers. In particular, participants realised that through early intervention of better education and relational empathy, situations could be transformed towards positive outcomes and avoid pain-points in user journeys. Participants saw the added importance and value of engaging with others who have lived experience of the condition as it was suggested that experiential insight and empathy was vital in ensuring effective learning and knowledge exchange. It was further suggested that this approach allows users to “educate yourself and others” (Figure 27). This supports that patient-to-patient learning and insight has been an under-utilised resource for those who self-manage a long term condition.

5.5 Discussion

From developing and delivering these findings, I will discuss how these outcomes answer my research question towards the evaluation of the effectiveness of my research practice.

Finding 1 relates to the core exploration of this research inquiry regarding self-management beyond the self. From the literature review, notions of relationships beyond the user and their self-

management devices were relatively undiscovered within this scope of context. However, from the situational and relational mapping activities undertaken, participants explored their broader health network visually as a discursive aid and tangible prompt during fieldwork engagement. This correlates with PD's emphasis on eliciting users' experiences and aspirations through creative methods (Spinuzzi, 2005). This practice indicated that self-management practice is beyond the singular self of the user and their devices and these mapping tools enabled participants to think beyond their periphery to discover new perspectives and encourage innovation as end-users. Hence, participants suggested that these further relationships beyond the end-user have not been fully considered within the design of self-management devices.

Finding 2 relates to the central problem of this research inquiry - trust as a barrier towards self-management relationships. From the literature review, it was suggested that digital self-management devices should improve user's trust towards their self-management practice due to the added insight these devices can generate. However, fieldwork showed how analogue self-management devices were notably more trusted by participants due to their reliability and accuracy over their digital counterparts as they were prone to functional issues. This correlates with PD's ability to help user's express experiences and needs in a way they can sometimes fail to describe individually (Sanders and Stappers, 2008) As such, throughout my fieldwork discovery, participants signalled that these devices did not fulfil user needs to self-manage effectively and user experience has been overlooked, resulting in a trust deficit. Therefore, if device manufacturers and the digital health and care industry could consider the holistic user experience of using these devices for long term conditions, they could design products and services that respond to real user needs and build trust within digital self-management systems.

Finding 3 relates to the foremost opportunity of this research - education and empathetic insight as facilitators to better self-management practice. From the literature review, it was implied that users could support their diabetes learning through digital self-management devices, even anticipate and prevent complications arising from systems like the artificial pancreas. However, throughout the interviews and workshop, participants acknowledged that within self-management relationships, users need to not only trust their device and support network but themselves and their ability to manage their diabetes. Throughout my fieldwork engagement, participants referred to education and long term condition awareness as a pivotal opportunity to improve self-management practice. Notably, from the collaborative discussion, participants learned from one another, and empathetic insight from others in similar situations was valued by participants

as an experiential resource, that they trusted more than conventional education approaches. Opportunities to explore empathy with non-diabetic people was a promising approach towards diabetes as a “new normal.” This correlates with PD’s ability to discover and drive front-end innovation (Pieters and Jansen, 2017). It is vital for those who self-manage to “educate yourself and others” by utilising broader networks and community connections as participants suggested that experiential insight and empathy was crucial for ensuring effective learning and knowledge exchange. This was supported through the workshop evaluation [Appendix E3] reinforcing the strength of this approach by showing the value of design-led approaches in exploring new perspectives while being engaging and enjoyable.

5.6 Constraints & Implications

Beyond the limitation of time for this MRes research project and scope of my inquiry, following completion of fieldwork and analysis, I have not yet had the opportunity to disseminate my research within the Digital Health and Care sector. However, with my Digital Health and Care Institute studentship, I intend to disseminate my research through DHI at industry conference events targeted at self-management and healthcare technology in 2020 to evaluate the impact of my project. Further opportunities for future research arose which I capture within Chapter 6.1

The implications of my research project and findings have relevance across many aspects of the Digital Health and Care sector audience, which is broad and diverse including; health boards, technology innovators, device manufacturers, policymakers as well as user research and experience designers with a focus on long term condition management. I would hope this research and its findings would enlighten this sector to consider the user’s experience and develop preferable relationships with technology - I further reflect on participatory design implications for this research in Chapter 6.2.

