

Navigating Do-It-Yourself Artificial Pancreas System: Developing a DIYAPS-readiness Tool

A Techno-Anthropological Digital Action Research Based on User Perspectives



MASTER'S THESIS BY
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STUDENT REPORT

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Master's Thesis

June 7th, 2024

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Abstract:

Background: This thesis aims to research the development of a DIY-readiness tool through a user-centered design approach with the Danish DIYAPS community and how it can support self-management for empowered people with type 1 diabetes prior to starting DIYAPS. This investigation is a continuation of a bachelor's project and is conducted with the inspiration from that.

Methods: This thesis follows the principles of Action Research to create a change for the DIYAPS-community. The data for this solution was collected through webnography, a think aloud test, semi-structured interviews and testing of a tool through interviews. We follow user-centered design (UCD) principles to develop a solution that could create a change.

Results: By synthesizing the data to understand what solutions could be relevant for the community, it became clear that there were specific areas where information was challenging navigating. Therefore, we compiled this data to develop a tool that could aid in the process prior to starting DIYAPS. The tool became a DIYAPS-readiness tool, where the results were developed to support encouragement through the concept of self-efficacy. The DIYAPS-readiness tool was evaluated and we iterated to accommodate these changes.

Conclusion: We deduce that our tool can support PWT1D interested in DIYAPS by encouraging their further research and future process with DIYAPS. The tool represents the interests of the DIYAPS-community because of their inclusion through a UCD approach.

A stylized handwritten signature in black ink, consisting of a large loop followed by the letters 'K.N'.

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Preface

This master's thesis is conducted with the inspiration of our bachelor's project in Techno-Anthropology at Aalborg University. The interest in doing a continuation within Do-It-Yourself-Artificial-Pancreas-System (DIYAPS) occurred as it was already an area we wished to explore further from our bachelor's project. By following the Facebook group 'Looped - Denmark', we have had the opportunity to observe the group for two years after handing in our bachelor's project. This made us aware of repeating questions on the Facebook group related to the starting phase of DIYAPS and thereby inspired the idea for this master's thesis. Since DIYAPS is not an acknowledged system in the healthcare sector, we find it interesting to help the DIYAPS community as it can be difficult to navigate the guidelines within the field.

We would like to thank all participants and peers who have participated and contributed with insights and feedback to the design and development of the DIYAPS-readiness tool. Additionally, we would like to thank the DIYAPS community for opening up to us, and being a part of the Facebook group 'Looped - Denmark' for nearly two and a half years. This has been a significant part of our research, which we could not have done without. Lastly, a big appreciation goes out to our supervisor Jeppe Eriksen. Thank you for always being a great motivator, inspiration and in good spirit when needed. And also a thank you for giving us relevant feedback and mentoring throughout our thesis.

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Introduction

In recent years a growing number of People With Type 1 Diabetes (PWT1D) have chosen to manage their condition through user-led systems, and open-source software with their existing hardware to automate insulin delivery and monitor blood glucose levels. This is also known as Do-It-Yourself Artificial Pancreas System (DIYAPS) or Do-It-Yourself-looping (DIY-looping). The phenomenon of DIYAPS was originated by the movement #WeAreNotWaiting in the year 2013 in the U.S. (Kesavadev *et al.* 2020). The focus was to create and develop improved diabetes technologies, due to citizens having trouble accessing these because of financial challenges. The creation of DIYAPS can be described as a leading example of democratization of medicine. However, DIYAPS is unregulated and unapproved, which means that those who choose to build these systems, do so at their own risk (Schippe *et al.* 2022). In the last couple of years, commercial companies have developed advanced diabetes technologies, also called Automated-Insulin-Delivery (AID) systems, which are commercialized health technologies to automate insulin delivery and monitor blood glucose levels. However, the path for these commercial devices can be difficult and has to undergo rigorous regulation for the devices to be approved, which can prolong the process. PWT1D have waited several years for an efficient and applicable solution to manage their chronic condition. But with the prolonged waiting time and financial constraints, PWT1D are turning to other alternative solutions, such as DIYAPS to achieve more self-management and better blood sugar regulation (Schippe *et al.* 2022). In a Danish context, it can be challenging to receive the desired diabetes technology, due to the national supply list and the geographical distribution of diabetes devices, which can be a reason for Danish PWT1D seeking solutions elsewhere (Festersen 2023b). Due to the demographic change, it is questionable whether the healthcare system can handle the long-term care, which affects the allocation of resources. At the same time, tasks and responsibilities are spread across multiple sectors, which also makes it difficult to provide more coherent treatment for the citizens who need it the most. In addition, social inequity can be seen as a problem in the Danish healthcare system, where the citizens who benefit most from healthcare services do not get the help they need (Danske Patienter N.D.). We recognize DIYAPS to be a user-led initiative by empowered people based on the challenges with resources regarding diabetes technologies in Denmark.

This master's thesis is based on our bachelor's project, which was regarding why PWT1D chose to start DIYAPS and what impact the relationship between people, and the technologies involved in DIYAPS have on their everyday life and quality of life in a Danish context. The outcome of our bachelor's project showed that PWT1D experienced an improved quality of life with DIYAPS. Additionally, it resulted in the chronic disease having less impact in their everyday life and created a more well-functioning life for the individual. However, it was shown that to DIY-loop the person with Type 1

Diabetes (T1D) needed specific competencies to succeed in building the system. The ability to be empowered, be technologically minded, have an understanding of English, and be patient and motivated was essential to start DIYAPS. However, with this in mind, we concluded that DIYAPS could create better health and well-being for PWT1D (Nielsen *et al.* 2022). Thereby, we acknowledge DIYAPS as an opportunity for PWT1D to achieve the desired treatment without the assistance of the healthcare system. With our bachelor's project in mind, we are curious about how we can support those who wish to be more self-managed through DIYAPS and who do not get the desired help in the healthcare system. Therefore, we find it interesting to investigate the following problem statement:

How can a DIYAPS-readiness tool be developed through a user-centered design approach with the Danish DIYAPS community, and how can it support self-management for empowered people with type 1 diabetes prior to starting DIYAPS?

This master's thesis highlights a techno-anthropological case of the development of a DIYAPS-readiness tool, to help the process prior to building and starting DIYAPS for empowered PWT1D. We aim to develop a DIYAPS-readiness tool for active co-participants to support their self-efficacy and support their empowerment to become more empowered and more self-managed (Botin *et al.* 2020). This thesis will be investigated through the approach of action research, with the aim of making a change within the DIYAPS community. Additionally, the field will be studied through the scientific framework post-phenomenology by Ihde (1990), where technology is acknowledged as a mediating factor between humans and the world. Based on this scientific framework, lifeworld will be applied to study the interwovenness of humans and technology in the life of having T1D. Self-efficacy by Bandura (2014), will be applied to understand how to create the tool that can encourage a person and what can affect the process. For the development of the DIYAPS-readiness tool, User-Centered Design (UCD) is included to define the iterative design process and how to be user-oriented during the development process of the tool. Quantitative and qualitative methods have been used to gather insights from the DIYAPS community to support the development of the DIYAPS-readiness tool to be pertinent for future use. Here a think aloud test is performed to get an overview of how open-source DIYAPS material is perceived. Additionally, interviews are conducted to get an understanding of the DIYAPS starting phase, as well as webnography to gain insight of the digital culture of the DIYAPS community. A questionnaire is created to be shared with the DIYAPS community to further explore the beginning phase of DIYAPS, and give the opportunity for more people to share their experiences. The DIYAPS-readiness tool will eventually be evaluated and tested with participants, as well as our peers to discover if our tool can be relevant for people who are interested in or who wish to start DIYAPS. Lastly, the relevance of the DIYAPS-readiness tool, and whether DIYAPS is a temporary solution will be discussed.

Chapter 1

Problem Analysis

1.1 Type 1 Diabetes - A Chronic Disease

In Denmark, there are approximately 34.500 cases of Type 1 Diabetes (T1D) as of 2023, which is the equivalent of 0.6% of the population, and the number rises with 0.02% per year ([Diabetesforeningen 2023](#)). T1D is an autoimmune and chronic disease that develops when cells in the body start to attack its own healthy cells specifically, the cells in the pancreas that develop the necessary hormone; insulin. The reason why the disease develops is unknown and can happen at any time, although it mostly develops in children. The cells will destroy all functionality of the pancreas, and thereby the possibility of insulin production. Therefore, it is necessary for these individuals to receive insulin through various methods ([Chiang *et al.* 2014](#)). Insulin is necessary to transform sugar, which stems from the intake of food or drinks containing carbohydrates, into energy for the body and thereby control Blood Glucose (BG)-levels. Typically, the diagnosis is based on different factors such as HbA1C-levels, which is an indication of how the BG-levels have been over a period of 2-3 months. This is measured through a blood test, and the optimal level is between 48 and 53 mmol/l. The HbA1C-levels are monitored each time the individual visits the hospital for consultations regarding their T1D ([Videncenter for Diabetes 2022b](#)). Therefore, People With T1D (PWT1D) have to monitor the status of their BG regularly, take insulin based on their BG-levels as well as when eating food consisting of carbohydrates to stay within the desired HbA1C. The normal range of BG-levels is considered to be between 4-10 mmol/l, depending on when it is measured. Anything outside of that range is considered dangerous and must be adjusted accordingly ([Videncenter for Diabetes 2023b](#)). Low BG can cause slurring of speech, dizziness, and in more extreme situations loss of consciousness. When caught it is treatable by eating or drinking something that contains sugar ([Videncenter for Diabetes 2023c](#)). High BG has a wider range than low and is treated by injecting insulin. It is individual when one starts to feel symptoms however, a BG over 15 mmol/l requires awareness since high BG-levels over a prolonged time can cause acid poisoning (ketoacidosis), which can result in hospitalization ([Videncenter for Diabetes 2021b](#)). If the BG-levels tend to fluctuate too much over an extended period of time, there is a risk of developing complications and other diseases. Because of this, PWT1D are advised to follow their treatment plan closely and keep their BG within the recommended range ([Videncenter for Diabetes 2022a](#)). The treatment of T1D is individualized and requires reevaluations throughout one's lifetime with the help of Health Care Professionals (HCP), this means that PWT1D are closely connected to the health care system from they have been diagnosed and onwards ([Chiang *et al.* 2014](#)).

