HOW PATIENT INSIGHTS HAVE AN IMPACT ON DIABETES TREATMENT SOLUTIONS

MEDTECH COMPANIES CAN LEARN FROM PARENTS & TEENAGERS AFFECTED BY T1D IN ORDER TO FUEL BETTER AND MORE SUITED SOLUTIONS

MASTER THESIS PROJECT

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ABSTRACT

Over the last decades the technological diabetes care market has undergone significant improvements and developments, which have resulted in an increased demand, as well as the continuous need for innovation among patients.

This research aims to investigate and assess different T1D patient groups' pains, gains, and needs of diabetes technologies in order to remedy the disconnection between diabetes treatment technologies and its users need, as well as improve how MedTech companies go about designing for diabetes patients. Secondly the research will investigate whether the results from the qualitative study can be used to construct a conceptual model which can assist designers and MedTech companies in designing and develop tech solutions which are better targeted toward diabetes patients, thus striving to increase empowerment, self-care, quality of life.

A qualitative study focus on teenagers affected by type 1 diabetes and parents with children affected by type 1 diabetes was conducted in order to identify the perceptions, needs, pains and gains of patients in terms of their treatment and their use of technology. I total 8 patient group semi-structured interviews where conducted.

The thesis found from the created personas perceive the technologies at hand somewhat differently and that parents valued a more reliable and easier to use technical system, whereas the teenagers emphasized the need for more simplistic and modern technologies

Lastly the conceptual model is presented. The model guides the designer through the elements essential for designing more targeted solutions for the patient groups. The model allows for dealing with rapid innovation, and the companies will have a tool which can guide then through every step of the diabetes technology eco-system and can assist the companies in becoming '*first-in-class*' with technologies which the patients will value and use.

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Miemaria Syhler
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PREFACE

This thesis started out as thesis partnership consisting of three group members:

Myself: Miemaria Jasmine Zofia Syhler
Christine Rosschou-Wichmann
Sirin Eissa

Due to circumstances this thesis partnership was terminated in the beginning of March, and on the 27th of March the exemption to split up the group was granted.

Following the CBS guidelines for terminating a thesis partnership, a list describing collaborative parts must be presented in a preface:

Collaborative parts:

- Interview guides
- Interviews with:
    - Kirsten Nørgaard
    - Rasmus Linnet
    - K.
    - H.
    - M.
    - P.
    - R.

Everything except the above-mentioned bullet points is my, Miemaria Jasmine Zofia Syhler, individual work.

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ABBREVIATIONS

CSII	Continuous Subcutaneous Insulin Infusion
CGM	Continuous Glucose Monitor
DT	Design Thinking
FGM	Flash Glucose Monitor
HCP	Health Care Professionals
MDI	Multiple Day injections
mHealth	Mobile Health
QoL	Quality of Life
SAP	Sensor-Augmented Pump Therapy
T1D	Type 1 Diabetes
T2D	Type 2 Diabetes
UCD	User Centered Design
UK	United Kingdom
UX	User Experience
WHO	World Health Organization

CLARIFICATION OF CONCEPT:

MedTech companies:

MedTech is short for medical technologies and devices.

Medtech companies (such as Medtronic, ABBOTT and more pharma companies like NovoNordisk) are defined as companies that develop MedTech products such as, Medtech products with or without software, regardless of classification, Medtech solutions, apps and data collection, MedTech services and MedTech innovation.

In the healthcare industry MedTech is the relations between healthcare equipment and services and pharmaceutical and biotechnology (Piester & Rosager, 2017)

CHAPTER 1 - INTRODUCTION

"Knowing others is wisdom. Knowing the self is enlightenment. Mastering others requires force. Mastering the self requires strength."

(Lao Tzu, ancient Chinese philosopher and writer)

Over the last decades the technological diabetes care market has undergone significant improvements and developments, which have resulted in increased demand, as well as the continuous need for innovation among patients and healthcare organizations (Jahns, 2018).

Patients with a chronic disease have a growing interest in “self-management” of their treatment and a lot of the new technologies being released emphasize the patient’s central role in managing their illness (Lorig et al., 2001). However, time-consuming and/or very often painful activities such as finger prick glucose monitoring, frequent insulin injections and the constant counting of carbohydrate intake can take its toll in everyday life as well as on the psyche of the patients (Bailey et al., 2018). A study conducted by Nielsen et al. in 2016 showed that type 1 diabetes (T1D) is associated with lower health-related quality of life in Denmark.

According to the Danish databank eSundhed, which is part of Sundhedsdatastyrelsen, as of January 1. 2019, at least 25.925 Danes have reported to have type 1 diabetes (T1D), and in 2018 there had been 1025 new diabetes type 1 cases nationwide (esundhed, 2020). From 1997-2011 Diabetesforeningen states that the number of new cases of children and adolescents (ages 0 - 19 years) with type 1 diabetes has increased by 61% and the prevalence is continuously growing (Diabetesforeningen, 2011). Diabetes is thus the disease with the third largest cost of both in and outpatient hospital visits compared to the other several other diseases (Flachs et al, 2015).

Unfortunately, treatment goals are often unmet and patients with T1D all too frequently experience acute and long-term complications due to their diabetes, in addition to having less than ideal psychosocial outcomes (Prahalad et al., 2018). Nonetheless, diabetes technologies can have a beneficial impact on psychosocial health by reducing the burden of diabetes. Innovators and companies face many challenges within the diabetes field and a key question is how they make sure that their innovations are of value and benefit to their potential users.

This research aims to investigate and assess different T1D patient groups' pains, gains, and needs of diabetes technologies in order to remedy the disconnection between diabetes treatment technologies and its users need, as well as improve how MedTech companies go about designing for diabetes patients.

A qualitative study will be conducted in order to identify the perceptions, needs, pains and gains of patients in terms of their treatment and their use of technology.

The user groups which will be studied are parents with children with diabetes, teenagers (14-17).

Secondly, the research will investigate whether the results from the qualitative study can be used to construct a conceptual model which can assist designers and MedTech companies in designing and develop tech solutions and optimizing the user experience of patients and thereby hopefully sustain success for the solutions, both in terms of market success and psychosocial outcomes, with increased benefits in the form of empowerment, self-care, quality of life.

Research question

How do teenagers and parents with children affected by type 1 diabetes perceive digital diabetes solutions, and how can a conceptual model assist MedTech companies in targeting their customers better?

Sub-questions

- What does the literature say about diabetes patients' use of diabetes technologies and how do companies go about designing treatment solutions to their users?
- What defines the patient groups in terms of characteristics, needs, pains and gains and how do they differ?
- How can MedTech companies approach the differences of the two patient groups, and which parts of the product do they need to emphasize?

Delimitation:

Diabetes mellitus have two types of diabetes; type 1 and type 2 and both disease types are comprehensive in terms of patient groups and underlying factors. During a meeting with Novo

Nordisk in mid-January it was found that parents with children affected by T1D and teenagers with T1D were underexplored and often overlook as a user group. This caught the attention of the group. Focusing on both types of diabetes mellitus would be too comprehensive for a thesis of this scope.

Despite taking a different approach to the project, as originally intended by the group before partnership termination, this thesis will focus exclusively on T1D.

Within diabetes treatments there are many options of treatment tools and medication. This thesis will mainly focus on the digital treatment solutions of T1D, as digital treatment solutions are the most used within the chosen patient groups.

The focus is set on Danish patients and the Danish health care system in relation to superficial economic perspectives mentioned in the practical implications part of the discussion in chapter five.

As this thesis will take its foundation in a qualitative analytical setting, focusing on insights from the patient groups, no deeper analysis will be conducted for economic implications.

CHAPTER 2 - LITERATURE BACKGROUND

The following chapter aims to understand and investigate how different diabetes patient groups benefit from treatment technologies and digital health solutions, and subsequently how companies can use insights from users/patients to target and design products that are better suited to their customers.

The literature review will cross-examine current relevant literature to the research topic.

2.1 TYPE 1 DIABETES

T1D is defined as a chronic autoimmune disease attributed to the conditional degradation of the insulin-producing beta cells in the pancreatic islets of the pancreas, and due to the endogenous production of insulin being absent or produced in very small quantities, continuous lifelong treatment with insulin is required (Bladbjerg et al., 2012). T1D usually occurs before the age of 35 and is one of the most frequent types of child and adolescent diseases which was previously known as juvenile diabetes (Hanås, 2006). Every day a child is diagnosed with T1D (Diabetesforeningen, 2011) and researchers have yet to discover the exact reason why some people develop type 1 diabetes. It is however suggested that genetics and exposure to various viruses and other environmental factors may have an impact (Bladbjerg et al., 2012; Mayo Clinic, 2017).

Many recent studies have focused on how T1D patients experience and live with their disease. Studies on adolescents and teenagers are particularly well represented. According to Huus and Enskär (2007), gaining insights into how these young people and their parents deal with diabetes in their daily lives is essential in order to provide appropriate interventions.

Five themes have been identified to occur frequently in this patient group: Being different, being treated differently, living a regular life, having knowledge of one's body and taking care of oneself. Adolescents with diabetes often feel more mature than, and thus, different to their peers. Several also described that they were being treated differently after they had received their diagnosis as they were, for example, unable to participate in the same activities as their peers. Moreover, adolescents often felt embarrassed when using their treatment equipment, such as the insulin pump. Many adolescents reported their parents to be stricter than their peers as they felt monitored more frequently, nevertheless, some adolescents perceived this strictness as their parents being protective and supportive (Huus & Enskär, 2007). However, too much parental involvement or treatment supervision can often lead to anger, annoyance and conflict within the family household, (Viklund & Wikblad, 2009).

It has been reported that adolescents felt more motivated and secure as well as inspired when they felt they were surrounded by social acceptance of their condition (Viklund & Wikblad, 2009; Karlsson et al., 2008; Ellis et al., 2016). A stable foundation for self-management and adolescent autonomy was acquired through confirmation by, and the support of others, helped achieve adherence to treatment. Parental encouragement increased the certainty of teenagers' standpoints on treatment and needs, but peer acceptance also facilitated the incorporation of daily self-management activities (Karlsson et al., 2008).

The effects of T1D on adolescents' psychosocial wellbeing comes down to various factors. How adolescent patients live and cope with T1D depends on parental and peer acceptance, autonomy and support. However, a teenager living with T1D will usually experience a lot of worries, anxiety and stressors which can harm psychosocial outcomes. It has been described that many of the studied adolescents expressed that they tried to view diabetes as *"just one part of their lives that they tried to handle and then get on with the rest of their lives"* (Davidson et al., 2004, p. 76). However, not many were able to sustain this idea and the teenagers revealed ambivalent feelings towards their disease due to it affecting them for the rest of their lives. Care management also contained stressors for the teenagers. This came in the form of treatment consistency, the visibility of their treatment and feeling guilty about having "bad numbers". Thus, support should always come in a clinical form but also from parents and peers and especially from others with T1D (Davidson et al., 2004).

Guthrie & Guthrie (2009) further explain that parents' role in sustaining the success of the treatment and maintaining adherent discipline is essential. The multiple tasks connected to T1D can lead to depression, obsessive compulsive disorder and anxiety, therefore, these daily tasks require discipline. It is hard for parents to balance the right amount of discipline with relaxation of guidelines and "*self-care and self-management choices require stable emotional coping skills along with knowledge of the choices available*" (Guthrie and Guthrie, 2009, p. 162).

Family members are a resource that supports self-management of T1D, but T1D seen from the parents' perspective is underexplored. During their child's early childhood, middle childhood, and adolescence, parents are greatly involved in the child's treatment and are the main enforcers of the treatment management, especially if the child was diagnosed at an early age. As the parents have a crucial involvement in their child's treatment, it is important to understand the parents' perceptions of their role and effort. Some of the most prevalent worries experienced by parents with children diagnosed with T1D were long-term complications to the child, their wellbeing when they were alone with people who did not know how to handle their diabetes and conflicts within the relationship between child and parents. However, several parents recognized positive aspects of T1D, for example "*strong bonds and relationships within their family and a healthier lifestyle, including better food choices, more exercise, and quitting smoking*" (Mellin et al., 2004, p. 227). Parents influence how seriously diabetes will affect their children because they have the greatest ability to prepare their children to independently manage their treatment when they are older and the biggest influence in assisting in incorporating lifelong healthy habits (Ginsburg et al., 2005).

There is a need for evidence-based interventions and improved innovations in order to sustain the success of treatment and reduce the risk of long-term complications. Support in incorporating diabetes care into changing lifestyles and emphasis on the importance of addressing psychosocial health is needed to promote healthy support systems among young adults with T1D. Further interventions and future research should focus on innovative designs in order to evaluate the impact on young adult health and related outcomes (Monaghan et al., 2015).

2.2 TREATMENT TECHNOLOGIES

Diabetes technology is a term that incorporates a range of technologies, devices, online resources, mobile apps and telemedicine (Kubiak et al., 2020). In general, diabetes treatment directly corrects the lack of insulin, where insulin administration can be carried out either as injections or as continuous infusion. Over the past decades technologies that support the management of TD1 have gone through great advances, especially when it comes to continuous subcutaneous insulin infusion (CSII), continuous glucose monitoring (CGM) and, flash glucose monitoring (FGM) (The Lancet, 2019). These types of diabetes technologies contribute to the patient’s ability to self-manage their disease on a daily basis, and mobile health applications can be used to deliver health services and self-management tools and communicate data in real time, which can be used for the patient’s own self-assessment (Hunt, 2015).

Many of these diabetes-specific technologies/innovations are tools used as part of a broader diabetes management package (Liberman & Barnard-Kelly, 2020). When examining and assessing new technology for diabetic patients “*acceptability, usability, device burden and benefits, visibility, and smooth integration into everyday living are all important factors that must be examined when considering the introduction of a new technology*” (Liberman & Barnard-Kelly, 2020, p. s-130). It is also stated that in a collected diabetes management package “[…] *expert advice, education, psychological support, self-management skills, and endurance*” (Liberman & Barnard-Kelly, 2020, p. s-130) play a crucial role in the patient’s experience of, and interactions with, the available technologies. These claims are further supported by Kubiak et al. (2020), who explain that “*psychosocial factors, including the attitudes and beliefs of the person with diabetes that may impact diabetes self-management are a key factor when it comes to diabetes technology uptake and successful use*” (Kubiak et al., 2020, p. 448). By not exclusively focusing on patients’ self-reported outcomes, but also on the psychosocial outcomes of diabetes technologies can pave the way for dedicated self-management interventions and innovations (Kubiak et al., 2020, p. 449).

Continuous subcutaneous insulin infusion – CSII

CSII involves attachment via a cannula on the outside of the patient’s body to an electronic insulin pump which is programmed to deliver insulin to match the individual’s treatment needs (Misso et al., 2010; Diabetes UK, 2019). The pump is similar to multiple daily injections, as both adjusts the dose in response to measured blood glucose values.

There are two types of CSII:

Tethered pumps	Patch pumps
A tethered pump is hung close to the body and uses a fine tube to connect the pump to the cannula which is attached to the body. The pump is usually worn or carried in the patient's pocket, waistband or in a pouch.	Patch pumps are placed directly on the patient's body and have a cannula underneath. Patch pumps have no extra tubing and work via a remote.

Table 1 (Diabetes UK, 2019)

The CSII deliver insulin continuously over 24 hours in small pre-programmed amounts. A CSII works in two ways: "*(1) a pre-programmed amount of insulin delivered continuously corresponding to the basal rate and (2) an amount of insulin delivered in a shot corresponding to the immediate insulin need for food eaten or high glucose correction*" (Reznik (Ed.), 2019, p. 23). Although the pumps are similar to multiple daily injections (MDI), which may be given via pen-usage. The advantage of using an insulin pump is their ability to deliver tiny amounts of insulin which are tailored to the different periods of the day in order to suit the individual's requirements (Reznik (Ed.), 2019), furthermore, insulin pumps include less painful injections in relation to MDI (Diabetes UK, 2019). "*CSII provides the freedom and flexibility of lifestyle and produces better coping and acceptance of the rigors of daily diabetes care, with improved quality of life and greater adherence to recommendations*" (Kollipara et al., 2009, p. 295). Several advantages and benefits of CSII can be highlighted on the quality of life in diabetes patients. CSII users have shown significantly higher scores for diabetes specific QoL and mental health perceptions than those that use MDI (Thabit and Hovorka, 2015). Health-Related Quality of Life is defined as a "*multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning*" (HealthPeople & U.S. Department of Health and Human Services [2], 2010), which measure effects of chronic illness, treatments, and short- and long-term health-related disabilities. QoL goes beyond general health measures like population health and life expectancy which traditionally have been used as key indicators of population health (HealthPeople & U.S. Department of Health and Human Services [1], 2010). But in 1995 the World Health Organization (WHO) recognized the importance of evaluating and improving people's quality of life (HealthPeople & U.S. Department of Health and Human Services [1], 2010). Health-Related QoL is also related to well-being which assesses positive aspects of a person’s life, such as positive emotions and life satisfaction which is connected to psychosocial outcomes (HealthPeople & U.S. Department of Health and Human Services [2], 2010).

However, research has also shown that higher levels of psychological distress in young adults were associated with the use of CSII and therefore lower levels of QoL. Although, it is unclear whether this was prior to patients being placed on CSII, or if it developed after the use of CSII (Hislop et al., 2008). However, research on who would benefit from CSII most are still needed (Thabit & Hovorka, 2015).

Insulin pumps also have disadvantages. Although the pump presents flexibility in dosage as opposed to the rigid dosage of MDI, the physicality of the pump is not flexible. The pump must be attached to the patient’s body at all times and may only be taken off for smaller breaks, such as showering, swimming or short interval exercise (Kollipara et al., 2009). It has been reported that day-to-day diabetes management with the pump have many benefits, but it involves some work and stress, especially related to changing the tube and cannula (Sullivan-Bolyai et al., 2004). However, the parents reported that they experienced an overall improvement in QoL, for them as parents, but also for the child, siblings and the family. Moreover, they experienced a new level of flexibility. It has been further reported that mainly fathers of children with T1D felt discomfort and had hesitations towards the pump and viewed the pump, in the beginning, as putting their child on ‘life support’ fearing the child would be bullied at school. Parents to smaller children expressed worry in relation to the size and weight of the pumps. Ultimately, the parents stated the pumps ‘gave them their children back’ and they were freed from the strict diabetes management which affected the entire family. They also reported less stress and the children seemed to have an increased concentration at school (Sullivan-Bolyai et al., 2004).

Despite the many reported disadvantages, teens and parents of T1D patients have reported high levels of satisfaction with CSII-diabetes management, such as increased responsibility in adolescents. Moreover, few issues related to body image, appearance or social aspects of the pump was reported. Further advancement of the diabetes technologies will provide the T1D adolescents with a brighter future (Battelino, 2006).

Continuous Glucose Monitor - CGM

CGM's are currently a major focus of research in diabetes management (Vaddiraju et al., 2010); (Reznik (Ed.), 2019), and have significantly advanced the care of T1D patients (Moser et al, 2012). In CGM's, continuous subcutaneous glucose measurement happens via a sensor which is coated with the glucose oxidase enzyme, which catalyzes the oxidation of glucose to gluconolactone in the interstitial fluid. This produces O_2, H^+. Glucose concentration is thus correlated to an electrical signal which is transduced to the transmitter. The signal is subsequently translated into glucose values that will be transmitted and displayed on a receiver/monitor as biofeedback in real time (Reznik (Ed.), 2019). For CGM's, this happens automatically and continuously at approximately every five minutes day and night (Diabetes UK, 2016).

The CGM, also known as a sensor, is worn under the skin and alerts the patient on a monitoring device if the levels are low or high. Certain companies also provide the option of connecting the CGM to your smartphone (Diabetes UK, 2016).

Most CGM systems need to be calibrated with regular capillary blood glucose values in order to properly associate glucose values to the electrical signal (Reznik (Ed.), 2019). However, this can have its disadvantages and, as explained by Moser et al. (2012), it can be problematic, as the first blood glucose measurements are not displayed until after 10 hours. Furthermore, data information overload can also be of worry and confusion to certain patients (Diabets UK, 2016). Nevertheless, CGM's are especially useful during times when the patient may not normally check their glucose level, such as while sleeping. It has been found that child sleep disturbances are negatively associated with parental QoL satisfaction, and that children who use CGM's experience fewer sleep disturbances than those who do not use CGM's. Nonetheless, the parents of children who used CGM's experienced the exact opposite than their children (Sinisterra et al., 2020).

Despite the disadvantages of the CGM, the sensor also has its advantages as it provides real-time display of glucose levels which can prevent hypoglycemia. CGM's can also be used in combination with CSII's – also known as sensor-augmented pump therapy (SAP). This type of technology can be especially useful at night, where hypoglycemia can be prevented without the patient actively taking action. Even though CGM holds major advantages it is not for everyone (Lange, 2016).

It has been stated that CGM provide a general feeling of relief in everyday life, and it is a painless and uncomplicated solution in relation to the finger prick blood glucose test. However, some patients feel that the alarms can be disturbing and make their diabetes audible to the outside world. Less experienced patients can be overwhelmed by the amount of data, which can lead to constant frustration, feelings of helplessness, resignation or depression. Furthermore, CGM also has advantages for adolescents who are beginning to detach themselves from their parents in line with their age and take responsibility for their diabetes treatment. The adolescents can easily self-monitor the diabetes on either device monitors or smartphones. The CGM data can simultaneously be transparent to their parents who can, with some CGM models, monitor the adolescent's glucose levels. This can lead to conflicts between concerned parents and adolescents with T1D due to unsatisfactory glucose data, as no adolescent will accept any form of constant control and incapacity and CGM treatment will not be a success if parents misuse the CGM data to fully monitor their adolescents. Only a constructive partnership-based cooperation between parents and adolescent can achieve a successful treatment (Lange, 2016).

Flash Glucose Monitor – FGM

FGM is a newer type of sensor glucose testing. It is a small sensor worn under the skin, like a CGM, which also record the glucose levels continuously day and night. However, FGM's do not have the hypo- or hyperglycemia alarms like the CGM. In order to access the recorded glucose data, the sensor must be scanned by swiping the sensor with a touchscreen reader device. For every swipe it usually accesses the last eight hours of sugar levels. The newer versions of the FGM's allow the patients to scan the sensor via their smart phone and the data will then be readable on a linked app. Unlike CGM, the Freestyle Libre system does not require finger prick calibration due to it being factory calibrated (Reznik (Ed.), 2019).

According Reznik (Ed.) (2019) the FGM's are not suitable for patients with hypoglycemia or hypoglycemia unawareness due to the lack of alarms of highs and lows of glucose levels and a 5 to

10 minute delay in glucose response (Reznik (Ed.), 2019; Abbott, 2017), meaning that the reading the patient gets is 5-10 minutes delayed, which can potentially be life threatening to a patient with chronic hypoglycemia or hypoglycemia unawareness. FGM's inability to provide real-time readings consequently requires the patient to do glucose level readings in the middle of the night.

Some research has identified FGM's advantage in improving glucose levels and a reduced time spent in hyperglycemia compared to glucose level tests done by finger prick blood glucose testing and thereby increasing QoL (Pintus & Ng, 2019). Hayek et al. (2017) supports the findings of Pintus & Ng (2019), as it was found that, if used frequent and adherent, the FGM reduced the frequency of hypoglycemia, levels of worry and increased QoL compared with self-testing by the conventional finger-pricking method (Hayek et al., 2017).

Insulin pens

An insulin pen is a device used to inject insulin and according to an article in *Medical News Today* by Felman (2019) insulin pens are becoming more popular for administrating insulin, despite the growing technological advances in diabetes care. The pens allow a more simple and invisible way for the patient to handle their diabetes treatment (Felman, 2019; Diabetes UK, 2018).

The pens mostly fall into two different categories: disposable pens and reusable pens.
The disposable pens contain a prefilled insulin cartridge and after use the entire pen is thrown away. The reusable pens contain replaceable insulin cartridges and after use only the cartridge is discarded. The patient subsequently installs a new cartridge in the pen. The injection itself happens in the fatty tissue under the skin (Diabetes UK, 2018).

One the of the disadvantages of the pens is that it offers very limited variation in dosage, which are set – as opposed to the pumps where it is possible to alter the dosage according to the patient's needs. However, many insulin patients emphasize that the biggest value of the pen is its portability, discretion convenience and that it requires little or no instruction (Pearson, 2010). Development is also happening within the insulin pen field in the form of 'smart pens'. The smart pens offer a memory log, which the patient can store and download to another device. But recent data of dosage can also be viewed on the cap of the pen (Reznik (Ed.), 2019). Hospitals are starting to rely more on digitally available data, and it is being discussed whether insulin pens in its analogue form, can keep up with the demands from the 'Digital Diabetes Ecosystem' (Klonoff, 2018). Patients that prefer traditional pens could benefit from shifting to a smart pen in order to optimize their treatment in terms of achieving more precise dosage intervals and remembering at what time they performed an injection (Reznik (Ed.), 2019).

2.3 DIGITAL HEALTH

Digital health is also known as 'eHealth' or 'Health 2.0', and according to the WHO, the term 'Digital health' often include electronic health such as health-related information, resources and services provided electronically (WHO Europe, 2019; Lupton, 2006). Smart phones, smart watches, wearable, implanted or inserted sensors, monitor devices etc. are all innovative technologies that deliver health services to people and can be incorporated into health systems and provide greater access to health services and data evaluation. Digital health also offers patients a way to perform self-care remotely and thereby monitor their own health well-being and physical function of either their disease or chronic condition (Lupton, 2013).

According to a report, there are seven areas of key opportunities within digital health: *"(1) More systematic and high-quality care, (2) more proactive and targeted care, (3) better coordinated care, (4) improved access to specialist expertise, (5) greater patient engagement, (6) improved resource management, and (7) system improvement and learning"* (Imison et al., 2016, p. 7).

Digital health technologies can also promote communication between healthcare providers and patients, which encourage patients to engage in health activities and ensure the patients adhere to treatment protocols and their own self-management. Especially greater patient engagement is a key area in diabetes treatment (Lupton, 2013). A patient's pursuit of acquiring self-knowledge and increase well-being involves adopting one or several methods and tools to collect data about the individual patient's performance in daily life and treatment, e.g. glucose levels (Sjöklint et al., 2015). Li et al. (2010) describe that these certain classes of systems is classified as '*personal informatics'* and can potentially motivate behavioral change due to the patients strive to obtain self-knowledge. It is further described that self-tracking devices "*may alter the individual's incentives to choose* *among daily activities, e.g., resting in the sofa or going for a short walk, through the information updates*" (Sjöklint et al., 2015, p. 4). With digital health the patients become 'participants' who is actively involved in their own treatment and self-care and are at the very center of action-taking with their own health (Lupton, 2013). This type of patient is also called a 'digitally engaged patient' to describe the "*phenomenon in which lay people have been encouraged to take an active role in producing and consuming information about health and medicine by using digital technologies*" (Lupton, 2014, p. 857).

The treatment types involve data readers, either as a stand-alone devices or smartphone integration, which the patient themselves must assess, and with the given data the patients must adjust the needs - thus, the patient act as their own care person (Reznik (Ed.), 2019). Due to T1D being a disease that usually occurs in either childhood, or adolescent years. Self-management of children and adolescents are a big step towards gaining independence in T1D management and many realize that independence is necessary in order to achieve autonomy (Tuohy et al., 2019). Carrying out successful T1D self-management, in terms of maintaining blood glucose readings within target ranges and becoming familiar with physical symptoms, but will also assist the child or adolescent to believe that medical targets are attainable can lead to an improved lifestyle, both at school and at home and with hobbies (Tuohy et al.,2019).

Lastly, online digital health platforms and applications for smartphones, also known as mHealth (Mobile Health), has also emerged. Mobile devices, especially smartphones, have revolutionized people's lives in the last decade - including the way patients seek medical information. The demand of smartphone health apps continues to rise, as it is estimated that by 2020, there will be 6.1 billion smartphone users globally. Smartphones revolutionized the way we communicate and with the rising of the smartphone, countless items were replaced – everything from books to flashlights to GPS and cameras. The area of diabetes is no exception and there is an increased demand to incorporate diabetes devices into the smartphone (Kao et al. (2017).

In the context of mHealth, patient monitoring is defined as using technology to manage, monitor, and treat a patient's disease from a distance (WHO, 2011). Using connected software, such as

Diasend, the patients can “*facilitate data transmission to the health service provider*”, who can then asses the data from a distance Information (Management Association et al., 2017, 1184).

Although diabetes management apps show great potential for diabetes self-management “*the adoption of diabetes management apps by diabetes patients is poor*” (Zhang et al., 2019, p. 1) and “*the factors influencing patients’ intention to use these apps are unclear*” (Zhang et al., 2019, p. 1). It was found that patients were more willing to use diabetes apps adherently if they believed that the apps would beneficial to them. However, in a previous study it was found that some patients were “*reluctant to continue using diabetes management apps because they thought the apps were useless*” (Zhang et al., 2019 [2], p. 11). Surveyed experts believed the apps lacked comprehensiveness in functionalities and wanted a more integrated solution where all diabetes management activities were integrated, such as “*physical activity, nutrition, blood glucose testing, medication, health feedback, and education*” (Zhang et al., 2019, p. 12). Zhang et al (2019) concludes that in order to support development and promotion of diabetes apps it is important to understand the behavioral intention of the patient.

Stage-Based Model

The stage-Based model by Li et al. (2010) can be used to further understand how patients collect and reflect on the data which they use in their self-care and management.

The model is split into five-stages and characterizes how people transition between preparation, collection, integration, reflection, and action (Li et al., 2010). The model describes the iterative nature and approach of these stages and the barriers that can prevent transitions (Li et al., 2010; Epstein et al., 2015). The *preparation stage* occurs before people start collecting personal information. This stage concerns patients’ motivation to collect personal information and how they will record it. The *collection stage* is where patients start to collect the data itself, such as, glucose levels and carbohydrate count (Li et al., 2010). The *integration stage* is crucial for the next steps. In this stage the data from the collection stage are prepared, combined, and transformed for the user to reflect upon. The integration stage is usually a long process for the user as they must perform multiple actions to prepare the collected data for the next stage - the *reflection stage* (Li et al., 2010). However, the integration can be short, meaning that “*the user bears little responsibility in* *preparing the collected data for reflection*" (Li et al., 2010, p. 561). The *reflection stage* is when the user reflects on the personal information collected. In this stage there are two types of reflections: short-term, which is immediate reflection of information, and long-term, which is reflection after several days or weeks. Both can be of value for diabetes patients as short-term makes the user aware of their current status in e.g. glucose levels and nutrition. Long term is of value because it allows patients to compare the collected information between different times of the day and can reveal trends and patterns. In the *action stage* the patient chooses what they are going to do with their newfound understanding of themselves. Additionally, some systems will provide the user with an alarm, which indicates that the user should take action.

After the reflection of the patient's information patients may tailor their behaviors to match their goals. It is emphasized that the stages are iterative and patients will constantly incorporate new data and processes as they progress through the stages. Sometimes these changes are going to require new tools, which will change the way data is transformed and visualized. However, this model shows that barriers cascade. Problems that occur in the early stages affect the later stages e.g. not selecting the right tool may lead to incorrect data and problems collecting data can lead to insufficient reflections. Each stage can be classified as *user-driven* or *system-driven* – or a combination of both. In the user-driven stage the patient is fully responsible for the activity in the stage, while in the system-driven stage the system is responsible for the activity. Furthermore, people's lives are composed of different facets. In general, many systems are uni-faceted and only show one aspect of a person's life. Nevertheless, diabetes management it the opposite – multi-faceted – due to systems being associated with multiple facets of the patients' health (glucose levels and food consumption/carbohydrates) (Li et al., 2010).

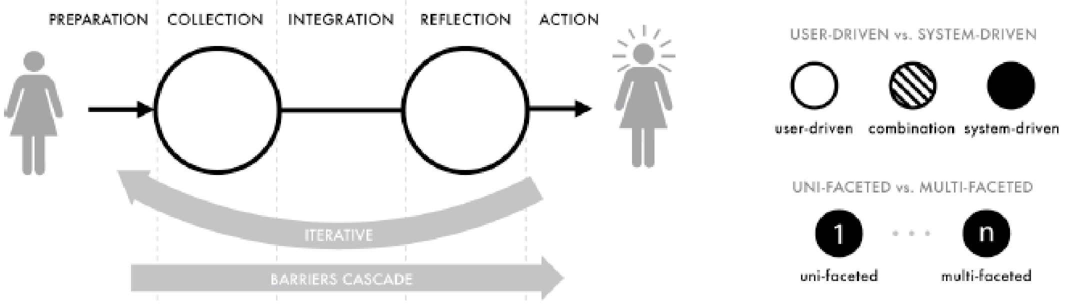


Figure 1 The Stage Based Model, Li et al. 2010

The UX Honeycomb

In order to improve patient engagement in self-management and tracking through digital health solutions – it is important to consider functionality and user experience (UX) factors during the development process so that the patients will adhere continuously to the technology and potentially reach patients/users who are skeptical when it comes to technology (Baek et al., 2018). UX is considered crucial to the success or failure of a product in the market and it enables design to focus on the user, especially with the growing number of mobile based technologies. Peter Morville, the creator of the model 'the UX Honeycomb', stated that there are seven factors that describe UX: *useful*; provides a purpose, *usable*; enabling users to effectively and efficiently achieve their end objective with a product, *findable*; ensures the product and its contents are easy to find, *credible*; ability to trust the product, *desirable*; desirability is reached through design, branding, image, identity, aesthetics and emotional design (Usability, 2013; Interaction Design Foundation, 2020). Desirability is not only about the aesthetics of a product, but how designers and companies can *"drive users to take action through design" using e.g. visuals, guides or forming elements such as buttons* (Riddle, 2012) . *Accessible*; can be accessed by user of a full range of abilities, and *valuable*; delivers value to the business and to the costumer and is a culmination of the other six factors (Usability, 2013; Interaction Design Foundation, 2020).

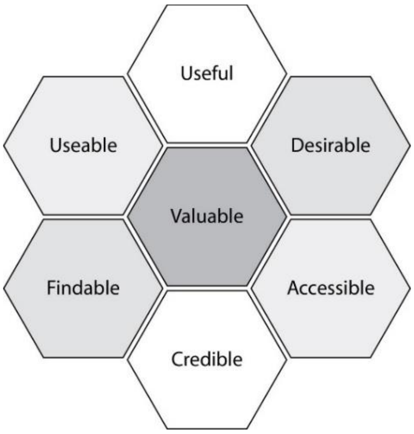


Figure 2 The UX Honeycomb

However, despite the UX Honeycomb being an established tool in design teaching, one of the weaknesses regarding the UX Honeycomb is the lack of connection and structure between the seven factors (Karagianni, 2018).

The Persona Method

Creating personas is a crucial part of a designer or company's journey in understanding the customer. Designers and companies usually design for people who are different from themselves The Persona Method is being used in many contexts including development of products, marketing, planning of communication, and service design (Nielsen, 2012). According to Nielsen and Hansen (2014), "*personas should be based on field data such as surveys, user interviews and observations*" (p.1665). Creating personas are of utmost importance as it connects the designers to the people they are creating their product/service for. "*Personas help prioritize audiences and bring about a focus on the most important audience(s). In line with these personas bring assumptions to the surface and challenge long-standing (and often incorrect) organizational assumptions about the customers.*" (Nielsen & Hansen, 2014, p. 1667). Cooper et al. (2007) explained: "*personas are not real people, but they are based on the behaviors and motivations of real people we have observed and represent them throughout the design process*" (p. 75). Nielsen (2012) support and uses the facts stated by Cooper et. al. (2007) and explains that, personas are a fictional stereotype of the user, which can assist in understanding the users' needs, experiences, behaviors and goals through an emphatic manner, and the design team can subsequently use the personas to imagine how a new system can be used and in what context. Ph.D. and specialist in personas and scenarios. An important notion is personas is that a persona isn't something that represents one person – it represents a user group (Nielsen, 2012).