5.7 Summary

In this chapter, I analysed the fieldwork practice outputs using situational and thematic modes of analysis to reveal codes and synthesised themes towards preferable self-management principles for device end-users. In the following chapter, I will provide an evaluative conclusion to the research project and offer final reflections on the value of my participatory design practice.

6. Conclusion

6.1 Future research

This research project considers the relational, trust and educational issues between users and their self-management devices. Due to this research inquiry focusing on the self with self-management devices, I limited my participant scope to end-users with type 1 diabetes. However, through my participatory design practice and relationship emphasis for this inquiry, I was constrained from exploring other stakeholders in a users health network further. In particular, gaining the perspective of a participant's mother during the participatory workshop revealed new insights and opportunities beyond the end-user. For future research, it would be valuable to undertake this participatory design practice with other stakeholders; such as parents, partners and members of the diabetes team. [\[Appendix F1\]](#) Presented with the opportunity to continue my research further, I would engage with these other stakeholders who are relationally affected by type 1 diabetes to discover if their barriers and facilitators of self-management are similar to end-users and explore how they can influence effective practice and positive approaches for the user. With a more diverse and broader research sample, I would establish user profiling, akin to the notion of high intensity users, to explore different types of user's within this context. Moreover, I would aspire to explore other long-term conditions, such as; chronic obstructive pulmonary disease (COPD), coronary heart disease and chronic obesity, to explore findings across long term conditions to develop universal self-management principles beyond type 1 diabetes.

6.2 Final Reflections

For this practice-based research project, reflecting on how participatory design practice can help discover the barriers and facilitators of type 1 diabetes self-management - the evidence from the evaluation showed the value of participatory design within this inquiry by demonstrating this approach built relationships, trust and educational insight between participants and the researcher. I acknowledge the size of the sample used for this study and the challenges towards the recruitment of participants, as I needed to go through trusted intermediaries to source prospective users. Within this limited sample, I was successful in engaging a good range of experiences to inform the study and beyond. From the situational and relational stakeholder mapping produced artefacts of co-production between both parties as it allowed an opportunity to interact, learn and exchange knowledge from each other during the engagements.

I found the contextual focus of type 1 diabetes as a vehicle for exploring self-management appropriate for this study, as before engaging with participants I found the condition challenging to understand and struggled to grapple with it objectively. Through my fieldwork discovering the subjective lived experience of self-managing diabetes, I could not only understand the condition better but appreciate the complexity of participants situations from the interactive interviews and participatory workshop engagement. Hence, no matter how capable or smart a digital self-management device or system will be, if the user cannot fully harness this high-level potential or use the device properly at low-level then it will not benefit their self-management practice, and in some cases can contribute to further mismanagement of their condition. As such, looking back to the Scottish Government's *2020 vision* of an integrated health system with a focus on "prevention, anticipation and supported self-management" (2013: 3), I feel this research has shown that current healthcare practice for long term conditions is not yet ready for anticipative or preventative paradigms until self-management can be fully considered and that users are supported through developing progressive relationships, education and trust within themselves as well as their digital self-management system and broader support network. Hence, through this practice-based research, I have shown that PD is a valuable approach in exploring the barriers and facilitators of a complex and experiential context with end-users who are affected most by the inquiry. With this, a further dissemination opportunity would be to develop the framework and tools used during my research process into *how to use* guides to share and evaluate with others beyond the limitations of this study. Through the design principles generated in this research, it shows the importance of considering user experience and needs for those with long term conditions and how to develop preferable relationships with self-management technology for users, collaboratively with users.