As mentioned above it is necessary to measure one's BG as well as take insulin to stay within the recommended range. This is possible to do in various ways. There are different diabetes technologies available in Denmark and these will be covered in the sections below.

Monitoring Blood Glucose-levels

The first approach is to use a BG-monitor to test BG-levels by finger pricks and drawing blood from a small strip in the device. This should be done 6-10 times a day. The second method is the use of a Flash Glucose Monitor (FGM). This coin-sized device embedded in the skin, measures the sugar levels in the tissue fluid, and glucose levels are available by scanning the FGM with a Near Field Communication (NFC)-device or a NFC-capable smartphone. This should be done at least six times a day. The final way is by the use of a Continuous Glucose Monitor (CGM). This device works the same way as the FGM however, the glucose levels are transmitted directly to a device or a smartphone for direct use. The FGM and CGM enable the measurement of Time In Range (TIR), which indicates how often one is within the acceptable BG-range of 4-10 mmol/l, collectively they can be referred to as sensor-based glucose monitors. The different technologies described are available on a prescription basis. The BG-monitor is given to all PWT1D, where the FGM and CGM are given based on the need of the individual person ([Videncenter for Diabetes 2021a](#)).

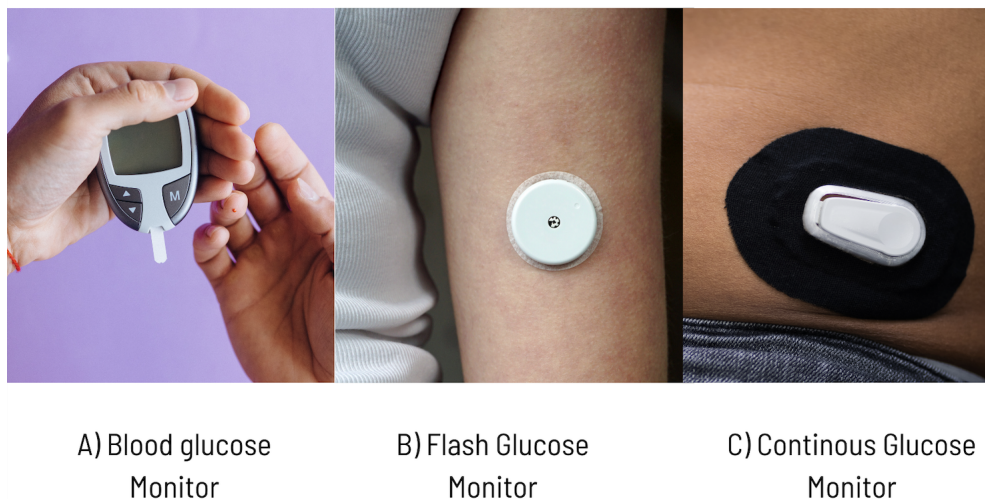


Figure 1.1: The different types of blood glucose monitors

Administration of Insulin

The first way to administer insulin is by injecting insulin into the skin by the use of an insulin pen, which can administer small and large amounts of insulin through a small needle. The insulin is given based on BG-levels and the intake of carbohydrates. The pen is reusable since insulin cartridges are changed approximately every three days. The needle should also be changed regularly ([Videncenter for Diabetes 2021c](#)). The second way to administer insulin is by the use of an insulin pump, which can have various sizes and looks. One type is a small battery-driven or rechargeable device with a tube connected to a needle embedded in the skin of the person. Insulin is injected continuously throughout the day, based on a dose decided between the person with T1D and a HCP. Furthermore, the person inputs carbohydrates and BG-levels either directly on the insulin pump or on a separate device to calculate the amount of insulin the pump should administer. It is also possible to have a disposable patch insulin pump, which is tubeless and sticks to the skin, which also has a needle embedded in the skin, which is only controlled on a separate device. Some of the available insulin pumps can receive BG-levels from a CGM and of these, some can control the amount of insulin given based on the BG-level ([Videncenter for Diabetes 2023a](#)).



A) Insulin Pen

B) Patch Insulin Pump

C) Tube Insulin Pump

Figure 1.2: The different types of insulin administration

These types of insulin pumps are referred to as Automatic Insulin Delivery (AID)-pumps. Research has shown that these have several benefits for PWT1D. AID-pumps are capable of simulating a pancreas and are therefore also called an artificial pancreas. However, they are not fully automatic since the person with T1D has to dose their carbohydrate intake. The results from using AID-systems are improved TIR, improved HbA1C, and in general a better quality of life ([Bassi *et al.* 2023](#)). In Denmark, three AID systems are approved and available, but are not assigned to all PWT1D reasons which will be elaborated in section 1.4 ([Steno Diabetes Center Copenhagen 2023](#)).

In general, an insulin pen is prescribed to all PWT1D in Denmark whereas, insulin pumps are given based on a set of principles decided by the Danish health authority in 2012, which each region then has to take into account when allocating insulin pumps to PWT1D. However, these principles have, as of December 2023, been declared outdated, and new principles have not been decided ([Sundhedstilsynet 2023](#)).

1.2 What is Do-It-Yourself Artificial Pancreas System?

Currently, the slow processes of approving medical equipment and the development of systems that do not fit users needs, has led to people deciding to find ways to combat issues with their medical devices themselves. However, doing so is at their own risk due to these solutions being unregulated and unapproved ([Kesavadev et al. 2020](#)). In the diabetes community, this has resulted in a movement called #WeAreNotWaiting, which originated in 2013 in the U.S. and has since spread globally. The challenges originally inspiring the movement stemmed from a lack of availability of diabetes technology, customization, and the high price of new technology. This led to the creation of Do-It-Yourself (DIY)-solutions that can simulate AID-systems at a lower cost, with the use of other diabetes technologies and different artifacts ([Kesavadev et al. 2020](#)).

The community exists online on different chat-services, Facebook, and websites dedicated to DIY and X (previously known as Twitter). The contribution of dedicated people is what has made modifications of diabetes technology possible ([Kesavadev et al. 2020](#)). The movement has emerged in Denmark, which is apparent through the Danish Facebook group 'Looped -Denmark' that has approximately 1300 members. Additionally, the Danish volunteer-based association, *Type1 - Think Tank for Diabetes*, has some articles dedicated to starting DIY-looping, as well as an article on how a Danish user got started. Although there are many members in the Facebook group, it is not known how many people in Denmark actively use DIY-diabetes technology. The movement has gained popularity especially because of the lack of allocation of AID-pumps and CGMs due to financial constraints, which will be further elaborated in section 1.4.

Literature gathered by [Kesavadev et al. \(2020\)](#) describes the barriers in having diabetes, as well as how this slow development and commercialization of diabetes technology hinders PWT1D in keeping control of their diabetes and gaining a better quality of life.

"People affected by Type 1 diabetes have been waiting for an affordable and efficient solution for the management of this chronic disease for decades. Lack of accessible and actionable data, unaffordability of the current systems, and long timeline of medical device development cycles have led to general exasperation in the T1D community."

([Kesavadev et al. 2020](#), p. 1220)

The movement inspired people with engineering and coding experience to find their own way to change the way they use their diabetes technology, and enable better supervision for parents of children with T1D, as they could follow the BG- and insulin levels from afar. They would take the cheaper and

older diabetes technologies and create new ways of using them. The Do-It-Yourself (DIY)-phenomenon thereby enabled better accessibility of diabetes technology, since it became available for use on smartwatches and smartphones (Kesavadev *et al.* 2020). One of the examples is Dana Lewis, who did not wake up from alarms about high or low BG-levels during the night. She decided to change these alerts, by developing a new app for her CGM through open source code. The use of open-source code would become the way most PWT1D came to change their diabetes technology for the better. Dana Lewis would go on to develop what has since been known as Open Artificial Pancreas System (OpenAPS), which was when she decided to create a system where her CGM data would be sent to her insulin pump and it could then make changes in her insulin dosage based on her BG-levels. A guideline on how to develop this system, and the necessary codes, was launched as free access for all who were interested, and inspired several other ideas on how to create systems that simulate the medically approved AID-systems from technology that is not originally made for it (DIYPS N.D.). These types of systems are defined as Do-It-Yourself Artificial Pancreas System (DIYAPS), and similar to the AID-pumps they have several benefits for PWT1D: *"The use of DIYAPS in these patients is expected to allow them to live a normal life, free from the nuances of minute-to-minute disease management burden."* (Kesavadev *et al.* 2020, p. 1219). Here it is relevant to mention that we do not differentiate between DIYAPS and DIY-looping, and will both be referred to regarding DIY-phenomenon throughout this thesis. The following section will describe the necessary artifacts to build DIYAPS.

1.3 Artifacts Used When Building a DIYAPS

Besides the medically approved components, of a FGM/CGM and an insulin pump, DIYAPS requires external modules so the technology can communicate with each other and a smartphone. These pieces are not medically approved and are sold by individuals online. This section will describe the artifacts that are necessary to DIY-loop and their functions.

First and foremost, it is necessary to have smartphone applications that can receive data from the technology, and forward it to other components. These apps will be described in an upcoming section. Secondly, it is important to make a distinction between what type of BG-sensor one has. If it is the FGM described previously, it is necessary to have a blucon reader, which serves as a transmitter. This is a small attachment that scans the FGM with NFC and sends the results via Bluetooth to a smartphone. The transmitter is available in different variations, the suggested ones are either MiaoMiao or Bubblan. It is attached to the skin and the FGM with adhesive and must be charged with a cord. However, if one has a CGM they are already capable of sending data via Bluetooth, and therefore a transmitter is not necessary (Kesavadev *et al.* 2020).