2.4 CORPORATE AND DESIGN APPROACH TO THE DEVELOPMENT AND MARKETING OF DIGITAL HEALTH

Designing digital health solutions or medical devices that add value to the patient as well as being profitable is a hard job for MedTech companies, and it requires a significant amount of effort to deliver a healthcare product that meets customer demands. An interview with three leading experts within MedTech, in 2018, discussed customer demands for expert level services which calls for '*first-in-class design*', as well as a "*patient experience that stands out in an increasingly crowded market*" (Nilsson & Sheppard, 2018) was conducted. When asked how they would describe "*today's medical-device landscape*", Norström stated that patients nowadays expect more from their products, as users are becoming more accustomed, as consumers, to "rapid innovation" as companies constantly deploy new technologies to improve the customer experience, moreover, patients expect a similar service from medical products. When asked what the obstacles are in order to achieve the wanted level of design and innovation, Liedtke explained that many MedTech solutions have been technology-centric rather than user-centric, as a result the technology itself has been optimized "*rather than addressing the entire patient journey*" (Nilsson & Sheppard, 2018). Eichmann supports this explaining "*In the past, some device companies assumed that complying with user-testing regulation and guidelines was enough to make them user-centric. That might have been true up to a point, but laws and regulations don't help you keep pace with design innovation, usability, software development, or technology advances*." (Nilsson & Sheppard, 2018). When asked what they can do in order to embrace design and meet the challenges Eichmann states that companies should look at the burden of the disease and the full patient experience – this means mapping out the full patient user journey from morning until night and understand "*the pain and frustration that the disease state can bring*", as well as thinking about the other stakeholders than the patients themselves, but HCP's and the family members (Nilsson & Sheppard, 2018). Patient insights and experience should therefore become a crucial part of the quality of any healthcare service.

Design Thinking (DT) & User Centered Design (UCD)

Solving problems and designing innovations can be both complex and interdisciplinary, especially within healthcare where companies strive to design both personalized, accessible and innovative solutions. But, how do companies find out what needs the end-users have, and how do they design solutions that matches those needs?

Design thinking is a problem-solving, non-linear iterative framework that strives for innovation and ideation in order to design innovative solutions for specific problems and is not limited to designing for only software e.g. interfaces or hardware e.g. devices (Interaction Design Foundation, 2016). Design teams use DT as a way to tackle ill-defined, unknown or unexplored problems and rethinks them in a human-centric-way, which allows them to focus on what is most important for the users (Interaction Design Foundation, 2016; Roger, 2009).

DT consists of five steps which can contribute to the entire design project, with the main goal being to gain a deep understanding of the product and its users. The five stages are: (1) Empathize, (2) define, (3) ideate, (4) prototype & (5) test (Interaction Design Foundation, 2016). The first step researches the user's needs and challenges. This can be done through interviews and/or observations. Due to DT being human-centered empathy is crucial as it allows the designer to set aside their own assumptions and gain real insights into the user. In the second stage the designer defines and accumulates the information gathered about the user and from there pinpoint what needs to be solved. In the third step the designers start to generate ideas and look for alternative ways to view the problem and identify innovative solutions, which the designers can prototype. Next is the fourth experimental step where designers start to create and prototype solutions for the problem. The prototypes are usually inexpensive low fidelity versions of the product. In the last and fifth step the designers test their solutions. As DT is an iterate model, the results generated will often lead to having to redefine a few things and thereby return to previous steps in the process in order to make further alterations and refinements until the product has a satisfactory solution to the defined problem (Interaction Design Foundation, 2016).

Like DT, UCD is about the designer putting themselves in the end-user's shoes and emphasizes the understanding of user (patient) characteristics and needs as the basis of the design (Mannonen, 2017). UCD aims to capture the entire user experience and is based upon the explicit understanding of the users, tasks and environments and is applied to computer-based interactive systems (ISO, 2010). UCD also aims to improve and enhance user satisfaction by improving usability, user experience and accessibility in the interaction with the product (Interaction Design Foundation, 2017). UCD consists of four phases: (1) Context, (2) requirements, (3) design & (4) evaluation (Interaction Design Foundation, 2017; Usability, 2015). In the first phase the designers specify the context of use; who are the users, why will they use the product, and in what environment will they use it (Interaction Design Foundation, 2017; Usability, 2015). In the second phase the designers specify the user's requirements such as user goals (Interaction Design Foundation, 2017; Usability, 2015). In the design phase design solutions are being developed based on the user goals. The iterative stage of the process will start in this phase (Interaction Design Foundation, 2017; Usability, 2015). In the fourth and last stage the designed product will be evaluated against the users' context and requirements, to investigate how well a design is performing. The team will from the evaluation stage move back and forth until the results of the evaluation is satisfactory (Interaction Design Foundation, 2017; Usability, 2015).

DT and UCD can be similar as they both assure the users' needs are at the very center of the design. However, there is a subtle difference between the two: DT emphasizes more on ideation and innovation of problem solving and developing new products, whereas UCD is practiced improving user experience and usability (Interaction Design Foundation, 2017 & 2016).

Co-design/Participatory Design

Solutions in which the user is actively participating, have within the last few years been described as promising and a new way of improving clinical decisions and thereby their quality. There are also high expectations of patient centered health technologies potential in improving patient involvement and empowerment, but also improvement of the patient's treatment (Bergstedt & Sølvkjær (Ed.), 2019). Patients are directly experiencing their disease on their own bodies, and chronic illnesses affect not only the body's functioning ability but the entire patient's everyday life, QoL and relationships with others (Bergstedt & Sølvkjær (Ed.), 2019). According to 'Center for Innovativ Medicinsk Teknologi', CIMT, which is a research- and innovation center for Odense Universitetshospital and Syddansk Universitet, several studies have shown that health innovation projects have failed to meet the requirements and needs of the patients. However, Participatory Design should be considered a cure for those mistakes. Furthermore, they state that through close cooperation between HCP's, designers and the patients the risk of redesigning the technology later or the technology never really coming into use is reduced. Participatory Design is often a process that consists of design workshops where all groups are gathered to ensure active user involvement in the design process (CIMT, 2017).

CHAPTER 3 – METHODOLOGY

3.1 PHILOSOPHY OF SCIENCE

This project has its foundation grounded on critical realism, which is found within the intrinsic ontological philosophy, thus the intention is to firstly obtain an objective view when conducting the research and analyzing the data. The world's constructs and environments will differentiate for each individual within it. Consequently, each individuals' experience of the surroundings can be shaped by their senses and a continuously evolving world (Moses & Knutsen, 2012; Saunders et al., 2009). Thus, critical realism encompass components of both objectivism and subjectivism, as it is argued by Fleetwood (2014), critical realism *"offers an opportunity to reject objectivist ideas about universal laws without accepting a subjectivist belief in multiple realities" (Fleetwood, 2014, referenced in* Kozhevnikov & Vincent, 2019, N.P.) *as it pursues the best of both worlds* (Kozhevnikov & Vincent, 2019). Therefore, this research will also have basic epistemological underlying assumptions about the nature of the knowledge obtained from the conducted interviews. As the researcher will always have an intentional relation to the research. Thus, it is recognized that it is not possible to achieve an objective truth but rather an interpretational truth. However, the knowledge must be justified in order to claim it as a truth (Sandberg, 2005).

It is recognized that each individual has different perceptions of digital health solutions provided to the treatment and management of T1D, furthermore the organizations will have a different perception as opposed to the patients, thus the organizational perspective will provide the foundation for the research. Therefore, the experience of digital health solutions offered to treat and manage T1D relates to the subjective world of the individual, thereby recognizing that the different patterns and layers within the world can be subjected to misunderstanding and complications. The patterns and layers create the environment in which the individuals perceive and interpret their experiences.

Using a critical realism paradigm, it is possible to examine the individuals' experience and perception of digital health solutions offered and describing its context as it is being continuously used and experienced (Moses & Knutson, 2012). The purpose of this perspective and theorizing is not to uncover an objective truth about the individuals' experiences and opinions on digital health T1D solutions. However, the purpose is to explore the subjective truths the individuals expresses regarding the needs, pains and gains of digital health T1D solutions and establish knowledge interpreted from the findings (Stinchcombe, 1991; Sandberg, 2005). Utilizing the critical realism perspective, it is further acknowledged that the environment which the individuals interact with can affect their experience, thus the individual will strive to find an understanding through socially constructed interpretations and perceptions (Saunders et al. 2009). These experiences and perceptions are externally influenced by the individual's surroundings and circumstances which will be presented in the analysis.

3.2 METHODOLOGICAL APPROACH AND RESEARCH DESIGN

The approach to this project will take an inductive point of departure. The project will be approached with an open mind in relation to the data collection while exploring the experience and assessment of T1D digital health solutions, whilst also exploring perspectives from several individuals in the medical and pharmaceutical industry. Moreover, perspectives from different patient groups will also help to provide a greater knowledge of the research at hand. Based on the empirical data, a qualitative research question has been constructed. This approach was chosen as there is room for a more in-depth outlook, as opposed to what a quantitative research question could offer (Matthews & Ross, 2010).

The approach to theory development in this thesis will be based on abduction as it has proven to be effective when analyzing qualitative data. The background for conducting an abductive research starts with an unmet expectation which is interpreted by using present theories, thus it is possible to analyze the research in a systematic manner (Timmermans & Tavory, 2012). It is argued that abduction is an interaction between present theories and empirical data which is advantageous to the research question, as it allows the research to explore new perceptions. Abduction is the result of a collaboration of induction and deduction, hence for abduction to be beneficial is must meet two requirements; first and foremost is, it must be possible to test it empirically, and lastly that test must be successful (Swedberg, 2016). As previously mentioned, the abductive approach starts with an unmet expectation, throughout the study it will be compared continuously to theory in order to interpret the new discovery. Abduction is evened between induction and deduction, hence it is possible to examine theories that may be plausible. As the unmet expectation uncovered can be analyzed in relation to magnitude, timing, frequency and location (Van Maanen et al., 2007)

Using the abductive research approach this project has collected data through semi-structured interviews. As abduction is a part of all phases in the continuous process of research, the empirical data will be followed by the use of relevant theories and theoretical concepts.

3.3 DATA COLLECTION

Interview Type and Design

The qualitative interview is a data generation method that seeks to capture and understand experiences and events from the interviewees' perspective (Kvale & Brinkmann 2009). Within the scope of qualitative interview styles, the open-ended, semi-structured interview was chosen. The semi-structured interview is a strategy where the researcher asks a series of predetermined open-ended questions, thus the researcher will have more control over the topics of the interview compared to structured interviews or set in stone questionnaires (Given,2008). The semi-structured interview allows the researcher to ask for concrete information and more narrative questions. In addition to these questions semi-structured interviews also allow for both set and improvised follow-up questions as further information is built through the researcher’s listening skills (Given,2008). Semi-structured interviews may also lead the conversation into areas which was not previously considered or prepared. These areas can contain significant contributions to further the understanding of the research being conducted (Saunders et al.,2009). However, a number of issues can be identified. Interview bias is where the researcher’s tone, comments or non-verbal behavior create bias, as it may influence how the interviewee respond and bias can also occur in how the responses are interpreted. Response bias in the view of the interviewee can also occur as the interview process can be deemed intrusive to sensitive subjects and interviewees may choose not to reveal or discuss one or several aspects of what the researcher wants to explore. Sanders et al. (2009) thereby states that the interviewees may wish to picture themselves in a more socially desirable role (Saunders et al., 2009).

Instead of conducting the interviews in the traditional manner of face to face 9/10 interviews had to be conducted via phone due to various obstacles. Even though the method of phone interviews is often connected to several issues such as reduced reliability, not being able to control the pace and flow of the interviews, and not being able to witness non-verbal behavior of the participant. The phone interview did allow for a more convenient data collection, and access to the interviewees, where it was deemed easier, as some interviewees lived in different regions of the country, and were not able to meet face to face, thus they would have been eliminated from the study.

For the design of the interviews, five semi-structured interview guides were designed with an arrangement of themes to be covered and prepared questions (Kvale, 2011). One for each of the practitioners and patients. In the medical practitioner interview the interview guide followed a structure that start out with introductory questions, followed by more in-depth questions. Lastly, as the interview progressed it was possible the widen the perspective to understand how the practitioner saw the user's experiences of treatment technologies under clinical circumstances, but also where research and development is going within T1D technologies.

For the corporate practitioner interview with the Associate Global Project Director in Novo Nordisk Sweden the interview also started with introductory questions which subsequently lead to more in-depth questions about users, the market regarding the new Smart Pens which are soon to be launched. In regard to the patient groups, all three interview guides had the same overall structure and generally contained some of the same questions, which was altered in order to fit the specific patient group**.** All interview guides where created prior to the group termination; thus, the interview guides and conducted interviews presents a somewhat different direction than this thesis. The questions in the three interview guides were however designed to somewhat cover stages of the Stage-Based model and a range of the factors in the UX Honeycomb, thus they were still valuable for this thesis direction. The interview guides started with a number of preliminary questions about specific treatment and age of diagnosis. This was followed by more narrative questions regarding their specific situation and questions which were designed to dig deeper into topics relevant for the specific patient group and perceptions of living with the disease.

The design of the questions and the interview guide itself were to be brief, simple and structured with open-ended follow-up questions to the main inquiries (Kvale, 2011; Matthews & Ross, 2010).

The interviewees in the patient groups were allowed to explain as much as they could, but they were sometimes asked to elaborate to gain a deeper understanding of the explained phenomena.

Identical for all interviews was the interview sessions started with a briefing of the purpose of the interview and the upcoming topics and structure to prepare them. According to principles by Kvale & Brinkmann (2009) this is done to avoid later tension or anxiety of the interviewee, as the subjects discussed are often personal and emotional and if not briefed the interviewee may also be left wondering about the purpose and later use of the interview. During the briefing the interviewees were also informed on how their data would be handled and for how long the data would be kept. Permissions to record the interviews was also collected. After the interviews a debriefing was held, and the interviewees were asked if they had any follow-up questions (Kvale & Brinkmann, 2009).

Selecting the interview participants

Due to the project's focus on parents' and teenagers' experience of living with diabetes, how technologies are used and assessed by patients, and how to optimize development and design of diabetes technologies, a purposive sample including parents of children with T1D, teenagers with T1D and practitioners within the field was selected. One young adult with T1D was also sampled in order to provide a retrospective view on how life as a teenager with T1D was. For practitioners, a clinical and corporate view was sought out as it was deemed important to provide a professional perspective on diabetes treatment in order to understand the 'eco system' of diabetes treatment technologies better and what factors practitioners take into account when it comes to advising patients on which treatment solution they should use, and how corporate practitioners go about developing and market to T1D patients.

Gaining access to interview participants

Due to unsuccessful first attempts an alternative approach was chosen to gather participants. It was decided to explore social media as an option for recruiting interview participants. Facebook group administrators were contacted in order to get permission to post in the groups. Getting consent from group administrators was deemed important as the validity of the administrators informed consent would depend on the credibility of the recruitment post. The groups "Forældre til børn med diabetes type 1.." and ”Diabetes i Danmark (os med type 1)” provided the majority of the participants. The participants replied to the post and contact was then established via private message or email. A date and expectations were then agreed upon. A contact via Instagram was also established via the Diabetesforeningens account. The participant was a teenage girl who was responsible for the current "Instagram take over" of Diabetesforeningens account. To gain access to practitioners a certain amount of networking was facilitated through the university and contact was then established.

Interview Execution and presentation of Interviewees

The collected semi-structured interviews were conducted in period starting on February 26th, 2020 to March 26th, 2020. The first interview was with Kirsten Nørgaard MD, DMSc., Specialist in endocrinology and internal medicine, Steno Diabetes Center Copenhagen. Later followed with another practitioner interview and interviews with parents, teenagers and a young adult.

In the following; table 1 contains information on duration of interview, date, grouping/position and the language in which the interview was conducted. Before starting the interview, the interviewees were asked if they would like to remain anonymous and if they would give consent to the interview being recorded for transcription purpose. Participants under 18 had to provide legal consent from their parents. It was decided after the first set of interviews to anonymize the remaining, as it was observed the majority of the participants wanted to remain anonymous. Some parents expressed the anonymity made them feel as if they could be more open.

Interviewee	Location of interview	Date of interview	Length of interview	Grouping/Position	Interview Language
Kirsten Nørgaard	Steno Office, Gentofte	26th of February	60 minutes	MD, DMSc., Specialist in endocrinology and internal medicine	English
Rasmus Linnet	Skype	28th of February	60 minutes	Associate Global Project Director at Novo Nordisk Sweden	English
K.	Messenger video call	1st of March	45 minutes	Teenager	Danish
H.	Phone call	3rd of March	40 minutes	Parent	Danish
M.	Phone call	3rd of March	38 minutes	Parent	Danish
P.	Phone call	5th of March	40 minutes	Parent	Danish

R.	Phone call	5th of March	30 minutes	Parent	Danish
E.	Phone call	8th of March	38 minutes	Teenager	Danish
S.W & A.	Phone call	9th of March	60 minutes	Parent & Teenager	Danish
S.	Phone call	26th of March	60 minutes	Young Adult	Danish

Table 1 Interviews

As shown in table 1, two interviews were conducted in English and eight in Danish. Both practitioners are working in environments where English is the norm or often used for academic communication, thus both of them expressed that they would like to do it in English to make the interview accessible and understandable for the other English-speaking group member at that time. The other interviews with parents, teenagers and the young adult were however conducted in Danish. This was done in order to accommodate the interviewees and make it easier for them as they were all Danish native speakers and thus being able to express themselves more open, naturally and easy. All the interviews were conducted via phone or skype, except the interview with Kirsten Nørgaard. Many, especially parents, expressed interviewing via phone was the best option for them as their everyday life was busy.

The role as researcher

During the collection of the qualitative data it is key to gain the trust and confidentiality of the interviewees due to the importance of achieving quality and depth of the generated knowledge, but also in having the participants feel that their information was treated morally responsibly (Kvale & Brinkmann, 2009). The social interaction which occurs in the interviews produces a collaborative creation in knowledge between the researcher and interviewees. Matthews & Ross (2010) states that during the interviews, it is the researcher's role to select the right techniques for asking questions and to listen attentively in order to encourage the interviewees to share their knowledge and stories. The role of the researcher also includes helping in creating a welcoming atmosphere in which the interviewee feels at ease and can open up and answer the questions honestly and comfortably (Matthews & Ross, 2010). As researcher it was important to continually throughout the interviews have an open mind and not judge the views of the participants (Matthews & Ross, 2010). This was achieved by behaving in a respectful, emphatic and calm manner and being sensitive towards the interviewee's boundaries and reactions during the interview. The consequence of this was that certain topics were too sensitive for the interviewee to elaborate on in depth. Further questions in regard to that topic was then avoided to maintain integrity as a researcher and a continuously safe environment. Each interview was adapted to the individual participant and how the questions were asked was attentively considered throughout the entire interview. However, according to Moses & Knutzen (2010), it is important to acknowledge that the researcher is part of the process of collecting data, therefore the presence of the researcher will have some social and biased influence on the participants and their answer.

3.4 DATA ANALYSIS

Transcribing

The interviews were transcribed in full detail including notes on the interviewees tone of voice and verbal reactions, such as laughter and expression of emotional state. The transcripts are produced in its original interview language but used quotes for the project will be translated into English. An approach such as this will be influenced by the chosen words and construction of sentences, thus a translation process will not be unbiased but affected by interpretation of what the interviewees' intention was with their statement.

Coding

Having collected and transcribed the qualitative empirical data, the data was then coded for further analysis. The coding was conducted using the software NVivo. The coding process was done over three cycles. The first coding cycle was conducted using a more deductive approach using several predetermined codes which matched the stages of the Stage-Based model. For the second cycle, the previous approach was repeated for the UX Honeycomb factors. For the third cycle a more inductive approach was undertaken using open coding as it secured a much broader understanding of the interviewees' perceptions in looking for ideas, insights and observations which went beyond the more rigid predetermined codes. The open codes were then categorized into wider-ranging categories relevant for the smaller categories in order to find existing patterns in the coded data (Miles et al., 2013).

Criteria of quality

Reliability:

According to Saunders et al. (2009) *"Reliability refers to the extent to which your data collection techniques or analysis procedure will yield consistent findings"* (Saunders et al. 2009, p. 156). Replicating the data is therefore possible for other researchers, were they to conduct the same study with the same applied methodology. The reliability criteria with qualitative data would not be expected to generate the precise same results, as the participants are all people with different perceptions and experiences. Hence, identical results cannot be achieved *"but it should be similar for similar groups of people"* (Matthews & Ross, 2010, p. 11). Reliable researches are not dependent on the individual researcher, hence achieving similar findings should be possible for other researchers. However, as the researcher works from the critical realism paradigm it is acknowledged that the researcher takes part in the process and the study is conducted from the researcher's interpretations and understanding of the experiences and reality of the interviewees (Matthews & Ross, 2010). It is therefore important to establish an interpretive awareness criterion, thus acknowledging the researcher's subjectivity throughout the process as opposed to neglecting it (Sandberg, 2005).

Validity:

Validity refers to whether the nature of the findings support the claims postulated in the research (Matthews & Ross, 2010).

By analyzing the findings using a communicative validity criterion, it is possible to achieve truth through community of interpretation, hence create an understanding between the researcher and the participants in order to create knowledge claims through the dialogue between the two. Thus, generating descriptions of the participant's lived experiences. It is imperative that the experience is conveyed through dialogue to achieve high communicative validity, as opposed to a one-sided interview with questions and subsequent answers.

Finally, to further justify the knowledge obtained, a transgressive validity must be achieved by searching for contradictions as opposed to coherence as the researcher may risk neglecting important elements such as ambiguity, complexity or multiplicity in the recounted experiences, thereby challenging the findings (Sandberg, 2005).

Models used to further analyze the collected data:

In order to take the data analysis further to analyze the two patient groups more in depth, a number of methods are taken into use. The Stage-Based model will be used to understand how the two patient groups go through the different stages; how they prepare to start collecting data and begin a treatment process, how they collect data to reflect upon, how they integrate and transform the collected data for reflection, how they take action on the accumulated knowledge from the previous stages and how they use it for their self-care and treatment management. For the analysis the UX Honeycomb will be set up against the stage-based model. Factors specifically relevant for the stages will be used as an extension to elaborate on their thoughts and experiences with each stage. The UX Honeycomb will be used to categorize what the patient groups say about the user characteristics of the UX and evidence will be given in the shape of quotes from the interviews emphasizing why it’s e.g. useful, usable, credible etc.

CHAPTER 4 - ANALYSIS

The following chapter creates the foundation for answering the first part of the research question: *"How do teenagers and parents with children affected by T1D perceive digital diabetes treatment solutions (…)"*.

The empirical data collected through the semi-structured interviews will be presented and split into three sections. The first section will present an analysis of the patient groups, teenagers and parents of children affected by T1D, perceptions of the UX using the factors from the UX Honeycomb, and how they maneuver around their diabetes treatment and self-management, based on the Stage-Based Model. The second part of the analysis will explore the differences between the two patient groups using descriptive personas of the specific patient groups based on the findings from the two models.

Disclaimer: Swearing occurs in the interviewee's quotes. In order to preserve integrity and authenticity, and trying to avoid bias as much as possible, it was decided to include the essence of their expressive freedom in order to emphasize their emotions and opinions. Thus, the quotes have not been censored.

4.1. PATIENT GROUPS EXPERIENCES AND PERCEPTIONS OF DIGITAL DIABETES TREATMENT SOLUTIONS

① PREPARATION STAGE

Parents:

As T1D is a disease that gets diagnosed early in a person's life, the parents will be the ones acting as primary carer and as "surrogate patients" as they support and care for the child(ren) every day, all year round as the main enforcers of the treatment management. Having a child diagnosed with T1D is a major situational disruption in the family and can often lead to sorrows and worrying. One parent describes:

"Suddenly you have a child with a chronic disease.. and let's just say that you cry a lot in the first period of time…" (M., Parent)

Not only is this new role as a parent mentally stressful, but being a parent to a child with T1D, they have a lot more to consider in terms of treatment, as they have full responsibility which can be demanding and challenging, "*you have to act as a nurse in some way because we actually have his life in our hands when he is not in the hospital"* (R., Parent).

When the child gets diagnosed with T1D it is the parents' responsibility to educate themselves in nutrition and how the different food types can affect glucose levels, but also recognize the symptoms of hyper- and hypoglycemia. Testing and keeping track of data, such as glucose levels, is also part of the daily and nightly routine of parents and especially learning how to dose the insulin while having these factors in mind can be challenging and overwhelming. Everyone getting diagnosed with T1D has to try out the basic insulin pen before going on a CSII, *"the starting point at the time" was that you have to learn the entire 'diabetes hell' before.. I mean.. manually before being offered a pump" (M., Parent).* M. also describes the overwhelming feeling of starting with understanding how everything interplays and the difficulties of learning the treatment processes, especially because: *"We were at the hospital, and my husband was talking to the nurse about V.'s lunch and said "oh well, then you have to do this, and then she has to have that, and then you have to give her two units", and I'm standing there "uuum why???" Two units? How… how do I calculate two units?". I couldn't figure it out… And I could not understand that "less is more"... I could not wrap my head around it..."* (M., Parent)

Applying for a CSII or CGM/FGM is a great motivational factor as it allows for an easier data collection. Getting the digital treatment tools after the insulin pen is a huge relief for many parents, and their children, and can lessen the burden of tracking the data. This is emphasized by parent M. who received the CSII for her daughter: *"When we got the pump… It did all the work for me... let's just say that I didn't cry that much anymore... It just became easier" (M., Parent).*

Parent P. emphasizes that whether parents choose pen or CSII it is important to involve the children. *"We can't just force it down over his head, we have to bring him along on the journey and say that we would like this to happen, but what do you think?"*. This emphasizes the need for getting the children on board as an active part of their treatment, as it prepares them to independently manage their own treatment when they get older, and parents play a very important factor in influencing how they can succeed in treatment and incorporate health habits.

However, applying and obtaining these tools can be challenging and lead to frustrations is the treatment solution is not a great fit. Parents seldom have a say in which type of brand or model they will receive. Thus, the parent S., who has two daughters with T1D, explains: *“In no way were we allowed to choose it, she just had it attached, and when everything is so new you just say “yes please”..”.*

Preparing for the upcoming stages involve understanding the parents’ situation and the knowledge they must gain in order to go through the upcoming stages. But, finding the right tool for collecting and managing data and treatment, which is suitable for the needs of everyone involved, can also be a difficult task and the families may have try different solutions in order to find an optimal fit.

Teenagers:

Living with T1D as a teenager, or getting diagnosed when you are a teenager, is challenging and often involve feelings of anxiety, distress and a sense of being different and being treated different. Displaying the disease and the treatment can cause the teenager to feel embarrassed and worst-case scenario avoid adhering to treatment.

SO., who is now a young adult, was diagnosed when she was 14 and explains the distress and fear she felt when she was a teenager and started using insulin pens. She elaborates she had a constant fear of losing her limbs, after a doctor had told her that having high levels of glucose for a long time could potentially results in having limbs amputated. Thus, she forced herself into having low glucose levels for a long time which caused her to have ten severe insulin shocks in just one year. She states: “*It’s just like people with anorexia, you get into this control situation where you don’t know how to control the situation, so you just do something that you think will solve the needs that you feel.. So, it all went to shit at the time and then I started seeing a psychologist*…”. She then explains that she started to feel better but looking back she explains that getting diabetes in her teens was devastating and *“No matter what I did I was almost consistently burdened by my diagnosis”.* She further explains, due to all the distress and trouble with achieving a healthier relationship with her diagnosis, she got a CSII to improve her treatment, self-management and increase her QoL: *“I then* *got the pump to somehow relax a little more because I did not have to take insulin.. so it was a more relaxed way to try and give me a better experience of my own disease".*

The example of SO. getting a pump in her teens is a fine example of having a more fitted tool provided to better fit the patients needs and manage one's disease. Not just technically and clinically, but also to provide her with a tool in order to improving psychosocial care and well-being, which will provide her with a better foundation to prepare her and assist her in adherence to treatment and self-management.

When it comes to preparing for self-management and treatment, or getting started with the treatment after diagnosis, the teenagers are not the ones applying for tools nor making the decisions, this is done by the parents and the HCP's.

When asked about who made the decision to start using a pump and sensor, teenager E. stated "*I'm, not quite sure, I think that it was a suggestion they gave to my parents that I too could get the pump, and I didn't really know what it was.. I was just told that this was an easier way to deal with my blood sugar and whatnot. So, my parents just thought that it would be for the best, because almost everyone got.. or.. almost every young person in Denmark gets one from the municipality or the hospital, or something like that.. So when I got the offer my parents took it. It was the best solution that they knew about, and that was it".*

E. also states that when asked what she prefers when it comes to collecting data and manage her disease, she prefers the pump over the pen: *"That is definitely the pump! Because it offers a lot more opportunities to faster regulate your blood sugar"*.

From the interviews it was evident that when it comes to preparation and understanding, it is also important to address when the teenager was diagnosed. The teenagers having been diagnosed at an early age was taught how to self-manage their treatment. However, the teens getting diagnosed will have to be educated in their disease and how to manage it. Teenager K., who was nine when she was diagnosed, expresses a mature view on her disease and explains she was taught about her disease when she was younger *"I had to get used to a lot of new stuff and I just had to figure out that diabetes was not as bad as it sounded at first. So, it was hard buy at the same time I felt insanely good at being there and I got a lot of help and some nice conversations where I gained a lot, so it was great being there"*. The interviewee SO. who got diagnosed when she was a teenager explained how hard it was to get diagnosed as a teenager, *"I was 13 when I got diagnosed.. really, really nice age I tell you.. really nice age to get diagnosed *laughs (sarcasm)*"*. She further elaborates she had a hard time coming to terms with her diagnosis and she refused to inject when she was at school because she was embarrassed, *"I felt like shit. I didn't do it, and when I finally did it I went to the toilet and stuff like that, I felt horrible… I couldn't stand any of it.. it was a really, really bad experience"*. Even though K. was diagnosed as a child she still recalls having similar feeling as SO., and K. explains that she also experienced some barriers to her treatment relating to issues with having to pull up her shirt and therefore she would rather have the pump, especially as a teenager: *"I could feel that I didn't like pulling my clothes up every time we had to eat, so I'd rather be on the pump".*

Being trained and getting used to a technology is also highly relevant for diabetic teenagers who were diagnosed several years earlier. Teenager K. expressed it was hard for her to change brands, but she explains, often the hospital will schedule a day where she will be taught how to use the new tools for her treatment*: "There have been times where I had to get used to it, everyone do, but I think that when I'm there and I get everything told, then they do a good job. Some days it's like 'Hey, would you like to try this pump?' and then 'Okay you would like to try it, then we can just find a day where you come over here and learn how this works', and then you get an entire day where they explain how they work exactly and the system".*

ASSOCIATED UX FACTOR: ACCESSIBLE

Parents:

Accessible technology is of utmost importance when it comes to preparing and managing a disease. In order for all users, parents and their children, to use the diabetes treatment solutions and prepare for collection of personal information, it must be accessible for all with all ranges of abilities and disabilities. P. who is worried about the technology emphasizes the importance for an accessible design: *"not all humans are equally technical... some people are just really good at it and can just fix an app and do whatever, and then all the sensors and pumps work, and then there are people who just messes up, and a lot is written in English - and I'm not very good at that"* (P., Parent). Another parent R. states that she is not worried about the technologies not being accessible enough for her son, but if a design is not accessible enough people would give up on it: *"He's turning 10, and he plays a lot of PlayStation so he will probably figure out everything and so will we, but of course, the less buttons you need to press and the easier that it's written, the more you will use it. Otherwise I think that you will get completely confused and give up in advance"*.

Teenagers:

Accessibility was not something the interviewed teenagers gave much thought. Some teenagers are completely self-reliant and independent in their treatment and show no signs of experiencing difficulties with the different treatment solutions they have. Nevertheless, some teenagers still choose to share their glucose levels via a followapp so their parents can check in on them, *"I have shared it with my parents.. so they can enter a followapp and then they can see my blood sugar and whatnot"* (E., Teenager). Also, some of the teenagers' parents still check their glucose levels at night, *"They also come at night sometimes if I have been high in the evening and take my blood sugar and it is super nice because I do not have to get up and I have school the next day, but it is lessened a bit after I am got older"* (K., Teenager). As the parents are still involved, it is crucial that the technologies are accessible for both the teenagers and parents.

② COLLECTION STAGE

Parents:

Collecting data for T1D treatment is a comprehensive chore that involves different tasks which make up the treatment and is required by doctors. Collecting data includes either glucose levels or carbohydrate counts for the next stages. Collecting these data can be done using different treatment tools such as CGM, FGM with connected app, mobile device scanner, or finger prick testing. For counting carbohydrates, mobile apps or integrated software in the pump are used. P explains: "*we use the app to see what's in the different foods.. when we are eating potatoes, then: "What's in potatoes?" *tap tap* how many grams do we have and so on*".

When collecting data, it can either be manually (user-driven) or automatic (system-driven). Using either an FGM, finger-prick glucose testing or plugging in carbohydrates are considered user-driven, as they must be conducted manually by the patient or primary carer. Using a CGM or having a SAP system is considered system-driven as data collection happens automatically.

Parent M. describes how her daughter on a normal school day manage her diabetes in a user-driven way when the parents are not around: *"She scans herself and the good thing is that when she's at school they eat reasonably continuously. She gets breakfast at home and then there is the 10-break, that means it's been three hours in which the opioid has been working in the body, so it fits well with her having food at 10:00. She then scans and type in carbohydrates, after a couple of hours she will have lunch and then she repeats"*.

There are, however, some barriers in this stage. CMG systems need to be calibrated several times a day in order to associate glucose values to the electrical signals and thus collect data. Not only are the calibrations painful but the glucose levels are not able to be displayed until after 10 hours. Though, S. explains that the FGM changed their life as collecting data through finger prick glucose testing was too much to handle, both for her and her youngest daughter:

"I couldn't cope if I had to finger prick my daughter every single day 8 .. 9 .. 12 .. 14 times. I mean.. I think it's abuse". This statement is also supported by R. who emphasizes: *"The one we have now has to be calibrated three times a day and he is getting tired of being stabbed in the fingers"*.

Another barrier is the nightly collection of data. P., who has a FGM for her son, explains that they want to change to a CGM due to the FGM having a delay in glucose measurement: *"I'm using it more at night at the moment, so I go to bed I check him before I get ready for the night and then I go in and check him again 5-10 min after because I can see if he is on his way up or down.. but we have signed up for a Dexcom G6 sensor because it can send alarms, and they measure every five minutes"*.

P. continues explaining that although this is going to be more beneficial a CGM will also have its barriers: *"He should then have a phone within a range of 6 meters... and I am slightly annoyed because I think, again, that it's a big responsibility to give a child, that now you also have to take care of this one... and a phone is expensive".*

Teenageres:
As stated in the parent-analysis, collecting data can either be manually (user-driven) or automatic (system-driven).

During the interview with parent S. and her teenage daughter A. it was discussed that, as a teenager, being able to scan for blood glucose via your phone would be the most optimized solution for the teenager to collect data, *“when you are a 15 year old girl, you always have your phone in your hand anyway, so it makes so much more sense to scan using that”* (S., Parent & A., Teenager).

When it comes to expressed barriers in terms of collection, SO. explains when she was a teenager, and went out partying, it was not easy to remember to check her insulin levels: “*When you stand in the toilet, you don’t really think “Oooh…” and you are so drunk.. It’s not exactly the time where you “Oooh yeah that’s right I have to remember to take my blood sugar and take my insulin”*. Teenager A. also explained that she started with using finger prick glucose testing because she did not want the FGM but ultimately changed to it because the doctor told her that she would lose sensation in her fingers.

The teenagers did however not provide much detail during the interviews on how they collect data. For them it is very straight forward, they use an app to assess their carbohydrate count, and subsequently enter the numbers into the CSII to check the glucose level, using either the CGM or scan with the FGM. The overall attitude is very relaxed and settled when it comes to the technical part and the teenagers felt more at ease having changed from insulin pen to CSII, hence, having been provided proper and more suited tools.

ASSOCIATED UX FACTORS: USABLE & FINDABLE

Parents:

When it comes to collecting data, it is important the users can easily find what they are looking for, but also finding the product. The product being usable goes hand in hand with findable when it comes to diabetes treatments, as you should conveniently and quickly find the functions you are a looking for. Usability ensures that the user can effectively and efficiently achieve their objective in an easy and appealing way.

H., who has a CSII/CGM system with a remote control for his son, emphasizes how easy and useful the system they have is: “*can reach so far that that I can just sit and watch his blood sugar levels on my phone and can deliver insulin with the remote control and then I sit there for 8 hours drinking coffee and watch football and when the day is over I look around and whatnot, and then he runs around with a chocolate biscuit in his mouth and eats between the matches, I then give* *him a little bit of insulin, pays attention and when the day is over N. says "Dad, it's like I don't even have diabetes" .. and then I don't say anything... I already have it fixed*".

He explains further that the type of CSII and CGM system that he has is not very disturbing for his son which he highly values: *"It makes a huge difference with the remote control for the pump, right? It's very disturbing if.. let say.. well now I can see that you are eating some pancakes or something like that, then I have to go over and take up the pump, and then we have to lift up the shirt and get the pump out of your belt and then I have to look at the pump or maybe even detach something"*.