References

- Aruba Networks. (2018) *Building the hospital of 2030*. URL: <https://www.arubanetworks.com/en-gb/press-release/healthcare-will-become-digitised-by-2030-to-keep-services-alive-experts-predict/?source=homepage> [accessed 20/08/19]
- Audit Scotland. (2017) *Transforming health and social care in Scotland*. URL: <http://www.audit-scotland.gov.uk/reports/e-hubs/transforming-health-and-social-care-in-scotland> [accessed 19/08/19]
- Bamberger, W. (2010) *Interpersonal Trust – Attempt of a Definition*. Scientific report, Technische Universität München.
- Bietz, M. J., Bloss, C. S., Calvert, S., Godino, J. G., Gregory, J., Claffey, M. P., Sheehan, J., and Patrick, K. (2016) *Opportunities and challenges in the use of personal health data for health research*. Journal of the American Medical Informatics Association : JAMIA, 23(e1), pp42–48.
- Black, E. (2018) *Diabetics are hacking old insulin pumps to make them smarter — here's what happened when I tried it*. CNBC. URL: <https://www.cnbc.com/2018/11/02/hacking-diabetes-with-this-diy-artificial-pancreas--review.html/> [accessed 22/08/19]
- Bødker, S. (1996) *Creating conditions for participation: Conflicts and resources in systems design*. Human Computer Interaction. 11 (3): pp215–236.
- Boer, L. and Donovan, J. (2012) *Provotypes for Participatory Innovation*. in Proceedings DIS '12 Designing Interactive Systems Conference, Newcastle Upon Tyne, UK, June 11–15, pp388–397
- Bolton, G. (2009) *Reflective practice: Writing and professional development* (2nd eds.). London: Sage.
- Bostrom, N. (2005) *A History of Transhumanist Thought*. Oxford: Faculty of Philosophy. Published in IEET Journal of Evolution and Technology Vol. 14 Issue 1.
- BDA [British Diabetic Association] (1993) *Recommendations for the Management of Diabetes in Primary Care*. London. BDA
- Braun, V. and Clarke, V (2006) *Using Thematic Analysis in Psychology*. Qualitative Research in Psychology, vol. 3. no. 2. pp77–101
- Bryman, A. (2012) *Social research methods*. Oxford University Press. doi: 10.1017/CBO9781107415324.004.
- Candy, L. (2006) *Practice Based Research: A Guide*. Creativity and Cognition Studios Report. pp1–19.
- Carmichael, F. (2019) *Who do you trust for health advice?* BBC Health. URL: <https://www.bbc.co.uk/news/health-48663843> [accessed 23/08/19]
- Clarke, A. E., Friese, C. and Washburn, R. S. (2017) *Situational analysis: grounded theory after the interpretive turn*. Sage Publications.
- Clarke E. A. (1974) *What is Preventive Medicine?* Canadian family physician Medecin de famille canadien, 20(11), 65–68. URL: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2274388/?page=1> [accessed 18/08/19]
- Clemensen, J., Danbjørg, D. B., Damkjær Syse, M., and Coxon IR. (2016) *The rise of patient 3.0: The impact of social media*. The 8th International Conference on e-Health. Accepted/In press.
- Creswell, J. W. (2009) *Research Design: Qualitative. Quantitative and Mixed Methods Approaches*. (3rd ed.) California: Sage.
- Creswell, J. W., and Miller, D. L. (2000) *Determining Validity in Qualitative Inquiry*. Theory into Practice, 39, [online] pp124–130, URL: https://people.ucsc.edu/~ktellez/Creswell_validity2000.pdf.
- Creswell, W. J., and Poth, N. C. (2018) *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). UK: SAGE publications Inc.
- Crotty, M. (1998) *The Foundations of Social Research: Meaning and perspective in the research process*. SAGE Publications.
- Coleman, C. (2016) *Connected Healthcare*. Telegraph. URL: <https://www.telegraph.co.uk/wellbeing/future-health/connected-healthcare/> [accessed 19/08/19]
- Constantinides, P. and Barrett, M. (2012) *A narrative networks approach to understanding coordination practices in emergency response*. Information and Organization 22(4), pp273–294
- Delamothe, T. (1993) *Wanted: guidelines that doctors will follow*. British Medical Journal 307, pp218–29
- Diabetes UK. (2019) *Diabetes and checking your blood sugars*. URL: <https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/testing> [accessed 16/08/19]