To control the insulin pump it has to be able to transmit data via Bluetooth as well. There are some insulin pumps that have this feature however, most of the ones that can be used for DIYAPS do not support this. To enable communication it is possible to buy a piece called a radiolink. This is a small piece of equipment that can receive radio frequency signals from insulin pumps, and send the information with Bluetooth to an app on a smartphone. Oppositely, the radiolink receives data via

Bluetooth and is received by the pump through radio frequency. There are different types of radiolinks, and it is based on insulin type which one should be bought ([Kesavadev et al. 2020](#)). The final system that creates the DIY-loop through the use of the aforementioned artifacts can be seen in the picture below.

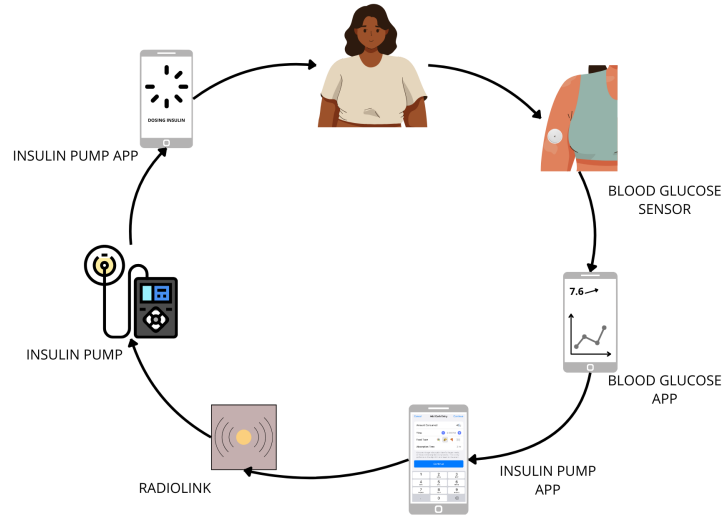


Figure 1.3: DIYAPS inspired by [Foreningen Type 1 \(N.D.\)](#)

1.3.1 How to Create a DIYAPS

When starting a DIYAPS journey a person has to follow a set of instructions. These are available in three different versions however, this thesis will focus on AndroidAPS and LoopDocs where one uses a smartphone to access their insulin pump. The previously mentioned OpenAPS system requires a small computer in the setup and does not require a smartphone ([OpenAPS Community N.D.](#)). It is therefore not relevant in this project since there is a focus on the accessibility of building the DIYAPS to have on smartphones.

Android: AndroidAPS

People wishing to build a DIYAPS who own an Android-based smartphone have to follow the Android Artificial Pancreas System (AAPS)-documents. These instructions are accessible online, and are originally written in English but have 10 other languages available written by community members however, as of February 2024 none of these are Danish. The algorithm for insulin dosage and BG-management used in this system follows the same algorithm created for OpenAPS. The front page is an introduction to AAPS and through that DIY, where it is also explained how to follow the instructions that should ensure that one is safe and confident while building the AAPS. There are separate pages dedicated to explaining safety precautions of starting AAPS, as well as how to ensure medical safety. Separately, there is also a page dedicated to HCPs where they can learn about AAPS and DIYAPS ([AndroidAPS Community N.D.i](#)). The web page can be seen as a step-by-step guide, or one can skip to the desired page. The next step of the process can be either accessed by clicking *next page* at the bottom of

the page, or one can choose a page on the table of contents to the left, which has a headline and then clickable pages. When clicked, most of the topics in the table of contents will have a fold-down menu to show more pages. Within the different pages, there are several hyperlinks to either further down the page, or to a separate page ([AndroidAPS Community N.D.i](#)).

To build the system, it is necessary to have the correct software on one's computer, besides the diabetes technology and artifacts that are compatible with AAPS. There are guidelines on how to download the correct applications on the AAPS website, which makes it accessible to follow the step-by-step. Additionally, there are lists of diabetes technology and information on how to obtain the DIY-artifacts. The components and necessary software that can be used with AAPS are as follows:

- **FGM/CGM:** Dexcom G5, Dexcom G6, Dexcom G7, Libre 1 (Transmitter Necessary), Libre 2, Libre 3, Eversense, Minimed Enlite (noted to be a complicated process) ([AndroidAPS Community N.D.b](#)).
- **Insulin Pump without RadioLink:** Accu-Chek Combo, Accu-Chek Insight, DanaR, DanaRS, Dana-i, Diaconn G8, EOPatch2, Omnipod DASH, Medtrum Nano, Medtrum 300U ([AndroidAPS Community N.D.e](#)).
- **Insulin Pump with RadioLink:** Omnipod Eros ([AndroidAPS Community N.D.e](#)), Medtronic 512 or 712 (any firmware), Medtronic 515 or 715 (any firmware), Medtronic 522 or 722 (any firmware), Medtronic 523 or 723 (firmware 2.4 or lower), Medtronic EU Veo 554 or 754 (firmware 2.6A or lower), Medtronic Canadian/Australian Veo 554 or 754 (firmware 2.7A or lower) ([AndroidAPS Community N.D.g](#)).
- **Computer Software:** Android Studio and Git (install availability is dependent on a computer system) ([AndroidAPS Community N.D.a](#)).

To receive the BG-levels in AAPS one has to download a separate application, which is open source and is dependent on which BG-sensor is chosen. However, the recommended application is xDrip+ ([AndroidAPS Community N.D.j](#)). Additionally, there is a list of smartphones that have been tested and are suggested to use ([AndroidAPS Community N.D.f](#)).

After ensuring that all the components have been downloaded and procured the building of the AAPS-application can be started. This is done on Android Studio while following the AAPS guide simultaneously. The source code for the application is available online through a link on Android Studio therefore, it is not necessary for the user to code the application themselves. Once the application build has finished, the app is ready to be transferred to the user's smartphone to begin the DIYAPS ([AndroidAPS Community N.D.d](#)). It is necessary to allow applications from outside the Google Play Store to be installed ([AndroidAPS Community N.D.h](#)). Once it has been transferred one can start using the application. On AAPS there are objectives to follow to gain access to all use modes of the application where the end goal is an AID-system substitute ([AndroidAPS Community N.D.c](#)). It is possible to use AAPS on most Android phones however, there is a list of tested phones on the website.

iPhone: LoopDocs

LoopDocs is a guide for Apple iPhone users. The website LoopDocs is created through the English language however, it is possible to translate the website into 26 other languages. The translation happens through Google Translate, where Danish is one of the 26 languages. LoopDocs is constructed with an introduction to DIYAPS and different steps to go through to develop DIYAPS, which are built, set up, and operate. Within the building step, LoopDocs has defined two different options on how to develop (LoopDocs Community N.D.a). The user can build DIYAPS with a browser or with an Apple Mac computer. However, building through a browser requires the user to have an Apple Developer Account, which costs around 700 Danish kroner pr. year (as of May 2024). The app needs to be rebuilt every three months with this method (LoopDocs Community N.D.b). Building with an Apple Mac computer also has some requirements such as having the application Xcode (should be updated regularly) and the Mac should be updated with the recent operating system. Additionally, the app needs to be rebuilt weekly unless one purchases an Apple Developer Account, thereafter it needs a rebuild once yearly (LoopDocs Community N.D.c). LoopDocs is mainly constructed by text and a few pictures. In addition, there are many hyperlinks, which will guide the user to for example Github or other websites to help the user build, set up, and understand the different steps of the DIYAPS. The amount of time to build, set up, and operate the DIYAPS can vary however, Loopdocs expresses that it can take a few hours (LoopDocs Community N.D.d).

To build with Loop it is necessary to have an Apple iPhone and a Mac computer or Apple Developer Account as mentioned above. However, as in AndroidAPS, there are also only a certain amount of diabetes technologies that can be used when building DIYAPS through Loop. These components are as follows:

- **FGM/CGM:** Dexcom G5, Dexcom G6, Dexcom G7, Dexcom ONE CGM (available in some countries), Minimed Enlite (can only be used with the Medtronic 522/722, 523/723, and 554/754 insulin pumps), Libre 1 (Transmitter necessary), Libre 2, Libre 3.
- **Insulin Pump:** Omnipod Eros Pumps, Omnipod DASH Pumps, Medtronic 515 or 715 (any firmware), Medtronic 522 or 722 (any firmware), Medtronic 523 or 723 (firmware 2.4 or lower), Medtronic Worldwide Veo 554 or 754 (firmware 2.6A or lower), Medtronic Canadian/Australian Veo 554 or 754 (firmware 2.7A or lower).

For all the insulin pumps mentioned, except one, it is necessary to have a radiolink to connect the insulin pump to the iPhone. However, Omnipod DASH Pumps do not require a radiolink since they have a Bluetooth connection embedded. Almost all Apple iPhones can be used for developing DIYAPS with Loop, with that said all the available devices are listed on the website. When the user has the right compositions of components mentioned above, the user is now ready to build the Loop App. However, the user is not required to code the application, because the code is retrievable online and can be downloaded by all. Once the application is built and set up the user can start using their insulin pump and sensor-based glucose monitor as a DIYAPS.

1.4 People with Type 1 Diabetes Caught in Geographical Inequity

It can be presented that there is a concern regarding geographical inequity in health related to T1D in a Danish context. A rapport from The Danish National Center for Ethics argues that unfair discriminatory treatment occurs in the Danish healthcare system. They state that the type and quality of the treatment depend on what illness the patient has. In addition, the rapport presents that the lack of knowledge results in not discovering the unfair treatment, that the politicians and the healthcare system are missing a fundamental reason for the prioritization, and that it is challenging to recognize the rationality behind the wishes and requirements for treatment. However, The Danish National Center for Ethics highlights that it is not possible to phrase a simple and explicit definition of what fair and equitable treatment is. The prioritization is closely connected to fundamental ethical dilemmas. Therefore, the ethical minimum requirements have to be met within treatment ([Nationalt Center for Etik 2018](#)). The minimum requirements are presented below.