A system, such as the one H. has for his son, is, not very widespread which is problematic for the next stage: *"I think we're the only ones using it there... and the nurse is slightly annoyed that they can't figure out how to extract the data"*

All diabetes treatments are in some way considered usable for diabetes patients as they make the user achieve their goals within the collection stage. Some solutions were better than others depending on the interviewee but finding the right technology to collect data provided the parents with greater flexibility and acceptance, as the parents and the children easily could use the technologies at hand.

None of the parents had any specific comments on whether the content of det tools where findable or not.

Teenagers:

These factors allow the teenagers to take more control over their disease and move towards independency

Teenager E. explains that she is more satisfied with the pump that she has now because she often forgot to collect her glucose levels: *"I actually like the one that I have now, with my previous one I often forgot to enter the blood sugar itself and then I just entered the carbohydrates instead.. but with this one you go step by step where you need to type in.. So I remember it much better now than I did with the other one. I really like the one that I have now"*.

The two teenagers E. and K. emphasized the importance they felt towards the technologies being usable and easy to use when collecting data, *"I really like that I can just take it out of my pocket like a phone and then sit there and write like 'now I need ten carbohydrates' or something like that, and then it automatically converts the carbohydrates into insulin and it's very good"* (K., Teenager). Teenager E also emphasizes, and supports, that the CSII is easy in terms of setting the carbohydrate count and that it is important it is not slow in functionality: *"It's important that the pump is not slow like a really old phone and such, because it's important that you quickly can stop the pump or quickly can get insulin from the pump if needed"*

All diabetes treatments are considered usable for diabetes patients as they make the user achieve their goals within the collection stage. But the teenage patient group differ in the way they expressed emphasis on the technologies' simplicity, ease of use in terms usability and findability.

③ INTEGRATION STAGE

Parents:

The integration stage happens between the collection and reflection stages. The collected data is prepared and transformed for the user to reflect upon.
For diabetes patients, integration is usually a short process as the patients bear little responsibility in preparing the data for reflection, as the CGM or FGM automatically integrates glucose data and transform it into a visualization, in the form of a graph, thus making the integration system-driven.

M. explains they integrate their data for reflection via a system called DIASEND: *"Every 14 days we upload data from Libre and data from the pump on that DIASEND so that we can look at graphs...".*

The integration phase can also be long for patients and care givers using more analogue methods, such as the insulin pen and finger prick glucose testing, as they have to manually write down data or transcribe the data into an Excel sheet, thus makes the integration user-driven.

Parent P., whose son uses pen and a sensor, integrate data differently than the other parents. While the other parents generally asses glucose level graphs more, P. assess carbohydrate graphs more and explains that for further reflection she brings her paper, with the numbers and the graph, to their doctor appointments, but she also uses the paper to keep track of her son's injections and explain that on the paper *"… there is time, and there's carbohydrates, and there is insulin, and something like that, and then you write down every time and those are the ones that we use"*. This is both a way to collect data but also to integrate the data for reflection.

There are other ways to integrate data for reflection when looking at diabetes treatment, one of which is to integrate and reflect on data by HCP's. The parents will upload data using either DIASEND or Carelink before coming into the clinic. The HCP's can extract the data and reflect on it, *"in there we have to upload it and then they can enter and see all the numbers in there"* (R., Parent)

Certain brands can have barriers in integrating data for HCP's. H. however, explains that using the specific system that he has for his son some graphs cannot be accessed by the doctors "*they don't know how to do it*" and "*…the nurse is slightly annoyed that they can't figure out how to extract the data".*

Teenagers:

Both teenagers explained they integrate data to be used by HCP's when they go to checkups. When asked if the collected data is shared the teenager K. explains *"I have been told they can just tap into my account and then they can see my graph for the last five days"*.

When asked about the data sharing and integration of data, the teenagers did not provide much insights and thoughts into how they dealt with the integration of data, whether it was integration for self-reflection, or integration for HCP's to reflect upon. The teenagers' short answers indicated a more natural approach and they may not have a say, or given much thought, related to transforming their data into reflection.

SO., however, explains a barrier with integrating data using the FGM Freestyle Libre, is if the patient gets too low or high glucose levels, the data cannot be integrated and transformed into a visualization for graph reflection, *"Compared to a normal blood glucose meter, it will say that your blood sugar is 1.6 right now, but with the Libre you get to a point where it doesn't tell you what your glucose levels are because it's so low it will just write NO. I can't use that for anything. You can of course say that if it is so low then it is because there is a problem, so no matter what, I have to get it up, so it doesn't matter if it is 2 or 1, then it just needs to get higher"*.

④ REFLECTION STAGE

Parents:

During the reflection stage, the user reflects on their personal information and explore the informational visualizations. Reflection can happen in two varieties, and diabetes patients use both. It can be short-termed which means the individuals reflect on their information immediately after having collected and integrated the data. The short-term reflection makes the user aware of their current status almost right away which most often leads to an action immediately.

Parent H. states: *"…I can just sit and watch his blood sugar levels on my phone…"* H. then reflect and act on the integrated data visualization. Parent R also explains they reflect on the data and then act, *"We will just look at the sensor and see some curves there and then it also provides us with the alarm when he is high and stop the insulin when he is low, I mean then we can go in and fix it now and there".* But reflecting on data here and now is more than just preparing to inject insulin, it is also about reflecting upon when to eat something, if the child has low glucose levels.

Reflection can also be long-term which means reflection happens over a longer period. Long-term reflection allows the parents to compare their child's information between different times, to identify trends and patterns. Parent M. explains: *"then we can maybe see that every day at 14:00 your blood sugar becomes low… then we have to go in and adjust on the pump ... it gives a completely clear picture of when there are irregularities"*. This is supported by H. who explains when they have integrated their data in DIASEND he can see and reflect on his son's glucose levels: *"There you can just access and see how it's going with his blood sugar. but it's just how his average blood sugar is. Then we have the follow-app where I can see his blood sugar on my phone".*

One of the barriers experienced in the reflection stage is issues with the vast amount of information which hinders the parents from exploring all information. This was for example experienced by R. who felt the long-term reflection graphs would overwhelm them and only cause more worry. They chose to only focus on the short-term reflection and act upon that, *"It is also something we can use ourselves, but those graphs .. we can't do that ourselves, so we have chosen not to do that, because if we start getting too much into it we would not be able to do anything else.. I mean.. we would constantly think 'What is this?? What is that??'. So I think that we will leave it to the professionals".*

Teenagers:

In continuation of the integration stage The teenagers explain the HCP’s will reflect on their data, collected over a longer period of time, and will from that alter their CSII’s insulin dosages: *“they use it to both look at how.. if.. my blood sugar fluctuates in some way or for example if it increases in the morning, then they use that to adjust my pump so that maybe I should have more insulin in the morning. So, in that way they use the graphs”* (E., Teenager).

This is supported by teenager A., who explains: *“They look at all of the times I measured my blood sugar and then they look at my pump’s settings, for example how much of my medication do I get in a day.. So, if they can see that if I am high in the morning then they will tell us that we should give me more medication in the morning or something like that. So, they use it to help us adjust the medicine and something like that”*.

Another type of reflection for the teenagers, especially the very active teenagers, is whether they can take off their pump during exercise. Both E. and K., who are competitive dancers, explain they, at the same time, reflect on whether their glucose level is optimal for the sort of exercise they are doing. If not, certain actions would have to be taken: *“if my blood sugar for example is very high or really high, then I will have it on and then I just dance with it, but it is like.. for example, if it’s 10 it’s still a bit high, but not terribly high, and it’s actually a really good blood sugar for example when you have to dance, so usually I just take off the pump if it’s at least 10 or below then, then I definitely take off the pump”* (E., Teenager). Teenager K. further explains: *“Yesterday I was at *anonymized for privacy*, but often I had to go out and drink some juice and something like that, but also because you are excited and when I have to give it my best I need a blood sugar of nine, if I have to dance. So, it's hard to find a way to actually keep my blood sugar for a whole day”*

The reflection stage is very user-driven, and the teenagers access the stage more hands-on and short-termed, as an integrated part of life which lead to the actions, they are taking based on the transformed data from the integrated stage. While addressing the more long-term reflection they put emphasis on it being done by health-care professionals.

ASSOCIATED UX FACTOR: CREDIBLE

Parents:

Credibility expresses the ability to trust a product. Since diabetes patient's lives depend on the diabetes treatment solutions, it is essential that they trust them, and subsequently the companies providing the solutions.

When asked if they trusted the way that companies and hospitals handled the data, both two parents answered, *"I'm not at all worried, I mean ... I trust that the data that we upload is being handled correctly, just like I trust 'e-boks' and other stuff"* (M., Parent) and *"I expect that they do that"* (H., Parent).

When parent S. was asked about the credibility and sharing of data, she explained supportively of open data sharing: *"you actually say yes to others looking into her numbers, because it is available in some sort of open forum where they can send .. *cuts her own sentence*... and I don't bloody care I mean... who is looking at her blood sugar, in no way do I think that it can be offensive, whereas the girl in no way is allowed to have either Instagram or snapchat or anything because that is a bit different to me.. this is purely medical data and it does not matter to me and if there is anything that can be used for research and improvement then I'm happy"*.

When talking about trusting the functionalities of the technologies M. explained: *"It will tell you "now there are three days left until it expires"… and then it continuously count down and say "now there are two hours left" and when you smack on a new one and then you place the scanner on top of the new one and then it will say that it found a new meter"*.

S. also elaborates by saying "*there are some irregularities in relation to the measurement, so there is some uncertainty and there is some delay in relation to the correct blood sugar and things like that"*, but according to the parent, the good outweighs the bad because with the FGM you do not need to do the painful calibrations as with the CGM's, hence, insecurities and variations in the data was not enough to compromise the credibility.

Teenagers:

Credibility expresses the ability to trust a product which is essential for diabetes patients. Teenager K. states: *"I actually do not like change in general, because when I first have a tool that I do not feel comfortable with, then I am afraid that I will get another tool that I am not happy with nor helps"*. This emphasizes the need for the patients to trust the tools and products.

K. also explains, when asked if she trusts the treatment solutions, as they might have different numerical values, she explained ultimately did because it will provide the same insulin dosages: *"you do not know if the pump has some other values, you just have to give it time in regard to how your blood sugar is connected, but its like.. it has the same settings inside the pump, so it won't give less or more insulin end what is installed in the pump".*

There is a common understanding being expressed in the interviews that they are aware of insecurities in the values of glucose measurements, but they still trust the technology and instead reflect on an overall level. SO. explain: *"If it says LO then it doesn't matter if it is two or one it just needs to get higher no matter what, and if it says 20 and my blood and my blood sugar *interrupts herself*… If it says 20 on the sensor but my blood sugar might be 18, no matter what it needs to go down, then I take what the pump recommends"*. She then further explains that she is also aware of her sensor's ten minute delay in glucose measurement, but still deem the sensor credible.

⑤ ACTION STAGE

Parents:

The action stage covers the many different types of actions the patients or care givers have to perform. The actions performed happen based on the understanding of the reflection. Long-term reflection may even alter the behaviors of the users who will then tailor their behavior and treatment to fit the potential newfound reflection and understanding.

Actions often happen in a user-driven fashion, as the user is responsible the decision to act, depending on the reflection's conclusion. A manual action can be the adjustment of the CSII's continuously basal insulin or using the insulin pen or adjusting the bolus insulin to adjust for exercise and meals. Parent H. explains a situation when his son was at football camp: *"suddenly five boys are* *sitting and eating in someone's caravan and some of us parents were sitting and having a nice time, then I can just stand outside the caravan and with the remote control I can just deliver insulin"*. H. also explains, with the remote control he can easily act on the alarms at night *"I have the remote control lying on my bedside table so when I get an alarm that he is either too low or too high I can just give some insulin".* When it comes to acting on the long-term reflections H. explains that he would rather be the one acting on it and be the one adjusting on the pump instead of the nurse *"it's very different for parents as there are some who are very insecure and would prefer that it is the diabetes nurse who alters the basal rates and then there are others like me who just looks at the curves and adjust the basal rates themselves"*.

Another type of user-driven action, which is not technical, is eating something to increase the glucose levels. During the interview with S. and her daughter A. it was observed during the phone call that A. had to leave as her mother told her to go and get some dextrose because her glucose levels were low due to having exercised. Parent M. also explains her daughter has a snack box at school so she always has something to eat if her glucose levels are too low: *"she has a box down in the kitchen with some granola bars, some dextrose, some juice, cocoa and some almonds and just everything that she needs to get up faster"*.

Actions can, however, happen automatically (system-driven) if the patient is on a SAP treatment solution as it will adjust insulin levels according to the changing glucose levels. Another type of system-driven action, is the CGM, which has the ability to provide alarms *"it will go in and provide an alarm if the blood sugar is too high or too low" (R., Parent),* which alert the user to take action or the system itself will take action; although, some CSII's are connected to CGM's without being SAP treatment. If the patient is getting low in glucose, the CGM sends a signal to the CSII which will stop the insulin, *"he has a sensor for his Medtronic which can go in and show.. I mean it can go in and stop at a too low blood sugar level"*.

Teenagers:

One of the system-driven actions, is the alarms provided by the CGM, *"you get alarms if your blood sugar is too high or too low or something like that or if the sensor needs to be changed, so it's what I use all the time to assess my blood sugar"* (E., Teenager)

For example, when the parents have the followapp, they too will get alarms and will text or call the teenager, asking them if they are doing okay and may also act as a reminder, if the teenager is unaware of the situation, *"if it's very low they may be a little worried, they may just think and write 'are you okay?' or something and then see if I reply or something like that … also at night … if my blood sugar is too high it gives off an alarm and maybe at night, then my blood sugar needs to be regulated"* (E., Teenager).

As both E. and K. are competitive dancers, they constantly have to maintain and manage their glucose levels, as exercise can change the glucose levels drastically. K. explains, while looking back at the day before with a dance activity, that she had to eat and drink continuously in order to manage her glucose levels making this action user-driven, *"I had to drink four juices in five hours yesterday because I was low all the time and then I have to eat food all the time as I get so excited then I get really low and whatnot and then I can't control it at all".* E. also explains that she had to take five minute breaks to drink some juice and run back and forth from her training *"I know that when I drink some juice it starts to rise slowly ... but I always eat something before training and I usually eat something after training… sometimes but not always, it also has something to do with how my blood sugar levels are"*

When at school E. also states that she has a lunchbox filled with for when she has to eat something to make her glucose levels rise *"I have a lunch box inside a closet in the classroom where I have juice and something called Hypo-Fit"*.

UX factor: Desirable

Desirability is an overall perception and does not fit into a specific stage. A technology or tool's desirability is essentially if it is enjoyable and compels the user to keep using the treatment solutions. Desirability is also how companies drive the users to take action through the design.

Parents:

Many parents found the ability to share and track the child on their own phone desirable and how their children felt using the pumps, both in terms of comfortability and psychosocial outcomes, such as self-esteem while wearing and using it. Parent S. explains that with her teenage daughter A. usability is not very valuable because she is 15 and can easily learn a system, but "*It is more important that she is comfortable with what is being put on her body*".

S. also explains that size and comfortability is a desirable factor, as many solutions are too big for children and way too many things can get stuck: *"I think that the size is super important. I mean, it is an instrument that is attached to your body. The smaller the better and so on.. right?.. and that is also why I think that something like the Omnipod vs the one M.'s Medtronic pump. With her pump I think that it's ginormous and there is a tube that can and get stuck and whatnot"*.

S.'s claims are also supported by R. who expresses: *"It's visible and, it's big and there is a cord and a tube which needs to be attached. I think that is a huge disadvantage because he was to wear it 24/7 in a belt and waist bag and he is constantly wearing it and I just think that it's so big and clumsy and then it can break.. I mean that part of it.. it would be smarter with something else"*. R. also explains they are looking forward to getting a new pump as it is deemed desirable that: *"then I can sit at home and watch and say 'okay now it's going wrong' and if he is at my mother's house I can call her and say "you have to go in and do this and this now" and it can also provide me with alarms, so we are really looking forward to that we can send him off without having to constantly worry and get a hold of the people the is with".*

For parent H., having a remote control for his son's CSII is highly desirable, as it is not disturbing his son when doing activities as he could easily provide his son with dosages of insulin from afar, which was also desirable at night because he would not have to get out of bed. H. also explains: *"by chance we got the one with this remote control. I have also talked to other parents who said "God, we wish that we had one of those" and then I actually called and talked to the company and I have also written others saying that they need to remember to tell and advertise how important this remote control is for parents".*

None of the parents expressed any significant desire in optimized visuals, guides or form elements such as buttons.

Teenagers:

For the teenagers, two very specific elements were continuously emphasized: Looks and size.

E. emphasized she would love to try something smaller than the CSII she has now. She had been looking into a patch CSII, however, as she has a more slender frame, the patch pumps were still too big for her: *"it is very big compared to my arms because my arms they are also not so big either.. so it was really big and such at least for mine"* (K. Teenager). E. also elaborates on the disadvantage to the pump size and explains it is very visible and people who do not know her will often stare, especially when she is dancing: *“The disadvantage is that the pump is very visible and the thing is that when someone doesn’t know me they stare a lot and something like that or if I’m somewhere they stare at my sensor but also my pump and think ‘what is that?’, but also because I go to a lot of tournaments and people stare a lot and if I have it on while dancing”*.

K. emphasizes that diabetes treatment solutions, such as tools and devices, *“look so clinical, I have never liked it because suddenly it screams from my appearance that I have diabetes”*.

Similar to E., K. describes the treatment devices and tools draw much attention, and she would rather have people come over and ask what it is she is wearing as opposed to people pointing out she has diabetes. Having a more modern looking technology, in K.’s case, is thus highly valued and desire. She explains the CSII she has now almost resembles a phone which she likes: *“I’m focused on if it’s not visible and looks too disease like, I like that. Just like this tandem pump, the T-slim, there is a touchpad and it looks like a smartphone when you take it out of your pocket, so it's super cool and is super easy to keep track on*”. She further explains *“Then they don’t know that I have diabetes when I’m just walking around”*.

The color of the devices and tools are also of importance and also important when avoiding the ‘disease like’ and clinical look. K. provides some thoughts on what she would find valuable when it came to the look of pens: “*If I had to choose I would rather have a completely white one or a black one instead of having... *interrupts her sentence*… I mean I remember that I had one and it had some doodles on it or something and something different and it almost made it look more disease like”*.

Taking the inputs into account, looks and size, but also comfortability, having a device on your body or a tool, such as the injection pen which you are not pleased with, can highly affect the self-esteem and emotions but also QoL as it can be a physical burden to wear a device, as it is often in the way which limits its user in movement.

UX FACTORS: VALUABLE AND USEFUL

A product being valuable and useful depends on the value it delivers to the users and the useful purpose it provides.

Parents:

Parent H. explains in detail the value and usefulness their diabetes solution, with a remote control, has for him and his son. Especially when it comes to his son playing with his friends:
"He can just play with his friends and then I can just look over my left shoulder and say.. 'oh heck now they are in there eating pancakes'. I can then give 30 carbohydrates and then that's fixed. The pump can only do so much, but it is so much more valuable having a remote control for the pump.. just like having a sensor". H. also explains that his son became happier when they got the pump and describes the awkwardness of having to inject in public: *"he felt happy getting rid of the pump. He thought that it hurt getting injected basal insulin in the morning and evening in his thigh, so I really think that he was happy. You don't need a lot of imagination to picture going to the zoo and having your parents go behind and give you insulin without noticing compared to having you sit on a bench and have you pull up our sweater and inject you in the stomach.. I mean, what would you want for yourself?"*

Another factor valued by parents is being able to let go of their child's disease when they are at school or sleeping at night and only waking up when they have to, *"We really want the alarms at night so that we don't have to set alarm clocks and just sleep until there actually is a problem. Sleep is what all parent to smaller children with diabetes would give up their right arm for, right?.. just being able to sleep for a whole night without having to get up and check. That would be damn awesome"* (S., Parent).

Parent S. also describes when their youngest daughter M. is at school they would rather not have alarms on their phone, because they had to trust that other adults would be able to assist her, or else it would be impossible to ever relax: *"Both my husband and I, we would rather not have alarms while M. is at school, because we have to have some sort of conviction that there is someone there, other adults, who take some responsibility because otherwise we can never relax, and what should we do if sit there and get an alarm that she is too high, should we then call the school and ask them to do something?.. because maybe they already have done something"*.

Teenagers:

A product being valuable and useful depends on the value it delivers to the users and the useful purpose it provides.

As shown in the previous section, desirability in technologies and tools is a distinct value for teenagers. Moreover, it must be modern, comfortable and discrete in order for them to feel good about themselves and assisting in them accepting their disease more.

Another value is the CSII's and CGM/FGM's are less painful and cause less discomfort, but they are also better and easier to use when regulating blood glucose levels, thus useful:

"The benefits are definitely that it's much easier to regulate ones blood sugar compared to using a pen and it's so much more painless… when using pump… and yes, you just have more options and you can also get temporary basal, so you can get that all the time on the pump whereas when using a pen it's something with having to inject the thigh in the morning and evening as temporary basal, but you can just adjust the pump and then you can just take it when you want, so I would say those are the benefits of it" (E., teenager).

A slightly different value presented by K. was she felt value in showing it off and telling people her story and thereby empowering herself by taking pride in herself and her disease: *"I also think that it is cool, for example, what with the sensor, and think that it is cool I can show it off as I do, but also others my age do it and it's a bit cool, and not walking around where people ask 'what is that' and then you're like 'oh I don't really want to tell you'. I'm fine with explaining my story and how I got it because I have no problem with it at all"*.

EXPERIENCED LIMITATIONS

Parents:

T1D is a lifelong disease and diabetes treatment technologies hold many advantages, however, they do come with some limitations, both in terms of functionality and integration in the user's life.

Some of the limitations found in the interviews were the annoying and painful calibrations of the CGM. Several of the parents expressed, even though they appreciated the alarms of the CGM, the calibrations were an inconvenience: "*It needs to be calibrated three times a day and he is getting really tired of it*" (R., Parent).

Parent S. also explained they were annoyed at the calibrations, hence they chose to go back to the FGM when on vacation in Thailand. But they also experienced that S.'s daughter M.'s CSII, which is a tethered pump, provided some limitations on the vacation:

"it needed to be detached when she has to go swimming, and that is bloody annoying when you are on a beach vacation", and then the mother decided to put on the older sisters patch pump on her youngest daughter. Parent M. also explains that *"we take it off"* when her daughter is doing sports because the pump is not waterproof and often in the way.

S. also explains they once tried an app called NightGuard, which is designed by a diabetes parent movement call #wearenotwaiting, to track the glucose. However, S. explains that the app was terrible and of no use: *"we have used nightguard in connection with the sensor, and it's terribly shit to say the least. It's really, really cumbersome... I think that we spend about three days just creating various accounts and whatnot".*

S. also states: *"But of course, there are some who have developed something themselves because they also have been annoyed and then they have made something themselves and they are not trained to do so, so it becomes some hocus pocus system and it never works.. I received alarms all the time on my phone every minute no matter how her glucose levels where, then you just stop wanting to use it"*

Limitations also happen in life settings and can provide limitations for the children's way of living, social cohesion and QoL. S explains her daughter have not had a sleepover since she got diagnosed, because the other parents are afraid to handle her: *"M. has not been to a sleepover for two years with her friends since she got diagnosed with diabetes, because no one dares, and she did before. So purely mentally and emotionally it is insanely hard for me as a mother that she has to give up on something because of a chronic illness"*

Parent P., whose son is using an insulin pen, describes some limitations of the dosages the pen can provide: *"the main limitation is that… I mean.. It's nice that it can provide half a unit.. but versus the pump which can give a 0.35 unit, then we will have to constantly round up, so do you need 1, 1.5 or 2.. we have to round up compared to his blood sugar.. whereas the pump is more accurate, because it can go in and say "oh you ate dinner and ate a portion and then the pump recommended that you should have this and you would like more, now you can get 0.35, but we can't do that with a pen".*

Teenagers:

Even though the teenagers showed a more relaxed perception of the different stages of self-management they do experience some limitations.

A technical limitation experienced by teenager E. was her sensor would malfunction saying '*sensor error'* for several hours, furthermore she could not be more than six meters away from her phone or else the phone and sensor would lose connection.

Exercise and sports have been a recurring topic during the interviews. E. experienced some limitations in her disease which are frustrating for her. She explains that when dancing, especially if it is a more demanding type of dance, she does not want to think about her disease and it is frustrating to interrupt the dance routine because she would rather focus on that, *"sometimes you just want to forget about it which might not be a good idea"*.

Teenagers E. and A. are a bit different, as they were diagnosed at different periods. E. was very young when she was diagnosed and A. was diagnosed as a teenager, a few months prior to the interview. They do however, both explain during the interview they experience some social limitations. A. explains she used to have overnight stays with her friends but this no longer happens, *"It's not like at 22:00 someone writes 'Do you want to come over and sleep?' … that is not happening anymore"*. E. also explains, generally she does not feel safe when it comes to overnight stays, *"It's not something I do that much, overnight stays… I don't really feel safe doing it… because of my diabetes".* E. further elaborates it is constantly in the back of her mind whether the people in her company can control it, *"… What if they can't control it, or something like that or do I need to do it myself, or what if I don't wake up from my alarms.. you can easily start overthinking a little"*.

Based on the expressed limitations, it is evident they are more related to how the disease affects the teenagers' social life and physical acitvities, as opposed to the parents who experienced technical limitations.

OTHER INSIGHTS

Parents:

M. voiced the general opinion that not many parents enjoy changing technology because they are so dependent one technology works: *"I can't even deal with it, because we already have something* *that works… and you should not fiddle with that.. I mean, our life is in boxes.. It's one big equation and a long scheme, so when you actually find something that works and think "this works, this is where is doing as good as she can", when you don't want to change it, you just want to stay"*

M. further elaborates, "*I think you have to be in a really lopsided period to say 'yes please' to try something new ... you almost have to be desperate.. what's what I think*"

Parent S. also explains that during hospital consultations, her youngest daughter does not want to sit around and hear about her numbers and tend to run off: *"She does not bother to be there and she does not bother sitting there listening to numbers or measurements and stuff like that, she simply runs off and finds the hospital clowns or she is riding a bike around the wards... she simply does not want to be there".*

Teenagers:

E. explained she has a friend who also has T1D, they are also dance partners and neighbors. She expressed experiencing a lot of support having a friendship with someone who has the same disease has herself, *"We have become really good friends since she moved here and we practically talk all the time about everything and also about diabetes if we have something and want to talk about"*. She further explains they support and remind each other to eat and drink during training, in order to keep their glucose levels up, *"We can see on one another if we have low blood sugar, for example in the eyes or something like that, so then we can say 'go over and take some juice' or something like that"*.

While interviewing A. and her mother S., it was stated by S. she felt it was important to emphasize to her daughter that life does not stop when you get diabetes and you still have to go out and have a good time and go to parties and drink, *"She has to go because I think that it's important to find out that ones life does not stop and her friends were really nice and tried to take care of her, but it's hard when the alcohol kicks in"*. Mother S. further elaborates, it comes down to experience and it is easier to just go out and learn about how alcohol affects A.'s body, and sometimes she would have to accept that her glucose levels would be really bad because she had a good time which S. finds important because A. should still be young and enjoy life as much as possible despite how T1D may overshadow her daily life. She explained that she had a hard time accepting that her glucose levels would fluctuate: *"A. finds it a bit troublesome right now, she wants it to be as perfect as possible,* *and that's really nice, but it is also important to have fun, and then say it's okay and that having high levels in 8 hours at a party will not kill me.. so, we need to work a bit on that".*

Teenager K. also expresses that dealing with alcohol were difficult: *"It was very difficult in the beginning. I had to be more in control of myself than the others, so I had to remind myself that I should not have as much alcohol as the others"*.

WANTS

Parents:

Parent S. stated she wanted the FGM to be built into the pump so that you only had one device: *"if you ask me what would be the optimal then it would be you built the Libre into the pump so you only had one device on you, so that you can measure both glucose numbers and you can control whether it gives something or stops if they were high or low"*.

A want stated by parent M. was she thought her daughter wished that it would be desirable if the FGM and pump insertion patch was not that visible and not white, because the other children stared at her, *"They are very visible. She's attending swimming classes, dance and karate, so she's often in a dressing room with many people and children.. adults too.. but especially children just completely stare if another child stands out"*.

Another want from parent P., whose child is using a digital (not smart) insulin pen, that the pen could provide 0,25 units instead of the more rigorous dosages of 0,5 and 1 unit.

Teenagers:

For the teenagers one type of wish was mentioned repeatedly – more interoperability. Many of the teenagers wanted to control their CSII and their CGM/FGM in the same place, and also that the data would be gathered and visualized in the same system. E. explains: "*It would be nice if one's blood sugar would be written inside the pump all the time"*. She further elaborates she wishes her CGM would work together with her CSII so she could compare her data in one place and thus detect patterns in her levels and make a better long-term reflection, *"Sometimes when you think about why your got so high and at the time you do not know why, then the pump could show you that maybe I took too little there, or that it's that bowl of candy you got the evening prior, because then*

I would know instead of being so confused over why my levels were so high the entire day, that would be super cool" (E., Teenager).

This is supported by K. who also stated in her interview, *"It would motivate me if I could, also with my pump, go in and see 'oh now I'm high here'. Usually I can't do anything about that, so that would be really cool, but for some it might of course be too difficult"*.

Another example of having the CSII and CGM/FGM working together was provided by A. who stated, she wished there was an app where you could control the pump and measure glucose levels but it should also be possible to enter carbohydrate counts: "*Then you could say that you get 30 carbohydrates, so instead of typing in on your pump, then you could do it in an app, then I would be able to control it from my phone"*. This was also to an extent supported by SO who stated she wished she could transfer data from her pump and sensor into the same app.

4.2 PATIENT GROUP PERSONAS:

The second part of the analysis will explore how the two groups differ and what the basic characteristics, needs, pains and gains are of the two generalized patient group personas, thus striving to answer the sub-question: *"What defines the patient groups in terms of characteristics, needs, pains and gains and how do they differ?*".

The following personas has been created using the findings of the Stage-Based model and the UX Honeycomb.

The theory of personas will be taken into use in an alternative fashion. Instead of inventing a fictional character the persona will be a generalized patient group. Thus, two personas will be created, one for parents and one for teenagers addressing the main characteristics, need, pains and gains of those patient groups based on the conducted analysis.

When designing a service or product, it is important to understand the target group that is being designing for. Thus, two stereotypical patient groups have been created as a result of the analyzed findings from the first section of the analysis.

CHARACTERISTICS, GAINS, PAINS AND NEEDS OF THE TWO PERSONA PROFILES:

PARENTS OF CHILDREN WITH T1D CHARACTERISTICS

- Generation X (approx. 1965 – 1980) and Generation Y (loosely approx. 1980 – 1995)
- Either 'Digital Immigrants' or 'Digital Natives' as they have either been growing up prior to the digital age or during the digital age
- 'Surrogate patients' as they take the place of the patient due to the caretaking of their children's treatment and disease
- High level of responsibility
- Either autonomous towards decision making or authority reliant
- Pragmatic attitude as they deal with the treatment and technology in a practical and result oriented fashion

GAINS

- The right technology can provide freedom for both the parent and child
- CGM/FGM's provide better blood glucose control for their children
- Followsapps provide better control and ease of mind to the parents
- Assured in the fact their children can learn and use the treatment tools
- Gets the job done
- The ability to reflect on data short-term. and long-termed on data

PAINS

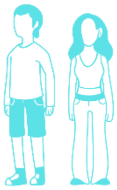
- Lack of sleep due to the nightly alarms
- Technologies can be difficult unless you are tech savvy
- Hard to understand the diabetes 'eco-System' when your child is diagnosed
- Data can be hard to interpret
- Rigid opportunities in terms of choice of treatment solutions
- Expensive solutions which can be paid out out of pocket as they are not reimbursed
- Distress about child's social relations

NEEDS

- Tools that are easy to use
- Solutions which are unburdening to the user
- Less interfering actions and activities of their child's social life
- Easy tracking and sharing of data
- More integrated solutions that work together

TEENAGER CHARACTERISTICS

- Generation Z (approx. 1995-2009)
- Technological-infused ‘Digital Natives’ as they have grown up with game-changing technological advancements and are the most comfortable with technology and social-media
- Main patients, the ones being assisted and treated
- Medium responsibility as they are starting to become more independent but still gets assisted by their parents, also regarding decision making
- Often authority reliant as they put trust in the parents and HCP when it comes to treatment
- Relaxed pragmatic visionaries as they also deal with the treatment and technology in a practical and result oriented fashion, but they often emphasize innovation and idealism, avoid viewing obstacles as set in stone and are very often highly opinionated
- Does not give a lot of thought to the treatment and self-management stages but focuses more on how the technologies impact their lives



GAINS

- The right treatment solutions can improve QoL and empowerment and social relations
- Being able to share data with e.g. parents
- Technologies can assist in adherence
- Less painful solutions. E.g FGM & CGM
- CGM/FGM’s provide better blood glucose control and improve adherence

PAINS

- Feelings of social stigma and feeling different from their peers
- Distress when newly diagnosed
- Difficulties dealing with the disease when diagnosed
- Situations may cause the teenager to not adhere to treatment
- The emotional and social part of the treatment is more challenging
- The technologies limit them in physical activities. E.g. exercising
- Technologies that causes social stigma due

<table>
<tr><td></td><td>to design. E.g look and sizing
- Limitations of social activities</td></tr>
<tr><th colspan="2">NEEDS</th></tr>
<tr><td colspan="2">- Psychological support of treatment and disease
- A need for modern looking solution designs that do not draw attention
- Better and less stigmatizing ways of communicating one’s disease
- More centralized systems and everything in one device or app</td></tr>
</table>

HOW THE PATIENT GROUPS’ PERSONA DIFFERS:

Managing a disease, such as T1D, involves certain activities that are immutable. Both patient groups go through the same collection stages. Their way of perceiving the stages and the UX factors do however differ.

Looking into the respective generations, of the interviewees, provide a foundation of their technological upbringing, and thus a generalized assumption about their technological abilities. The parents of children with T1D can either be considered “Digital Immigrants” or “Digital Natives” as they have either grown up prior to, or during, the digital age. The teenagers are considered only as “Digital Natives”. While interviewing the parents two types were identified: the very technologically savvy who were often more autonomous towards decision making, as opposed to those who felt more insecure. One parent had also given up on learning the technologies. The latter were often more authority reliant when dealing with the disease and often left the decision making to the HCP’s. The parents are also considered more pragmatic with the management of the treatment, as they are the primary caretakers of the children. As Parent R. described: “*you have to act as a nurse in some way because we actually have his life in our hands when he is not in the hospital”*, thus they show a more rigid, practical and result oriented way of dealing with their child’s disease as they have high responsibility for their child’s well-being. Furthermore, the parents can be considered ‘surrogate patients’ as they, to an extent, have to take the place of the patient, due to the caretaking of the treatment and disease, but also in educating themselves and the child about the disease.

They also fully participate in the hospital consultations, as some children can decide to run off. Hence, the two groups have different roles, as the teenagers are the main patients being treated and the ones living with the disease. The teenagers generally displayed a more relaxed pragmatic view of their disease. They acknowledged their disease came with certain activities that need to be performed, but they did not give the stages a lot of thought. However, they emphasized how the technologies impacted their lives, both physically and mentally, and voiced what they wanted to be different and what could be better in terms of design and functionality. Consequently, they are characterized as “Relaxed pragmatic visionaries” as they emphasize, they also deal with the treatment and technology in a practical and result-oriented fashion. Although, innovation and idealism was often emphasized, as they are opinionated and do not view obstacles as set in stone.
Generally, the gains come down to what benefits the product/services created for the user. The parents indicated they benefit from having a solution that ‘gets the job done’ for both the parents and children in an easily and efficiently. Consequently, the CGM’s and FGM’s can provide better blood glucose control which help the parents gain a better state and ease of mind. Connected “followapps” can provide the parents with an overview of the child’s health state, even from afar. Despite the parents’ highly pragmatic approach they still want technologies that are less interruptive of their child’s every day and social life, as they aspire for their children to live their life and not be overly burdened by their disease. The teenagers indicated they gain a better way of life when their treatment solutions are more simplified, modern and less painful which could assist them in adhering to treatment. Teenager K. stated she felt good and exhibited empowerment when people showed interest in her technologies because her pump looked like a smartphone instead of symbolizing a disease, and thus being stigmatized and compromising social relations.