- Dias, D. and Paulo Silva Cunha, J. (2018). *Wearable Health Devices-Vital Sign Monitoring, Systems and Technologies*. Sensors (Basel, Switzerland), 18(8), 2414: pp1-28. <https://doi.org/10.3390/s18082414>
- Diffen. (2019) *Data vs Information - Difference and Comparison*. URL: https://www.diffen.com/difference/Data_vs_Information. [accessed 14/08/19]
- Digital Health & Care Scotland. (2018) *Scotland's Digital Health & Care Strategy*. URL: <https://www.digihealthcare.scot/wp-content/uploads/2018/04/25-April-2018-SCOTLANDS-DIGITAL-HEALTH-AND-CARE-STRATEGY-published.pdf> [accessed 10/08/19]
- Dunne, A and Raby, F. (2013) *Speculative Everything: Design, Fiction, and Social Dreaming*. MIT Press
- Dustin, J. (2018) *Moving towards interoperability within healthcare*. URL: <http://digitalhealthage.com/moving-towards-interoperability-within-healthcare/> [accessed 13/08/19]
- Eaton, S., Roberts, S. and Turner, B. (2015) *Delivering person centred care in long term conditions*. BMJ 2015; 350 :h181 URL: <https://www.bmj.com/content/bmj/350/bmj.h181.full.pdf>
- Edwards, C. (2018) *Remote health monitoring: the benefits of keeping in touch*. Verdict Medical Devices. URL: <https://www.medicaldevice-network.com/features/remote-health-monitoring-benefits/> [accessed 19/08/19]
- Ericsson. (2017) *From Healthcare to Homecare*. URL: https://www.ericsson.com/assets/local/trends-and-insights/consumer-insights/consumerlab/reports/2017/global-deck-healthcare-to-homecare_final.pdf [accessed 14/08/19]
- Farrington, C (2017) *Hacking diabetes: DIY artificial pancreas systems*. The Lancet. URL: [https://www.thelancet.com/journals/landia/article/PIIS2213-8587\(16\)30397-7/fulltext/](https://www.thelancet.com/journals/landia/article/PIIS2213-8587(16)30397-7/fulltext/) [accessed 16/08/19]
- Ferguson, B. (2016) *Investing in prevention: the need to make the case now*. Public Health England. <https://publichealthmatters.blog.gov.uk/2016/02/22/investing-in-prevention-the-need-to-make-the-case-now/> [accessed 12/08/19]
- Flick, U. (2008) *Designing Qualitative Research*. Book 1 of The SAGE Qualitative Research Kit. London/ Thousand Oaks, CA/ Dehli: Sage
- FQS. (2010) *Sample Size and Saturation in PhD Studies Using Qualitative Interviews*. URL: <http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027> [accessed 19/08/19]
- Frayling, C. (1993) *Research in Art and Design*. Royal College of Art Research Papers.
- Forcare (2017) *Why Interoperability Is So Important*. URL: <https://www.forcare.com/blog/why-interoperability-is-so-important> [accessed 24/08/19]
- Foster, D. (2017) *High intensity users: reducing the burden on accident & emergency departments*. URL: https://www.telstrahealth.com/content/dam/telstrahealth/pdfs/Dr-Foster_High-Intensity-Users-Report.pdf [accessed 14/08/19]
- Gagnon, S. and Chartier, L. (2012) *Health 3.0—The patient- clinician “arabic spring” in healthcare*. Health, 4, pp39-45. doi: 10.4236/health.2012.42008
- Genes, N., Violante, S., Cetrangol, C. Rogers, L. Schadt, E.E. and Chan, Y. Y. (2018) *From smart phone to EHR: a case report on integrating patient-generated health data*. npj Digital Med 1, 23 (2018). URL: <https://doi.org/10.1038/s41746-018-0030-8> [accessed 15/08/19]
- Gillies, J. C., Baird, A. G., and Gillies, E. M. (1995) *Balancing proactive and reactive care*. Occasional paper (Royal College of General Practitioners) ,71 (1995): 15-8. URL: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2560283/?page=1> [accessed 04/08/19]
- Gold, R. (1958) *Roles in sociological field observation*. Social Forces, 36, 207-213.
- Grant, R. (2015) *Proactive Health: The Elements of a Provider's Commitment*. URL: <https://www.evariant.com/blog/the-elements-of-a-providers-commitment> [accessed 09/08/19]
- Gray, D. E. (2014) *Doing Research in the Real World*. (3rd ed.), SAGE.
- Gray, H., Gray, K and Wegner, D (2007) *Dimensions of mind perception*. Science 315(5812): 619.
- Grayson, K., Halasyamani, L. and Dahl, D. (2018) *How to solve healthcare's trust deficit*. URL: <https://insight.kellogg.northwestern.edu/article/how-to-solve-healthcares-trust-deficit> [accessed 03/08/19]
- Halse, J., Reynolds, L. and Attenborough, J. (2018) *Creating new roles in healthcare: lessons from the literature*. Nursing Times [online]; 114: 5, 34-37. URL: <https://www.nursingtimes.net/roles/nurse-educators/creating-new-roles-in-healthcare-lessons-from-the-literature/7024293.article> [accessed 01/08/19]