- Non-discrimination: Patient groups in the same situation should not be discriminated against on the basis of ethically irrelevant differences such as gender and ethnicity
- Fair distribution: A fair prioritization practice should be based on both the patients' situation (e.g. the severity of their disease) and the benefits of a given intervention (number of life years and health-related quality of life)
- Fair process: Prioritization decisions should be made in a democratically legitimate way according to the principle of "accountability for reasonable decisions". This means, for example, that prioritization decisions and their rationale should be made openly available so that those who have to live with the consequences have the opportunity to understand the decision and possibly object

(([Nationalt Center for Etik 2018](#)))

However, it can be questioned if the minimum requirements are too wide and if the interpretation of the prioritization values can affect inequity within treatment. Unfair prioritization within treatment can also be seen in the allocation of diabetes technologies, also called *The Zip Code Lottery*. The sensor-based glucose monitor is an example of a diabetes technology, which is only assigned for PWT1D who have badly regulated BG-levels. In Denmark, there are two different ways to gain access to diabetes technology. It is necessary for a lot of PWT1D to apply to have the sensor approved as an assistive device by the municipality. Diabetes technology can also be allocated as a treatment tool by the regions and as an assistive device by the municipalities. However, the allocation of diabetes technology depends on the person with T1D's address. This means that not only is the BG regulation a factor but also where you live in the country, thereby the name *The Zip Code Lottery* ([Festersen 2023b](#)). In March 2023 The Danish Health Technology Council made a rapport where they recommended a sensor-based glucose monitor should be a treatment tool for all PWT1D. In the rapport, it has been documented that a sensor-based glucose monitor improves quality of life and has a positive economic impact over

a lifetime compared to a traditional glucose monitor. At the same time, The Danish Health Technology Council addresses concerns regarding *The Zip Code Lottery*, and the council therefore recommends ensuring equal access across the country [Tingkær \(2023\)](#). In October 2023 all five regions announced that they would offer sensor-based glucose monitors to all adults *primo* 2024, as The Danish Health Technology Council recommended. However, the budgeting for all regions in 2024 showed that only three out of five regions will allocate sensor glucose monitors for PWT1D. The remaining two regions elaborated a five-year plan and expressed that over the next five years they will make it possible to assign sensors to all PWT1D in the given region ([Festersen 2023a](#)).

In terms of diabetes technology, the allocation of an insulin pump is based on whether a person with T1D has highly fluctuating BG. However, even if the citizen is qualified, there are still financial constraints in regard to allocating an insulin pump. This is also concerning when it comes to the unfair prioritization within treatment for T1D ([Brejner 2019](#)). In Denmark, the process is based on a national supply list from which the regions have the opportunity to buy from. The supply list includes different insulin pumps, sensor-based glucose monitors, and related products. However, each region is in control of how they want to prioritize the different diabetes technologies ([Festersen 2021](#)).

Insulin pump technology is evolving rapidly, but because of the supply list, the economy is still the fundamental factor. Even though there is great progress in the development of AID-pumps, these are still not readily available for all Danes to access through the healthcare system ([Brejner 2019](#)). However, because of the free choice of hospital, it is possible for all PWT1D to change outpatient clinic if the diabetes outpatient clinic does not offer the wanted diabetes technology. But the technology has to be a part of the local supply list before the hospitals can allocate it. This process of moving, based on hospital is similar to the aforementioned *Zip Code Lottery* ([Foreningen Type 1 2022](#)). A study from the Danish Diabetes Association shows that in 2022 22% of PWT1D had an insulin pump, and 58% had a sensor-based glucose monitor. Compared to other countries in Europe, Denmark has a much lower proportion of adults with a sensor ([Diabetesforeningen 2023](#)).

1.5 The Danish Online DIY Community: Looped - Denmark

Since the DIY-movement started and spread online, we found it interesting to explore these with digital ethnographic methods. Facebook and online communities can be an important part of starting the DIY-process, which will be further elaborated in the section below. Ethnographic studies online, digital or virtual have lots of different terms, but in this case, it will be referred to as *webnography*. Webnography as a method does not require the researcher to interact verbally with the community but insists on acknowledging people's online existence as well as their physical appearance. The online culture must be examined through traditional ethnographic methods in the same way as any other field. The internet is not considered as an object or the context of analysis, but as a technological infrastructure through which the world can be studied ([Albris and Wahlberg 2018](#)).

In this study, we have used webnography to examine the Facebook group 'Looped - Denmark'. Because

of our bachelor project regarding DIYAPS, we have been a member of the group since February 2022. We have had the opportunity to observe the interaction and activity within the group. Therefore, we found it interesting to research how many posts that have been posted between January 1st 2023 to February 21st 2024 about the initial phase of DIY-looping, because it was something that caught our interest during our bachelor's project. Through webnographic research on the Facebook group, we identified 66 posts about helping to set up and get started on DIYAPS. This made us more curious about how the DIY-guidelines are constructed, how helpful they are, and what importance an online community has when starting a DIYAPS journey. Therefore, we have explored the Facebook group closer, which will be presented in the section below.

Different posts have been examined regarding questions about setup and starting DIYAPS in the Facebook group 'Looped - Denmark'. Due to ethical reasons and confidentiality, we chose not to dive further into the different posts in correlation with details and specific comments and we therefore explored the posts with a quantitative approach. Through reviewing the different posts, we have categorized them into seven different themes:

- Components
- Benefits/challenges of DIYAPS
- Setup/build of DIYAPS
- Technical skills and adjustments
- Guideline challenges
- Time
- Other

From the seven different themes, *Components* and *Setup/build of DIYAPS* were the two categories there were the most questions about. Therefore, we find it interesting to further examine the challenges within these themes in chapter 3. When exploring the different posts it became clear that the members were interactive with almost every post, when people asked for help regarding the starting process of DIYAPS. We therefore also find it interesting to further investigate the importance of a community within DIYAPS which will be analyzed in section 3.4.2.

To get an understanding of the DIYAPS field and research that has been elaborated, we have conducted a scoping review, which will be presented in the next section.

1.6 Scoping Review

To further explore the topic of challenges and enablers met when starting DIYAPS, we have conducted a literature search on the literature databases Scopus, CINAHL, and PubMed. Scopus was chosen because the literature found there is multi-disciplinary since it represents both nature science, health science, social sciences, and more (Elsevier N.D.). PubMed is a biomedically focused database (U.S. National Library of Medicine N.D.). CINAHL is a database for nursing sciences (EBSCO N.D.). Because we have worked with this topic before, we wanted to be specific in the search to ensure that we found new articles focused on this topic. Previously in our bachelor's project, we researched the efficacy, safety, and overall outcomes when using an insulin pump with AID features as well as different perspectives on DIYAPS.

The research question for this search is: *"What factors are identified as essential for DIYAPS users within the existing research?"* To answer this question, we did the following searches within available abstract, title, and keywords with the results:

Search String	Scopus Hits	CINAHL Hits	PubMed Hits
"type 1 diabetes" AND diy-loop*	0	0	0
"type 1 diabetes" AND "do it yourself"	45	42	28
"type 1 diabetes" AND diyaps	7	8	1
"type 1 diabetes" AND diy	24	24	5
"type 1 diabetes" AND diy* AND user	18	14	3
"type 1 diabetes" AND "do it yourself" AND start*	3	4	0
"type 1 diabetes" AND "do it yourself" AND learn*	2	2	0
"type 1 diabetes" AND "do it yourself" AND educatio*	12	8	2
Total amount of articles	111	102	39

Table 1.1: Literature search on three different databases March 5th

Because of our experience with searching within this topic, we were knowledgeable on different terms used to describe the movement in articles. Additionally, for all searches, we had chosen to add exclusion criteria to avoid research surrounding specific topics. The chosen exclusions were added to each string with AND NOT in front of each: child*, adolescen*, pregnan*. In the searches, we also chose to use an asterisk, which allows different endings of a word. For example with the word "diy*" it should show results of "diy", "diyaps", "diyp", "diying" and others. Furthermore, we used a ditto mark also known as a quotation mark. This will ensure that the order of the words within the marks, as well as those specific words, will be present in the search, and hereby filter out for example type 2 diabetes.

After doing the searches, all articles were collected on RefWorks to go through. The choice of RefWorks is due to a licensing agreement between Aalborg University and RefWorks, which means we can use it free of charge. First, we collectively read through all the titles and chose those articles whose abstracts we would read. Afterwards, abstracts were read and we filtered out anything unrelated based on our chosen exclusion criteria for the sorting process. We discussed exclusion criteria for our sorting process based on our interests for the future of this thesis. The exclusions were:

- Articles exclusively from a health care provider perspective
- Articles mainly focused on safety and outcomes of DIYAPS use
- Articles written to support statements from diabetes organizations
- Articles written from a different cultural aspect within a healthcare system

Finally, we divided the last articles between the two of us and did a full-text read-through, and discussed our findings with the focus of choosing the final articles for this scoping review. Afterwards, we were left with 10 articles. The sorting process can be seen in the figure below:

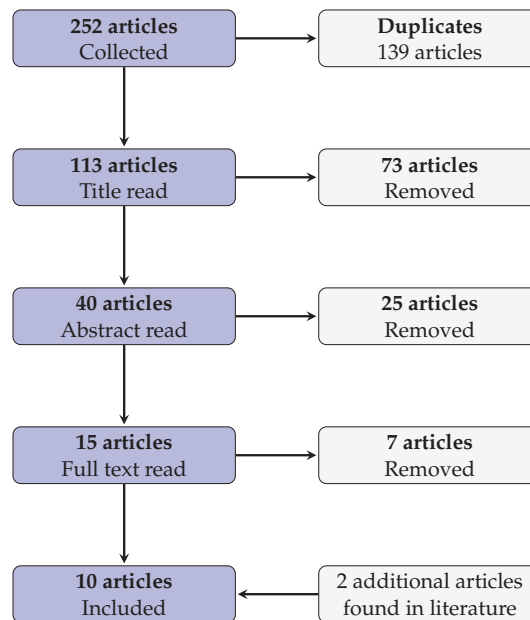


Figure 1.4: The sorting process of the 252 articles found on Scopus, Cinahl and PubMed