The pains identified in the patient groups are; negative emotions, costs and risks of the technologies and disease. The parents interviewed described experiences related to device burdens, such as not being able to turn off alarms which caused them distress. Many of the parents also described lack of sleep due to the nightly FGM scanning’s and alarms. If the respective parent is struggling with technology and data understanding this is also a pain as they may not achieve optimal use and benefits of the technologies. Experienced pains can also be; parents do not have any say in which type of product they receive. However, this depends on the regions and municipalities of the patients. Doctor Kirsten Nørgaard explains: *“we do have tenders in the entire country.. So, for a two* *year period, we can choose among this and that pump and then we have that for a couple of years"*. Another pain which is more associated with the child, but still causes distress for the parents is; they experience their disease is hindering the child in developing social relations, as many parents to other children do not feel calm about having them over and find that it is too difficult. Thus, many T1D children do not have the same experiences as other children. Teenagers also experience issues with social relations as they often feel stigmatized by their peers, or they themselves are afraid of going out and have over night stays. Getting diagnosed as a teenager can be a complicated time as many changes are occurring both hormonally and socially, but teenagers who has had T1D for several years have to learn how to navigate around their friends, and for both types of teenagers, adhering to treatment can be complicated. Many of the teenagers also have active lifestyles and find that e.g. the pump may be in the way of performing.

Looking into the needs of the two patient groups, the needs themselves do not differ significantly. Both groups value and express the need for more simple and integrated solutions. Both groups preferred to have a more centralized and integrated solution either in the pump or in an app. The teenagers, however, emphasized the need of having psychological and peer support in treatment, life and disease. They also highly expressed the need for having modern looking solution designs that does not draw attention which will increase their QoL and empowerment.

CHAPTER 5 – DISCUSSION

This chapter will in the first section discuss the research question of "*how do teenagers and parents with children affected by type 1 diabetes perceive digital diabetes solutions"* using the findings of the analysis from chapter four and the literature review from chapter two. The second section will discuss improvements of the used model which were used for the analysis. The third part of the discussing will discuss practical implications and thus answer the research questions *"How can MedTech companies approach the differences of the two patient groups, and which parts of the product do they need to emphasize?"* and *"and how can a conceptual model assist MedTech companies in targeting their customers better?"*.

5.1 PATIENT GROUPS AND CHARACTERISTICS

The following section will discuss the patient groups and their usage of treatment technologies and how these affect their lives. Furthermore, a general set of characteristics, presented in the analysis, derived from these patient groups will be discussed, as it provides key insights about where there are still challenges with the technologies.

As illustrated in the analysis, even though it is the child who is diagnosed with T1D, the parents will be so involved they become 'surrogate patients'. Hence, their perceptions and opinions are equally important as the diagnosed child's. However, it is the parents who has the most interaction with these technologies, whereas the child lives with the diagnosis. It can therefore be argued that addressing the parents' concerns and perspectives are imperative. During the interviews it was found that there were two types of parents: the more technological savvy and the ones how are more hesitant towards technology. It could be argued that the two types of parents would have different needs and values in different variations. Both types of parents called for technologies that were easy to use and accessible for both themselves, the children, and also the teachers at school. Furthermore, it was found in the analysis that data information overload could cause worry and confusion, but also that the alarms from the CGM were considered disturbing by some parents, thus increasing the device burden. Literature do however argue that a that CGM's generally provide a feeling of relief in everyday life and being a less painful solution compared to other more manually solutions (Lange, 2016). The parents showed a lot of worrying especially when the children were alone with people who did not know how to handle their child's diabetes, this is also supported by Mellin et al. (2004) and thus again the parents call for technologies that are easy to use so that the children might become more self-sufficient but also a way for other people to understand the system. As found in the analysis, having a child getting diagnosed with T1D can cause a lot of distress for the parents, however parents' perspective has underexplored by academic research (Mellin et al., 2004). Nevertheless, the parents reported that they experienced an overall improvement in QoL when changing from insulin pen to CSII, especially for parents who were not very tech savvy.

An ingesting observation was made during the analysis of the teenagers. It was found in the analysis that teenagers did not give much though to the stages of doing self-treatment and showed a relaxed relationship with the technical elements of the treatment solutions compare to the parents. They did, however, emphasize that the solutions made them feel in regard to psychosocial outcomes, such as social relations and self-esteem from being stigmatized and treated differently (Huus & Enskär, 2007). Thus, they emphasized in the analysis that they needed more modern and simplistic technologies than having comprehensive treatment software integrated into the treatment solutions. thus elude the feeling of embarrassment and stigmatization (Huus & Enskär, 2007).
Despite the teenagers being very opinionated on the technologies, Battelino, 2006 however, suggest that few issues related to body image, appearance or social aspects of the pump. It can then be argued that further interventions and future research should focus on innovative designs in order to evaluate the impact on adolescents health and increase positive and empowering psychosocial outcomes using diabetes technologies and thus provide adolescents with a brighter future (Battelino, 2006)

When observing the interviewees and reading into the literature it can be argued that the teenagers do not perceive the positive elements of the treatment solutions as they an integrated part of their lives. Thus, they have a more neutral perception of the treatment, but they do however emphasize that they dislike. This is supported theoretically as they negative perceptions makes the teenagers notice how they differ from their peers. However, as seen in the analysis, the parents are better at assessing the pain and gains of the technologies viewed from afar as they are not the ones wearing it.

The perceptions of the two patient groups then created the basis for the persona which creates a crucial foundation for a designer or MedTech company's journey in understanding the users' needs, experiences, behaviors and goals through an emphatic manner (Nielsen, 2012).

5.2 THE CIRCULAR STAGE-BASED MODEL & THE DIABETES UX PYRAMID:

The following section will discuss two alternative versions the models used for the analysis which will take its basis on the findings of the analysis:

The Circular Stage-Based Model:

In the approach to understanding the patient groups' perceptions of the treatment solutions, and their self-management, predefined codes were used to match those of the stages of the Stage-Based model. As a result of the analysis it was found that self-monitoring and collecting personal informatics within T1D exceed the stages set by Li et al. (2010).

Using diabetes treatment technologies is not just about collecting personal data, it is also a way of treating the disease (Lupton, 2013). T1D patients, using digital health solutions tools to collect personal informatics about their disease, have different needs than individuals looking to collect personal informatics to improve different lifestyle aspects. T1D is a chronic autoimmune disease which requires continuous lifelong treatment with insulin, the very linear stages of the model is therefore not a perfect fit for T1D patients, as their treatment will never end and continuous changes occur throughout the life stages (Bladbjerg et al., 2012).

In order to assess how T1D patients obtain self-knowledge and track data, a more fitted model is needed so designers can aim their designs more accurately for T1D patients and their requirements.

Keeping the essence of the original Stage-Based Model in mind was still deemed important as the model continues to be iterative as patients will constantly incorporate new data, processes and technologies as they progress through the stages (Li et al., 2010). It is essential for designers to address what factors drive the stages, in order to assess the needs and requirements of the users.

A more circular model representing the continuous treatment management is therefore proposed:

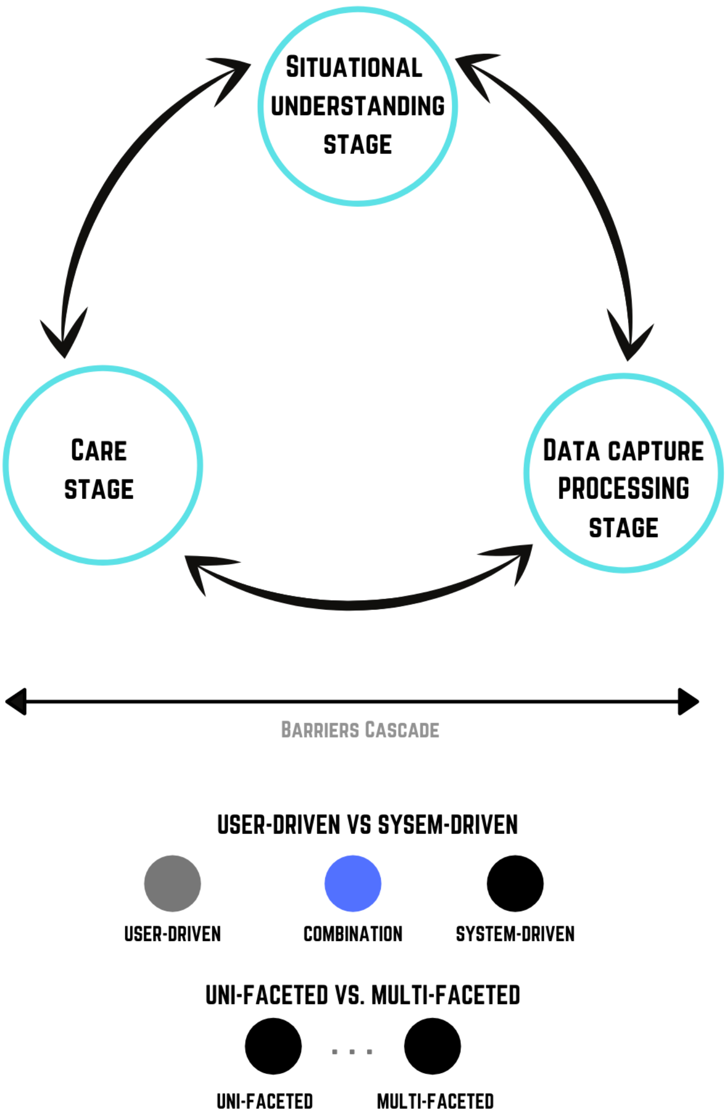


Figure 3 The Circular Stage-Based Model

Li et al. (2010) states the *preparation stage* is the stage where individuals concentrate on their motivation to collect personal information and determine how they will record it. It is however hard for T1D patients, or primary carers, such as parents, to have a great motivational freedom, as getting a diagnosis, such as T1D, forces the user to collect personal data, as glucose levels and carbohydrates, to know how big a dosage of insulin is required, in order to ensure stable glucose curves, and even survival, using specific, often predetermined, diabetes treatment technologies and tools. However, if the patient experiences social acceptance and support from their peers, achieving motivational freedom is more obtainable (Viklund & Wikblad, 2009; Karlsson et al., 2008; Ellis et al., 2016).

Looking into *situational understanding* is therefore a more relevant stage for e.g. designers, as it provides an understanding of the individuals' situation and uncertainty, as they are often inexperienced in both knowledge about the disease and the treatment solutions used. Getting started with data collection for the treatment always begin with a critical moment of sudden sickness or finally getting a diagnosis after weeks of sickness. Meaning, the individuals suddenly get a life changing message, which can be emotionally stressful as well as having a very rigid scheme of disruptive actions being forced into their lives. For the individuals affected by T1D, to understand and being able to handle the responsibilities of the disease, acquiring knowledge and educating oneself is of utmost importance (Liberman & Barnard-Kelly, 2020). As illustrated in the analysis, a lack of knowledge can result in dangerous side effects. *Understanding the situation* and disease is therefore crucial in order to start collecting and reflect on the data, but also for designers to understand the disruptive nature of T1D is of high importance as it can assist in optimizing the overall UX, meaning that it has to be easy to use for all types for users. *Situational understanding* can occur and change multiple times throughout the patient's life as they can experience having to change treatment tools, e.g. new systems, but also changes in the disease itself which calls for change in the understanding of the patient's situation. If designers do not consider these implications they risk developing an unsustainable product (Liberman & Barnard-Kelly, 2020).

In the *collection stage* Li et al. (2010) states that this is when people collect information about themselves. Within the digital diabetes treatment eco-system, collection is a hard stage to segregate, as the collected data is immediately integrated and transformed into a visualized graph. From the analysis it was found that the users immediately reflected on the visualized data which leads to the next stage. The circular model, fitted for chronic diseases, calls for the three stages from the Stage-Based model by Li et al. (2010) to be integrated into a more fitting stage called "Data Capture Processing".

The third step looks into the *action stage* presented by Li et al. (2010). The activities performed are usually a onetime action. However, based on the previous step, the patient or carer will perform a repeated action. The action conducted is more of an activity the user will do in order to treat and care for their disease, such as adjusting insulin dosages or eating, in order to increase blood glucose.

Thus, the stage has been revised to reflect the continuous care and actions required when treating T1D.

It can be argued patients or carers who use more analogue treatment solutions may not fully benefit from the Circular Stage-Based Model, as it is less restrictive in terms of flexibility. Moreover, it targets digital treatment solutions, thus some elements from an analogue treatment solution may not fit the model. However, although the model targets digital treatment solutions better the fundamental elements in the model are still valid and useful for analogue treatment solutions, as the core actions to treat T1D are the same.

The Diabetes UX Pyramid:

From the analysis it was also found diabetes patients view and assess UX in ways that go beyond the UX honeycomb. From the first section of the analysis it was found that the interviewees' assessment of the UX factors overlap, and certain themes were more present than others. As explained in chapter two, in order to improve patient engagement in self-management, and tracking through digital health solutions, it is important to consider functionality and user experience factors, thus making the patients continuously adhere to the technology treatment. Moreover, also potentially reaching technologically skeptical patients/users, for example non-tech savvy parents (Baek et al., 2018). Hence, it is imperative to go more in-depth with what the patient groups were saying that exceeded the UX Honeycomb's scope.

From the analysis, four specific factors were identified: *Ease of use, comfortability, reliability* and *device burden*. Thus, 'The UX Triangle of Diabetes' was created. The model is a compressed thematic version of the factors derived from the UX Honeycomb and emphasized notions from the interviewees:

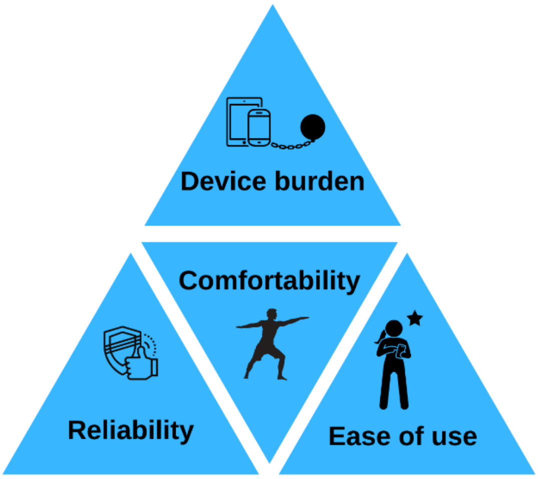


Figure 4 The Diabetes UX Pyramid

Ease of use:

The first factor is *ease of use*. It is of high importance when living with T1D and is one of the carrying factors, as it can either make or break a product. *Ease of use* measures how easy the product is to use regarding its targeted end-users. *Ease of use* have to accommodate a large number of users with different ranges of abilities, thus, it must deliver a design which is *usable*, *findable* and *accessible.* The perception of *ease of use* is dependent on the patient group as their values differ. One patient group may value functionality over aesthetics whereas the other patient group may have the opposite values, as was illustrated in the analysis. For parents this would be ease of integration in the different systems, understandable language and ensuring it is accessible for parents and children alike, no matter their technical abilities. For teenagers' ease of use it is simple and an easily maneuvered interface. Simplicity can also help with lessening the stigma as it will be easier to administer insulin without having to leave the room. As, both patient groups highly value *ease of use* and it is crucial to the accessibility of the treatment solutions, hence it has been put into the foundation of the pyramid.

Reliability:

Reliability is another important factor in the pyramid, and it is essential that it goes hand in hand with credibility, despite the interviewees put more emphasis on reliability. *Reliability* emphasizes the users need to have reliable technical solutions. *Credibility* is the user's ability to trust the product and handling of data. The emphasis for *reliability,* as user experience, comes down to the many comments by the interviewees. For example, CGM/FGM's malfunctioning and delays in measurements. If the treatment tools are not reliable in functionality the user experience is compromised and the users will not gain any value. The teenagers described, despite having integrated digital mindsets, they were afraid to try new tools if the one tool they were using was not functioning. The parents displayed a more positive mindset towards *credibility* and seemed more likely to accept and adjust to variance in, for example, data. That *credibility* would however be compromised if the technologies were not reliable.

If the user experiences a lack of *reliability*, it compromises the UX and will thus make them want to change technology. *Reliability* is a fundamental factor and is therefore a part of the foundation of the pyramid.

Comfortability:

Comfort is a subjective term as it can depend on social, physical and mental terms. During the interviews repeated aspects regarding sizing and looks were emphasized. The parents emphasized the existing CSII's are too big for their child and, thus, compromise *comfortability*. *Comfortability* is one of the main points expressed by teenagers. The mental *comfortability* is the burden the tools provide as *comfortability* is compromised, if the treatment solutions do not provide the users with increased psychosocial outcomes. *Comfortability* can also happen in social relations and if, for example, the pumps look like a smartphone, or is more fitting in size, it might assist the user in not experiencing they are distancing themselves, socially, from others.

Comfortability is thus placed at the center of the pyramid as it creates the overall value. Its users must experience the technologies as an extension of their own body.

Device burden:

Device burden is how the treatment tools impact the life of the users. Many parents described the alarms can be a huge burden but are inevitable for the treatment. The UX is essentially the accumulated amount of burdens, thus the less burdens the device provides the better UX. The *device burden* can also be how it burdens everyday life and the physical state. Both patient groups emphasized, for example, the painful daily calibrations of the CGM's. As *device burden* is inevitable in diabetes treatment technologies which can only be adjusted, it will always compromise the UX, thus it is on top of the foundation of the pyramid.

5.3 PRACTICAL IMPLICATIONS

The following section will show the outcome of the accumulated findings in the analysis and the previous discussion sections, thus presenting the conceptual model assisting MedTech companies in targeting their customers better.

Practical implications from the analysis:

From the perceptions of the patient groups several practical interventions could be proposed to MedTech companies. The following list includes the most emphasized interventions:

- It is crucial for the users that the companies start focusing on *comfortability* as a UX factor and thus agreeingly stat developing e.g. CSII's in different sizes as 'one size does not fit all'. Especially when it comes to children and teenager's ability to stay active, as having a CSII which is not proportional to the child's body, will highly increase a physical device burden and thus compromising comfortability.

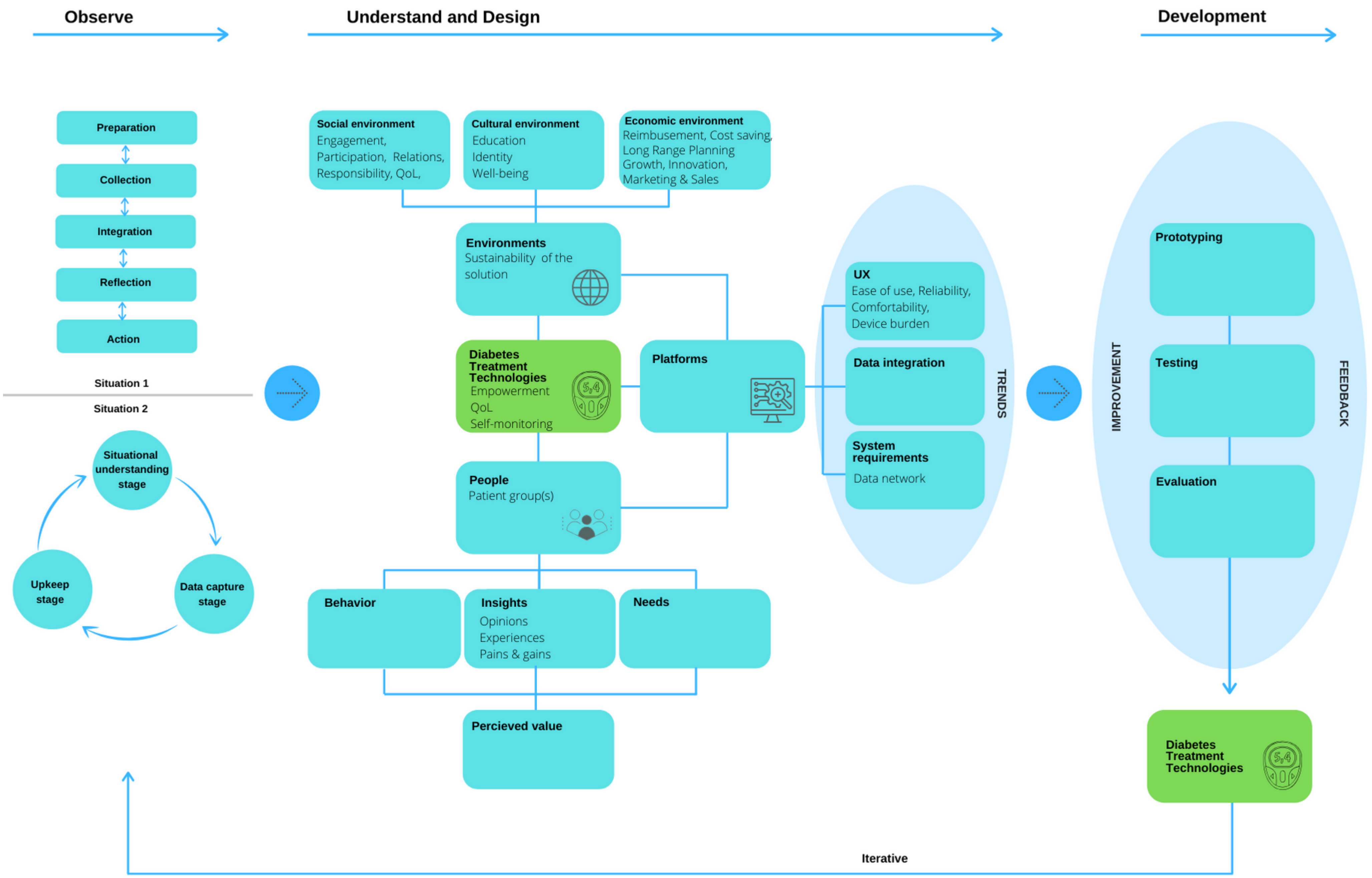
- Developing more modern and less stigmatizing solutions should be highly taken into account by companies when it comes to addressing teenagers and if they wish to ensure sustainability of the product and strive to ensure positive psychosocial outcomes for the users.

- Designing more simplistic interfaces and form elements would increase *ease of use* as the users would not have to perform actions which caused attention by other people. This would also improve social relations and QoL as the users would not necessarily need to distance themselves and leave the company. A simplistic design would also assist in making the patients disease more hidden.

- More integrated and centralized treatment technologies would assist in decreasing the device burden as they would have everything, they needed in one device (e.g. either in the pump or phone). Having an app was emphasized by several interviewees to expressed that they wanted to be able to control the pump from their phone.

The conceptual model:

Designing digital treatment solutions for T1D that add value for the patient as well as being profitable for the company a significant amount of effort and understanding (Nilsson & Sheppard, 2018). Using the finding of the analysis and insights from the discussion as well as insights from the literature, a recommended develop and design approach is thus suggested in the shape of a conceptual model to assist the companies in targeting their users better and fuel more suited solutions:


Observe
Understand and Design
Development
Preparation
Collection
Integration
Reflection
Action
Situation 1
Situation 2
Situational understanding stage
Data capture stage
Upkeep stage
Social environment
Engagement, Participation, Relations, Responsibility, QoL,
Cultural environment
Education
Identity
Well-being
Economic environment
Reimbusement, Cost saving, Long Range Planning
Growth, Innovation,
Marketing & Sales
Environments
Sustainability of the solution
Diabetes Treatment Technologies
Empowerment
QoL
Self-monitoring
Platforms
People
Patient group(s)
Behavior
Insights
Opinions
Experiences
Pains & gains
Needs
Percieved value
UX
Ease of use, Reliability, Comfortability,
Device burden
Data integration
System requirements
Data network
TRENDS
IMPROVEMENT
Prototyping
Testing
Evaluation
FEEDBACK
Diabetes Treatment Technologies
Iterative

The model takes it inspiration from the design thinking as the model goes through three phases: *observe, understand and design* and *development* and strives for a non-linear iterative framework that for innovation and ideation in order to design and fuel more suited and innovative solutions for specific problems, situations and people.
In the first step of the model two situations are presented based upon the stage-based models. Firstly the designer and developers must observe how the patients situation and how they manage their disease in order for the designer to move forward into the next step. This also symbolizes what this thesis has analyzed and observed during the analysis.

The second step calls for the designer to understand the environments and the behavior, insights and needs of the targeted user group which gives them a perceived value. The people element symbolizes the persona method used in the thesis. The environments help the designers understand the important environmental factors of how the technology can sustain successful sustainability. Social environment calls for social relations, which was been an occurring theme in this thesis, but also active participation and engagement, QoL and also responsibility, e.g. teenagers taking over treatment. Cultural calls for a more general societal view as well-being is often how the patient live and cope with the provided technology. In a cultural society of diabetes educating oneself is of utmost importance in sustaining success of the product has they will have to learn the different functionalities and their impact. Economic environment calls for the companies to understand how treatment technologies are reimbursed in a Danish healthcare setting and how they could make long termed planning of improved technologies and how they should market the products. The environment to however exceed the scope of this thesis and will have to the assess in future research. The designer would then have to look at the UX, e.g. the factor of UX Diabetes Pyramid proposed in this thesis, but also data integration and system requirements, all of these elements are circled by *trends* as trends will always have an impact on the specific elements. The two elements, expect the UX element, exceed the scope of this thesis and will have to the assess in future research. All of these main elements, people, environments and platforms are the essence of the treatment technology; thus the technology is place in the middle. The model then moves over to the last step, this expresses a general DT and UCD approach which is constantly being improved and provided with feedback, thus is being iterative. The finished product in then being out at the marked, but the cycle does not end as even fully developed technologies still go trough iterations and improvements as the world, technologies and people constantly change.

The model allows for dealing with rapid innovation, and the companies will have a tool which can guide then through every step of the diabetes technology eco-system and can assist the companies in becoming '*first-in-class*' with technologies which the patients will value and use (Nilsson & Sheppard, 2018). However, it should be stated that no model will fit everyone and there will always be patients that do not fit into any boxes. Nevertheless, this conceptual model allows for many variations and iterations assisting in finding the right solutions.

CHAPTER 6 -CONCLUSION

The aim of this thesis was to research how teenagers with T1D and parents with children affected by T1D perceived diabetes solutions using the Stage-Based Model and the UX Honeycomb and how a conceptual model could assist MedTech companies in targeting their customers better. This represents the main research question:

Research question
How do teenagers and parents with children affected by type 1 diabetes perceive digital diabetes solutions, and how can a conceptual model assist MedTech companies in targeting their customers better?

In order to provide a more in depth understanding three sub-questions would also be answered; *What does the literature say about diabetes patients' use of diabetes technologies and how companies go about designing for users?* And *What defines the patient groups in terms of characteristics, needs, pains and gains and how do they differ?* And *How can MedTech companies approach the differences of the two patient groups, and which parts of the product do they need to emphasize?*

The thesis found from the created personas perceive the technologies at hand somewhat differently. It was found that parents valued a more reliable and easier to use technical system, whereas the teenagers emphasized the need for more simplistic and modern technologies as it would improve their QoL and increased the psychosocial outcomes. The teenagers perceived the technologies in a very relaxed fashion whereas the parents perceived it very pragmatic and rigid.

From the Stage-Based Model and the UX Honeycomb analysis and the persona analysis. Two alternative models were presented from the findings and then discussed. The two models where essential in creating the conceptual model.

A few concrete examples of possible solutions and interventions were presented in Practical implications and within the examples emphasis was put on the fitting patient group.

Lastly the conceptual model was presented. This model was a culmination of the analysis, personas, discussion and literature. The model guides the designer through the elements essential for designing more targeted solutions for the patient groups. The model allows for dealing with rapid innovation, and the companies will have a tool which can guide then through every step of the diabetes technology eco-system and can assist the companies in becoming '*first-in-class*' with technologies which the patients will value and use.

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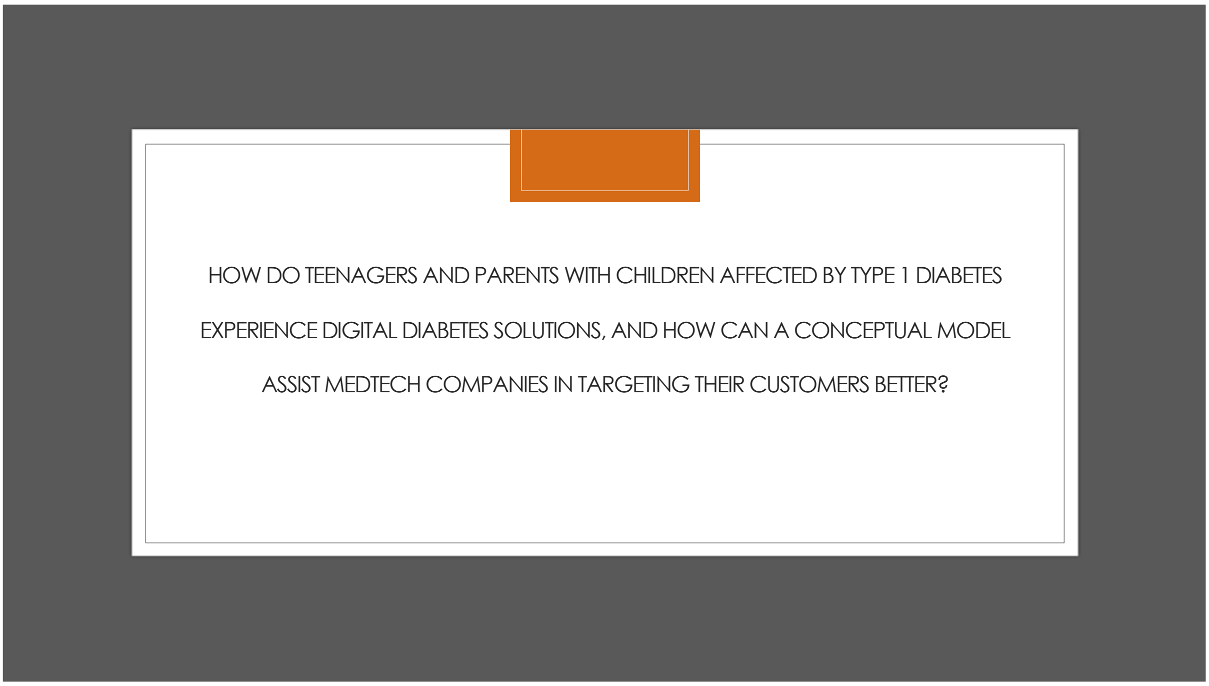
APPENDICES

APPENDIX 1: [redacted]

The presentation for Claus Rehfeld was conducted on the 12th of may at 10:00.

PATIENT INSIGHTS ARE BOUND TO MAKE AN IMPACT ON YOUR INNOVATIONS

- WHAT MEDTECH COMPANIES CAN
LEARN FROM PARENTS & TEENAGERS AFFECTED BY T1D IN ORDER TO FUEL BETTER
AND MORE SUITED INNOVATIONS

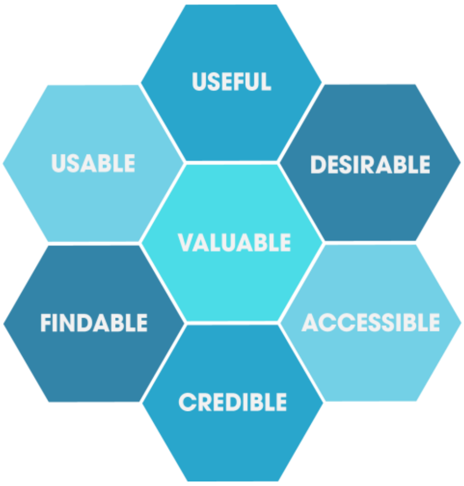


HOW DO TEENAGERS AND PARENTS WITH CHILDREN AFFECTED BY TYPE 1 DIABETES EXPERIENCE DIGITAL DIABETES SOLUTIONS, AND HOW CAN A CONCEPTUAL MODEL ASSIST MEDTECH COMPANIES IN TARGETING THEIR CUSTOMERS BETTER?

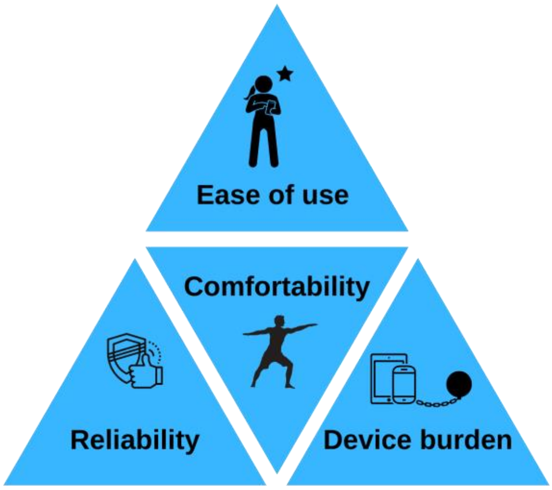
STAGE-BASED MODEL OF PERSONAL INFORMATICS

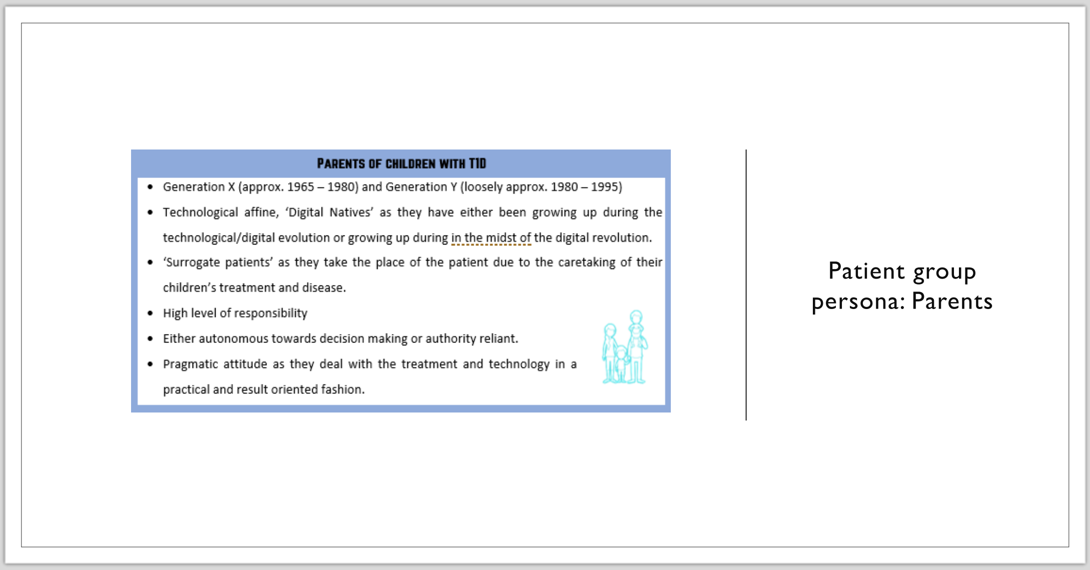
THE
CONTINUOUS DIABETES
STAGE-BASED
MODEL

THE USER EXPERIENCE HONEYCOMB



THE DIABETES UX TRIANGLE

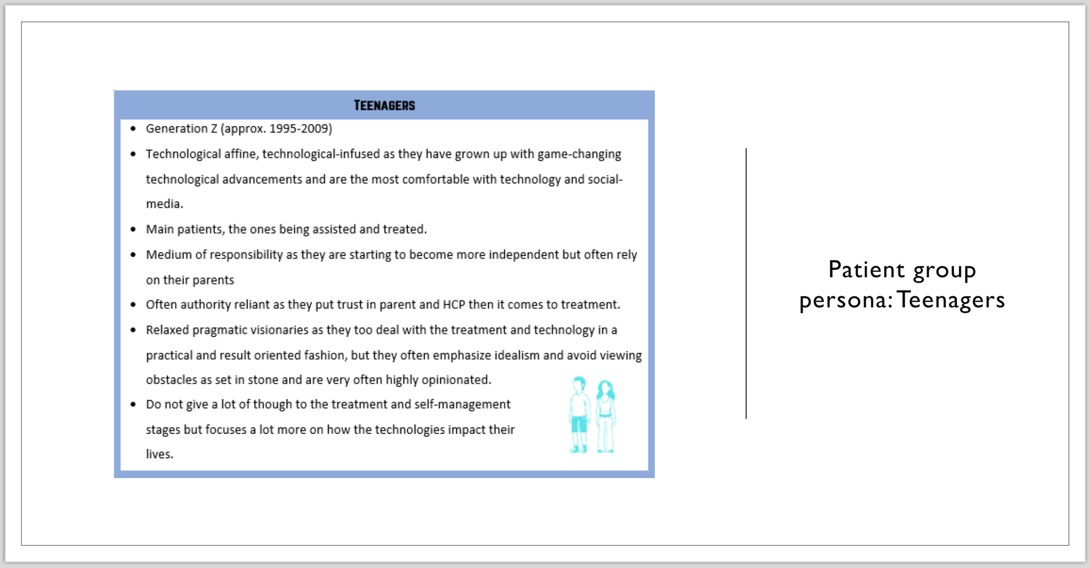




PARENTS OF CHILDREN WITH T1D

- Generation X (approx. 1965 – 1980) and Generation Y (loosely approx. 1980 – 1995)
- Technological affine, 'Digital Natives' as they have either been growing up during the technological/digital evolution or growing up during in the midst of the digital revolution.
- 'Surrogate patients' as they take the place of the patient due to the caretaking of their children's treatment and disease.
- High level of responsibility
- Either autonomous towards decision making or authority reliant.
- Pragmatic attitude as they deal with the treatment and technology in a practical and result oriented fashion.