- Hammer, R. (2016) *30 Healthcare Statistics That Keep Hospital Executives Up At Night*. URL: <https://getreferrallmd.com/2016/08/30-healthcare-statistics-keep-hospital-executives-night/> [accessed 01/08/19]
- Hamzah, A. and Wahid, F. (2016) *Participatory Design in the Development of Healthcare Systems: A Literature Review*. 10.1145/3018009.3018010.
- Heintzman, N. D. (2016) *A digital ecosystem of diabetes data and technology*. J. Diabetes Sci. Technol. 10, 25–41
- Hendricks, D. (2015) *The Trouble with the Internet of Things*. London Datastore. Greater London Authority.
- Hixon, T (2014) *The Huge, Neglected Opportunity For Proactive Medicine*. URL: <https://www.forbes.com/sites/toddhixon/2014/08/19/the-huge-neglected-opportunity-for-proactive-medicine/#40a3a9de61e1> [accessed 02/08/19]
- Hookway, B. (2014) *Chapter 1: The Subject of the Interface*. Interface. MIT Press. pp. 1–58. ISBN 9780262525503.
- Hopkins, A. Gabbay, J and Neuberger J. (1994) *Role of users of health care in achieving a quality service*. Qual Health Care (4):203–209. doi:10.1136/qshc.3.4.203
- Javors, J and Bramble, J. (2003) *Uncontrolled chronic disease: patient non-compliance or clinical mismanagement?* NCBI. URL: <https://www.ncbi.nlm.nih.gov/pubmed/14570385> [accessed 09/08/19]
- JDRF. (2019) *Artificial Pancreas*. URL: <https://jdrf.org.uk/our-research/about-our-research/treat/artificial-pancreas/> [accessed 12/08/19]
- Kato, T. and Kinoshita, M. (2017) *Preemptive medicine - a case study of diabetes*. New Business & Technology Department. Mitsui & Co. Global Strategic Studies Institute. URL: https://www.mitsui.com/mgssi/en/report/detail/_icsFiles/afiedfile/2018/01/15/170907m_katokinoshita_e_2.pdf [accessed 13/08/19]
- Kelly, J. (2014) *Designing for a Relationship other than Use*. PhD thesis, University of Southern Denmark.
- Kelly, J. (2018) *Towards Ethical Principles for Participatory Design Practice* (AOM). CoDesign. ISSN 1571-0882.
- Kelly, M. P., & Charlton, B. G. (1992) *Health promotion: time for a new philosophy?* The British journal of general practice : the journal of the Royal College of General Practitioners, 42(359), pp.223–224.
- Kelly, M. P. (1992) *Health Promotion in primary care: taking account of the patients point of view*. Journal of Advanced Nursing 17, pp.292–6.
- Kensing, F. and Blomberg, J. (1998) *Participatory design: Issues and concerns*. Computer Supported Cooperative Work (CSCW). 7, 3-4, pp.167-185.
- Krawiec, R.J., Nadler, J. Kinchley, P. Tye, E. And Jarboe, J. (2015) *No Appointment Necessary: How the IoT and patient-generated data can unlock health care value*. URL: <https://www2.deloitte.com/tr/en/pages/life-sciences-and-healthcare/articles/internet-of-things-iot-in-health-care-industry.html> [accessed 15/08/19]
- Kolko, J. (2010) *Abductive Thinking and Sensemaking: The Drivers of Design Synthesis*. Design Issues. 26, 15–28. 10.1162/desi.2010.26.1.15.
- Krippendorff, K (2004) *Content analysis: An introduction to its methodology*. Thousand Oaks: Sage
- Kidd, L. Fenner, L. Fagan, P and De Longh, A. (2005) *A practical guide to self-management support*. The Health Foundation. URL: <https://www.health.org.uk/publications/a-practical-guide-to-self-management-support> [accessed 14/08/19]
- Kumar, R. B., Goren, N. D., Stark, D. E., Wall, D. P., & Longhurst, C. A. (2016) *Automated integration of continuous glucose monitor data in the electronic health record using consumer technology*. Journal of the American Medical Informatics Association : JAMIA, 23(3), 532–537. URL: doi:10.1093/jamia/ocv206 [accessed 14/07/19]
- Lincoln, Y. S., and Guba, E. G. (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Luhmann, N. (2005) *Risk: a sociological theory*. Aldine Transaction.
- Mann, M. (2016) *This Diabetes Activist Hacked Her Medical Device and Made an Artificial Pancreas*. VICE. URL: https://www.vice.com/en_us/article/aekkyj/this-diabetes-activist-hacked-her-medical-device-and-made-an-artificial-pancreas [accessed 13/08/19]
- Mantzana, V., Themistocleous, M., Irani, Z., and Morabito, V. (2007) *Identifying healthcare actors involved in the adoption of information systems*. European Journal of Information Systems. 16, 1, pp.91-102.
- McCormick, J. (1994) *Health Promotion: the ethical dimension*. Lancet 344, pp.390-91.
- Mckenzie, D. (2015) *Generative Prototype Iteration in the Front End of the Design Process*. DS82: Proceedings of the 17th International Conference on Engineering and Product Design Education (E&PDE15), pp.272–277.
- Mackenzie, H. (2017) *Building Trust in Healthtech*. Edelman. URL: <https://www.edelman.co.uk/insights/building-trust-healthtech>