The articles selected for this review were chosen to answer the research question for the scoping review, and are focused on qualities that are necessary as a user of DIYAPS. Three components were identified during the read-through of the articles: the ability of self-management, technical competencies, and community-based Support. In the following sections, the existing research that presented essential factors for DIYAPS users will be described and discussed. The chosen articles can be seen in the following table:

Author(s) and year	Title	Research aim	Methods
Burnside <i>et al.</i> (2020)	Do-It-Yourself Automated Insulin Delivery: A Leading Example of the Democratization of Medicine	Illustrate DIY as an example of democratization of medicine	Compilation of literature, discussion piece
Crocket (2020)	Peer Mentoring in the Do-it-Yourself Artificial Pancreas System Community	Highlight the role of mentors in the DIYAPS community	Semi-structured interview
Heinemann and Lange (2019)	“Do It Yourself” (DIY)—Automated Insulin Delivery (AID) Systems: Current Status From a German Point of View	Identify the current status of the DIY development with discussion from a German point of view	Discussion piece based on current literature
Litchman <i>et al.</i> (2019)	Twitter Analysis of #OpenAPS DIY Artificial Pancreas Technology Use Suggests Improved A1C and Quality of Life	Examine Twitter data to understand the perception of, influence of, and emotional and physical effects of OpenAPS	Qualitative netnography
Litchman <i>et al.</i> (2020)	Patient-Driven Diabetes Technologies: Sentiment and Personas of the #WeAreNotWaiting and #OpenAPS Movements	Identify the types of personas and their views on OpenAPS	Symplur Analytics of Twitter data
O’Donnell <i>et al.</i> (2023)	Barriers to uptake of Open-Source automated insulin delivery Systems: Analysis of socioeconomic factors and perceived challenges of adults with type 1 diabetes from the OPEN survey	Investigate perceived barriers when starting DIY from non-users	Survey
Palmer <i>et al.</i> (2020)	Using a Do-It-Yourself Artificial Pancreas: Perspectives from Patients and Diabetes Providers	Understand patient experiences with DIY and the perspectives from patients and providers	Survey
Schipp <i>et al.</i> (2021)	How Adults with Type 1 Diabetes Are Navigating the Challenges of Open-Source Artificial Pancreas Systems: A Qualitative Study	Understand users’ experiences with DIY to understand how they navigate challenges	Semi-structured interview
Schipp <i>et al.</i> (2022)	‘We’re all on the same team’. Perspectives on the future of artificial pancreas systems by adults in Australia with type 1 diabetes using open-source technologies: A qualitative study	Understand users’ perspective on the future of DIY	Semi-structured interview
Suttiratana <i>et al.</i> (2022)	Qualitative Study of User Experiences with Loop, an Open-Source Automated Insulin Delivery System	Understand pros and cons of Loop	Focus Group

Table 1.2: Articles included in the scoping review of this thesis

1.6.1 Ability of Self-Management

In the articles by Schipp *et al.* (2021), Suttiratana *et al.* (2022), Heinemann and Lange (2019) and O’Donnell *et al.* (2023) it is stated how users of DIYAPS have to be able to manage and understand their T1D independently. Especially because of the lack of knowledge about DIYAPS from their HCP. This is resonated in the article by O’Donnell *et al.* (2023), who surveyed non-users of DIYAPS through a questionnaire. The reasons for why they had not started was due to the uncertain reactions from their HCPs. The participants in this study were *“afraid of losing their healthcare providers’ support”* (O’Donnell *et al.* 2023, p. 3). Additionally, 42% of those surveyed expressed that their HCPs had a lack of general knowledge about diabetes technology and were therefore not able to aid in the build of DIYAPS. The fear of losing support was due to the missing regulatory approval. It is also clear that the participants had a sense of being overwhelmed by the material on how to build DIYAPS, as well as the time it could take to understand the technology and how it would increase the responsibility of their diabetes management (O’Donnell *et al.* 2023).

This described heightened need for self-management is clear in the article by Schipp *et al.* (2021), which is a qualitative study of semi-structured interviews about navigating the challenges of DIYAPS from a DIYAPS-user perspective. Self-sufficiency when starting and maintaining DIYAPS is explicitly stated in the article by Schipp *et al.* (2021) as one of the strategies to using DIYAPS. They write that because of the absence of support from HCPs PWT1D become *“more active in their diabetes management and decision-making. They were both burdened and empowered by this”* (Schipp *et al.* 2021, p. 549). The lack of aid from HCPs was, however a problem since some participants wished that there was support for

their choices. Although they had this wish, there was a sense of empowerment because they were obligated to be more in control of their own diabetes management. Furthermore, they had a clearer sense of their diabetes because they felt that DIYAPS was a better system for having more insight into how their diabetes was regulated (Schipp *et al.* 2021). This is resonated in the article by Suttiratana *et al.* (2022), which is a qualitative study with data from focus groups on experiences with using DIYAPS. Participants in this study mention how they have gone back to studying both general diabetes management, as well as understanding their own body's reaction to different settings and insulin dosages. This is a result of their providers not being able to support them with both technical and management aspects, so they have had to take charge of their disease in a new way. Simultaneously, some participants mentioned that there was an ambivalence from their HCPs, which was perceived as general disinterest in what diabetes technology they were utilizing. Despite this, the participants stated that the heightened self-management still led to them being less burdened by their T1D (Suttiratana *et al.* 2022). In the article by Heinemann and Lange (2019) they state that there are "high demands on users" because they have to understand their personal diabetes therapy, know how to adapt dosages based on BG-levels and DIYAPS requires constant monitoring because of updates to software or hardware (Heinemann and Lange 2019). The article is a status report on DIYAPS from a German perspective. The authors state that DIYAPS is not for those who wish to not be involved with their T1D and should be pertained to the PWT1D who are motivated and technology-interested (Heinemann and Lange 2019). The literature above argues that it is important for users of DIYAPS to be aware of how to be independent with their diabetes management because of a lack of HCP support. Moreover, the build and maintenance of a DIY-system require constant surveillance and awareness it is not a system that can be forgotten. This leads to the second component highlighted in the results of this literature search, which is a sense of technical competency.

1.6.2 Technical Competences

As suggested above, it is required that users of DIYAPS are prepared to be more technically involved in the management of their T1D, especially because there are no companies to contact if a component stops working and their HCPs are not necessarily equipped to help them. In the Twitter analysis of the #OpenAPS by Litchman *et al.* (2019), they researched how OpenAPS is perceived, what personal effect the use has, and how it influences daily life. Users would tweet when they were having trouble with their build, which is described as "growing pains" (Litchman *et al.* 2019, p. 168), or they would mention if they had trouble finding the right components or material on how to solve their problems. The article highlights tweets surrounding this topic of technical hurdles as one of the main themes of what PWT1D tweets with #OpenAPS (Litchman *et al.* 2019). Participants in the qualitative interview study by Schipp *et al.* (2022) highlights that although many could benefit from the use of DIYAPS, there is a level of technical understanding that is necessary (Schipp *et al.* 2022). In the article by Schipp *et al.* (2021), participants mentioned "needing to be 'tech savvy' to set up their open-source APS. Some lacked this technical knowledge and struggled with issues such as programming software for the first time." (Schipp *et al.*

2021, p. 548). This is again a highlight of the need for having some technical competencies however, it is important to remember that they managed to start and maintain their systems (Schipp *et al.* 2021). In the article by O'Donnell *et al.* (2023) they question whether IT-literacy of users and participants in research should be questioned, prior to the research since participants in their survey felt their lack of programming would lead to an unsuccessful build of DIYAPS. Therefore, they suggest more research where persons who are involved in the research perceive their IT-literacy as low (O'Donnell *et al.* 2023). Interestingly, in the article by Suttiratana *et al.* (2022) some participants expressed weariness due to the descriptions of the online guidelines for DIYAPS, as well as the discussions surrounding the build. In spite of this, after starting the setup process the participants deemed it to be easier than expected, although there were some technical issues and the setup required a certain understanding, which could lead to more time spent on the build. This is also interesting to compare with results from the study by Palmer *et al.* (2020), which is a survey study of people using DIYAPS. In this investigation, the respondents were asked to determine their own computer literacy, whereas 31% of the 101 respondents answered moderate and 31% limited. There were 13% who said they had minimal knowledge. The remaining respondents replied they had 6% extensive knowledge, and 20% said they had expert knowledge. This could indicate that general technical knowledge can be sufficient enough to maintain a DIYAPS. Two participants, however, did mention frustrations and working with the setup longer because they found it difficult (Palmer *et al.* 2020). This questions whether the technical competencies have to be high to start, or if the lingo surrounding DIYAPS is interpreted as needing a higher level of IT literacy. In the previously mentioned article by Heinemann and Lange (2019) they also highlight how it is not necessary to know the intricate details of the hardware and software, but they must know enough to start and know about their own diabetes as mentioned in the section above. Additionally, they claim that a liability issue arises when the DIYAPS-user asks for help from others. This is fascinating since the foundation of the DIY-movement is based on a community where PWT1D are helping each other (Heinemann and Lange 2019). Heinemann and Lange (2019) states that this liability question is especially if the build is done by someone else than the person. This issue is not analyzed in other articles. Nevertheless, it is important to highlight this because the different online communities of DIYAPS are where most seek help and knowledge. This is the third component that is focused on in most of the articles.