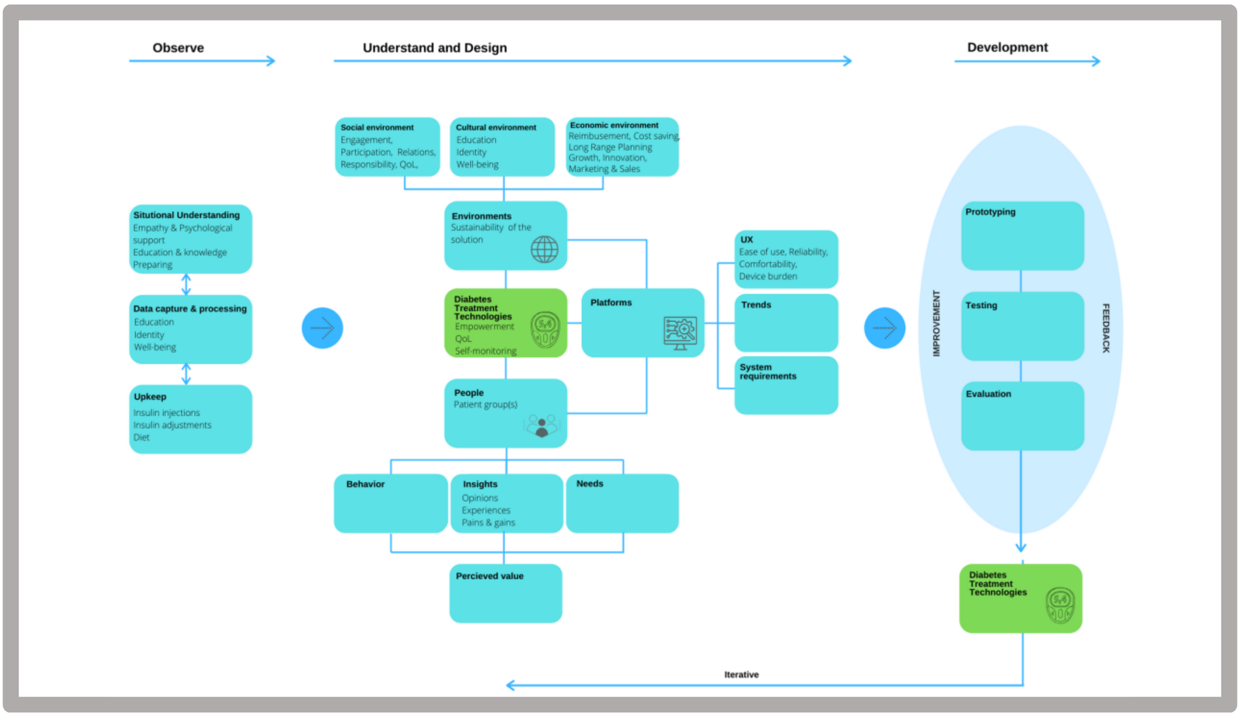
Patient group persona: Parents



TEENAGERS

- Generation Z (approx. 1995-2009)
- Technological affine, technological-infused as they have grown up with game-changing technological advancements and are the most comfortable with technology and social-media.
- Main patients, the ones being assisted and treated.
- Medium of responsibility as they are starting to become more independent but often rely on their parents
- Often authority reliant as they put trust in parent and HCP then it comes to treatment.
- Relaxed pragmatic visionaries as they too deal with the treatment and technology in a practical and result oriented fashion, but they often emphasize idealism and avoid viewing obstacles as set in stone and are very often highly opinionated.
- Do not give a lot of though to the treatment and self-management stages but focuses a lot more on how the technologies impact their lives.

Patient group persona: Teenagers


Observe
Understand and Design
Development
Social environment
Engagement,
Participation, Relations,
Responsibility, QoL,
Cultural environment
Education
Identity
Well-being
Economic environment
Reimbusement, Cost saving,
Long Range Planning
Growth, Innovation,
Marketing & Sales
Situtional Understanding
Empathy & Psychological support
Education & knowledge
Preparing
Data capture & processing
Education
Identity
Well-being
Upkeep
Insulin injections
Insulin adjustments
Diet
Environments
Sustainability of the solution
Diabetes Treatment Technologies
Empowerment
QoL
Self-monitoring
Platforms
People
Patient group(s)
UX
Ease of use, Reliability,
Comfortability,
Device burden
Trends
System requirements
Behavior
Insights
Opinions
Experiences
Pains & gains
Needs
Percieved value
IMPROVEMENT
Prototyping
Testing
Evaluation
FEEDBACK
Diabetes Treatment Technologies
Iterative

APPENDIX 2: INTERVIEW GUIDES

Doctor interview guide:

Interviewee	
Interview setting	

Introduction:

We are a group of three master-students from CBS who are writing a thesis on the values and benefits of diabetes e-health solutions. We are also looking into how you as a user adapts to these technical solutions. The two groups that we are interested in looking at are teenagers in the ages 15-17 and parents with children aged 6-14

We have some questions that we would like to ask you.

But before we start, we would like to know if it's okay that we record the interview?

Preliminary questions:

- What are the most popular way of injection?
- Which are more popular?
    - Disposable?
    - Reusable?
        - Smart pen?
        - Pump?
- What apps are the most popular?
    - Which do you recommend to your patients?
- Is it normal for your patients to use these apps coherently with their treatment?
- Do you encourage patients to use apps?
- What do you think about the diabetes treatment today and where do you see it in the future?

Going into depth:

- How do you think e-health and smart pens will affect the doctors and patients with diabetes?
- Where do you hear about new trends/products?
- What key things happened to the diabetes market in the last 5 years?
- What key things do you expect to happen in the next 5 years?
    - trends, opportunities?
- What type of treatments and e-health solutions do you offer your patients?

- Describe your typical consultation with the patient?
- How do you assess the data and collect the data from the patient?
- How do you feel about disposable pens vs reusable pens?
    - Do you prefer one over the other?
        - Why?
        - Advantages and disadvantages?
    - Which do you prescribe the most?
        - Does reimbursement have a saying?
    - Which are easier to use?
    - How do you recommend your patients to keep track of their injections?
        - Digital (e.g. apps)?
        - Analog (e.g. notebook etc.)?

- How do you feel like pumps vs pens?
- Do you prefer one over the other?
    - Why?
    - Advantages and disadvantages?
    - which specific patients do you recommend one or the other to?

- [*depending on answer above*]… why do you think that [*pen/pump*] is more popular than the other?
    - Benefits?
    - Value to patient?
- What makes you think that the patients choose one pen over the other?
    - Or do they even have a saying?
    - Does reimbursement have something to say?

- What do you think about data collection with a smart pen?
    - How do you use the collected data?
    - Do you trust the data that the pen provide?
        - Please elaborate.
- Do you think that this sort of data collection and self-monitoring could provide the patients with an increased or decreased sense of freedom?
- Would you as a professional feel an increased or decreased responsibility in your treatment.

<u>User Behavior:</u>

- What are your patients using?

- What are you recommending to your patients?

- What are your previous experiences with e-health technologies in your practice?
- How would you describe your past and current experience with diabetes apps?
    - What are the options? (e.g. tracking, uploading data etc.)

- Is there anything you or the patients often look for in diabetes apps that is missing or hard to find?
- Do you think that the current e-health solutions are supporting the diabetes patients to the fullest?

- How do you make sure that the patients are enrolled in using these products?

The Novo Pen 6/Echo+:

- What do you think of this product?
- Why do you think someone would use this product?
- Could us as a professional trust this product and the data It provides?
- How do you think this product could be of to help you as a professional?
  - Would this product provide you an increased or decreased sense of freedom for you and the patients?
  - What impact do you think a product like this would have on the patient's responsibility of their treatment?
- Do you see yourself recommending this product to patients?
  - Which types of patients?
  - Some patients that it might
- What might keep people from using this product?
- Does this remind of you any other products? .. or do you have any knowledge of similar products?

- Do you get reimbursement for the insulin-cartridge thats inside the new Smart-pens or do the users have to pay that for themselves?

The two groups that we are interested in looking at are teenagers in the ages 15-17 and parents with children aged 6-14

  - What would you say are the biggest benefits that Novo will have on these groups?
  - What are the biggest obstacles that these groups could face using these pens?
  - What are your experiences in working with these groups?
  - Do you have partnerships with partnerships where you test products?
  - Is sustainability and recycling a topic that comes up in conversations with patients?
  - Go you have any patient groups we can get access to?
  - More people we can talk to (specialists etc.)?

Novo Nordisk interview guide:

Interviewee	
Interview setting	

Introduction:

We are a group of three master-students from CBS who are writing a thesis on the values and benefits of diabetes e-health solutions. We are also looking into how you as a user adapts to these technical solutions. We are focusing on Novo Nordisk new pens NovoPen 6 and Echo+.

We have some questions that we would like to ask you.

But before we start, we would like to know if it's okay that we record the interview?

Preliminary questions:

- What is your position? Global team in digital health
- For how long have you been a Associate Global Project Director In Novo Nordisk Sweden?

Going into depth with the NovoPens:

The market:

- How did you identify / discover the need for smart pens?
- What is your thought about the future trend in diabetes treatment? What is Novo Nordisk's role?
- How did you market the product?
- Have you done any market analysis that we can have a look into?
- Are you aware of other competitors that are available in the market? Companian medico INPEN - https://www.companionmedical.com/
- Who was your customer segment (target audience) at the launch?
    - Why?
- How is the buying journey in Sweden? Is it prescribed by the doctor or tha patient need to ask for it?
- What was your business model? What channels have you used to reach the patients?
- What is your thought about the partnership in digital health? How was your experience in that?
    - Does partnership in digital health create value for the patients?

Patients:

- Are there patients who are still using the NovoPen 6/Echo+?
    - What about NovoPen 5 ?
    - What was the feedback on the use of NovoPen 5 ?
- Do patients mostly use Pens or pumps according to your research?
    - Which patient group uses which?
- Do you have numbers of how many patients change from disposable pens to reusable pens NovoPen5 ?

NovoPen6 / Echo plus

- What are the main improvements that were added to NovoPen5 / Echo?
- From your perspective, why would a patient prefer to use NovoPen 6 ?
    - What if they are already using NovoPen 5?
- Is the Pen reimbursed by the government in Sweden?
    - What about pumps?
- What was the issue that caused the product recall?
- What was the feedback from the test group for NovoPen 6?
- Did you do a report on the feedback that they provided?
    - If yes: Would it be possible for us to see it?

- During our meeting with Thomas in the danish Novo office, we saw the presentation of the pens. In this presentation we saw that a lot of values for patients and doctors had been mapped out. How did you conclude these values?
- Are there any news on when the product will relaunch?

App use and interoperability:

- *With the new novopens their logging system is going to be interoperable with an app.*
    - What would you say are the biggest benefits of apps, sensors and pens working together?
    - What are the hopes for this interoperability?
        - More partnerships with apps and sensors?

Questions about our target groups:

- The two groups that we are interested in looking at are teenagers in the ages 15-17 and parents with children aged 6-14.
    - What would you say are the biggest benefits that Novo will have on these groups?
    - What are the biggest obstacles that these groups could face using these pens?

Future:

- Where do you see the market in 5 years?
- What will potentially be developed in the future?
- Will the (potential) development of an artificial pancreas be a threat to the pumps and pens?

<u>End question:</u>

- Do you think it would be possible to contact some of the patients who you tested the product on?

Forældre (Parent) interview guide:

Navn på informant	
Interview setting	

Introduktion:

Vi er en gruppe af tre masterstuderende fra CBS, der skriver en speciale om værdier og fordele ved diabetes e-sundhedsløsninger. Vi undersøger også, hvordan du som bruger tilpasser dig disse tekniske løsninger, og hvordan i som forældre og familie lever med diabetes.

Vi har nogle spørgsmål, som vi gerne vil stille dig.

Men inden vi starter, vil vi gerne vide, om det er okay, at vi optager interviewet?

Preliminary questions:

- Hvor længe har dit barn haft diabetes?
- Hvem følger dit barns behandling (læge, Steno, børnelæge, lokalt hospital etc.)
- Hvis du har et spørgsmål om dit barns diabetes, hvem kontakter du?
    - Hvis ja - hvordan ved du hvem du skal kontakte?
    - Hvis nej - hvordan ville du få kontakt til nogen?
- Hvilken type diabetes behandling får dit barn nu?
- Hvilke typer behandlinger (penne, pumper osv.) har i prøvet førhen? De har prøvet pen
- Hvilken type kunne du lide bedst, og hvorfor?
- Bruger du diabetesrelaterede teknologier eller apps i forbindelse med dit barns behandling?
- Beskriv en typisk dag med diabetes behandling?
    - Giver det jer vanskeligheder på arbejde eller skole?
    - Hvordan introducerer i nye teknologier i jeres hverdag og barns liv?
- Hvordan husker i at kontrollere jeres barns glukosemålinger, og hvad kan potentielt få jer til at glemme det?

Forældre med diabetiske børn i alderen 6-15 år:

- Hvordan havde i det da jeres barn/børn fik konstateret diabetes?
- Finder du det værdifuldt, at du kan holde styr på dit barns behandling og glukoseniveau?
- Hvordan er samtalen med dit barn om behandling og diabetes?
- Hvordan administrerer dit barn disse injektioner, når de er i skole eller hjemme hos venner?
    - Er skolen / venners forældre involveret, og hvor meget?
    - Ved skolen / eleverne, hvad de skal kigge efter med hensyn til tegn, der kan vise, at dit barn ikke er okay på grund af lavt / højt glukoseniveau?

- Oplever du, at dit barn har de samme muligheder som andre børn (sportsaktiviteter, sove hos venner, fødselsdagsfester, spisevaner osv.)?
- Hvor involveret er folk omkring jer (nær familie, venner af familien osv.)
- Hvordan ser du fremtiden for dit barn? Har du ønsker om dit barns fremtidige behandling eller en optimal behandlingsløsning til dit barn?
- Har du nogensinde oplevet problemer med behandlingen mens dit barn var hjemme hos en ven?
    - Forstår vennernes forældre?
    - Ville et device som en smart pen være af værdi i denne situation?

Going into depth

Hvis patienten bruger pumpe:

- Har I benyttet jer af pen før pumpen?
    - Hvis ja: hvad var jeres oplevelser med pennen og hvilken type brugte i?
- Hvorfor valgte i pumpen (Pumps vs pen) ?
    - Hvem tog beslutningen om, at I skulle have pumpen?
    - Hvorfor valgte du den specifikke pumpe som jeres barn bruger nu?
        - Valgte i selv eller gjorde hospitalet?
        - Har I prøvet andre før?
            - Var de værre eller bedre?
- Hvilke fordele er der ved pumpen?
    - Fordele over pennen?
- Hvad er ulemperne?
- Hvad med komfort og bekvemmelighed?
- Har du nogensinde haft nogen skader pga pumpen?

Hvis patienten bruger engangspenne:

- Hvorfor valgte du en engangspen (f.eks. fremfor pumpen)?
- Har jeres læge præsenteret jer for flere forskellige muligheder?
- Hvordan har i det med engangspennene?
    - Er de lette at bruge?
    - Hvordan bortskaffer i pennene?
    - Er de lette at bortskaffe?
    - Hvilke muligheder har du?
- Hvordan holder i rede på injektionerne?
    - Digital?

    - Analog (f.eks. Notebook osv.)?
    - Har i prøvet forskellige måder at holde styr på dem (notebook, forskellige apps (hvilke)?) Hvilken var den bedste, og hvorfor?
- Hvad er fordelene ved at bruge en engangspenne?

  ... ulempen?

- Med dine egne ord; hvordan kommer engangspennen jer til gode i hverdagen?

- Kender i til genanvendelige penne? / Hvad er dine synspunkter på genanvendelige penne?
- Har i prøvet dem:
    - Hvis ja: hvorfor skiftede i tilbage til engangsen?
    - Hvis nej: kan du forklare, hvorfor i ikke har prøvet det?
- Ser i det som en mulighed at begynde at bruge en?
- Hvad tror i kan være fordelene ved en genanvendelig pen?

Hvis patienten bruger en genanvendelig pen:

- Hvordan fik i kendskab til den genanvendelige pen? / Hvem præsenterede jer for muligheden?
- Hvilket mærke af genanvendelig pen bruger i?
- Hvor længe har i brugt den genanvendelige pen?
- Hvorfor valgte i den genanvendelige pen frem for engangspennen?

- Er det en smart pen, hvor du kan uploade data?
    - Hvis nej: hvorfor? (afhængigt af svaret) .. Og har du overvejet fordelene ved at holde styr på dine data?
    - Hvis ja:
        - Hvordan bruger du de indsamlede data?
        - Deler du dem med din læge?
        - Har du tillid til de data, som pennen leverer?
        - Giver det jer en øget eller formindsket følelse af frihed?
        - Føler i et øget eller nedsat ansvar i behandlingen?
        - Hvad er fordelene ved en genanvendelig pen?
        - Hvad er ulemperne?

<u>interoperabilitet og apps:</u>

- Hvis de bruger apps:
    - Hvilken app bruger du?
    - Er i konsekvente med at logge data?
    - Synes du, at dine enheder fungerer godt sammen?
- Hvor mange apps har I brugt i alt?
    - Hvilke er de bedste?

  - Hvordan vil du beskrive din tidligere og nuværende oplevelse med diabetes-apps?
  - Oplever I begrænsninger med disse apps?

- Har I haft nogen dårlige oplevelser med apps?
- Er det svært at tilpasse sig nye apps?
- Har I tillid til disse apps?
- Hvad var dine muligheder? (f.eks. Tracking af BS, upload af data osv.)
- Er der noget, du ofte kigger efter i diabetes-apps, der mangler eller er svært at finde?
- Er der nogen måde, din nuværende diabetes-app ikke understøtter jeres behov?
- Kunne mere datakontrol øge værdien af din behandling?

- Med dine egne ord: hvordan kunne en 360-løsning af smart pen / pumpe, sensor og app gavne dig som [forælder (r))?
- Bruger lægerne eller sygeplejerskerne det data som i opsamler?

<u>Encryptions and data protection:</u>

- Er datakryptering og sikkerhed vigtig for dig?
- Har du tillid til, at dine data håndteres med omhu?
- Føler du dig usikker, hvis de data, du indsamlede, ville blive delt til forskning i en anonym form?
  - i så fald hvorfor?
  - Hvorfor ikke?

Novo Pen 6 + / Echo:

- Kender du til pennene?
- Hvad synes du om dette produkt?
- Hvorfor tror du, nogen ville bruge dette produkt?
- Minder dette dig om andre produkter? .. eller har du noget kendskab til lignende produkter?

- Tror du, at deling af dine data ville gavne din samtale med din læge?
- Synes du det er motiverende at i kan holde så tæt øje med behandlingen?
- Ville en 360-behandlingsmetode (pen / pumpe, sensor & app) have en fordel?
- Tror du, at dette kunne være et værktøj for både jer som forældre - men også for skolerne?

<u>Evaluating the device and diabetes devices in general - using the UX honeycomb:</u>

- Hvor vigtig er brugervenlighed og design for jer?
  - Er det vigtigt at det tilpasser jer mest eller jeres barn?

- Hvad kan afholde folk fra at benytte sig af sådanne et produkt?
- Hvad er det mest, du ville være villig til at betale for dette produkt, hvis du selv skulle betale for produktet?

    - eller vil du kun bruge det / købe det, hvis der er delvis tilskud eller fuldt tilskud?
- *hvis du bruger pumpe: Ville en smart pen som denne få dig til at vende tilbage til at bruge pen i stedet for pumpe?*

Teenage interview guide:

Interviewee	
Age	
Diabetes for how long?	
Diabetes technologies currently using	
Interview setting	

Introduction:

We are a group of three master-students from CBS who are writing a thesis on the values and benefits of diabetes e-health solutions. We are also looking into how you as a user adapts to these technical solutions and how you as a young person lives with diabetes?

We have some questions that we would like to ask you.

But before we start, we would like to know if it's okay that we record the interview?

Preliminary questions:

- For how long have you had diabetes?
- Who follows your treatment (GP, Steno, pediatrician, local hospital etc.?)
- If you have a question regarding your diabetes who do you contact?
    - If yes – how do you know?
    - If no – how would you go about contacting someone?

- What type of diabetes treatment are you on now?
- What types of treatments (pens, pumps etc.) have you tried in the past?
- Which type did you like the best and why?
- Please tell me about yourself and your relationship to your diabetes treatment?
    - How did you/your parents feel when it was discovered that you had diabetes?
- Do you use any diabetes related technologies or apps ?
- Describe your typical day with the treatment?
    - Does it provide you with any difficulties at work or school?

- What helps you remember to check your glucose and what can potentially get you off track?

Teenagers, ages 14-17:

- How do you feel about having diabetes?
- Have you ever forgotten to inject (if they use pen or have used)?

- How do/did you feel when you have to inject when you are out with peers or at school(if they use pen)?
- Have you started to think about (or have experience) with dealing with your diabetes at parties?
- Do you feel that you can do the same/have the same possibilities as your friends (sports activities, eating habits, parties etc.?
- Do your peers know about you having diabetes?
    - Are they understanding of you having diabetes?
    - Have you talked to them about warning signs/things that can show them that you're not okay and might have low/high level of glucose?
    - Is there something what you wished that your peers knew about you having diabetes?
- Do your work place/school teachers/sports club etc. know about you having diabetes?
    - Are they understanding of you having diabetes?
    - Have you talked to them about warning signs/things that can show them that you're not okay and might have low/high level of glucose?
- Are your parents involved in your treatment or do they leave it to you?
    - How much are your parents involved? Do they keep track of your treatment and daily glucose levels?
    - How is the conversation about your treatment between you and your parents?
- How do you see your future with diabetes and your treatment? Do you have any wishes for your treatment or an optimal treatment solution for you?
- Do you think about the environmental and sustainable factors for your treatment?

<u>Going into depth</u>

If the patient uses a pump:

- Did you use a pen before the pump?
    - If yes: what was the experiences with the pen and which type?
- Why did you choose the pump? (Pumps vs pen)
    - Why did you choose the specific pump that you are using now?
        - Did you try other before?
- What are the benefits of the pump?
    - Benefits over the pen?
- What are the disadvantages?
- What about comfortability and convenience?
- Have you ever had any injury with your pump?

If the patient use the disposable pens:

- Why did you choose a disposable pen?
    - Did your doctor present you with different options?
- How do you feel about disposable pens?
    - Are they easy to use?
    - How do you dispose your pen?
        - Are they easy to dispose of?
        - What options do you have?
    - How do you keep track of your injections?
        - Digital?
        - Analog (e.g. notebook etc.)?
        - Have you tried different ways of keeping track (notebook, different apps (which ones?)? Which was the best and why?
- What are the advantages of using a disposable pen?
- … the disadvantage?
- In your own words; how does the disposable pen benefit you in your everyday life?

- Do you know about reusable pens?/What are your views on reusable pens?
    - Have you tried them:
        - If yes: why did you change back to the disposable?
        - If no: can you explain why you have not tried it?
            - Do you see yourself potentially starting to use one?
            - What do you think could be the benefits of a reusable pen?

If the patient uses a reusable pen:

- How did you come to know of the reusable pen?/Who presented you with the option?
- Which brand of reusable pen do you use?
- For how long have you been using the reusable pen?
- Why did you choose the reusable pen over the disposable one?

- Is it a smart pen where you can upload data?
    - If no: why? (depending on the answer) ..And have you considered the benefits of keeping track of your data?
    - If yes:
        - How do you use the collected data?
            - Do you share them with your doctor?
        - Do you trust the data that the pen provides?
            - Please elaborate.
        - Does it provide you with an increased or decreased sense of freedom?
        - Do you feel an increased or decreased responsibility in your treatment?
        - What are the advantages of a reusable pen?
        - What are the disadvantages?

interoperability and apps:

- *If they use apps:*
    - Which app do you use?
    - Are you consistent plugging in data?
    - Do you find that your devices are working well together?
- How many apps have you used in total?
    - Which is the best ones?
- What sort of limitations do you experience with these apps?
- Do you have any bad experiences with apps?
- Is it hard to adapt to new apps?
    - Do your trust these apps?
- How would you describe your past and current experience with diabetes apps?
    - What were your options? (e.g. tracking, uploading data etc.)
- Are there anything you often look for in diabetes apps that is missing or hard to find?
- Are there any way your current diabetes app isn't supporting your needs?

Encryptions and data protection:

- Is data encryption and security important to you?
- Do you feel unsafe if the data you collected would be shared for research in an anonymous form?
    - if so why?
    - Why not?

The Novo Pen 6+/Echo:

- Do you know about the pens?
- What do you think of this product?
- Why do you think someone would use this product?
- Does this remind you of any other products? .. or do you have any knowledge of similar products?

- Do you think that sharing your data would benefit your conversation with your doctor?
- Do you find it motivational to track your treatment?
- Would a 360-treatment approach (pen/pump, sensor & app) have a benefit?

Evaluating the device and diabetes devices in general - using the UX honeycomb:

- What might keep people from using this product?
- What’s the most you would be willing to pay for this product if you had to pay for the product yourself?
    - or would you only use it/buy it if it is partly reimbursed or fully reimbursed?
- *if using pump:* Would a smart pen like this one make you go back to using pen instead of pump?

APPENDIX 2: TRANSCRIPTIONS

TRANSCRIPTION E.

G
omkring en halvtime ..40 min maks

E
okay yes

G
så det burde ikke tage så lang tid men jeg kan bare lige fortælle dig hurtigt hvad det er jeg går og laver ..vi er igang med mig og to andre at skrive vores speciale over på copenhagen buisness school og vi har en linje der omhandler sundhedsinnovation og vi er jo så igang med at skrive om diabetes type 1 og de teknogliger som man bruger som diabetes type 1 patient egentlig og hvordan man drager fordeling af det og hvordan man egentlig bare bruger det..så jeg vil egentlig bare stille dig nogle spørgsmål om din diabetes og lidt hvordan det er at være teenager med diabetes og så vil jeg bare gå lidt i dybden med den behandling du egentlig får ..og det vil egentlig bare være det..men jeg kan jo starte med hvor lang tid har du haft diabetes?

E
altså jeg er 14 år og jeg har haft det siden jeg var 7 år såå jeg må jo så have haft det i syv år

G
ja det er jo egentlig også halvdelen af livet

E
ja

G
hvem følger egentlig din behandling?

E
det gør min mor og min far og altså selvfølgelig dem jeg bliver behandlet af ude på sygehuset og sådan noget

G
hvilket sygehus er i koblet til?

E
OUH odense universitetshospital

G
okay super er det en fast læge og diabetessygeplejeske i har derude?

E
ja det er det faktisk

G
Jeg kan nemlig forstå at der er en masse der har fået tilbudt af at der kommer en ud på f.eks. skolerne og taler ..har der været det med dig?

E
ja altså da jeg lige sådan var kommet på..eller da jeg lige havde fået diabetes så gik jeg jo i første klasse så der kom der en diætist ud og ligesom snakkede og lærte min klasse om sådan noget

G
okay super og forstod din klassekammerater hvad det var der foregik ?

E
Jaja det gjorde de

G
og de støtter dig i det hele også i hverdagene?

E
Ja og de er jo blevet meget vant til det nu så det er ikke rigtig noget de sådan tænker over på den måde

G
nej? jamen det var da dejlig

G
hvilken type behandling får du nu?

E
øøh jeg får bare sådan novorapid som den normale insulin af en pumpe..øøhm… og så blodsukker og sådan noget får jeg af en Dexcom sensor den har jeg haft ret meget glæde af jeg har dog lige ..altså ikke lige, jeg fik den nok til...jamen jeg fik den til september sidste år..så det er stadig sådan lidt nyt men det er jeg er blevet meget vant til den

G
okay er du glad for den?

E
ja den er jeg rigtig glad for

G
det var godt hvad med har du prøvet nogle andre sensore før ?

E
ja jeg har haft freestyle libre den har jeg haft i meget lang tid..men ellers har jeg ikke sådan haft deciderede sensore så har jeg jo selvfølgelig haft fingerprik og alt det der

G
ja og du startede også ud med at bruge pen de første par måneder eller hvordan?

E
ja det gjorde jeg det er faktisk de første ..ihvertfald det første år der hvor jeg brugte pen

G
okay hvordan havde du det med at bruge pennen

E
altså sådan i starten der var det jo sådan ret irriterende sådan men..men det var jo også fordi der var jeg jo kun syv år så det der med nåle der det var jeg jo ikke sådan vildt glad for og sådan noget..men man blev jo sådan..altså jeg blev ihvertfald rigtig rigtig hurtig vant til det så det var egentlig ikke noget senere hen som gjorde mig sådan irriteret det var mere det der med at så gjorde det måske lidt ondt fordi man begyndte jo ligesom at få noget arvæv eller sådan noget som godt kunne irritere en rigtig meget

G
ja det kan jeg forestille mig ja ...var det så rart da du kom af pennen eller?

E
ja det var faktisk rigtig rart fordi så var det der med at så skulle man ikke lige stikke sig så mange gange om dagen ..altså man skulle overhovedet ikke stikke sig kun hver tredje dag var det jo så der i den

G
det var da dejligt..hvad var du egentlig mest glad for hvis man skal veje det lidt sådan op mod hinanden..pennen eller pumpen?

E
øh det er helt klart pumpen! fordi den giver mange flere muligheder for at man hurtigere sådan kan regulere sit blodsukker

G
og hvilken type pumpe er det du har nu?

E
jeg har en medtronic pumpe ..jeg kan faktisk ikke lige..det er medtronic minimed pumpen..den hedder 64..øøh nej 640 G..så

G
okay og kan du på den sidde og skrive kulhydrater ind?

E
øøh ja det kan jeg

G
okay super ....hvad med apps har i brugt det til din behandling?

E
øøh ja altså Dexcom sensoren det er jo en der følger over telefonen..sådan så man ligesom får alarmer hvis en blodsukker er for højt eller for lavt eller sådan noget i den stil eller hvis sensoren skal skiftes eller et eller andet i den stil så det er ligesom den jeg bruger hele tiden for ligesom at kunne kigge på mit blodsukker

G
okay så du..er du fuldkommen selvkørende selv med din behandling eller er dine forældre inde over den?

E
altså det er jo sådan..man kan sådan dele sådan..jeg har sådan delt den med mine forældre som ..så de kan gå ind på sådan en followapp og så kan de ligesom se blodsukker som.. de kan se mit blodsukker

G
okay ...hvordan har i brugt den sammen med dine forældre..har de nogen gange skrevet til dig at det kunne være du lige skulle tjekke eller hvordan`?

E
f.eks. hvis det nu er meget meget meget lav så bliver de jo måske lidt sådan bekymret kan man jo godt sige øhm... så der kan de godt lige finde på måske lige at skrive "er du okay?" eller et ellerandet og lige se om jeg svare ellers sådan noget fordi ja....også om natten f.eks. så æh...hvis det er nu at mit blodsukker er for højt så giver den alarm... hvis om natten og skal ind ligesom og regulere mit blodsukker

G
Hvordan da du fik diabetes dengang, nu ved jeg godt du kun var syv år, men kan du huske hvad du tænkte dengang da i fik at vide du havde fået det?

E
ææææh...altså.(nervøs grin)...jeg kom jo derud...også ..altså ud på sygehuset...jeg ved ikke sådan rigtig lige hvad det var der sådan lige skete og sådan noget..men jeg kan huske at i starten...altså jeg var egentlig ikke særlig bange for det der med at bruge pen..jeg kan huske at efter sådan måske...jeg var indlagt i to uger i alt..mmh men jeg kan huske at efter fire, jeg mener at det har jeg har fået fortalt at det var cirka fire natte eller aftener så øh så øh begyndte jeg ligesom selv at

ville..ville stikke mig selv istedet for at lægerne skulle stikke mig med pennen...det havde jeg egentlig bare det sådan lidt bedre med på en eller anden måde det der med jeg selv at havde kontrol over at stikke mig selv

G
er det noget du føler du kan mangle idag..kontrollen?

E
øøøhm ja fordi altså ...f.eks. hvis jeg nu er til f.eks dans eller sådan noget i den stil så øhm så kan jeg jo sådan..så hvis jeg nu danser noget meget hård dans eller noget i den stil så kan det meget hurtigt sådan måske lige komme lidt hvor man ikke lige gider tænke på det for nu laver man lige noget som måske er man synes er meget sjov og sådan noget og det gider man ikke sådan rigtig afbryde sådan man vil hellere tænke på dansen i stedet for hele tiden at skulle tænke på diabetes øøøhm.....også kan man nogen gange bare sådan godt lige lige ligge det lidt på hylden hvilket måske ikke er en særlig god ide(nervøst grin)..men øhm ..men øhm ja på den måde kan man godt sige jeg måske nogen gange ikke har så meget kontrol over det

G
hvad med pumpen har du den på når du danser ?

E
det kommer meget an på sådan hvordan mit blodsukker ligger ...fordi hvis mit blodsukker foreksempel er meget sådan højt eller sådan rigtig højt så har jeg den på og så danser jeg ligesom bare med den men hvis det sådan f.eks. ligger på 10 det er stadig lidt højt men det er ikke så forfærdeligt højt det er faktisk et rigtig godt blodsukker f.eks at danse på så der plejer jeg bare at tage pumpen af hvis det ihvertfald er 10 eller under så tager jeg ihvertfald pumpen af

G
okay hvad med at kontrollere det..hvis vi nu siger du tager pumpen af når du danser regulere du det nogen gange med at drikke en juice eller spise et eller andet?

E
øh ja altså hvis mit blodsukker nu bliver lavt det kan jeg jo sådan mærke sådan for det meste kan jeg jo ligesom mærke når mit blodsukker bliver lavt eller højt øhm og så plejer jeg egentlig bare at gå lige hen måske lige og tage fem minutters pause lige drikke en juice og der er det egentlig sådan og.. det kommer selvfølgelig an på hvor lavt det er men så plejer det egentlig at komme okay hurtigt op..nogen gange drikker jeg også bare juicen og skynder mig ud og danse igen for jeg ved jo at når jeg har drukket en juice så begynder det jo ligesom langsomt at stige...men jeg spiser altid noget inden træning øhm og jeg spiser oftest noget efter træningen nogen gange det er ikke altid..det har også noget at gøre med det der med at hvordan mit blodsukker ligger

G
føler du nogen begrænsninger når du går til dans med at du har pumpen og diabetes?

E
øjhhhhh jaa(tøvende sagt)...det føler jeg egentlig nogen gange..fordi det er med, som jeg sagde lige før, hvis det nu er jeg lige sætter mig og får en pause hvor jeg sidder og drikker en juice med lavt blodsukker så kan jeg jo ikke være med i den tid hvis det nu er jeg er rigtig dårlig eller sådan er svimmel eller noget i den stil så kan jeg jo ikke være med og på den måde så begrænser det jo lidt sådan hvor meget jeg får gjort fordi jeg danser jo kun i sådan cirka..i den første time der danser jeg jo kun i tre kvarter og det er jo ikke sådan sindsygt meget øhm....også de der fem minutter det er aligevel sådan ret meget man springer fra hvis man kan sige det på den måde

G
føler du at du oplever andre begrænsninger....eller måske spørge på en bedre måde...føler du har de samme muligheder som de andre på din egen alder?

E
ne...altså ...altså hvis det nu er at jeg.. hvis det nu er mit blodsukker ligger rigtig rigtig dårligt eller sådan noget og vi sidder f.eks. hele familien eller sådan noget i den stil og spiser slik eller noget i den stil så er det jo selvfølgelig sådan lidt irriterende fordi så kan man f.eks ikke sidde og spise slik sammen med alle de andre hvor de andre de spiser slik eller noget i den stil..eller hvis man er til en fødselsdag ligesom i dag så når ....lige nu ligger mit blodsukker rigtig højt og så kan jeg jo ligesom ikke bare lige gå sådan hen og tage en sodavand eller tage et stykke kage eller sådan noget fordi at så kommer man ligesom hen til det høje blodsukker igen hvis man nu lige har fået det ned ...så

G
ja okay...og hvad med, jeg hopper lidt over til din skole hvordan eh...er det den samme skole du har gået på altid?

E
ja det er det..den har jeg altid gået på

G
så de kender...også dine undervisere har styr på at du har diabetes og de ved hvis der sker noget med dig hvordan de skal gøre osv.?