[accessed 03/08/19]

McIntosh, R. Ahn, S. Szczypka, M. Zhang, X. and Zhu, Y. (2018) *NHS 24 Connected Community*. GSA MDes Design Innovation and Service Design. URL: <https://mastermcintosh.myportfolio.com/nhs24-connected-community> [accessed 26/07/19]

McIntyre, A. (2008) *Participatory Action Research: Qualitative Research Methods*. Thousand Oaks: Sage Publications.

MedicineMatters (2017) *The artificial pancreas: Potential to transform diabetes care*. URL: <https://diabetes.medicinematters.com/artificial-pancreas-systems/the-artificial-pancreas-potential-to-transform-diabetes-care/12111508> [accessed 09/08/19]

mHealth (2019) *Changing Healthcare Forever: Digital Solutions for Long Term Condition Management*. URL: <https://mymhealth.com/file/mymhealth/pdf/mymhealth.pdf> [accessed 08/08/19]

Mitchell, V., Ross, T., Sims, R. and Parker, C. J. (2015) *Empirical investigation of the impact of using co-design methods when generating proposals for sustainable travel solutions*. CoDesign. 12 (4): 205–220. doi:10.1080/15710882.2015.1091894.

Nielson, J. (2000) *Why You Only Need to Test with 5 Users*. Nielson Norman Group. URL: <https://www.nngroup.com/articles/why-you-only-need-to-test-with-5-users/> [accessed 11/08/19]

Nielsen, J. and Landauer, T. (1993) *A mathematical model of the finding of usability problems*. Proceedings of ACM INTERCHI'93 Conference (Amsterdam, The Netherlands), pp.206–213.

NHS Education for Scotland (NES) (2018) *Digital Literacy Research Report*. URL: <https://www.nes.scot.nhs.uk/publications-and-resources/corporate-publications/digital-literacy-research-report.aspx> [accessed 01/08/19]

OpenAPS (2019) *What is #OpenAPS*. URL: <https://openaps.org/what-is-openaps/> [accessed 11/08/19]

Palau, J. (2018) *How smart, portable medical devices are changing lives*. URL: <https://life.spectator.co.uk/articles/how-smart-portable-medical-devices-are-changing-lives/> [accessed 10/08/19]

Parmiggiani, E and Mikalsen, M. (2013) *The Facets of Sociomateriality: A Systematic Mapping of Emerging Concepts and Definitions*. In: Aanestad M., Bratteteig T. (eds) Nordic Contributions in IS Research. SCIS 2013

Patton, M. Q. (2002) *Qualitative research and evaluation methods*. Qualitative Inquiry. doi: 10.2307/330063.