1.6.3 A Community-based Support

In numerous articles, it is mentioned that community is a key factor of the DIYAPS movement, especially because it started through the sharing of knowledge on different ways to DIY diabetes technology. This can be seen in the article by Litchman *et al.* (2019) since this is a gathering of tweets where people speak about their experiences as well as help each other through online media. The users who asked questions were referred to the community where their questions could be answered. Litchman *et al.* (2019) also mentions that DIYAPS users rely on the guidelines and the support in the community. Furthermore, the developers of the different systems use Twitter and other platforms to share news

about updates, articles, or events. This shows that the online community is essential for communication surrounding developments in the system (Litchman *et al.* 2019). In 2020 Litchman *et al.* (2020) describes the personas of DIYAPS based on the twitter data collected. The personas are six different types of people who contribute to the community of DIYAPS: Fearless Leaders, Loopers living it up, Parents on a mission, The tech titans, Movement supporters, and Healthcare provider advocates. The articles highlight how these personas possibly could be present in other online communities, and they are the ones who contribute to sustaining the communities (Litchman *et al.* 2020).

In the discussion piece by Burnside *et al.* (2020) about DIYAPS as an example of democratization medicine, they call DIYAPS a leading example of this because it fulfills several pillars of democratization. These are mentioned as being *"intelligent computing; sharing (of information); and security privacy and safety."* (Burnside *et al.* 2020, p. 878). For this section, the second pillar of sharing information is relevant. They highlight how it is a core of the DIYAPS community, especially the spread of the movement because it is freely available. They argue that this is one of the ways many overcome the previously mentioned technical challenges, because of how the online forums offer support for technical challenges, as well as overall social and emotional support. Additionally, the help is more readily available which is quicker than most HCPs (Burnside *et al.* 2020). This is also resonated in the article by Palmer *et al.* (2020), where the online community and guidelines are mentioned more than traditional resources like HCPs. Similarly in the study by Schipp *et al.* (2021), one participant mentions that they would not be able to gain a hold of their HCP, as fast as they get help from the online community. Again the community is called attention to as a main factor in what helped them with building their DIYAPS. The main aspect of DIY and diabetes management is that the participants mention that the mentality of the DIYAPS community is *"pay-it-forward"*, and there is a heightened sense of confidence in the peers in the community because they have *"shared experience in managing type 1 diabetes"* (Schipp *et al.* 2021, p. 548). This mentality is also underlined in the article by Crocket (2020), which is an interview study of peer-mentoring in the DIYAPS community. They discuss how in the beginning there were several super-users who took the role of mentoring new users. However, it has changed now because so many are involved with DIYAPS that there are more to answer simple questions, which allows the super-users to address bigger issues, as well as continue the development of the systems. The participants mention the mindset of delivering help for not just one but for many, which is why they encourage users with problems to report them on online platforms where they can then get help. This would then lead to others seeing the answers and perhaps gaining help from those posts. Moreover, they had an empathetic approach to helping where they would try to *"assist users to solve their current problem while building users' broader problem-solving skills."* (Crocket 2020, p. 1024). This is interesting when looking at how the articles mentioned in this section describe the usefulness of the help offered on online platforms. In the article by Schipp *et al.* (2022) the community is described as *"very generous and giving"* (Schipp *et al.* 2022, p. 5). The argument of faster support than from commercial companies and HCPs are also resonated in this article. Simultaneously, the article calls attention to the development being user-led, because the community provides the ability of commenting on wishes for

changes. They underline this as a reason for why DIY-systems may not be outperformed by commercial companies in the eyes of DIYAPS-users (Schipp *et al.* 2022). Finally, in the article by Suttiratana *et al.* (2022) the community is defined as a beneficial aspect of DIYAPS: *"Most participants expressed gratitude for the Loop community that formed around empathy, collaboration, and shared experiences."* (Suttiratana *et al.* 2022). Besides technical support, emotional support is mentioned again, which highlights the empathetic approach to helping each other referred to in the previously mentioned articles. Additionally, the community is highlighted as a motivator to become more technical with one participant stating they felt supported in going from an insulin pen to an insulin pump (Suttiratana *et al.* 2022).

Throughout the literature, the community of DIYAPS is introduced as a unique phenomenon, because of how information and help are spread quicker than traditional care. The first two factors described in this review were based on one's own limitations however, they were most often encouraged or helped by the community to overcome them. The community is therefore a relevant element to include when researching DIYAPS.

1.7 Scope and Delimitations

Although there is a wide range of available diabetes technology, the slow processes of approving commercialized medical equipment and the development of systems have resulted in PWT1D seeking systems elsewhere such as DIYAPS. As mentioned, DIYAPS is a customized and user-led system that emerged from the #WeAreNotWaiting movement to achieve more self-management and better blood sugar regulation. However, because of the unapproved and unacknowledged systems, DIYAPS can be difficult to navigate since one has to seek the information alone.

In our bachelor's project, we identified benefits and barriers to using DIYAPS (Nielsen *et al.* 2022). Additionally, we identified that those using DIYAPS have reached a certain level of empowerment. Additionally, the data in the chosen literature represented multiple perspectives, which we find interesting since the movement was started by users for other users. Based on these findings, our research will be focused on user perspectives.

Therefore, this master's thesis focuses on how we can support the DIYAPS community to help navigate DIYAPS information through action research. With action research, we aim to make a change and generate knowledge about the world with people from the DIYAPS community. Initially, we have conducted fieldwork and observation digitally on the Facebook group 'Looped - Denmark', to collect data and initiate the involvement of Danish users through a User-Centered Design (UCD) approach.

Based on our problem analysis, initial webnographic research and the scoping review above, we have formulated the following problem statement:

How can a DIYAPS-readiness tool be developed through a user-centered design approach with the Danish DIYAPS community, and how can it support self-management for empowered people with type 1 diabetes prior to starting DIYAPS?

Chapter 2

Methodological and Theoretical Framework

In the following chapter, our methodological and theoretical framework will be presented. Firstly our positioning will be clarified, to be transparent and to get an understanding of our standpoint. Thereafter, our scientific approach will be elaborated as well as our approach within action research, due to our aim of creating change within the Do-It-Yourself Artificial Pancreas System (DIYAPS) field. Then the theoretical concept of self-efficacy will be explained and how it is relevant for the development of our DIYAPS-readiness tool. Afterwards, the approach of User-Centered Design (UCD) will be presented with a focus on the iterative process when designing. Additionally, qualitative and quantitative methods such as webnography, survey, think aloud and interview will be elaborated to get an understanding of how we have gathered our empirical data. Lastly, our data process will be specified with a focus on how we have reviewed and worked with our data gathering during our thesis.

2.1 Positioning

This project is shaped by our previous experiences in similar fields, as well as our personal lives. Therefore, we have to take our positioning into account while doing this research. Through our techno-anthropological education, we have been driven to work with and for the users of technology. As we have mentioned before, the topic of DIYAPS is not new to us, and we have written our bachelor's project about the benefits and challenges of using DIYAPS. Because of this, we have gained knowledge on how the use of a DIY-looping system can have an effect on quality of life for users, as well as what opportunities and barriers are present with the users. We have taken this knowledge with us when investigating the Facebook group 'Looped - Denmark', as well as talking with individuals who are currently DIY-looping. Additionally, because of our bachelor's project, we have been a part of the Facebook group 'Looped - Denmark', which led us to the topic of this master's thesis, because we followed along in the posts on the group through the past two years. However, it is also important to highlight that one of us has Type 1 Diabetes (T1D) and has personal experience with the disease, as well as DIYAPS. This is because she started DIYAPS when we started writing our bachelor's. She therefore has personal experience with the process of acquiring components, building the DIYAPS, and using it on a daily basis. This positions her in a situation where she has her own experiences with the system and the building process.

2.2 Scientific Approach: Post-phenomenology

As our project is engaged with both people and technology, we recognize post-phenomenology as our scientific framework, as we find it relevant when working in the field of DIYAPS. Post-phenomenology originates from Don Ihde to progress the understanding and principles behind phenomenology. It is based on the acknowledgment of technology as a mediating factor between humans and the world. Therefore, Ihde provides the following framework as *Human-Technology-World*. Technology and science help to shape our relation to the world, instead of distancing us from it, where post-phenomenology reconceptualizes by fundamentally examining the mediating characters. Additionally, it presents that there is only an indirect relation between subject and object, contrary to phenomenology. Technology helps to shape human subjectivity and the objectivity of the world. Material technological artifacts are acknowledged as an important part of the way human beings interpret the world and how the world is interpreted (Rosenberger and Verbeek 2015).

Within post-phenomenology, Don Ihde borrows the phenomenological term '*lifeworld*' from Edmund Husserl and Martin Heidegger to express how technology can be interpreted to have a significant purpose. According to phenomenology, lifeworld is the way people individually experience the world. It is not only the physical part but also the social, cultural, and historical contexts in which they are situated. Ihde (1990) conveys the term lifeworld with the addition of technology. According to Ihde (1990), technology has an essential role in the way we experience the world. Technology can be understood as simple and complex however, it does not only expand our opportunities but also shapes our interaction, perception, and understanding of the world around us. In this sense, technology becomes an integrated part of our lifeworld and affects how we engage with and make sense of our environment (Ihde 1990).

In this thesis, post-phenomenology is relevant due to the understanding of how technology is a part of People With Type 1 Diabetes' (PWT1D) lifeworld, and how it affects them. They have specific diabetes technology that affect their place in the world. Therefore, we recognize that starting DIYAPS can affect the experiences in their lifeworld, because of the changes it has in their lives.

2.3 Action Research

Kurt Lewin shaped *action research* as an effort to develop a social technology to solve social conflicts. He expressed, that contemporary research was not capable of producing relevant knowledge regarding solving problems in a social context. According to Lewin the aim of action research is to create a research approach, which creates a closer contact between the researchers and the practitioners within a particular field. Thereby, the practitioners could be called co-researchers and contribute to the investigation. Through analysis and experiments in the field, the practitioners have the opportunity to contribute to solving social problems. Lewin argued, that relevant knowledge in research could only emerge with the involvement of practice engagement and localization. Therefore, the practitioners' engagement is important within action research, because they contribute to a possible solution for the

problem field and evaluate if the practice improvements have made any reasonable difference. As interventional field research, action research would through diverse experiments and projects, develop a comparative research to the conditions of social action and effects, where it would create insights into what characterizes social life (Christensen and Nielsen 2022).