E
ja det ved de godt øhm og de sådan kigger også meget godt efter om jeg er sådan..jeg har sådan en kasse inde i vores skab i klassen hvor jeg har juice liggende og sådan nogle HypoFit liggende og der kan de godt lide nogen gange lige at kigge oppe i den kasse der om jeg har puttet nogle juice derop eller sådan noget..mmh og ja så altså de ved egentlig alle sammen godt hvad det er de skal gøre hvis det nu er jeg f.eks. falder om eller noget i den stil

G
har du nogensinde oplevet at det er sket?

E
altså faldet om?

G
ja

E
æææh ja en enkelt gang men det var også oppe i skolen det var bare sådan...det var ...ja.ja det mener jeg faktisk jeg har der var jeg ikke så gammel ..tror jeg gik i fjerde eller femte klasse..

G
var du på pen dengang?

E
nej det var jeg ikke

G
okay det var pumpen ja.....hvad med med hensyn til pumpen fordi man høre jo nogen gange at der er nogen der kommer lidt galt afsted med de der pumper ved at den f.eks river sig løs og eller man banker den ind i et bord nogen gange og man slår sig med den har du oplevet det nogensinde?

E
øøøøhm altså nogen gange hvis den sådan f.eks. øøøh falder sådan af ...du ved buksen sådan hvor klipsen sådan ligesom river sig løs..så kan den godt sådan hive i selve kateteret som ender på balden eller jeg ved ikke hvor så kan det ligesom godt rive lidt men jeg har egentlig ikke oplevet at jeg har slået mig med den..decideret slået mig med den....mmh men der er f.eks nogen gange hvis man nu tager nyt kateter på eller noget i den stil så ..øhm...så plejer det jo ligesom at ...så kan det nogengange godt gå lidt galt hvor den f.eks trækker kateteret med ud når man allerede har sådan stukket sig eller så er den der sådan selve slangen den er måske bukket eller sådan noget i den stil (læs lige efter 13:25)

G
hvad med f.eks. overnatter du nogen gange hos veninder?

E
øhm det gør jeg faktisk ikke så tit faktisk ..jeg har været på sådan nogle lejre..det er ikke noget jeg gør mig så meget i det der med at sove ude ...det er jeg er heller ikke så tryg ved..det der med min diabetes fordi sådan..ja

G
ja for det var nemlig det jeg ville spørge dig lidt ind til ..hvaa..hvordan oplever du at du ikke er tryg ved det?

E

det er lidt mere hvis det nu er at ..nu har jeg jo ikke sådan rigtig sovet hjemme ved nogen sådan særlig meget...ligesom det der med om de sådan...det sidder lidt i baghovedet det der med har de nu styr på det? eller sådan noget og ellers skal jeg ligesom gøre det selv hvis jeg nu ikke vågner af mine alarmer eller sådan noget i den stil...man kommer måske hurtigt lige til at overtænke lidt

G
ja..og dine venner er også indforstået med at det så også giver altså..nu ved jeg ikke om det er noget i taler om dig og dine venner ?

E
nej men de fleste de er indforstået med at jeg ikke er så tryg ved det når det er jeg har den sygdom jeg har

G
okay super ...hvad med dine forældre..ved du om de har en dialog med dine venners forældre hvis du er hjemme hos dem?

E
øøøøhm....det var faktisk lidt mere sådan i de mindre klasser sådan hvis jeg nu var til en børnefødselsdag eller noget i den stil så var det mere i de mindre klasser tror jeg at de lige skrev hvad er det i skal have og spise og sådan noget det var ligesom for at vide øh hvor mange kulhydrater jeg skulle tage for det for der var det jo sådan meget nyt og sådan noget

G
hvad med ...hvad tænker du egentlig i fremtiden at der skal ske med din behandling..ønsker du at forsætte med pumpen eller ønsker du at skifte til en pen?

E
altså jeg ville ikke foretrække at skifte til en pen fordi jeg har været meget mere glad for at bruge pumpe da man ikke skal stikke sig så meget og man sådan hele tiden kan regulere sit blodsukker uden at man skal stikke sig så altså jeg ville foretrække at beholde min pumpe

G
hvad med eh...den dialog der er mellem dig og dine forældre har i talt om at i fremtiden at hvis du skal gå til nogle fester eller sådan noget hvordan i vil tackle det? er det en snak i overhovedet er begyndt at have endnu?

E
ja fordi at sådan hvis vi kigger på sådan min klasse så er de fleste faktisk begyndt allerede at drikke i 14-års alderen og altså det synes jeg jo ..ret tidligt synes jeg ihvertfald..øhm..og så jeg er egentlig bare sådan nået lidt en aftale med mig selv at jeg ikke sådan lige typen endnu som går ud og drikker endnu..men altså jeg skal ikke kunne sige om det måske vil komme til at ske at jeg bliver interesseret for det om to måneder eller om et halvt år eller alt sådan noget..jeg begynder i 9. så tror jeg vel at jeg måske begynder at få interesse for det men det er jo også sådan noget vi snakker med f.eks . sygehuset om hvor de måske giver nogle fif og sådan noget

G
så det er ikke noget i har talt med sygehuset om endnu ihvertfald?

E
nej vi har kun talt om at vi skal have en snak om det på et tidspunkt

G
okay fint nok..øhm men nu vil jeg lige gå lidt tilbage og sådan til generelt lidt med pumpen..hvem var det der tog beslutningen om du skulle have pumpe?

E
øh det ved jeg faktisk ikke helt fordi at jeg tror bare det var et forslag vi fik..jeg tror det var mine forældre der fik forslaget om jeg kunne få en pumpe også..jeg vidste jo egentlig ikke helt hvad det var jeg fik bare at vide at det kunne være en nemmere måde at håndtere mit blodsukker på og sådan noget og så havde mine forældre egentlig bare tænkt at det ville være det bedste fordi de fleste de får jo..eller næsten alle unge får jo en pumpe i danmark ihvertfald der får de fleste jo en pumpe af kommunen eller af sygehuset eller noget i den stil og det fik jeg så tilbuddet om og mine forældre tog så det tilbud for det ...det var jo det bedste havde de hørt og det var det jo også.

G
ja super hvis du sådan lidt sort og hvidt måske skal forklare i korte træk hvad er fordelene ved pumpen og hvad er ulemperne ved pumpen?

E
Ulemperne ved pumpen det er nok det der med den er meget synlig, det der med at sådan hvis der er nogen der ikke kender mig så kan de godt finde på at kigge eller sådan eller hvis jeg nu er nogen steder henne så kigger de jo både på min sensor men også på min pumpe og tænker hvad er det? også fordi jeg går jo til mange tuneringer og der kigger folk jo også rigtig meget og hvis jeg nu har den på imens jeg danser øhm ...men fordelene er jo helt klart at det er meget nemmere at regulere ens blodsukker end det er når man bruger pen og det er også meget mere smertefrit(nervøst grin)..når det er man bruger pumpe...og ja man kan bare meget mere man kan også sådan få midlertidig basal og sådan noget kan man jo få hele tiden få på ens pumpe hvor at da man brugte pen så var det jo sådan noget med ..sådan noget med man skulle stikke sig i låret morgen og aften som midlertidig basal og det kan man jo egentlig bare installere på sin pumpe og så kan man tage det på når man vil såå det vil jeg sige er fordelene ved det

G
ja...hvad med sensoren skal den nogen gange skiftes?

E
ja den skal skiftes hver 10. dag og min gamle sensor den skulle så skiftes hver 14. dag så ..men det er ikke noget der gør den store forskel

G

okay..gør det ondt at få skiftet sensoren?

E
øh nej det gør det faktisk ikke..altså jo hvis man rammer en blodåre eller noget i den stil så gør det jo ondt eller rammer en nerve eller et eller andet i den stil så gør det jo ondt men eller så gør det ikke ondt

G
okay super ...scanner i nogle gange ..du havde libren før sagde du..der skal man manuelt scanne den hvis jeg husker korrekt ikke?

E
ja det er rigtig

G
skulle i så også nogen gange manuelt scanne om aftenen eller om natten? undskyld

E
ja det var sådan de satte en alarm på deres telefoner til forskellige tidspunker også øhm så vågnede de ligesom af den der alarm også gik de ligesom ind og scannede mig

G
okay ...og vågnede du nogensinde af det?

E
ja nogen gange hvis jeg f.eks. lå på min sensor eller sådan noget så hvis min far han lige skulle vende mig om så kunne jeg godt finde på at vågne men altså hvis det lavt så skulle jeg jo også have noget at drikke så..så vågnede jeg nogen gange men der var også nogen gange hvor jeg bare drak..det gør jeg stadigvæk sådan drikker noget i søvne

G
hvad med har i ..hvor længe har du haft den sensor du har nu?

E
den har jeg haft i et halvt år (meget tøvende)..ej..jooo det må det jo næsten være ..et halvt år cirka

G
Hvad for en havde du før det kan jeg slet ikke huske om jeg spurgte dig om?

E
det var en libre

G
det var en libre okay..også selve pumpen?

E
øøh altså pumpen der havde jeg jo en anden pumpe før...det var den samme bare en anden model

G
okay så også en medtronic

E
ja også en medtronic

G
okay hvad for en kunne du bedst lide af de to pumper du havde?

E
der kan jeg faktisk bedst lide den jeg har nu fordi at æh ved min anden så var det sådan der kom jeg meget tit til at glemme at taste selve blodsukkeret ind øhm og så bare tastede kulhydraterne ind i stedet for...men ved den her er det ligesom sådan lidt mere trin for trin så man skal ligesom taste du ved ind..så det husker jeg meget bedre nu end jeg gjorde ved den anden så jeg kan meget bedre lide den jeg har nu

G
okay hvad med størrelsen er den nogenlunde samme størrelse eller?

E
ja det sådan..ja det er det

G
kunne du tænke dig i fremtiden noget der var mindre eller ?

E
jaa altså sådan ...ja jeg kunne da meget hellere tænke mig en der var noget mindre..øhm men altså jeg har også prøvet sådan det hedder en omnipod mener jeg det er sådan en der sidder på armen men den er også meget stor for jeg har ikke særlig meget fedt på kroppen så den er meget stor i forhold til mine arme fordi mine arme de er heller ikke så store..så den var ordentlig stor og sådan ihvertfald til min ....(kan ikke høre hvad der bliver sagt 24:01)

G
har du samtaler med hospitalet om den ..måske den næste pumpe du skal skifte til?

E
øøh nej fordi det er sådan at når man får en pumpe skal man have den i fire år inden man kan få en ny pumpe og så ..så nej for den her har jeg kun haft i ..tror jeg har haft den i et år nu så nej vi har engentlig ikke snakket om sådan at jeg skal have en anden pumpe..det kommer vi nok først til at snakke om om nogle år fordi at så er det måske lidt mere relevant men der kommer der jo..der er jo sikkert nogen helt vildt nye smarte pumper som kommer til næste gang jeg skal have en pumpe

G
ja jeg kunne forstå at der er mange ihvertfald på din alder som bruger en der hedder T-slim som er sådan en meget lille en der sidder ihvertfald jeg tror den hedder T-slim

E
den har jeg aldrig hørt før om tror jeg....nååååååååårhhhhh den nååårh ja den har min veninde

G
er hun glad for at bruge den?

E
hun er glad for den..men den virker meget ligesom den jeg har og så stor størrelsesforskel er der heller ikke der er den der med det der ..der er touchskærm og sådan noget og ...ja men der er ikke den store størrelsesforskel den er lidt mere tynd og så ligner det lidt mere en meget lille telefon...den er sådan lidt mere teknologisk ud

G
ja fordi jeg talte nemlig med en anden pige der var et år ældre end dig nemlig og hun brugte nemlig T-slim nemlig og var faktisk egentlig også danser og hun synes faktisk egentlig det var det der havde fungeret bedst for hende og om man især var danser ihvertfald

E
hvad hed hun?

G
hun hed Camille

E
nåh okay

G
ja jeg fik kontakt med hende igennem fordi hun havde lavet instagram takeover for diabetesforeningen

E
nååårh hende kender jeg godt camille

G
ja camille eller kamille ja

E
ja hende kender jeg godt

G

ja ..men hende talte jeg ihvertfald med omkring T-slim ihvertfald

E
ja

G
men nu siger du også at du har en veninde der også har diabetes taler i nogle gange omkring diabetes sammen? og giver hinanden ideer

E
altså det er sådan at hun bor lige overfor mig og så er vi dansepartnere

G
ja nej gud hvor sjovt

E
så vi snakker rigtig meget f.eks til dans vi kan nærmest se på hinanden hvis det er at vi har lavt blodsukker f.eks i øjnene eller sådan noget så kan vi se på hinanden hvis det er vi har lavt blodsukker så kan vi lige gå hinanden "ej gå lige hen og tag en juice tak" eller sådan noget...så vi snakker rigtig tit om det vi kan også låne ting af hinanden hvis det nu er vi lige mangler noget så kan vi også nogen gange, f.eks. vi har begge to DeX-com så kan vi nogen gange hvis vi ikke lige har fået bestilt nogen så kan vi lige låne en også når vi får hjem så kan de lige få en af os..så

G
nåh jamen det var da smart

E
ja

G
fø..det må da så også være ja være rart for jer alle sammen af at man har nogen i hverdagen man kan snakke med

E
ja

G
gælder det også for dine forældre..taler de også med hendes forældre omkring det hele?

E
ja altså det er jo sådan vi er sådan lidt sådan..nu er vi jo blevet rigtig rigtig gode venner sådan siden hun sådan flyttede herop og sådan op til hvor vi boede der er vi blevet rigtig rigtig gode venner så vi snakker sådan nærmest hele tiden sammen om alt mulig også om diabetes nogen gange hvis vi har et eller andet og som vi vil snakke om

G
okay nåh jamen det var da rart...kan du huske, nu tager jeg lidt tilbage til dengang med pennen, nu ved jeg godt du kun var syv år, kan du huske om det var sådan en man smed ud igen når man var færdig med at bruge den?

E
nej det var det ikke det var sådan bare en ..det var mere den man brugte på sygehuset mener jeg end at smide ud igen..men den dem som jeg ligesom havde det var sådan nogle stålpenne hvor at man så skulle sætte en ny nål på hver gang og så kunne man ligesom bare bruge den igen og igen

G
okay ..kan du huske mærket?

E
øøhm...det er novonordisk

G
var det en novopen?

E
ja !

G
var det sådan en hvor man skiftede ampuller i den?

E
øøøh ja altså nålene

G
ja nålene okay

E
ja det var dem man skiftede,... man skiftede også den der når man ligesom havde opbrugt insulinen inden i så skiftede man jo til en ny insulin der skulle ind i den

G
okay ..tror du den hed en fleXpen eller en novopen kan du huske du det?

E
åh det kan jeg faktisk ikke huske(griner)

G
det er også helt i orden(griner) det er fordi jeg sidder med en case nemlig hvor at de...det er fordi novo nordisk skal igang med at sætte, selvom de egentlig medicin mest så er de igang med at sætte en genanvendelig pen på markedet.... nemlig hvor at man egentlig bare skal putte ampuller

ind i og så vil der være en lille log i der fortæller hvor stor ens dosis var også hvornår man sidst har stukket sig selv nemlig

E
ja okay

G
ja men nu vil tage dig lidt frem nemlig for nu er det sådan noget med lidt med apps vi skal snakke om..f.eks. der er jo meget her for tiden af hvad vi har fundet ud af ihvertfald af at rigtig mange firmaer er igang med at udvikle det man kalder en 360 løsning hvor at alting ligesom skal kunne hænge sammen f.eks. at en pen eller en pumpe, sensor og app skal simpelthen hænge sammen af at du så kan se alting inde på samme app så kan du se dit blodsukker og så kan du også se hvornår at du har f.eks. hvis det er en pumpe hvornår den sidst har givet dig insulin og hvor stor den dosis var og hvis det var pennen så kan den også holde styr på "okay kl hvad tog jeg den og hvor stor var den dosis jeg tog nemlig..ville det være noget du ville synes var en...eller var det noget du kunne tænke dig at tage brug af hvis det kom på markedet?

E
øh ja altså det kunne da være.. altså jeg ville nok snakke med mit sygehus først sådan det der med at ville det kunne være noget der ligesom ville passe til hvordan mit blodsukker det ligger sådan til daglig og sådan noget..men ja altså hvis det var...hvis jeg fik lidt mere info om hvad den gjorde og alt det der hvis jeg sådan virkelig ville sådan se at den var en virkelig virkelig god fordel så ja så ville jeg helt klart foretrække den

G
og du ville have det fint med at man kunne se at det hele ligesom kørte i en kurve sammen ?

E
ja det gør man jo også sådan lidt.. på DeXcom der kan man jo se hvordan ens blodsukker ligger i en kurve så ja det ville jeg have det fint med

G
okay ..de data som deXcommen den opsamler hos dig er det noget i bruger til at snakke med lægerne om

E
ja det bruger de jo ligesom både til at kigge på hvordan..hvis mit blodsukker nu svinger nogle forskellige steder øhm f.eks. hvis det nu stiger rigtig meget om morgenen f.eks. så bruger de det jo til at stille min pumpe om til at jeg måske skal have mere insulin om morgenen..så på den måde kan man godt sige at den bruger kurverne til det

G
så det er simpelthen hospitalet der sidder og justere den pumpe du har ?

E

ja

G
okay og det gør de bare når du er der eller tager det et stykke tid inden det begynder at virke?

E
altså når vi er der så stiller vi jo om på selve pumpen sammen så det begynder at virke ligeså snart det er at vi har fået det gjort

G
jeg kan jo høre du har jo skiftet lidt imellem også med sensore og pumper..synes du det er svært eller nemt at tilpasse sig og vænne sig til de nye gadgets du får ?(grin til sidst)

E
nej fordi at nu er det jo egentlig meget ens dem som jeg ligesom har byttet imellem altså forskellen på libre og deXcom var jo egentlig bare at man ikke skulle scanne det var jo egentlig bare at man skulle kigge på sin telefon istedet for og den så blimmede når det var det var for højt eller for lavt og der er jo nærmest ikke rigtig nogen forskel på en ny pumpe så jeg vil ikke rigtig sige det var besværligt..at skifte

G
hvordan oplevede du det der med f.eks hvis der er noget der har, det er ihvertfald hvad jeg har kunnet forstå på andre ihvertfald jeg har interviewet af at af at der er ligesom en proces når man får en ny pumpe eller sådan noget så skal man lige ..man skal lige begynde at stole på den igen? er det noget du har oplevet ?

E
det er det nok sådan lidt..hvis man nu ..man ved jo ikke om den har nogle andre værdier den pumpe..så man kan godt sådan lige sådan lige ..man skal lige se tiden an med hvordan ens blodsukker hænger sammen men det er jo også mere sådan man har jo de samme indstillinger inde på pumpen så den giver jo ikke mere eller mindre insulin end der er installeret på pumpen

G
hvad med udover deXcom appen har i brugt andre apps til din behandling?

E
nej det har vi ikke..jo det ..jo det passer faktisk ikke vi har brugt sådan en app der .. det var lige der jeg tror ikke engang den er der mere den hedder kulhydrattæller eller sådan noget ..det var mere i starten den bruger vi ikke rigtig mere for nu sidder det lidt i hovedet hvor mange kulhydrater men den gang brugte vi rigtig meget kulhydrattællere men ellers så nu der bruger jeg nogen gange det er ikke så tit der bruger jeg nogen gange lifesum fordi der kan man gå ind på sådan en stregkode og så kan man f.eks .en muslibar så kan man lige scanne stregkoden på en muslibar og så står der hvor mange kulhydrater der er i den muslibar..så den bruger jeg engang imellem hvis det er noget nyt jeg spiser

G
okay har du haft nogle dårlige oplevelser med de her apps du har brugt?

E
åh ja deXcom kan godt være sådan lidt nogle gange fordi så står der noget med sensorfejl eller noget i den stil så skal man vente f.eks to timer..ej det passer ikke. der står man kan vente op til tre timer før den virker igen..men det er mere for at folk ikke ringer ind efter en halv time og ringer til deXcom og siger der er et eller andet galt øhm ..men men også det der med at man ikke kan være mere end seks meter væk fra sin telefon når man har den her sensor så mister den forbindelsen og så kan man ikke tjekke sit blodsukker øhm men ellers nej så vil jeg ikke sige der som sådan er nogen ulemper ved det

G
nej okay hvad med hvis deXcom appen her stopper med at virke har du så en backup?

E
altså jeg har jo altid en fingerprikker, jeg har flere af slagsen og så har jeg jo også en libre stadigvæk

G
okay så du kan bare skifte til libren hvis der skulle ske noget med deXcommen ?

E
ja men øhm men ellers ville man også bare ringe til sygehuset ligesom og snakke med dem om hvad der lige skete

G
hvad med sådan noget som brugervenlighed og design af de her apps og pumper og sensore er det noget der er vigtigt for dig og eventuelt hvad er vigtigt?

E
øøhm altså jeg vil sige at det ligesom er nemt og kunne installere hvor mange kulhydrater hvad ens blodsukker er på altså at pumpen ikke er sådan langsom ligesom en telefon der er mega gammel det er sådan ret vigtigt at man ligesom hurtigt kan stoppe pumpen eller hurtigt kan få insulin af pumpen..hvis man har brug for det

G
okay ..den pumpe du har nu opsamler den noget data?

E
nej det gør den ikke fordi at jeg har ikke sensoren som der høre til den men den har ellers en sensor hvor at man kan sådan spille sammen med en sensor der ligesom også er fra medtronic men den har jeg ikke

G

nu skal jeg lige se om jeg har flere spørgsmål...jo det kan måske være at er der nogen infomationer du egentlig føler at du godt kunne tænke dig var mere samlet?

E
åhh det ved jeg faktisk ikke...altså joo sådan det kunne da være rart hvis ens blodsukker kunne stå inde på pumpen hele tiden men det kan det jo ikke rigtig hvis det er jeg gerne vil have den på min telefon og hvis jeg ikke skal stikke mig og sådan noget fordi så skal man jo ligesom stikke sig i fingeren tre gange om dagen og sådan noget og det vil jeg ligesom gerne undgå men ellers så tror jeg ikke rigtig

G
jamen ved du hvad emma jeg tror faktisk det var alle de spørgsmål jeg egentlig havde

TRANSCRIP[redacted]

HH
De gange hvor hun vågner har har skulle passe ham og hvor han har sovet - altså hen over natten eller om aftenen, så har jeg bare lagt sådan en skriftlig vejledning. Hvis ringer og siger at du skal give ham 30 kulhydrater så skal du trykke det og det og så næste næste 30. så det er jo simpelt men det kan folk jo ikke huske

G
Kan du huske hvad det var for en pind i brugte der i starten?

HH
det var sådan en almindelige novo (kan simpelthen ikke høre hvad mærket er00:36) der er sådan en rød og en blå

G
og pumpen hvem tog den beslutning? det var ..i blev fremlagt den fra lægerne?

HH
ja og diabetes sygeplejesken og det var sådan en ny en..der var kommet en ny og den skulle være det smarte og så ved et tilfælde har vi så fået den med den der fjernbetjening.. hvor jeg så har talt med en del diabetesforældre der siger "gud bare vi havde haft den" og så har jeg faktisk ringet og snakket med firmaet og jeg har også skrevet ud til nogle andre at de skal huske og fortælle og reklamere hvor vigtigt det er med den der fjernbetjening

G
Jeg tror ikke jeg kender den version

HH
det gode ved den den har en fjernbetjening til pumpen ikke men den er bluetooth det vil sige at jeg ikke behøver være helt i nærheden af ham.. og der er kommet sådan en ny der hedder et eller andet TX SLIM halløj ...hvor man skal afgive insulin ved at trykke på pumpen og det er jo mega bøvlet at du skal have pumpen frem for nikolaj han har jo den der pumpe siddende i et mavebælte.

G
okay den sidder på maven

HH

Ja .... og den har han jo aldrig nogensinde.. der sidder den jo bare og så med en ledning om til et indstik men han røre aldrig den pumpe fordi han bruger..eller vi bruger den der fjernbetjening...(noget med en halt??02:13) han spiller jo helt vildt meget fodboldt der kan jeg jo godt sidde og være ude og se ham når han er ude og spille stævne og spille fodbold.. der kan den række så langt at jeg sådan set kan sidde og se hans blodsukker på min telefon og så kan jeg afgive insulin med den der fjernbetjening og så sidder jeg der i 8 timer og drikker kaffe og ser fodbold og når dagen så er omme så kigger jeg sådan og så løber han rundt med snolder og en chokoladekiks i munden og render rundt og spiser mellem kampene og så giver jeg lidt insulin følger med og når dagen så er omme siger nikolaj "ej far det er jo som om jeg slet ikke har diabetes" og så siger jeg ikke noget..det har jeg så ordnet

latter overlapper hvad han siger

HH
Hvis man sammenligner det med at skulle hen og forstyrre ham og sige nu skal du med en pind have noget ...nu kan jeg se at du står med vommen fuld af kanelgifler nu skal jeg give dig insulin til det eller jeg skal lige scanne dig med det der libre eller jeg skal fingerprikke dig..og den anden løsning det er jo helt vild så lidt indgribende den er ..i forhold til hans aktiviteter ..altså jeg har jo insulin på noget lejr sådan en fodboldlejr hvor jeg kan jo.. hvor de lige pludselig sidder fem drenge og spiser i en eller andens campingvogn og vi er nogle forældre der bare sidder og hygger. altså så kan jeg bare stille mig uden for campingvognen og med den der fjernbetjening bare afgive insulin. Så opdager han det ikke engang og det gør jo så også altså vi har jo den der aftale han skal lige nævne hvad det er for noget han spiser.. så han råber jo bare "far jeg spiser lige et eller andet " og så siger jeg super..og så giver jeg noget insulin og plus det er også om natten det er jo så det værste ved det..det de der natte...(hvad siger han der?04:12) der kan jeg så også bare have den der fjernbetjening liggende på mit natbord så når jeg får en alarm om at nu er han høj eller lav så giver jeg bare noget insulin eller slukker for pumpen(er det den han slukker?04:21) uden at gå ud af sengen..det er jo også meget fedt

G
er der nogle ulemper ved den pumpe?

HH
Nej jo den der fjernbetjening er helt vildt langsom men det er jo fordi det er noget ældgammelt teknologi..altså inden det kommer igennem FDA approval og sådan noget så er det jo forældet..så det er jo bare sådan det er ..men ellers er den super god

G
Hvad med komfort og bekvemmelighed i forhold til den pumpe for nikolaj at have den på? har han slået sig med den på?

HH
nej altså jeg tror han nærmest føler det er en del af ham altså han har jo gået med det mavebælte nærmest 24/7 i næsten 10 år..

G
Man høre tit om folk der har pumpe at de så går de ind i et bord og sådan

HH
den er lille faktisk den er lille og så er den jo foran den i bokseshorts sådan der..så den genere ham heller ikke...og selvom han har..han har jo sådan en sensor skudt ind...han har kun de der ting siddende på balden...så jeg tror ikke det er sådan..altså han tyre rundt så det er jo ikke sådan at han passer på ...så jeg tror ikke han tænker over at han har de der indstik på sig...og nogle gange af og til bliver de også..altså det der med at lige pludselig har han et megahøjt insulintal(kan ikke høre hvad han siger her 05:52)

G
I bruger så ikke nogle apps eller noget i den retning?...sådan nogle til tracking eller blodsukker ?

HH
jooo der er sådan en der hedder DIASEND...øh og der kan man bare gå ind og se hvordan det går med hans blodsukker..,men det er bare sådan det er hvordan ligger hans gennemsnitsblodsukker..og så tog vi den der followapp...altså det er en app hvor jeg ser hans blodsukker på min telefon

G
og den hedder?

HH
Den hedder DEXCOM follow

G
den hedder DEXCOM follow

HH 06:52 (hør lige det her og tjek om det er rigtig)
og han har jo så på hans telefon nikolajs telefon..han har jo så også en DEXCOM altså den der jo ligesom sender altså det fungere jo sådan at han går rundt med et Ipunkt på maven i en undertrøje...og så sender sensoren op til den og så sender den ud i skyen og så får vi det derfra...så han har jo altid en iphone i undertrøjen, sin pumpe på maven, et indstik på sin ene balde til insulin og et indstik på den anden balde til sensor. Hvis du spørger om han ville være fri ville han nok gerne det men jeg tror ikke det genere ham

G

synes du de der enheder.. de forskellige enheder fungere godt sammen..appen sensor...pumpe det hele ..lige ud over fjernbetjening som du sagde ?

HH
Jaja det fungere rigtig godt og libre målte rimeligt præcist op og den her DEXCOM måler super præcist op

G
har du prøvet andre apps end dem der du bruger nu

HH
i starten brugte vi den der kulhydrat fra diabetesforeningen til at tælle kulhydrater..men nu kan man næsten alle fødevare i hovedet

G
Ja det lærer man efterhånden

HH
det er også ..jeg vejer jo ikke mere..jeg kan jo se på tallerknen hvad der er ...så det er sådan set kun moren der står og vejer

G
Oplever i nogen begrænsninger med de her apps

HH
nej

G
har i haft nogle dårlige erfaringer eller dårlige oplevelser?

HH
Nej

G
i har fuld tillid til dem at de er præcise og rigtige ?

HH
ja..men som sagt så bruger vi dem ikke så meget

G
Føler i jer usikre med datahåndteringen fra?

HH
nej overhovdet ikke

G
det stoler i på er?

HH
Jaja

G
er der nogle login funktioner til de her apps som i har..noget tofaktor eller ?

HH
Nej ...det er bare registreret....via nikolajs telefon invitere han followere..eller det ved jeg ikke om man kan kalde tofaktor altså...jeg går jo ind via. nikolajs app og så invitere jeg hende sonja der er hans hjælp og sender hende en mail..og så godkender hun den og så er hun follower og kan så se hans blodsukker indtil jeg siger hun ikke må

G
føler du at de her data som bliver indsamlet i den her apps er det noget i bruger når i f.eks er til konsultationer hos en sygeplejeske eller en læge?

HH
ja hvis de kan finde ud af det...og det kan de godt..jeg får jo nogle kurver over nikolajs blodsukker som de ikke har ...og hvis jeg kan se at han ligger han ligger en lille smule højt kl 2 om natten ..så går jeg jo ind og sætter (?? er ikke sikker på hvad der bliver sagt fra dette punkt frem?10:24) så må ambulatoriet downloade de her data og sige han ligger en lille smule højt...og der tror jeg bare...var der en af jer der var sygeplejeske?...jeg tror bare jeg gør deres arbejde....det er jo klart jeg er jo bare ekspert i nikolajs system...de skal jo kende til alle mulige systemer..så jeg ved jo lidt mere om det end det sygeplejesken gør...og det siger de jo også.. det er meget forskellige der er nogen der er meget utrygge og bedst kan lide det er diabetessygeplejesken der står for at ændre basalraterner og så er der andre som mig der bare kigger på kurverne og så ændre basal raterne selv...det er jo sådan lidt igen...alle gør det jo så godt de kan

G
det er jo også noget hvordan man selv går op i det og stoler på det

HH
jaja hvis du synes du er dårlig til at regne.. og synes du er dårlig til insulin så er det jo selvfølgelig lidt...så skal man jo ikke gå ind og ændre på en basalrate...hvis man så risikere og at barnet bliver gigalavt ?11:42 fordi du kommer til at sætte et nul for meget...så er det bedre at overlade det til nogle sundhedsprofessionelle..så det er meget forskelligt

G
den her pumpe som i har fået ..den har i ikke betalt noget for ? den har i fået fra hospitalet?

HH
Ja

G
Novo nordisk er i gang med at udvikle nogle nye pinde som har en funktion hvor de husker lidt ligesom sensor..de huske..de har sådan en indbygget funktion der husker hvad den har taget af insulin og hvornår du har taget det, hvad dit blodsukker var og sådan nogle ting..dem har du ikke hørt om før sagde du?

HH
Jo dem har jeg hørt om

G
Hvad tænker du om det her produkt? det er måske ikke så relevant for jer

HH
Nej jeg tænker det der med insulinmængderne er lidt irrelevant..

G
det er lidt irrelevant

HH
ja fordi vi laver så mange korrektionsdoser altså vi har prøvet hvor meget er basale hvor meget er det ene og det andet altså det er sgu lidt svært..okay det er regnvejr hele dagen så får han lige nogle enheder mere og så har han den dag brugt..altså så skal man jo virkelig sidde hvis man skal bruge det korrektionsnoget..den opsamlende funktion så skal du jo nærmest have hvad var vejret, hvad var aktivitetsniveauet..hvad var kulhydratindtaget, hvad var..altså det tager jeg sgu lidt pænt som det kommer

G
Sådan et produkt her det er helt udelukket for jer ?

HH
Ja

G
det kan jeg godt høre. det lyder som at det fungere rigtig godt for jer med pumpe og sensor

HH
ja altså det vil vi aldrig nogensinde af med..nej

G
tilbage til da nikolaj brugte pind...kunne sådan en pind her så måske have gjort det bedre for jer?

HH
nej det tror jeg ikke...det var jo igen det der med at vurdere..altså det der er svært er jo det der med okay nu skal han spise det her og han skal til fodbold..han skal et eller andet og hvad er hans

blodsukker på ...okay skal han så have en halv og en hel og en kvart og en skive rugbrød med nutella inden partis(??14:37) som så dækker ham henover det der fodbold..det er det der er svært...det kan vi ikke rigtig hjælpe med

G
hvordan havde nikolaj det med at skifte fra pind til pumpe?

HH
det havde han det dejligt med..han synes det gjorde ondt og få den der basal om morgen og om aftenen i låret...og så tror jeg også at han har været glad ...det skal der jo ikke så meget fantasi til at forestille sig altså over i zoologisk have ..øhm at forældrene går bagved og giver dig insulin uden at du opdager det..sammenlignet med at du skal hen og sidde på en bænk og der skal hives op i en trøje og du skal stikkes i maven....hvad vil man helst selv

G
ja der er pumpen da klart det ...

HH
her gør det igen en kæmpe forskel at den kan fjernbetjenes pumpen ikke ? for det er jo lige så forstyrrende hvis man skulle sige..nåh nu kan jeg se at du spiser en eller anden pandekager eller sådan noget ..så nu skal jeg lige hen og have pumpen op..nu skal du løfte op i trøjen og så skal jeg have pumpen op af dit bælte og så skal jeg se på pumpen og afkigge et eller andet...det ødelægger jo lidt af ideen....han kan jo bare lege med sine kammerater og så kan jeg lige kigge over venstre skulder også kan jeg se..åh for pokker nu er de derinde hvor man spiser pandekager...jeg giver en(??? 16:10) og så er den fikset ....pumpen gør meget men fjernbetjeningen til pumpen gør faktisk også rigtig meget..ligesom sensoren gør meget i forhold til.. (han hvisker lidt her16:20)

G
Når i får tilbudt den her Dash omipod som i bruger nu..er der fuld tilskud til den eller var der noget selvbetaling i den ?

HH
jeg ved ikke hvad vi får tilbudt endnu..men jeg ved bare den kommer og så håber jeg den kommer med i det udbud der er fordi regionen de laver et eller andet udbud og hvis vi så ikke kan lide de pumper de har i OH så er der i princippet fri syudvalg(???16:57) Vi kan så vælge at skifte nikolaj til en...det håber jeg så ikke bliver nødvendigt...vi kan så i princippet skifte ham til en anden region hvor de havde det udvalg af pumper .. så jeg håber den Omnipod Dash kommer ind i et eller andet udbud et eller andet sted...fordi den er så entydigt...altså OH har spurgt vi ikke nok vil skifte pumper og vi har sagt nej..vi er super glade for det her system og nægter simpelthen at skifte pumpe før der kommer en der kan det samme

G
så de har allerede tilbudt jer noget andet men det har i ikke?

HH

ja fordi vi ..jeg tror vi er de eneste der bruger den der..og sygeplejesken er sådan lidt irriteret over de ikke kan finde ud af at få data ud af den og så har jeg sagt til dem....at det må de gerne ...det er fordi det skal de kunne...man skal kunne ringe ind...og så har jeg ligesom sagt jeg har faktisk lavet sådan et eXcel ark hvor de så kan kigge ned i og se indstillingerne..fordi skal opfylde en forpligtelse til at det skal de have tilgængeligt og så har de så fået lov til at beholde den selvom de ikke kan finde ud af aflæse den..

G
Hvad har i fået tilbudt som alternativ?