Piai, S. and Claps, M. (2013) *Bigger data, bigger healthcare*. URL: <https://www.intel.com/content/www/us/en/healthcare-it/solutions/documents/bigger-data-better-healthcare-idc-insights-white-paper.html> [accessed 02/08/19]

Pieters, M. and Jansen, S. (2017) *The 7 Principles of Complete Co-creation*. Amsterdam: BIS Publishers. p. 15. ISBN 978 90 6369 473 9.

Qazi, H. (2018) *Power & Participation: A guidebook to shift unequal power dynamics in participatory design practice*. The School of Design: Carnegie Mellon University. [online] Available at: <http://www.maymoon-design.com/guidebook/2018/8/25/participation-book>

Ragan, S. M. (2018) *Medicine Ignored This Insulin Problem. Hackers Solved It*. Medium. URL: <https://medium.com/neodotlife/dana-lewis-open-aps-hack-artificial-pancreas-af6ef23a997f> [accessed 13/08/19]

Robertson, T. and Simonsen, J. (2013) *International Handbook of Participatory Design* (1st. ed.). New York: Routledge.

Rouse, M (2019) *Internet of things (IoT)*. IOT Agenda.

Rothmann, M. Danbjørg, D. Jensen, C.M and Clemensen, J. (2016) *Participatory design in health care: participation, power and knowledge*. pp127–128. 10.1145/2948076.2948106.

Sage. (2008) *Gatekeeper*. URL: <https://methods.sagepub.com/reference/encyclopedia-of-survey-research-methods/n200.xml> [accessed 17/08/19]

Samuel, S. (2019) *How biohackers are trying to upgrade their brains, their bodies — and human nature*. Vox. URL: <https://www.vox.com/future-perfect/2019/6/25/18682583/biohacking-transhumanism-human-augmentation-genetic-engineering-crispr> [accessed 12/08/19]

Sanders, E. B. N. (2002) *From user-centered to participatory design approaches*. In Design and the Social Sciences: Making Connections. Taylor & Francis, 1–8.

Sanders, E. B. N. and Stappers, P. J. (2008) *Co-creation and the new landscapes of design*. CoDesign. 4, 1, pp.5–18.

Schaefer, J. (2017) *Industrial Internet of Things - Connected Everything*. URL: <https://www.ifm.eng.cam.ac.uk/insights/automation/iiot-report/> [accessed 03/08/19]