Based on this, we explore the field of what we will interpret as digital action research. Through digital action research, we involve participants through digital media to contribute to research. As mentioned in section 1.5, we have been members of the Facebook group 'Looped - Denmark' since 2022 and at the same time conducted a bachelor's project within the same field. This means that we have followed the community as well as worked with them before. We argue, that being a part of the group over this extended period of time has given us insight and interest in their perspectives, which can contribute to a digital action research process. So when Lewin argues that relevant knowledge can only be produced by the involvement of practice engagement and localization, we would argue that the collaboration and the involvement of different actors in the Facebook group can be called digital action research. In this context, the physical field or localization has been replaced with the digital space, but our research is still based on the same methodological principles as traditional action research.

Action research has two different goals to make a change and to generate knowledge about the world. This means that knowledge about the world is created through an attempt to change the world. Additionally, an action research project is formed by the directions of the participants (Laursen 2015). The problem with the use of research-based knowledge has been translating the knowledge to action. For example, evidence-based knowledge would typically identify and present certain forms of actions and methods, which has proven to provide the desired results. However, it becomes complicated to collect evidence-based knowledge within specific contexts, when the local reality often never fits what the pre-written research assumes. Therefore, action research can contribute to promoting the translation in a collaboration between practitioners and action researchers when working with further development of knowledge-based practices (Kildedal and Laursen 2015). Within action research, there are three different aspects of the working process: The work division between researcher and participant, description and mirroring, and the experiment. However, we will not go into detail with description and mirroring as we do not find it relevant within the digital field.

The experiment

Presenting different proposals for a new practice for the participants is also a central element of action research. The experiment can be understood as the practice that has not been carried out in the given context based on the action researcher's description of and dialog with the field. Experiments are based on thoroughly researched hypotheses. Thus, assumptions about the given practice can take place in a better way, which is proposed by the researcher. The proposal can be validated through the practical execution of the experiment. Through different roles, the researcher and the participants enable the participants to get involved in the assessment of the experiment. However, it is important to point out that the assessment is not only based on the participant's self-assessment (Laursen 2015). In this

context, the practical execution of the experiment was performed in the Facebook group, as our solution was based on a digital tool since we were exploring and investigating a digital field. The assessment of the DIYAPS-readiness tool was performed through interviews with relevant actors in the Facebook group, as well as the involvement of group members through posts and private messages.

Work division between researcher and participant

The collaboration between the researcher and the participants is a fundamental factor in the creation of knowledge within action research. Generally in action research, the researcher is not participating in practice. The researcher can be defined as an *outsider*, who seeks to understand the meaning of the observed behavior. However, the interaction between the researcher and the practitioners ensures that the observations and proposals from the researcher will get a concretization, which makes it applicable in the development of a practice (Laursen 2015). In this context, the collaboration between us (the researchers) and the participants happened by involving relevant actors from the Facebook group through interviews, a questionnaire, and written correspondence through posts and private messages. Additionally, the observation did not happen in a physical space as we performed observations in the Facebook group, and therefore acknowledge that in this context the digital field is as relevant as a physical space, which will also be elaborated in section 2.6. Here it is important to mention, that we did make the group aware of our master's thesis and that those participating have given consent to be included in our project.

Conducting action research digitally has both strengths and limitations. Through digital action research, we argue that the participants are more accessible, due to the possibility of quick and easy contact. With the Facebook group, we have the opportunity to reach out when it is relevant and at the same time receive feedback fast. However, performing the research digitally also means that it is challenging to sense a room as well as people's physical behavior. You could assume that physical presence produces different results than when it is online. Additionally, there is a barrier with the digital respondents, because our research relies on their participation and their engagement. This can be identified as a limitation because there is a probability of people not answering and engaging with our content.

2.4 Theoretical Concept: Self-Efficacy

During our current and previous research surrounding DIYAPS, it has become clear that the process of starting DIYAPS requires a sense of motivation and trust in oneself. Because of this, we find it is relevant to understand how people perceive themselves. Here the term of *self-efficacy* becomes pertinent. A person is reluctant to take on tasks that they do not have an understanding or control of. The more likely they are to take on the challenge can be measured through their self-efficacy. It is a person's perception and beliefs about themselves, which are determined by their previous experiences with similar tasks. Therefore, if there is failure in a task a person is less likely to try that task or similar tasks again. Oppositely, if a task has succeeded then they will continue trying that task or similar tasks (Bandura

2014).

According to [Bandura \(1995\)](#), the beliefs of efficacy are developed based on four different forms of influence. The first one, mastery experience, relates to previous experiences with similar tasks. The second one, vicarious experience, relates to one observing others' experience with a task. The third one, social persuasion, is if you experience encouragement from others to perform a task. The final fourth one, physiological and emotional state, relates to the feelings you experience while performing or in anticipation of performing a task ([Bandura 1995](#)). In this project, we want to highlight the last three influences, since we are not able to determine people's experiences with similar tasks, and therefore, mastery experience is not relevant for this project. The influence of vicarious experience is building self-efficacy by observing others succeed, which then in turn encourages belief in oneself. However, it is important that the person who is modeling is similar to oneself to ensure being able to see oneself complete the given task ([Bandura 1995](#)). In regards to social persuasion, the core is that when people receive encouragement from others, they are more likely to ignore self-doubt. Although, it should be noted that *"It is more difficult to instill high beliefs of personal efficacy by social persuasion alone than to undermine them. Unrealistic boosts in efficacy are quickly disconfirmed by disappointing results of one's efforts."* ([Bandura 1995](#), p. 4). As a result of this, it is important to convey positivity, while also creating situations where success is more likely to happen. The influence of physiological and emotional state is interesting for this project, because of how stress can influence the perception of one's performance. It is therefore relevant for people to have an understanding of their physical status, as well as reducing stressful situations. Understanding this reminds us that self-doubt can lead to not fulfilling something ([Bandura 1995](#)).

2.5 User-Centered Design

Because this thesis is focused on developing a DIYAPS-readiness tool to aid in the process of starting a DIYAPS, it is imperative to understand ways of designing and involving those who could be using the tool. The chosen approach of UCD is relevant in this project because the focus is on creating solutions that are simple and based on the users' needs. The choice of UCD comes from the focus on the importance of involving users, because of their expertise in the field we are designing this tool for, which also follows the principles of action research. However, in more recent times the use of 'user' has been challenged because of the distancing from the person who is using the design. In 2008 [Norman \(2008\)](#) wrote that *"We depersonalize the people we study by calling them 'users'. Both terms are derogatory. They take us away from our primary mission: to help people."* ([Norman 2008](#)). This is important for us to highlight as well, because of our own acknowledgment of those we spoke with as being individuals with their own backgrounds and opinions. The use of UCD in the project stems from the relevance of the approach, but it should be noted that moving forward we will be referring to them as participants/their anonymized names.

As mentioned, we follow the approach by [Norman \(2002\)](#), who states one should *"... make sure that (1) the user can figure out what to do, and (2) the user can tell what is going on."* ([Norman 2002](#), p. 188).

Norman (2002) aims to ensure that the design should be instinctual and without training. Therefore, it is important that tasks involved with the design should not be complex. UCD is an iterative design process. One must observe the users, design a solution, involve the users in the testing and evaluation, and then re-think the solution based on the feedback and observed needs. There are four stages, where one continuously must assess whether it is necessary to go back and look into the previous stages (Interaction Design Foundation 2024).

1. **Research:** The focus is to understand the user's needs by collecting data. In this project, we collect data through surveys, interviews, think aloud testing, and online observation.
2. **Requirements:** What could be solved based on the observed problems from the data?
3. **Design:** The solution is designed in a prototype or mockup version.
4. **Evaluation:** The design is tested with users or potential users with the goal of identifying issues or improvements.

(Interaction Design Foundation 2024)

When designing user-centered one must follow these stages, while also understanding the four principles of user-centered design. The principles, besides the focus on users, include choosing the correct problem to solve, understanding that everything is connected, and not rushing to one solution without taking various factors into account (Interaction Design Foundation 2024).

Our involvement of the participants followed the UCD-approach, where we collected data and used this to shape the design, while also testing iterations with people to gain continuous data. We acknowledge that the degree of involvement, therefore is on the lower spectrum. However, due to our participants being located online and in a special type of community we have had to test with persons around us and not just those in the community. The above has shaped our process with the development of the tool, and our approach to our research. We have gone back to our bachelor's research and identified data, while also shaping our current methods continuously towards gaining knowledge that could contribute to finding a solution to identified problems.

2.6 Webnography

As mentioned in section 1.5, webnography is a digital method to explore the digital world. In this context, we find it relevant to further express the method of webnography in correlation with action research and the online Facebook community 'Looped - Denmark'.

The characteristic of webnography is to dive into the online world and conduct participant observations through an online presence. However, it is not a requirement to interact offline or verbally with the participants like a traditional fieldwork. In many ways, online fieldwork differs from traditional fieldwork. The physical world that you would normally observe and participate in has changed to text, pictures, and icons on a screen. Therefore, it is important for the ethnographer to be aware that

the fieldwork is conducted with different terms and conditions (Albris and Wahlberg 2018). As mentioned previously, we have had access to the private Facebook group 'Looped - Denmark' since 2022 due to our bachelor's project. This has given us the opportunity to follow the group and the different interactions since then. During this period of time, we have not interacted with the community, which can be defined as lurking. We have been anonymously lurking on posts since our presence was not announced during this period of time which could result in ethical issues (Garcia *et al.* 2009). However, we argue that we are no longer lurking in the group since we have announced our presence through posts regarding this thesis. In this case, we perceive 'Looped - Denmark' as the field and the "place" where we have conducted our fieldwork. Observing the Facebook group and the different posts made it possible for us to get an overview of how the group is used by the members and what content is mainly posted. Additionally, we also identified which members were the most active and often responded to the different posts. Due to confidentiality, we chose not to express details from the Facebook group however, this also made it challenging for us to collect data, as well as involve the members in our process. In correlation with action research and our interest in the DIYAPS community, it became apparent that reaching out to members individually was time-consuming. Therefore, we chose to create a questionnaire for members in the Facebook group to answer, and thereby involve relevant users in our action research process. How the survey has been conducted, will be further elaborated below.