HH
Jeg er faktisk ikke gået så meget op i det fordi jeg ved det er sådan noget medtronic pumpe som ikke er specielt god et eller andet T...et eller andet SLIM.......som heller ikke har..sådan en der er lidt lækker iphoneagtig...men ikke har en fjernbetjening..så den er vi heller ikke interesseret i....den nuværende omnipod hvor der heller ikke er nogen ordentlig fjernbetjening...som vi så også har takket nej til...det er så den der kommer i den der omnipod når den kommer i den løsning der hedder dash..så er vi interesseret så er der en bluetooth baseret fjernbetjening og den er primært i USA og den er ved at blive rullet ud i Europa..og den burde komme til danmark i løbet af i år og så har vi sagt...jamen ligeså snart vi kan få den vil vi gerne skifte og ellers vil vi ikke skifte..fordi det er helt eXceptionelt velfungerende som det er lige nu..

G

jeg tror ikke vi har mere....

mødet afsluttes her

Du har haft diabetes siden du var ni år?

ja det har jeg

Hvordan fandt i ud af det kan du fortælle lidt om det?

Altså jeg har været meget syg i løbet af hele var faktisk hvad jeg havde ikke rigtig kunne finde ud af hvad det var der foregik jeg havde også været til en masse forskellige læger indtil at jeg så til sidst… jeg tror det var lige efter jul.. Der tog jeg hen til en børnelæge som noget af det samme sagde at vi skulle tage en urin prøve, vi skal se om du har diabetes. Og så fandt ellers ud af det er der hvor jeg blev selvfølgelig ked af det og glad jo fordi jeg har jo gået et helt år og været syg i mange måneder og jeg kunne da ikke være sammen min venner eller yde noget godt fagligt i skolen eller sådan noget så det var både en befrielse for mig få nu fandt jeg jo ligesom ud af at det er bare en sygdom jeg skulle leve med for resten af mit liv så det var jo også lidt hårdt.

Hvordan havde du det da i fandt ud af at du havde diabetes?

Altså det er jo det der med at jeg var jo glad og ked af det og jeg vil rigtig gerne tilbage til mine venner og alt det der og jeg har jo heller ingen anelse om at det var så stort som det var på det tidspunkt fordi at diabetes lyder jo som en lille ting når man bare siger det sådan, men personligt er det er jo en kæmpe stor ting fordi jeg skal med dig resten liv og det er fandt jeg først ud af senere da jeg kom over på hospitalet og der lærte de mig en del omkring det at være diabetiker.

Havde du et forløb på hospitalet hvor de sætter en af de her ting?

Ja jeg tror jeg var der i to uger tid er det omkring, altså nu ved jeg ikke hvordan det er med andre men jeg lærte dig ret hurtigt og jeg har lige været bange for sådan noget med prøver og stikke sig i fingeren og sådan noget. Så det var egentlig nemt nok lige at få ind i systemet. Det startede egentlig også ud med at de tog mit blodsukker om natten, så de kom ind om natten og det var jo meget fedt for så fandt mine forældre ud af at det kan de også gøre selv om natten når vi kom hjem. Så det var fedt at være der over i et stykke tid og lære en del om det.

Så du var egentlig indlagt i 14 dage?

Ja jeg tror det var der omkring, men jeg tror at det var sådan lidt on and off fordi at der var en håndboldkamp som jeg skulle til og så tog vi lige hjem der, så det var sådan lidt…ja altså… Jeg var der i hvert fald lidt tid for at jeg kunne nå at lære det hele.

Var det rart at have det her forløb på hospitalet eller var det hårdt at være ni år og tage frem og tilbage fra hospitalet?

Kirsten Steno 25/02/2020

Introduction was not recorded – the practitioner did not wish for that to be recorded, and then gave us the sign afterwards when it was okay to being the recording

M:
[00:00:00] Which is it the most popular treatment option?

K:
Can you define what is popular? How can you define what is popular?

M:
The most used by patients.

K:
The most prevalent?

M:
I'm sorry, yes, I meant prevalent.

K:
Yes. Okay, that was better.. so.. the most prevalent for adults is the injection pens.
So I think it's around 70 to 80 percent of adults nationwide using pens. But here it's around one third using pumps, so two third, using pens.

M:
[00:00:33] Are they the disposable ones or the reusable ones?

K:
I don't know. I have the numbers, but it is a few percentage using the disposable pens.

S:
What about reimbursement?

K:
No, no, no. Everything is free and everything is reimbursed. But it's not fully reimbursed as insulin is like all other medications in Denmark. In contrast to Sweden, where it's fully reimbursed, but people need to pay something. But it's the same per unit for a for the two kind of pens.

S:
Is the pen itself reimbursed? I'm mean for the reusable pen.

Rasmus Linnet Interview 28-02-2020.m4a

Introduction of the project and the programme not transcribed on purpose

[00:01:10] First we would like to ask: how did you discover the need for smart pens?

[00:01:17] Yes. That was not something we did specifically in Sweden, but that has been done though our development processes and of course, always look into what are the trends and what are the issues and need.

[00:01:38] And it has been expressed, not from patients, but from the doctors, nurses that can make a connected smart insulin pen, because it's difficult to treat patients because we cannot really see how that goes in term of dosis behavior.

So if you think about being at the dentist they might be asking you how often you use your tooth brush or your dental floss, and the person sitting in the chair is probably not always tell the full truth about how often the dental floss is being used.

[00:02:28] But the thing we're taking the medicine in this case, insulin. Insulin doesn't work if you don't take it. And it can be difficult to help the patient. If you don't really know what is going on. It's because you can see you can see it is the patient's blood sugar is often not in full control.

[00:02:55] But there could be so many parameters. That is the reason why the blood sugar was not in control so by having an insight into insulin injection behavior then at least you can detect a parameter and then make sure that you are guiding and telling the patient what to do in a better way.

[00:03:19] We cannot solve all because there are a lot of parameters. *unclear sound* but at least those parameters visible so you can have a discussion around if you're taking the doses too late or not enough doses or whatever might be the problem. So it has been it has been a wish for many years from doctors and nurses to have this, because it's kind of the missing information and the trend the last couple of years have been that more and more patients have a what is called a continuous glucose....It's a long time sensor. So thereby you have much better visibility into how the glucose levels are. [00:04:22] So that has taken a big step forward, and then you you can only see kind of the result in terms of glucose control. You cannot see elements of behavior and that is what the insulin smart pen is providing them as far the next innovation step.

RK
Ja hej det er rikkie

MM
Hej rikkie det er miemaria forstyrre jeg

RK
Nej nej det gør du ikke i havde jo snakket om at i ville ringe

MM
Super nogen gange kan det jo godt være der er noget der går i vejen

RK
Det kunne sagtens være ja

MM
vi er ihvertfald glade for at du har tid.
RK
det har jeg

MM
super Jeg kan lige fortælle dig kort at vi kommer fra CBS og vi læser en kandidat der hedder "innovation and Healthcare". Og vi er lidt en blandingsgruppe f.eks jeg er uddannet IT-mediciner hvor jeg er blevet uddannet til at kigge på sundhedsteknologi og min makker som sidder ved siden af mig hedder christine og er sygeplejeske

Chri
Hej Rikkie

MM
Så har vi også et tredje gruppemedlem hun snakker desværre ikke dansk så hun er ikke lige med i det her interview. Hun hedder hedder sirin og har en buisnessbaggrund.

Vores speciale handler om diabetes type 1 og de teknologier der bliver brugt og behandlingsmetoder og vi kigger ind på hvordan man som forældre, børn og teenagere ligesom tilpasser sig de her forskellige innovationer og drager fordel af dem og hvilken værdi man ligger i dem. Så der er nogle generelle spørgsmål vi vil spørge dig om og så vil vi spørge dig ind til hvordan det er at være forældre til et barn med type 1 diabetes. Så vil vi gå lidt mere i dybden med den type behandling i bruger og så vil vi spørge lidt ind til noget apps og noget data og så tager vi den derfra og jeg lover vi prøver at holde den på en halv time nu i skal ud af døren
RK
ja det er fint det er fin

MM
Det var din søn valdemar..og i har skrevet en bog og det hele

RK

Sanda og Amalie 09/03/2020

Into ikke optaget

M:
Er det dig A. og din søster som har diabetes?

A:
Ja..

M:
Hvor længe har i hver især haft diabetes?

A:
Jeg har haft i snart to måneder og M. har haft det i snart to år.

M:
Hvor gammel er det du er A.?

A:
Jeg er lige blevet 15..

S:
Det var hendes fødselsdagsgave nærmest *griner*

M:
Hvem følger jeres behandling?

S:
Det er Roskilde Sygehus.

M:
Er det den samme læge og diabetes sygeplejerske der har fulgt jer igennem et forløbene? - og eventuel begge forløb?

S:
Vi har faktisk skiftet både børnelæge og diabetes sygeplejerske med M., men det var efter eget ønske. Der er to diabetes sygeplejerske og to børnelæger tilknyttet og vi havde selv ønsket at skifte, men nu.. Vi er kommet cirka ottende uge til kontrol, hvor hver anden gang har været med læge og hver anden gang har kun været sygeplejerske, og det er lige blevet lavet om nu og vi skal på torsdag for første gang til sådan en gruppekonsultation. De har delt alle diabetes børnene op der er i mellem 7 og 12 år ind i grupper og så kommer man ind og er sammen i grupperne hvor man så hver især går ud og snakker lidt med læger og sygeplejersken, men så samtidig så sidder de andre forældre og snakker om hvordan det er at være diabetesforældre, så er børnene sammen med en sygeplejerske og en diætist inde og lave noget mad sammen og inde og hygge sig imens at vi kører alt det tekniske, sådan så

Posedum på informant	S.
Hvor længe har patienten haft diabetes?	I 14 år (diagnostiseret som 13 årig)
Hvilke diabetes teknologier bruger patienten nu?	Medcom pumpe & Libre sensor
Interview setting	Phone

01:08

M:

I hvor lang tid har du haft diabetes?

S:

uuuuuhhh..... jeg er 27... åhr det må være12-13 år tror jeg. Nej det er ikke engang det.. det er 14 år. Jeg har været 13 år da jeg fik det - rigtig, rigtig god alder siger jeg dig .. rigtig god alder at få det i *griner*.

01:41 M:

Jeg har også talt med nogle teenagere, og jeg kan forstå at det ikke er helt nemt at være teenagere og få diabetes.

S:

Nej, jeg tror ihvertfald ikke at mine forældre havde det så sjovt kan jeg sige *griner*

M:

02:00 Hvordan det?

S:

Ej men deet...altså jeg kan så sige at jeg er den yngste ud af tre søstre, og så være lige lovlig forkælet og være lidt for meget vant til at få sin vilje og være så ekstrem humør syg i forvejem og sådan nogle ting. - og så lige pludselig også få sådan en diagnose oven i. Som der skabte endnu mere sådan humørsyge og sådan nogle ting. ejjjj Jeg var sjov i den periode hold nu kæft da.

02:32 M:

Hvem følger din behandling i dag?

M
det er malene

G
Hej malene det er miemaria

M
hej

G
Hej forstyrre jeg?

M
nejnejnej jeg har også holdt dig i min kalender så det er fint

G
lækkert okay super tak nåh men jeg kan jo lige fortælle hurtigt også lidt som jeg skrev på facebook at vi er fra CBS og vi læser den her uddannelse der hedder "Innovation and healthcare" og vi er igang med vores speciale som omhander diabetes teknologier og vores fokusgrupper er; forældre med børn med type 1 diabetes og så teenagere med type 1 diabetes, og vi vil egentlig bare stille nogen generelle spørgsmål til behandling og så vil vi også høre lidt om hvordan det er at være forældre med børn med type 1 diabetes så vil vi gå lidt i dybden med den type behandling i modtager og så vil vi tale lidt om apps og lidt datadeling og så vil vi også ..fordi vi har nemlig en case der fokusere på den nye pen fra novonordisk der hedder novopen siX og høre lidt om dine holdninger til det ..fordi jeg kunne se i havde brugt pen før i tiden

M
yes det den pen som du nævner der den kender vi ikke

G
nej super det er så fint...men eh vi kan bare starte nu hvis det er ? hov ja og jeg sidder ved siden af med mit gruppemedlem hun hedder christine og hun er sygeplejeske

M
yes

G
Hej malene

M
hej velkommen til

G
hahahaha tak...det var en datter du havde?

M
ja vi har vilma på 8

G

G
Behandling er han på nu?

P
hvad tænker når du siger sådan ?

G
Pumpe, pen ?

P
han er på pen og iport ikke..det er er pen men iport er den der sidder på maven for ikke at skulle stikke ham direkte i maven og så har han libre

G
han har libre okay...har i tanker om at begynde at bruge pumpe i fremtiden? eller er i tilfredse med den pen i har nu ?

P
umiddelbart er vi tilfredse og min søn ønsker ikke at få en pumpe så lige nu er det ikke noget der ligger i langtidskortene

G
hvordan kan det være..hvad tænker han om det?

P
Jeg tror han er bange for det ..for ...**(Jeg kan ikke forstå hvad der bliver sagt fra 00:41 - 00:47)** jeg tror det er alt det der usikre du ved hvad skal det nu ske?..at der bliver stukket så meget i dem.....nu har han faktisk vænnet sig til at have den her I-port og det koster jo faktisk 400 kr for at få ham til at have den der i-port på fordi han bare ikke vil det...så det er simpelthen bolchepædagogik ham...bare for at få ham til at prøve den i tre dage fordi han simpelthen var så bange for at skulle....så jeg tror det lidt handler om de tanker der sidder i hovedet ..alt det ukendte man ikke ved hvad er ..så vi har fået overtalt ham til at vi skal have en ny sensor ..vi er blevet skrevet op til en deXcom**(**01:27 **er det rigtigt navn?)** fordi vi har natteproblemer så vi kan få noget med alarm på ...det er han gået med til..men det der med pumpe kan vi godt glemme alt om det har jeg virkelig forsøgt at tegne og fortælle at det kunne være bedre..det kunne være så federe...det ville han bare ikke han fungere på pen og det er fin for ham .

G
Hvilken pen bruger i?

P
sådan en junior pen..eller tænker du på insulinen?

G
begge dele

P
vi bruger en juniorpen..en juniorpen eren..jeg ved ikke om i kender dem,...men det er jo en pen der kan give halve enheder.. det kan de der engangspenne du køber på apoteket ikke. de kan

APPENDIX 4: CODING

Accessibility:

<Files\\Rikkie fra esbjerg> - § 1 reference coded [2,52% Coverage]

Reference 1 - 2,52% Coverage

Sådan noget med brugervenlighed altså hvor nemt det er at bruge og design af de her produkter hvor vigtigt er det for jer og er det vigtigste at det tilpasser sig jeres behov eller hans behov?

RK
Lige nu, altså nu fylder han 10, det er jo meget det der altså nu spiller han meget playstaition så han skal nok hurtigt finde ud af de ting og det skal vi også nok. men jeg tænker da helt klart at jo nemmere det er, jo mindre tryk man skal ind på for at komme ind på det og jo nemmere det står jo mere vil man også bruge det. Ellers tror jeg godt man kan blive sådan helt forvirret over det og opgive det på forhånd.

<Files\\transkribering af malene> - § 1 reference coded [2,20% Coverage]

Reference 1 - 2,20% Coverage

så når vi stod oppe på hospitalet og min mand stod og snakkede med sygeplejesken om vilmas frokost og så sagde "nåh jamen så skal du gøre og så skal hun have og så skal hun have to enheder"..så stod jeg lidt og tænkte...øøøh hvorfor? to enheder hvordan hvordan regner...jeg kunne ikke finde ud af at regne tingene ud...jeg kunne ikke forstå at "less is more" ..altså jeg kunne slet ikke mit hovede kunne slet ikke rumme alt det der ..så da vi fik pumpen ..og den gjorde arbejdet for mig ..så blev det hele lidt..så græd jeg ikke så meget lad mig sige det på den måde...det blev bare nemmere...jeg vil ved gud håbe at alle der får muligheden for at få sådan en pumpe.. tager den.. fordi det er noget helt andet

<Files\\Transkribering Pia> - § 1 reference coded [0,81% Coverage]

Reference 1 - 0,81% Coverage

alle mennesker er jo bare ikke lige tekniske..der er nogen der er mega gode til at sætte sig ind i det der og bare lige fikse en app og bare lige gøre et eller andet..og så virker alle de der sensor, pumpe ting og så er der nogen der kokser rundt i det og mange ting står på engelsk og det er jeg ikke særligt god til

Accidents:

<Files\\emma transkribering> - § 1 reference coded [2,11% Coverage]

Reference 1 - 2,11% Coverage

øøøøhm altså nogen gange hvis den sådan f.eks. øøøh falder sådan af ...du ved buksen sådan hvor klipsen sådan ligesom river sig løs..så kan den godt sådan hive i selve kateteret som ender på balden eller jeg ved ikke hvor så kan det ligesom godt rive lidt men jeg har egentlig ikke oplevet at jeg har slået mig med den..decideret slået mig med den....mmh men der er f.eks nogen gange hvis man nu tager nyt kateter på eller noget i den stil så ..øhm...så plejer det jo ligesom at ...så kan det nogengange godt gå lidt galt hvor den f.eks trækker kateteret med ud når man allerede har sådan stukket sig eller så er den der sådan selve slangen den er måske bukket eller sådan noget i den stil

<Files\\kamille transription> - § 1 reference coded [1,96% Coverage]

Reference 1 - 1,96% Coverage

Har du nogensinde kommer til skade med din pumpe?

Det gør hele tiden det kan man næsten ikke undgå, men nu har jeg gjort med de tanker at der skulle mere til før at den blev siddende på kroppen fordi min falder også meget tit af især fordi at dyrker sport, så sveder man jo og så bliver man jo fugtig og så kan den jo løsne sig på grund af det der plaster og så fandt vi nogle sprays som så kan hjælpe med at holde dig tæt i længere tid eller tage plaster uden over så man kan få på hospitalet.

<Files\\Rikkie fra esbjerg> - § 1 reference coded [2,53% Coverage]

Reference 1 - 2,53% Coverage

Chr
har valdemar nogensinde slået den ind i noget eller nogen skader på grund af den pumpe? den har ikke været gået i stykker endnu?

RK
Jo mange gange altså den får et par ridser og det sagde vi også for den gang han var mindre klatrede han jo endnu mere rundt omkring og der har den været skiftet ud ..den han har lige nu er faktisk helt defekt den virker næsten ikke men vi går bare og venter på den anden kommer så vi ikke skal have den her byttet fordi at det er jo også sådan noget med penge og levealderen og kommunerne og den garanti er udløbet altså den er ihvertfald ikke vandtæt mere. så den får nogle slag

<Files\\sofie transscibtion> - § 2 references coded [1,80% Coverage]

Reference 1 - 0,75% Coverage

siddet til et møde hvor at jeg sad og tog mit blodsukker og jeg tænkte at det kunne jeg da godt gøre lige her sådan lidt diskret, hvorefter at jeg tog det i min finger og så sagde det bare WUUUP og så flyver det bare ud og sådan nogle ting det er altid SÅ FEDT! Vi ELSKER det!

Reference 2 - 1,05% Coverage

<Files\\emma transkribering> - § 7 references coded [9,95% Coverage]

Reference 1 - 1,25% Coverage

G
okay super ....hvad med apps har i brugt det til din behandling?

E
øøh ja altså DeX-com sensoren det er jo en der følger over telefonen..sådan så man ligesom får alarmer hvis en blodsukker er for højt eller for lavt eller sådan noget i den stil eller hvis sensoren skal skiftes eller et eller andet i den stil så det er ligesom den jeg bruger hele tiden for ligesom at kunne kigge på mit blodsukker

Reference 2 - 1,76% Coverage

G
okay ...hvordan har i brugt den sammen med dine forældre..har de nogen gange skrevet til dig at det kunne være du lige skulle tjekke eller hvordan`?

E
f.eks. hvis det nu er meget meget meget lav så bliver de jo måske lidt sådan bekymret kan man jo godt sige øhm... så der kan de godt lige finde på måske lige at skrive "er du okay?" eller et ellerandet og lige se om jeg svare ellers sådan noget fordi ja....også om natten f.eks. så æh...hvis det er nu at mit blodsukker er for højt så giver den alarm... hvis om natten og skal ind ligesom og regulere mit blodsukker

Reference 3 - 1,61% Coverage

hvad med pumpen har du den på når du danser ?

E
det kommer meget an på sådan hvordan mit blodsukker ligger ...fordi hvis mit blodsukker foreksempel er meget sådan højt eller sådan rigtig højt så har jeg den på og så danser jeg ligesom bare med den men hvis det sådan f.eks. ligger på 10 det er stadig lidt højt men det er ikke så forfærdeligt højt det er faktisk et rigtig godt blodsukker f.eks at danse på så der plejer jeg bare at tage pumpen af hvis det ihvertfald er 10 eller under så tager jeg ihvertfald pumpen af

Reference 4 - 2,31% Coverage

hvis mit blodsukker nu bliver lavt det kan jeg jo sådan mærke sådan for det meste kan jeg jo ligesom mærke når mit blodsukker bliver lavt eller højt øhm og så plejer jeg egentlig bare at gå lige hen måske lige og tage fem minutters pause lige drikke en juice og der er det egentlig sådan og.. det kommer selvfølgelig an på hvor lavt det er men så plejer det egentlig at komme okay hurtigt op..nogen gange drikker jeg også bare juicen og skynder mig ud og danse igen for jeg ved jo at når jeg har drukket en juice så begynder det jo ligesom langsomt at stige...men jeg spiser altid noget inden træning øhm og jeg spiser oftest noget efter træningen nogen gange det er ikke altid..det har også noget at gøre med det der med at hvordan mit blodsukker ligger

Reference 5 - 0,34% Coverage

<Files\\emma transkribering> - § 1 reference coded [1,36% Coverage]

Reference 1 - 1,36% Coverage

hvordan oplever du at du ikke er tryg ved det?

E
det er lidt mere hvis det nu er at ..nu har jeg jo ikke sådan rigtig sovet hjemme ved nogen sådan særlig meget...ligesom det der med om de sådan...det sidder lidt i baghovedet det der med har de nu styr på det? eller sådan noget og ellers skal jeg ligesom gøre det selv hvis jeg nu ikke vågner af mine alarmer eller sådan noget i den stil...man kommer måske hurtigt lige til at overtænke lidt

<Files\\Transkribering Pia> - § 1 reference coded [2,52% Coverage]

Reference 1 - 2,52% Coverage

Jeg tror han er bange for det ..for ... jeg tror det er alt det der usikre du ved hvad skal det nu ske?..at der bliver stukket så meget i dem.....nu har han faktisk vænnet sig til at have den her I-port og det koster jo faktisk 400 kr for at få ham til at have den der i-port på fordi han bare ikke vil det...så det er simpelthen bolchepædagogik ham...bare for at få ham til at prøve den i tre dage fordi han simpelthen var så bange for at skulle....så jeg tror det lidt handler om de tanker der sidder i hovedet ..alt det ukendte man ikke ved hvad er ..så vi har fået overtalt ham til at vi skal have en ny sensor ..vi er blevet skrevet op til en deXcom**(**01:27 **er det rigtigt navn?)** fordi vi har natteproblemer så vi kan få noget med alarm på ...det er han gået med til..men det der med pumpe kan vi godt glemme alt om det har jeg virkelig forsøgt at tegne og fortælle at det kunne være bedre..det kunne være så federe...det ville han bare ikke han fungere på pen og det er fin for ham .

<Files\\emma transkribering> - § 1 reference coded [1,25% Coverage]

Reference 1 - 1,25% Coverage

G
hvilken type behandling får du nu?

E
øøh jeg får bare sådan novorapid som den normale insulin af en pumpe..(lidt usikker mumlen) og så blodsukker og sådan noget får jeg af en DeX-com sensor den har jeg haft ret meget glæde af jeg har dog lige ..altså ikke lige jeg fik den nok til...jamen jeg fik den til september sidste år..så det er stadig sådan lidt nyt men det er jeg er blevet meget vant til den

<Files\\kamille transription> - § 1 reference coded [1,10% Coverage]

Reference 1 - 1,10% Coverage

Hvilken type er du på?

Jeg er på pumpe og sensor, der har jeg Dexcom.

Bruger du en app til at holde styr på alt det her?

Ja jeg har min Dexcom app hvor at jeg kan se det på mobilen hver gang der sker noget

Hvilken type pumpe er det du bruger?

Det hedder en T-slim.

<Files\\Rikkie fra esbjerg> - § 3 references coded [1,47% Coverage]

Reference 1 - 0,59% Coverage

MM
hvilken behandling får han?

RK
Han får insulin gennem en insulinpumpe

MM
Hvilket mærke er pumpen

RK
Lige nu er det en medtronic

Reference 2 - 0,46% Coverage

MM

<Files\\emma transkribering> - § 3 references coded [3,90% Coverage]

Reference 1 - 1,51% Coverage

G
okay og kan du på den sidde og skrive kulhydrater ind?

E
øøh ja det kan jeg

G
okay super ....hvad med apps har i brugt det til din behandling?

E
øøh ja altså DeX-com sensoren det er jo en der følger over telefonen..sådan så man ligesom får alarmer hvis en blodsukker er for højt eller for lavt eller sådan noget i den stil eller hvis sensoren skal skiftes eller et eller andet i den stil så det er ligesom den jeg bruger hele tiden for ligesom at kunne kigge på mit blodsukker

Reference 2 - 1,50% Coverage

G
okay hvad for en kunne du bedst lide af de to pumper du havde?

E
der kan jeg faktisk bedst lide den jeg har nu fordi at æh ved min anden så var det sådan der kom jeg meget tit til at glemme at taste selve blodsukkeret ind øhm og så bare tastede kulhydraterne ind i stedet for...men ved den her er det ligesom sådan lidt mere trin for trin så man skal ligesom taste du ved ind..så det husker jeg meget bedre nu end jeg gjorde ved den anden så jeg kan meget bedre lide den jeg har nu

Reference 3 - 0,89% Coverage

der bruger jeg nogen gange lifesum fordi der kan man gå ind på sådan en stregkode og så kan man f.eks .en muslibar så kan man lige scanne stregkoden på en muslibar og så står der hvor mange kulhydrater der er i den muslibar..så den bruger jeg engang imellem hvis det er noget nyt jeg spiser

<Files\\Henrik Holm Transkribering> - § 5 references coded [12,12% Coverage]

Reference 1 - 2,17% Coverage

De gange hvor hun vågner har har skulle passe ham og hvor han har sovet - altså hen over natten eller om aftenen, så har jeg bare lagt sådan en skriftlig vejledning. Hvis ringer og siger at du skal give ham 30 kulhydrater så skal du trykke det og det og så næste næste 30. så det er jo simpelt men det kan folk jo ikke huske

Reference 2 - 1,40% Coverage

der kan den række så langt at jeg sådan set kan sidde og se hans blodsukker på min telefon og så kan jeg afgive insulin med den der fjernbetjening og så sidder jeg der i 8 timer og drikker kaffe og ser fodbold

<Files\\emma transkribering> - § 1 reference coded [2,13% Coverage]

Reference 1 - 2,13% Coverage

G
hvordan oplevede du det der med f.eks hvis der er noget der har, det er ihvertfald hvad jeg har kunnet forstå på andre ihvertfald jeg har interviewet af at af at der er ligesom en proces når man får en ny pumpe eller sådan noget så skal man lige ..man skal lige begynde at stole på den igen? er det noget du har oplevet ?

E
det er det nok sådan lidt..hvis man nu ..man ved jo ikke om den har nogle andre værdier den pumpe..så man kan godt sådan lige sådan lige ..man skal lige se tiden an med hvordan ens blodsukker hænger sammen men det er jo også mere sådan man har jo de samme indstillinger inde på pumpen så den giver jo ikke mere eller mindre insulin end der er installeret på pumpen

<Files\\kamille transription> - § 1 reference coded [0,84% Coverage]

Reference 1 - 0,84% Coverage

jeg faktisk ikke kunne lide forandringer generelt, fordi at jeg føler når jeg først har en ting som jeg ikke føler mig tilpas med så er jeg bange for at jeg får en anden ting som jeg ikke er glad ved eller hjælper

<Files\\Sanda og Amalie transkribering> - § 2 references coded [1,36% Coverage]

Reference 1 - 0,33% Coverage

der er nogle ujævnheder i forhold til målingerne, altså der er noget usikkerhed og det er noget forsinkelse i forhold til det reele blodsukker og sådan nogle ting.

Reference 2 - 1,03% Coverage

der siger man jo faktisk ja til at andre må kigge på hendes tal fordi det ligger i sådan et åbent forum på en eller anden måde hvor det kan sende ...og jeg er sgu ligeglad altså..hvem der kigger på hendes blodsukkertal altså ...det jeg synes ikke på nogen måde det kan være krænkende hvorimod at tøsepigen må hverken få instagram eller snapchat eller noget fordi det er lidt noget andet for mig..det her er rent medicinsk data og det gør mig ikke noget og hvis der er noget der kan bruges til forskning og forbedre

<Files\\sofie transscibtion> - § 1 reference coded [0,85% Coverage]

Reference 1 - 0,85% Coverage

hvis det er der står LO så er det lige meget om det er to eller en det skal op uanset hvad og hvis der står 20 og mit blodsukker..hvis der står 20 på sensoren men mit blodsukker rent faktisk er 18..uanset hvad skal det ned så så jeg tager det ligesom det som pumpen..altså altså jeg tager det som pumpen anbefaler

<Files\\emma transkribering> - § 2 references coded [2,65% Coverage]

Reference 1 - 1,18% Coverage

jeg kunne da meget hellere tænke mig en der var noget mindre..øhm men altså jeg har også prøvet sådan det hedder en omnipod mener jeg det er sådan en der sidder på armen men den er også meget stor for jeg har ikke særlig meget fedt på kroppen så den er meget stor i forhold til mine arme fordi mine arme de er heller ikke så store..så den var ordentlig stor og sådan ihvertfald til min

Reference 2 - 1,47% Coverage

hvad med sådan noget som brugervenlighed og design af de her apps og pumper og sensore er det noget der er vigtigt for dig og eventuelt hvad er vigtigt?

E
øøhm altså jeg vil sige at det ligesom er nemt og kunne installere hvor mange kulhydrater hvad ens blodsukker er på altså at pumpen ikke er sådan langsom ligesom en telefon der er mega gammel det er sådan ret vigtigt at man ligesom hurtigt kan stoppe pumpen eller hurtigt kan få insulin af pumpen..hvis man har brug for det

<Files\\kamille transription> - § 2 references coded [3,47% Coverage]

Reference 1 - 1,80% Coverage

Hvor af hvis jeg skulle vælge jeg helst have sådan en helt hvid en eller en hel sort en I stedet for at have..altså nu kan jeg huske at jeg havde sådan en og den havde sådan kruseduller på og sådan noget og noget forskelligt og det fik den næsten faktisk mere til at ligne noget sygdoms-agtig-noget, men jeg kan godt lide pen fordi den er så nem at tage op og så måske bare lige vende ryggen til og give sig noget Levemir eller Novorapid, det er meget fedt.

Reference 2 - 1,67% Coverage

Det var meget interessant at du sagde det designet betyder meget ..det vil jeg rigtig gøre høre mere om.

Det med at de ser så kliniske ud det har jeg aldrig kunne lide for pludselig skriger mit udseende at jeg har diabetes, så kan jeg bedre lide at folk kommer over og siger hvad er det du har i stedet for at folk kommer og siger 'ej har du en sygdom'. Så man ved ikke ligefrem at man har diabetes når man bare går rundt.

<Files\\Rikkie fra esbjerg> - § 1 reference coded [1,57% Coverage]

Reference 1 - 1,57% Coverage

vi glæder os til den nye pumpe så kan jeg sidde herhjemme og sidde og kigge og sige okay nu er det ved at gå galt og hvis han er hjemme ved min mor kan jeg ringe til hende "du skal gå ind og gøre det der nu" eller den kan nemlig også give mig alarmer så det er det vi glæder os meget til at vi kan sende ham afsted og stadigvæk uden hele tiden at skal have fat i dem han er sammen med

<Files\\emma transkribering> - § 3 references coded [3,40% Coverage]

Reference 1 - 1,03% Coverage

altså forskellen på libre og deXcom var jo egentlig bare at man ikke skulle scanne det var jo egentlig bare at man skulle kigge på sin telefon istedet for og den så blimmede når det var det var for højt eller for lavt og der er jo nærmest ikke rigtig nogen forskel på en ny pumpe så jeg vil ikke rigtig sige det var besværligt..at skifte

Reference 2 - 0,89% Coverage

der bruger jeg nogen gange lifesum fordi der kan man gå ind på sådan en stregkode og så kan man f.eks .en muslibar så kan man lige scanne stregkoden på en muslibar og så står der hvor mange kulhydrater der er i den muslibar..så den bruger jeg engang imellem hvis det er noget nyt jeg spiser

Reference 3 - 1,47% Coverage

hvad med sådan noget som brugervenlighed og design af de her apps og pumper og sensore er det noget der er vigtigt for dig og eventuelt hvad er vigtigt?

E
øøhm altså jeg vil sige at det ligesom er nemt og kunne installere hvor mange kulhydrater hvad ens blodsukker er på altså at pumpen ikke er sådan langsom ligesom en telefon der er mega gammel det er sådan ret vigtigt at man ligesom hurtigt kan stoppe pumpen eller hurtigt kan få insulin af pumpen..hvis man har brug for det

<Files\\kamille transription> - § 4 references coded [3,73% Coverage]

Reference 1 - 1,03% Coverage

Hvis du skulle sige med dine egne ord hvad er så fordelene og ulemperne ved en pumpe?

Jeg tænker at fordelen er at den giver Levemir i løbet af hele dagen og det er jo meget lækkert så mange ligger fint, hvor at en pen giver Levemir to gange om dagen i låret.

Reference 2 - 0,47% Coverage

så kan jeg også godt lide pumpen fordi at jeg ikke skal gøre så meget selv og trækker op i tøjet som jeg skulle engang.

Reference 3 - 0,92% Coverage

Jeg kan meget godt lide at jeg bare kan tage den op af lommen som en mobil og så sidde der og skrive at nu skal jeg have ti kulhydrater og sådan noget, og så det med at den selv omregner kulhydraterne til insulin og det er meget godt.

Reference 4 - 1,31% Coverage

Hvad med pennen da du var på den, hvilke fordele ulemper var der med den?

<Files\\emma transkribering> - § 1 reference coded [2,67% Coverage]

Reference 1 - 2,67% Coverage

G
Hvordan da du fik diabetes dengang, nu ved jeg godt du kun var syv år, men kan du huske hvad du tænkte dengang da i fik at vide du havde fået det?

E
ææææh...altså.(nervøs grin)...jeg kom jo derud...også ..altså ud på sygehuset...jeg ved ikke sådan rigtig lige hvad det var der sådan lige skete og sådan noget..men jeg kan huske at i starten...altså jeg var egentlig ikke særlig bange for det der med at bruge pen..jeg kan huske at efter sådan måske...jeg var indlagt i to uger i alt..mmh men jeg kan huske at efter fire, jeg mener at det har jeg har fået fortalt at det var cirka fire natte eller aftener så øh så øh begyndte jeg ligesom selv at ville..ville stikke mig selv istedet for at lægerne skulle stikke mig med pennen...det havde jeg egentlig bare det sådan lidt bedre med på en eller anden måde det der med jeg selv at havde kontrol over at stikke mig selv

<Files\\emma transkribering> - § 2 references coded [3,28% Coverage]

Reference 1 - 1,50% Coverage

G
okay hvad for en kunne du bedst lide af de to pumper du havde?

E
der kan jeg faktisk bedst lide den jeg har nu fordi at æh ved min anden så var det sådan der kom jeg meget tit til at glemme at taste selve blodsukkeret ind øhm og så bare tastede kulhydraterne ind i stedet for...men ved den her er det ligesom sådan lidt mere trin for trin så man skal ligesom taste du ved ind..så det husker jeg meget bedre nu end jeg gjorde ved den anden så jeg kan meget bedre lide den jeg har nu

Reference 2 - 1,78% Coverage

G
nu skal jeg lige se om jeg har flere spørgsmål...jo det kan måske være at er der nogen infomationer du egentlig føler at du godt kunne tænke dig var mere samlet?

E
åhh det ved jeg faktisk ikke...altså joo sådan det kunne da være rart hvis ens blodsukker kunne stå inde på pumpen hele tiden men det kan det jo ikke rigtig hvis det er jeg gerne vil have den på min telefon og hvis jeg ikke skal stikke mig og sådan noget fordi så skal man jo ligesom stikke sig i fingeren tre gange om dagen og sådan noget og det vil jeg ligesom gerne undgå men ellers så tror jeg ikke rigtig

<Files\\kamille transription> - § 1 reference coded [0,92% Coverage]

Reference 1 - 0,92% Coverage

Jeg kan meget godt lide at jeg bare kan tage den op af lommen som en mobil og så sidde der og skrive at nu skal jeg have ti kulhydrater og sådan noget, og så det med at den selv omregner kulhydraterne til insulin og det er meget godt.