- Schön, A. D. (1991). *The reflective practitioner: How professionals think in action*. UK: Arena, Ashgate Publishing Limited.
- Schuler, D. and Namioka, A. (1993) *Participatory Design: Principles and Practices*. CRC Press.
- Scottish Government (2017) *The Scottish Health Survey 2017* URL: <https://www.gov.scot/publications/scottish-health-survey-2017-volume-1-main-report/> [accessed 24/07/19]
- Scottish Government. (2017) *Realising Scotland's full potential in a digital world: a digital strategy for Scotland*. URL: <https://www.gov.scot/publications/realising-scotlands-full-potential-digital-world-digital-strategy-scotland/> [accessed 20/07/19]
- Scottish Government. (2013) *Route Map to the 2020 Vision for Health and Social Care*. URL: http://www.sspc.ac.uk/media/Media_473395_smx.pdf [accessed 20/07/19]
- Scottish Government. (2017) *Targets and Indicators in Health and Social Care in Scotland*. URL: <https://www.gov.scot/binaries/content/documents/govscot/publications/research-finding/2017/11/review-targets-indicators-health-social-care-scotland/documents/00527689-pdf/00527689-pdf/govscot%3Adocument> [accessed 24/07/19]
- Scottish Government. (2018) *Practising Realistic Medicine*. URL: <https://www.gov.scot/publications/practising-realistic-medicine/> [accessed 20/07/19]
- Shah, N. and Villanueva, E. (2018) *The Promise of the Artificial Pancreas*. Empower. URL: https://www.empoweryourhealth.org/magazine/vol7_issue2/the-promise-of-the-artificial-pancreas [accessed 14/08/19]
- Slater, T. (2012) *What is Interoperability?* Network Centric Operations Industry Consortium - NCOIC
- Smith, S. (2017) *Global Sensors in Internet of Things (IoT) Devices Market, Analysis & Forecast: 2016 to 2022; (Focus on Pressure, Temperature, Light, Chemical, & Motion Sensors; and Applications in Healthcare, Manufacturing, Retail & Transportation)*. URL: https://www.researchandmarkets.com/research/bvgxvl/global_sensors_in [accessed 09/08/19]
- Smith, P., Morrow, R. and Ross, D. (2015) *Field Trials of Health Interventions: A Toolbox*. 3rd edition. Oxford (UK): OUP Oxford; Chapter 2, Types of intervention and their development. URL: <https://www.ncbi.nlm.nih.gov/books/NBK305514/> [accessed 14/07/19]
- Spence, J. (1960) *The Purpose and Practice of Medicine*. Oxford University Press for University of Durham Publications. pp.273-4.
- Spinuzzi, C. (2005) *The Methodology of Participatory Design*. Technical Communication (Washington), 52(2), pp 163–174.
- Ssozi-Mugarura, F. Blake, E. and Rivett, U. (2017) *Codesigning with communities to support rural water management in Uganda*. CoDesign, 13:2, pp.110-126.
- Stappers, P. and Giaccardi, E. (2019) *Research through Design*. URL: <https://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/research-through-design> [accessed 10/08/19]
- Trischler, J, Simon J. P, Stephen J. K. and Don R. S (2018) *The value of codesign: The effect of customer involvement in service design teams*. Journal of Service Research, 21(1): pp.75-100.
- Sanders, E. and Stappers, P. J. (2008) *Co-creation and the new landscapes of design*. CoDesign. 4(1): pp.5-18.
- Whitehead, J. (2017) *Practice and Theory in Action Research: Living-Theories as Frameworks for Action*. in Rowell, L., Shosh, J., Riel, M., . (ed.) The Palgrave International Handbook of Action Research. New York: Palgrave Macmillan, pp.387–401.
- Velden, M. and Mörtberg, C. (2014) *Participatory Design and Design for Values*. In: van den Hoven J., Vermaas P., van de Poel I. (eds) Handbook of Ethics, Values, and Technological Design. Springer, Dordrecht.
- Visser, F., Stappers, P., van der Lugt, R. and Sanders, E. (2005) *Contextmapping: experiences from practice*. CoDesign, 1(2), pp.119-149.
- Wolfson, D. (2019) *Erosion of trust threatens essential element of practicing medicine*. Modern Healthcare. URL: <https://www.modernhealthcare.com/opinion-editorial/commentary-erosion-trust-threatens-essential-element-practicing-medicine> [accessed 19/08/19]
- WHO. (2019) *Medical Device – Full Definition*. URL: https://www.who.int/medical_devices/full_definition/en/ [accessed 12/08/19]
- Wolcott, H. F. (2001) *The Art of Fieldwork*. Altamira Press.
- Wood, W. A., Bennett, A. V., & Basch, E. (2015) *Emerging uses of patient generated health data in clinical research*. Molecular oncology, 9(5), pp.1018–1024. URL: <https://doi.org/10.1016/j.molonc.2014.08.006> [accessed 10/08/19]

Appendices

Appendix A - Introduction

Appendix A1 - Previous Research

Appendix A2 - Long Term Condition Analysis

Appendix B - Literature Review

Appendix B1 - T1D Self-Management Devices

Appendix B2 - 'Signal' Scoping

Appendix C - Methodology

Appendix C1 - Methodological Positioning

Appendix C2 - Ethics Documentation

Appendix D - Fieldwork

Appendix D1 - Recruitment

Appendix D2 - Interview Interviews

Appendix D3 - Participatory Workshop

Appendix E - Analysis & Discussion

Appendix E1 - Fieldwork Transcripts

Appendix E2 - Situational Analysis

Appendix E3 - Thematic Analysis

Appendix F - Conclusion

Appendix F1 - Future Research Dissemination

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