<Files\\emma transkribering> - § 1 reference coded [0,58% Coverage]

Reference 1 - 0,58% Coverage

G
så det er simpelthen hospitalet der sidder og justere den pumpe du har ?

E
ja

G
okay og det gør de bare når du er der eller tager det et stykke tid inden det begynder at virke?

<Files\\Henrik Holm Transkribering> - § 3 references coded [6,10% Coverage]

Reference 1 - 1,85% Coverage

der er sådan en der hedder DIASEND fordi der kan man bare gå ind og se hvordan det går med hans blodsukker..,men det er bare sådan det er hvordan ligger hans gennemsnitsblodsukker..og så tog vi den der followapp...altså det er en app hvor jeg ser hans blodsukker på min telefon

Reference 2 - 2,72% Coverage

G
føler du at de her data som bliver indsamlet i den her apps er det noget i bruger når i f.eks er til konsultationer hos en sygeplejeske eller en læge?

HH
ja hvis de kan finde ud af det...og det kan de godt..jeg får jo nogle kurver over nikolajs blodsukker som de ikke har ...og hvis jeg kan se at han ligger han ligger en lille smule højt kl 2 om natten ..så går jeg jo ind og sætter på basal raten.

Reference 3 - 1,52% Coverage

det er meget forskellige der er nogen der er meget utrygge og bedst kan lide det er diabetessygeplejesken der står for at ændre basalraterner og så er der andre som mig der bare kigger på kurverne og så ændre basal raterne selv

<Files\\kamille transription> - § 3 references coded [2,81% Coverage]

Reference 1 - 0,92% Coverage

Jeg kan meget godt lide at jeg bare kan tage den op af lommen som en mobil og så sidde der og skrive at nu skal jeg have ti kulhydrater og sådan noget, og så det med at den selv omregner kulhydraterne til insulin og det er meget godt.

Reference 2 - 1,07% Coverage

Da du/I skulle skrive ned mht pennen gjorde i det på papir?

<Files\\emma transkribering> - § 8 references coded [12,73% Coverage]

Reference 1 - 1,90% Coverage

så hvis jeg nu danser noget meget hård dans eller noget i den stil så kan det meget hurtigt sådan måske lige komme lidt hvor man ikke lige gider tænke på det for nu laver man lige noget som måske er man synes er meget sjov og sådan noget og det gider man ikke sådan rigtig afbryde sådan man vil hellere tænke på dansen i stedet for hele tiden at skulle tænke på diabetes øøøhm.....også kan man nogen gange bare sådan godt lige lige ligge det lidt på hylden hvilket måske ikke er en særlig god ide(nervøst grin)..men øhm ..men øhm ja på den måde kan man godt sige jeg måske nogen gange ikke har så meget kontrol over det

Reference 2 - 2,36% Coverage

føler du nogen begrænsninger når du går til dans med at du har pumpen og diabetes?

E
øjhhhhh jaa(tøvende sagt)...det føler jeg egentlig nogen gange..fordi det er med, som jeg sagde lige før, hvis det nu er jeg lige sætter mig og får en pause hvor jeg sidder og drikker en juice med lavt blodsukker så kan jeg jo ikke være med i den tid hvis det nu er jeg er rigtig dårlig eller sådan er svimmel eller noget i den stil så kan jeg jo ikke være med og på den måde så begrænser det jo lidt sådan hvor meget jeg får gjort fordi jeg danser jo kun i sådan cirka..i den første time der danser jeg jo kun i tre kvarter og det er jo ikke sådan sindsygt meget øhm....også de der fem minutter det er aligevel sådan ret meget man springer fra hvis man kan sige det på den måde

Reference 3 - 2,05% Coverage

hvis det nu er mit blodsukker ligger rigtig rigtig dårligt eller sådan noget og vi sidder f.eks. hele familien eller sådan noget i den stil og spiser slik eller noget i den stil så er det jo selvfølgelig sådan lidt irriterende fordi så kan man f.eks ikke sidde og spise slik sammen med alle de andre hvor de andre de spiser slik eller noget i den stil..eller hvis man er til en fødselsdag ligesom i dag så når ....lige nu ligger mit blodsukker rigtig højt og så kan jeg jo ligesom ikke bare lige gå sådan hen og tage en sodavand eller tage et stykke kage eller sådan noget fordi at så kommer man ligesom hen til det høje blodsukker igen hvis man nu lige har fået det ned

Reference 4 - 0,83% Coverage

overnatter du nogen gange hos veninder?

E
øhm det gør jeg faktisk ikke så tit faktisk ..jeg har været på sådan nogle lejre..det er ikke noget jeg gør mig så meget i det der med at sove ude ...det er jeg er heller ikke så tryg ved..det der med min diabetes fordi sådan

Reference 5 - 1,36% Coverage

hvordan oplever du at du ikke er tryg ved det?

<Files\\Henrik Holm Transkribering> - § 4 references coded [9,02% Coverage]

Reference 1 - 1,16% Coverage

jeg faktisk ringet og snakket med firmaet og jeg har også skrevet ud til nogle andre at de skal huske og fortælle og reklamere hvor vigtigt det er med den der fjernbetjening

Reference 2 - 2,57% Coverage

det gode ved den den har en fjernbetjening til pumpen ikke men den er bluetooth det vil sige at jeg ikke behøver være helt i nærheden af ham.. og der er kommet sådan en ny der hedder et eller andet TX SLIM halløj ...hvor man skal afgive insulin ved at trykke på pumpen og det er jo mega bøvlet at du skal have pumpen frem for nikolaj han har jo den der pumpe siddende i et mavebælte.

Reference 3 - 1,97% Coverage

er der nogle ulemper ved den pumpe?

HH
Nej jo den der fjernbetjening er helt vildt langsom men det er jo fordi det er noget ældgammelt teknologi..altså inden det kommer igennem FDA approval og sådan noget så er det jo forældet..så det er jo bare sådan det er ..men ellers er den super god

Reference 4 - 3,33% Coverage

kunne sådan en pind her så måske have gjort det bedre for jer?

HH
nej det tror jeg ikke...det var jo igen det der med at vurdere..altså det der er svært er jo det der med okay nu skal han spise det her og han skal til fodbold..han skal et eller andet og hvad er hans blodsukker på ...okay skal han så have en halv og en hel og en kvart og en skive rugbrød med nutella inden partis**(??**14:37**)** som så dækker ham henover det der fodbold..det er det der er svært...det kan vi ikke rigtig hjælpe med

<Files\\Rikkie fra esbjerg> - § 4 references coded [4,79% Coverage]

Reference 1 - 0,57% Coverage

man man skulle agere sygeplejeske på en eller anden måde for vi har jo faktisk hans liv i vores hænder når det er at han ikke er på sygehuset

Reference 2 - 1,24% Coverage

chr
Hvad med skolen var de meget involveret i hans behandling?

RK

<Files\\Rikkie fra esbjerg> - § 2 references coded [3,69% Coverage]

Reference 1 - 1,79% Coverage

MM
hvad synes i om pinden da i prøvede den ?

RK
Altså der skulle man ihvertfald være god til matematik...øhn jeg synes det var besværligt at finde ud af og heldigvis var han meget sej til de der stik der eller er det jo mange stik og det er også meget udregning i at nu kan du ikke spise mere og nu skal du spise og hvor meget spiser du ..det kan man ikke til en femårig...fordi du ved ikke spiser du hele madpakken eller gør du ikke

Reference 2 - 1,89% Coverage

MM
Da i prøvede den der engangspind ..nu kan jeg ikke engang huske om jeg har spurgt om det.. hvad var det bedste og værste ved den der pind der?

RK
Altså det bedste var jo nok det der med at så havde du en dreng der ikke var synlig du havde ikke noget på dig du havde ikke nogle indstik du havde ikke øhm..han kunne gå i svømmehal f.eks. lige nu har han to indstik på balderne altså det er jo meget tydeligt. Det var det jo ikke med pinden det kan du ikke se ja

<Files\\transkribering af malene> - § 1 reference coded [0,46% Coverage]

Reference 1 - 0,46% Coverage

udgangspunktet på det tidspunkt var ligesom at man skal lige lære hele det her diabeteshelvede inden ..altså manuelt inden man får tilbudt en pumpe

<Files\\emma transkribering> - § 2 references coded [3,04% Coverage]

Reference 1 - 0,72% Coverage

hvad var du egentlig mest glad for hvis man skal veje det lidt sådan op mod hinanden..pennen eller pumpen?

E
øh det er helt klart pumpen! fordi den giver mange flere muligheder for at man hurtigere sådan kan regulere sit blodsukker

Reference 2 - 2,32% Coverage

hvem var det der tog beslutningen om du skulle have pumpe?

E
øh det ved jeg faktisk ikke helt fordi at jeg tror bare det var et forslag vi fik..jeg tror det var mine forældre der fik forslaget om jeg kunne få en pumpe også..jeg vidste jo egentlig ikke helt hvad det var jeg fik bare at vide at det kunne være en nemmere måde at håndtere mit blodsukker på og sådan noget og så havde mine forældre egentlig bare tænkt at det ville være det bedste fordi de fleste de får jo..eller næsten alle unge får jo en pumpe i danmark ihvertfald der får de fleste jo en pumpe af kommunen eller af sygehuset eller noget i den stil og det fik jeg så tilbuddet om og mine forældre tog så det tilbud for det ...det var jo det bedste havde de hørt og det var det jo også.

<Files\\Henrik Holm Transkribering> - § 1 reference coded [3,53% Coverage]

Reference 1 - 3,53% Coverage

G
hvordan havde nikolaj det med at skifte fra pind til pumpe?

HH
det havde han det dejligt med..han synes det gjorde ondt og få den der basal om morgen og om aftenen i låret...og så tror jeg også at han har været glad ...det skal der jo ikke så meget fantasi til at forestille sig altså over i zoologisk have ..øhm at forældrene går bagved og giver dig insulin uden at du opdager det..sammenlignet med at du skal hen og sidde på en bænk og der skal hives op i en trøje og du skal stikkes i maven....hvad vil man helst selv

<Files\\kamille transription> - § 5 references coded [8,41% Coverage]

Reference 1 - 2,19% Coverage

Hvordan havde du det da i fandt ud af at du havde diabetes?

Altså det er jo det der med at jeg var jo glad og ked af det og jeg vil rigtig gerne tilbage til mine venner og alt det der og jeg har jo heller ingen anelse om at det var så stort som det var på det tidspunkt fordi at diabetes lyder jo som en lille ting når man bare siger det sådan, men personligt er det er jo en kæmpe stor ting fordi jeg skal med dig resten liv og det er fandt jeg først ud af senere da jeg kom over på hospitalet og der lærte de mig en del omkring det at være diabetiker.

<Files\\emma transkribering> - § 3 references coded [4,74% Coverage]

Reference 1 - 1,76% Coverage

G
okay ...hvordan har i brugt den sammen med dine forældre..har de nogen gange skrevet til dig at det kunne være du lige skulle tjekke eller hvordan`?

E
f.eks. hvis det nu er meget meget meget lav så bliver de jo måske lidt sådan bekymret kan man jo godt sige øhm... så der kan de godt lige finde på måske lige at skrive "er du okay?" eller et ellerandet og lige se om jeg svare ellers sådan noget fordi ja....også om natten f.eks. så æh...hvis det er nu at mit blodsukker er for højt så giver den alarm... hvis om natten og skal ind ligesom og regulere mit blodsukker

Reference 2 - 1,61% Coverage

hvad med pumpen har du den på når du danser ?

E
det kommer meget an på sådan hvordan mit blodsukker ligger ...fordi hvis mit blodsukker foreksempel er meget sådan højt eller sådan rigtig højt så har jeg den på og så danser jeg ligesom bare med den men hvis det sådan f.eks. ligger på 10 det er stadig lidt højt men det er ikke så forfærdeligt højt det er faktisk et rigtig godt blodsukker f.eks at danse på så der plejer jeg bare at tage pumpen af hvis det ihvertfald er 10 eller under så tager jeg ihvertfald pumpen af

Reference 3 - 1,38% Coverage

G
okay ..de data som deXcommen den opsamler hos dig er det noget i bruger til at snakke med lægerne om

E
ja det bruger de jo ligesom både til at kigge på hvordan..hvis mit blodsukker nu svinger nogle forskellige steder øhm f.eks. hvis det nu stiger rigtig meget om morgenen f.eks. så bruger de det jo til at stille min pumpe om til at jeg måske skal have mere insulin om morgenen..så på den måde kan man godt sige at den bruger kurverne til det

<Files\\Henrik Holm Transkribering> - § 2 references coded [6,70% Coverage]

Reference 1 - 3,98% Coverage

nu kan jeg se at du står med vommen fuld af kanelgifler nu skal jeg give dig insulin til det eller jeg skal lige scanne dig med det der libre eller jeg skal fingerprikke dig..og den anden løsning det er jo helt vild så lidt indgribende den er ..i forhold til hans aktiviteter ..altså jeg har jo insulin på noget lejr sådan en fodboldlejr hvor jeg kan jo.. hvor de lige pludselig sidder fem drenge og spiser i en eller andens campingvogn og vi er nogle forældre der bare sidder og hygger. altså så kan jeg bare stille mig uden for campingvognen og med den der fjernbetjening bare afgive insulin

Reference 2 - 2,72% Coverage

<Files\\transkribering af malene> - § 2 references coded [2,29% Coverage]

Reference 1 - 1,13% Coverage

altså det kan jeg slet ikke overskue for nu har vi noget der virker ...og det skal man ikke begynde at lave...altså vores liv er jo i bokse ..og det er et stort regnestykke og en lang tabel så når man har ..når man finder en sådan en vej hvor man tænker "her virker det her ligger hun så godt som man kan ligge" så laver man ikke om på noget så bliver man bare der

Reference 2 - 1,16% Coverage

M
sætter man en ny på og så..den kommer og fortæller dig "nu er der tre dage til den udløber" jeg tror den første melding man får det er når der er tre dage tilbage...og så kommer den efterhånden og tæller ned og siger "nu er der to timer tilbage" og så knalder man en ny på og når man så tager scanneren hen på den nye så kommer den og siger at nu har den fundet en ny måler

<Files\\sofie transscibtion> - § 5 references coded [5,23% Coverage]

Reference 1 - 2,31% Coverage

Jeg har i mange år været rigtig dårlig til at tage mit blodsukker konsekvent. Især efter jeg startede på arbejdet jo lige pludselig var der noget der og noget der og så HOV nu skal de mennesker du skal til frokost med de går ned nu og - nåårh ja - jeg har sgu glemt at tjekke blodsukker. Jeg har da før siddet til et møde hvor at jeg sad og tog mit blodsukker og jeg tænkte at det kunne jeg da godt gøre lige her sådan lidt diskret, hvorefter at jeg tog det i min finger og så sagde det bare WUUUP og så flyver det bare ud og sådan nogle ting det er altid SÅ FEDT! Vi ELSKER det! 11:34 såå det gjorde mig måske også lidt mere - der kunne gå rigtig rigtig mange timer hvor jeg ikke fik taget mit blodsukker og så kunne jeg se, åhr shit det er 17, og så aner man ikke i hvor lang tid at det har været højt. Altså har det også været højere eller hvad.

Reference 2 - 0,96% Coverage

Jeg får ikke rigtig insulinchok mere men problemet er at det sådan lige i morgentimerne hvor man sover ekstra tungt, og det er lidt bekymrende når man så vågner op og bor alene og sådan nogle ting, at man næsten konsekvent har det hver morgen, og især fordi at jeg kan gå i seng og det er sådan at det er normalt og så pludselig så skøjter det helt ned

Reference 3 - 0,88% Coverage

det som jeg synes der er svært at få et ordentlig overblik over sådan når det nu Libre og Medtrnic ikke taler sammen det er lige som at kunne se..jeg har haft det her blodsukker.. og så har jeg taget så meget insulin og nu er det kommet herned på...det øhm det synes jeg ikke at jeg har...det synes jeg er lidt halvkringlet.

Reference 4 - 0,35% Coverage

men det er ikke så nemt at få en meget meget..det er ikke nemt at få så meget værdi ud af den data når man bare kigger på skærmen

Reference 5 - 0,74% Coverage

der er især for den får man en god ide om hvad er så den effekt af insulinen jeg har taget har haft..uden at skulle sammenligne ordentlig..uden at skulle stå og sammenligne med libre..men fordi de ser så forskellige ud i layoutet så begynder min tålmodighed at løbe op her

<Files\\sofie transscibtion> - § 5 references coded [6,02% Coverage]

Reference 1 - 0,81% Coverage

fra da jeg fik konstateret den her diagnose til at jeg kom på pumpe - de første par år da jeg var på pen efter jeg fik stillet diagnosen der tog jeg voldsomt meget på fordi at jeg simplethen tvang og tog alt for meget insulin og det var ikke fordi jeg var .. altså.. bange for at få højt blodsukker

Reference 2 - 1,46% Coverage

16:56 M:

Hvis vi lige hurtigt hopper lidt tilbage til det der med at være teenager og da du fik diagnosen. Hvordan oplevede du at du følte dig anderledes ens andre og følte du at du havde de samme muligheder, og hvordan oplevede du hele den her tid?

17:34 S:

Jeg er aldrig blevet mobbet for det eller haft sådan nogle oplevelser. Men altså.. men i en periode hvor at man bare gerne være sammen med sine venner og hvor at man bare gerne vil have lov til at drikke sig tæske fuld og man gerne vil have lov til at være dum og hjernedød.

Reference 3 - 1,02% Coverage

jeg festede lidt meget okay da jeg blev teenager! *griner* Men altså man går ikke lige der og tænker der at man skal huske sit blodsukker og hvis man så gør det så skal man pludselig så stå og regne i hovedet - altså den gang jeg var på pen så skulle man stå og regne i hovedet, hvordan er det lige præcis at jeg skal tage og sådan nogle ting. Det var jeg ikke pisse god til.

Reference 4 - 0,46% Coverage

20:48 M:

Følte du at dine forældre holdt meget øje med det?

S:

Ja det gjorde de.

M:

Lavede det nogle friktioner?

S:

Ja dét er der slet ikke nogen tvivl om

Reference 5 - 2,27% Coverage

<Files\\emma transkribering> - § 5 references coded [9,44% Coverage]

Reference 1 - 0,96% Coverage

G
okay så du..er du fuldkommen selvkørende selv med din behandling eller er dine forældre inde over den?

E
altså det er jo sådan..man kan sådan dele sådan..jeg har sådan delt den med mine forældre som ..så de kan gå ind på sådan en followapp og så kan de ligesom se blodsukker som.. de kan se mit blodsukker

Reference 2 - 2,66% Coverage

Hvordan da du fik diabetes dengang, nu ved jeg godt du kun var syv år, men kan du huske hvad du tænkte dengang da i fik at vide du havde fået det?

E
æææææh...altså.(nervøs grin)...jeg kom jo derud...også ..altså ud på sygehuset...jeg ved ikke sådan rigtig lige hvad det var der sådan lige skete og sådan noget..men jeg kan huske at i starten...altså jeg var egentlig ikke særlig bange for det der med at bruge pen..jeg kan huske at efter sådan måske...jeg var indlagt i to uger i alt..mmh men jeg kan huske at efter fire, jeg mener at det har jeg har fået fortalt at det var cirka fire natte eller aftener så øh så øh begyndte jeg ligesom selv at ville..ville stikke mig selv istedet for at lægerne skulle stikke mig med pennen...det havde jeg egentlig bare det sådan lidt bedre med på en eller anden måde det der med jeg selv at havde kontrol over at stikke mig selv

Reference 3 - 1,91% Coverage

så hvis jeg nu danser noget meget hård dans eller noget i den stil så kan det meget hurtigt sådan måske lige komme lidt hvor man ikke lige gider tænke på det for nu laver man lige noget som måske er man synes er meget sjov og sådan noget og det gider man ikke sådan rigtig afbryde sådan man vil hellere tænke på dansen i stedet for hele tiden at skulle tænke på diabetes øøøhm.....også kan man nogen gange bare sådan godt lige lige ligge det lidt på hylden hvilket måske ikke er en særlig god ide(nervøst grin)..men øhm ..men øhm ja på den måde kan man godt sige jeg måske nogen gange ikke har så meget kontrol over det
G

Reference 4 - 2,56% Coverage

men nu siger du også at du har en veninde der også har diabetes taler i nogle gange omkring diabetes sammen? og giver hinanden ideer

E
altså det er sådan at hun bor lige overfor mig og så er vi dansepartnere

G
ja nej gud hvor sjovt

<Files\\emma transkribering> - § 3 references coded [2,68% Coverage]

Reference 1 - 0,24% Coverage

okay og kan du på den sidde og skrive kulhydrater ind?

E
øøh ja det kan jeg

Reference 2 - 0,96% Coverage

G
okay så du..er du fuldkommen selvkørende selv med din behandling eller er dine forældre inde over den?

E
altså det er jo sådan..man kan sådan dele sådan..jeg har sådan delt den med mine forældre som ..så de kan gå ind på sådan en followapp og så kan de ligesom se blodsukker som.. de kan se mit blodsukker

Reference 3 - 1,47% Coverage

hvad med sådan noget som brugervenlighed og design af de her apps og pumper og sensore er det noget der er vigtigt for dig og eventuelt hvad er vigtigt?

E
øøhm altså jeg vil sige at det ligesom er nemt og kunne installere hvor mange kulhydrater hvad ens blodsukker er på altså at pumpen ikke er sådan langsom ligesom en telefon der er mega gammel det er sådan ret vigtigt at man ligesom hurtigt kan stoppe pumpen eller hurtigt kan få insulin af pumpen..hvis man har brug for det

<Files\\Henrik Holm Transkribering> - § 1 reference coded [1,97% Coverage]

Reference 1 - 1,97% Coverage

er der nogle ulemper ved den pumpe?

HH
Nej jo den der fjernbetjening er helt vildt langsom men det er jo fordi det er noget ældgammelt teknologi..altså inden det kommer igennem FDA approval og sådan noget så er det jo forældet..så det er jo bare sådan det er ..men ellers er den super god

<Files\\kamille transription> - § 1 reference coded [2,09% Coverage]

Reference 1 - 2,09% Coverage

Jeg tænker at fordelen er at den giver Levemir i løbet af hele dagen og det er jo meget lækkert så mange ligger fint, hvor at en pen giver Levemir to gange om dagen i låret. Og så kan jeg også godt lide pumpen fordi at jeg ikke skal gøre så meget selv og trækker op i tøjet som jeg skulle engang. Jeg kan meget godt lide at jeg bare kan tage den op af lommen som

<Files\\emma transkribering> - § 1 reference coded [1,62% Coverage]

Reference 1 - 1,62% Coverage

G
hvad med pumpen har du den på når du danser ?

E
det kommer meget an på sådan hvordan mit blodsukker ligger ...fordi hvis mit blodsukker foreksempel er meget sådan højt eller sådan rigtig højt så har jeg den på og så danser jeg ligesom bare med den men hvis det sådan f.eks. ligger på 10 det er stadig lidt højt men det er ikke så forfærdeligt højt det er faktisk et rigtig godt blodsukker f.eks at danse på så der plejer jeg bare at tage pumpen af hvis det ihvertfald er 10 eller under så tager jeg ihvertfald pumpen af

<Files\\kamille transription> - § 1 reference coded [1,23% Coverage]

Reference 1 - 1,23% Coverage

På Dexcom appen du har, der kan du se dit blodsukkerniveau, kan du putte andet ind på den app, kan du for eksempel putte andre data ind?
Nej det kan man ikke man kan kun se min kurve i løbet af dagen, og så sender den jo til mine forældre så de også kan se det på deres mobiler men jeg kan ikke skrive andet ind.

<Files\\sofie transscibtion> - § 1 reference coded [0,34% Coverage]

Reference 1 - 0,34% Coverage

Det var en der registrerede selv og den begyndte altså sådan at bippe sådan mange gange i undervisningen så det var ret akavet

<Files\\emma transkribering> - § 4 references coded [5,27% Coverage]

Reference 1 - 0,62% Coverage

E
altså sådan i starten der var det jo sådan ret irriterende sådan men..men det var jo også fordi der var jeg jo kun syv år så det der med nåle der det var jeg jo ikke sådan vildt glad for og sådan noget

Reference 2 - 0,96% Coverage

G
okay så du..er du fuldkommen selvkørende selv med din behandling eller er dine forældre inde over den?

E
altså det er jo sådan..man kan sådan dele sådan..jeg har sådan delt den med mine forældre som ..så de kan gå ind på sådan en followapp og så kan de ligesom se blodsukker som.. de kan se mit blodsukker

Reference 3 - 1,83% Coverage

men fordelene er jo helt klart at det er meget nemmere at regulere ens blodsukker end det er når man bruger pen og det er også meget mere smertefrit(nervøst grin)..når det er man bruger pumpe...og ja man kan bare meget mere man kan også sådan få midlertidig basal og sådan noget kan man jo få hele tiden få på ens pumpe hvor at da man brugte pen så var det jo sådan noget med ..sådan noget med man skulle stikke sig i låret morgen og aften som midlertidig basal og det kan man jo egentlig bare installere på sin pumpe og så kan man tage det på når man vil såå det vil jeg sige er fordelene ved det

Reference 4 - 1,85% Coverage

deXcom kan godt være sådan lidt nogle gange fordi så står der noget med sensorfejl eller noget i den stil så skal man vente f.eks to timer..ej det passer ikke. der står man kan vente op til tre timer før den virker igen..men det er mere for at folk ikke ringer ind efter en halv time og ringer til deXcom og siger der er et eller andet galt øhm ..men men også det der med at man ikke kan være mere end seks meter væk fra sin telefon når man har den her sensor så mister den forbindelsen og så kan man ikke tjekke sit blodsukker øhm men ellers nej så vil jeg ikke sige der som sådan er nogen ulemper ved det

<Files\\Henrik Holm Transkribering> - § 3 references coded [11,37% Coverage]

Reference 1 - 2,57% Coverage

det gode ved den den har en fjernbetjening til pumpen ikke men den er bluetooth det vil sige at jeg ikke behøver være helt i nærheden af ham.. og der er kommet sådan en ny der hedder et eller andet TX SLIM halløj ...hvor man skal afgive insulin ved at trykke på pumpen og det er jo mega bøvlet at du skal have pumpen frem for nikolaj han har jo den der pumpe siddende i et mavebælte.

Reference 2 - 3,51% Coverage

<Files\\Henrik Holm Transkribering> - § 4 references coded [18,38% Coverage]

Reference 1 - 5,98% Coverage

HH
ja og diabetes sygeplejesken og det var sådan en ny en..der var kommet en ny og den skulle være det smarte og så ved et tilfælde har vi så fået den med den der fjernbetjening.. hvor jeg så har talt med en del diabetesforældre der siger "gud bare vi havde haft den" og så har jeg faktisk ringet og snakket med firmaet og jeg har også skrevet ud til nogle andre at de skal huske og fortælle og reklamere hvor vigtigt det er med den der fjernbetjening

G
Jeg tror ikke jeg kender den version

HH
det gode ved den den har en fjernbetjening til pumpen ikke men den er bluetooth det vil sige at jeg ikke behøver være helt i nærheden af ham.. og der er kommet sådan en ny der hedder et eller andet TX SLIM halløj ...hvor man skal afgive insulin ved at trykke på pumpen og det er jo mega bøvlet at du skal have pumpen frem for nikolaj han har jo den der pumpe siddende i et mavebælte.

Reference 2 - 3,61% Coverage

der kan den række så langt at jeg sådan set kan sidde og se hans blodsukker på min telefon og så kan jeg afgive insulin med den der fjernbetjening og så sidder jeg der i 8 timer og drikker kaffe og ser fodbold og når dagen så er omme så kigger jeg sådan og så løber han rundt med snolder og en chokoladekiks i munden og render rundt og spiser mellem kampene og så giver jeg lidt insulin følger med og når dagen så er omme siger nikolaj "ej far det er jo som om jeg slet ikke har diabetes" og så siger jeg ikke noget..det har jeg så ordnet

Reference 3 - 3,51% Coverage

hvordan havde nikolaj det med at skifte fra pind til pumpe?

HH
det havde han det dejligt med..han synes det gjorde ondt og få den der basal om morgen og om aftenen i låret...og så tror jeg også at han har været glad ...det skal der jo ikke så meget fantasi til at forestille sig altså over i zoologisk have ..øhm at forældrene går bagved og giver dig insulin uden at du opdager det..sammenlignet med at du skal hen og sidde på en bænk og der skal hives op i en trøje og du skal stikkes i maven....hvad vil man helst selv

Reference 4 - 5,29% Coverage

G
ja der er pumpen da klart det ...

HH
her gør det igen en kæmpe forskel at den kan fjernbetjenes pumpen ikke ? for det er jo lige så forstyrrende hvis man skulle sige..nåh nu kan jeg se at du spiser en eller anden pandekager

<Files\\emma transkribering> - § 1 reference coded [0,83% Coverage]

Reference 1 - 0,83% Coverage

E
det gør min mor og min far og altså selvfølgelig dem jeg bliver behandlet af ude på sygehuset og sådan noget

G
hvilket sygehus er i koblet til?

E
OH odense universitetshospital

G
okay super er det en fast læge og diabetessygeplejeske i har derude?

E
ja

<Files\\kamille transription> - § 1 reference coded [1,41% Coverage]

Reference 1 - 1,41% Coverage

Hvor involveret at din forældre hvor er du blevet 15?
De er bare sådan nogen som går ved siden af mig og spørger har du husket at tage dit blodsukker og har du dit og dat, og det er jo meget fedt for ellers ville jeg jo ellers gå og glemme det, jeg tror simpelthen at jeg ville glemme at jeg havde diabetes hvis det ikke var for dem til at minde mig om det.

<Files\\Rikkie fra esbjerg> - § 1 reference coded [0,55% Coverage]

Reference 1 - 0,55% Coverage

MM
hvem følger egentlig valdemars behandling?

RK
vi har en sygeplejeske. altså overlægen på ..det er så esbjerg vi er tilknyttet

<Files\\Sanda og Amalie transkribering> - § 2 references coded [0,45% Coverage]

Reference 1 - 0,13% Coverage

M:
Hvem følger jeres behandling?

S:
Det er Roskilde Sygehus.

Reference 2 - 0,32% Coverage

<Files\\emma transkribering> - § 1 reference coded [1,78% Coverage]

Reference 1 - 1,78% Coverage

G
nu skal jeg lige se om jeg har flere spørgsmål...jo det kan måske være at er der nogen infomationer du egentlig føler at du godt kunne tænke dig var mere samlet?

E
åhh det ved jeg faktisk ikke...altså joo sådan det kunne da være rart hvis ens blodsukker kunne stå inde på pumpen hele tiden men det kan det jo ikke rigtig hvis det er jeg gerne vil have den på min telefon og hvis jeg ikke skal stikke mig og sådan noget fordi så skal man jo ligesom stikke sig i fingeren tre gange om dagen og sådan noget og det vil jeg ligesom gerne undgå men ellers så tror jeg ikke rigtig

<Files\\kamille transription> - § 3 references coded [6,23% Coverage]

Reference 1 - 1,61% Coverage

jeg har kigget på det det er looping, hvor at jeg har tænkt at det er bare lyder så smart og det kunne jeg godt tænke mig, fordi med det så er det som om at man slet ikke ved at man har diabetes og at man bare lige 80 % af dagen kan lade som om at lade som om at man ikke har diabetes, det er jo er mega sejt at jeg kan gå rundt ligesom alle andre uden at jeg skal tænke på om jeg er høj eller lav i blodsukker

Reference 2 - 1,80% Coverage

Hvor af hvis jeg skulle vælge jeg helst have sådan en helt hvid en eller en hel sort en I stedet for at have..altså nu kan jeg huske at jeg havde sådan en og den havde sådan kruseduller på og sådan noget og noget forskelligt og det fik den næsten faktisk mere til at ligne noget sygdoms-agtig-noget, men jeg kan godt lide pen fordi den er så nem at tage op og så måske bare lige vende ryggen til og give sig noget Levemir eller Novorapid, det er meget fedt.

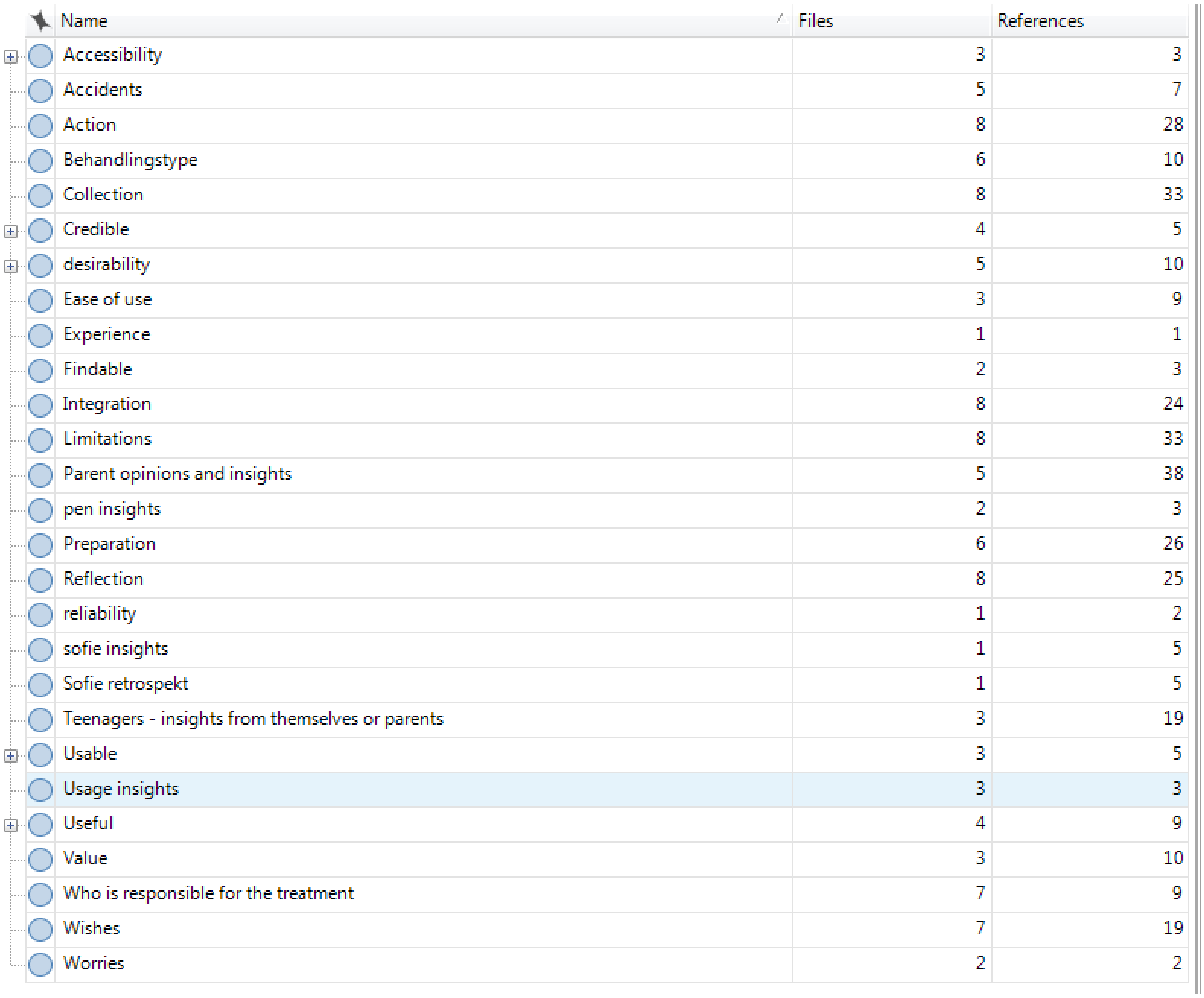
Reference 3 - 2,81% Coverage

Føler du at der er nogle begrænsninger ved disse apps?

Altså ved Dexcom'en kunne jeg godt tænke mig at den kunne arbejde sammen med pumpen og så det med at jeg kunne skrive det med kylhydrater ind og hvor mange man har fået i løbet af dagen og sådan noget og så kunne man ligesom sammenligne det hele samlet på ét sted, der er f.eks. nogle gange hvor man tænker hvorfor jeg pludselig blevet så høj på det tidspunkt så det ved jeg jo ikke, så kunne den jo vise fra pumpen af at jeg måske har taget for lidt her, eller at det er den skål slik man fik aftenen inden, så jeg vidste det i stedet for at jeg blev forvirret over at jeg lå så højt eller havde lavt blodsukker hele dagen, ville jeg synes var rigtig fedt.

<Files\\Rikkie fra esbjerg> - § 1 reference coded [0,96% Coverage]

Reference 1 - 0,96% Coverage



Name	Files	References
Accessibility	3	3
Accidents	5	7
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