2.7 Survey

A survey is a method to collect information and data quantitatively in a defined group of people. Surveys are characterized as a systematic or structured set of data and are considered quantitative and positivistic. Data gathered with surveys will provide systematic data that allows comparison between collected data (Vaus 2002c). Representativeness is also a characteristic of surveys. The intent is to adequately represent the population that is researched to take several dimensions into account. However, this can ideally never be fulfilled. Therefore, we are aware of *bias* when creating the survey, as well as when data has been collected (Hesse 2006).

One of the most common ways to collect survey data is through questionnaires, which will be our main focus. Questionnaires can be described as structured and a straightforward way of collecting information. In other words, it provides information that can also be referred to as *the hard evidence*, as for example factual and descriptive information (Vaus 2002c). Questionnaires can be done face-to-face, by mail, by phone, etc. However, in this context, we have conducted what can be called an *internet survey*. With an internet survey, it is possible for the receiver to access the questionnaire online and thereby complete and submit the answers when wanted to. At the same time, it also made it possible for us to reach out to more people in the community compared to a face-to-face questionnaire (Vaus 2002a). Through the questionnaire, we were interested in the Facebook group members' experience with the beginning phase of DIYAPS. The aim was to create a questionnaire where all members could answer, even though they were experienced with DIYAPS. The questionnaire was therefore designed in three different steps and with multiple branches adjusted to the different phases of DIY-looping,

which were determined by the authors. This was a prioritization within the questionnaire, which also determined the choice of web page. The branching is depicted in the figure below:

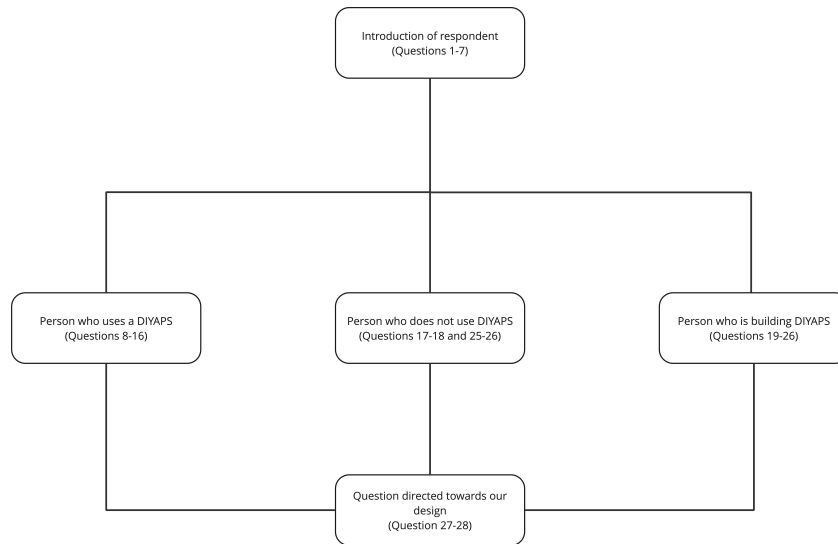


Figure 2.1: A flowchart of how the questionnaire is structured

In this project, we have formulated a questionnaire in Danish that has been posted on the Facebook group 'Looped - Denmark'. Here we are aware that people who actively interact in the group, are more likely to answer the questionnaire due to notification and interest. At the same time, we are also aware that the questions asked in the questionnaire are biased because of our own previous knowledge in the field. However, through observation in 'Looped - Denmark' and the initiating webnographic research, we have formulated questions based on relevant data and observation. Additionally, when we posted the questionnaire in this particular Facebook group, we were aware that the members who chose to engage with the questionnaire also were interested in DIYAPS. Because of this, we assume that those who replied to our questionnaire are involved in the community and have a preexisting interest.

The questions in the questionnaire can be seen in Appendix A. However, the questions are gathered one after the other where each question is not for each person taking the questionnaire. The structure of this is seen in the figure above. In this way, it was possible for us to create questions adjusted to the person in the given phase of DIYAPS and thus collect relevant data from the different branches. The data from each branch is not generalizable since each person's experience is subjective. It is necessary to highlight that we are aware of how the collected data will affect the development of the project since the questionnaire is developed with a broader perspective in mind. All branches ended with questions about possible changes and transformations they envisioned to be a part of the starting process of DIYAPS (Vaus 2002b).

The questionnaire seemingly has 28 different questions however, as mentioned not all questions are presented to every person who answers. The purpose of the questions and which questions has what type of question is displayed in the table below (Vaus 2002b). The full questionnaire can be seen in Appendix A, where the results can be seen in Appendix B.

Question Type	Purpose	Used in question
Single Choice	Specific questions to determine age, type of DIY etc.	1, 2, 4, 5, 7, 8, 9, 19, 20
Multiple Choice	Statements regarding use of DIY, start of DIY etc.	6, 10, 12, 17, 21, 25, 27
Likert Scale	Assess their technical competencies in a scale form from 1-10; how useful the Danish Facebook group is etc.	3, 15, 23
Write-in Option	Possibility to elaborate their answers to multiple choice	11, 13, 14, 16, 18, 22, 24, 26, 28

Table 2.1: Question types used in our questionnaire and their purpose

In this context, we gathered nine answers on the questionnaire, which is interpreted as low compared with approximately 1300 members of the Facebook group. The response rate therefore was 0.0069%. Therefore, the questionnaire is assessed as not representative of the target group. However, we argue that the activity in the Facebook group is low, with circa two questions a week. The aim of the questionnaire was not to have quantifiable data but to gain a deeper insight. We chose to include the answers in the thesis, as we acknowledge all participants as individuals who have insights and experiences that are relevant to the further development of our research.

2.8 Think Aloud

To investigate how the guidelines, described in section 1.3.1, are perceived by persons without any prior knowledge of the websites, we have chosen to conduct a think aloud test with a non-user of DIYAPS. Since they do not have previous experience with the websites, we found it interesting to explore their perception, and thereby give us impartial insight through a first-hand experience. The think aloud method originates from psychology but has moved into other areas such as computer design. The method can be used when testing an interface, where one then asks participants to speak their thoughts while exploring. For some participants, it can seem unnatural to do this task and therefore, it is important for us as facilitators to prompt them if they are silent. This can for example be done by asking *"what are you thinking?"*. Additionally, it is also important to not help the participant, which is why we must be aware of how we answer any questions posed during the test (Nielsen 1993). Using think aloud will give qualitative insight into participants' opinions and experiences when using a particular system: *"... the think aloud method shows how users interpret each individual interface item."* (Nielsen 1993, p. 195).

As mentioned, the facilitators should also be aware of their role during this test. During the test notes of what the participant is doing should be taken. Here it is highlighted by [Nielsen \(1993\)](#) that one should not rely on what the participant says if they for example try to make up for a previous mistake. This is the reason why taking notes of the actions is critical. However, the participant voicing issues with the look of the interface or completing tasks is important, since this is what in the end can lead to new design ideas. Furthermore, the facilitators need to let the users talk and only interrupt when a new task needs to be given ([Nielsen 1993](#)).

In this project, we performed this method with websites that we had not designed ourselves. The goal was to gain insight into how participants perceived the current option while figuring out how someone unfamiliar with the website navigates it. We have been on the websites multiple times before and because of this we are not unbiased when using them. Therefore, we have done this method with a participant who has not started a DIY-journey. The participant has T1D and has an understanding of what it would mean to change diabetes systems. We defined a set of nine tasks for the participants, based on the most common themes discovered during the first exploration of 'Looped - Denmark' explained in section 1.5. The participant's screen and what they said were recorded during the test for later data processing purposes. Following the think aloud test, we conducted an interview about their experience with the website. This was a semi-structured interview with a focus on debriefing after the test, where questions were asked based on the experience of the website. The process and the details of this will be described in the following section.

2.9 Interview

The method of interview has been chosen to collect data surrounding different topics. Interviews are conducted to gain insight into a person's experience with a specific phenomenon in their life world ([Tanggaard and Brinkmann 2020](#)). Therefore, the interview topics were shaped based on who the specific person was. The chosen form of interview is semi-structured interviews since this allows for a conversation surrounding a topic where there are specific questions to be asked. Simultaneously, there is space for the participants to shape the interview based on their experience, which can lead to follow-up questions outside of the interview guide. The questions in a semi-structured interview are few and open, with the goal of getting the participant to dive into the topic and give detailed descriptions ([Tanggaard and Brinkmann 2020](#)). The formulated questions are defined as descriptive questions, which are inspired by [Spradley \(1979\)](#). Additionally, the method of interview has been performed to test and evaluate our DIYAPS-readiness tool with our participants however, this was done through informal conversations.

Since there were different topics depending on who we were interviewing, several interview guides were formulated to fit the specific person. The first interview we conducted with the participant of the think aloud test, had the topic of experience with the DIYAPS guidelines from an outsider's perspective. The think aloud session as well as the interview then shaped the questions for the remaining interviews. The topic of these interviews is the experience of building DIYAPS and what helped the

participants through their process. The interviews were recorded and all participants signed a consent form, stating that they would be anonymized and that they could retract things they said during the interview at any time.

2.10 Data Processing

Empirical data collected during our study were processed differently, based on what type of collection method that was used. Afterwards, the data was read-through to be analyzed and applied in the design of our DIYAPS-readiness tool. The recordings have been transcribed or taken notes on. Additionally, notes from the think aloud test have been gathered into one file and the questionnaire data has been sorted.

2.10.1 Transcription of Audio Recordings

We have developed our own guidelines for transcription, which are inspired by [Tanggaard and Brinkmann \(2020\)](#). Since there is a difference between how one speaks and one writes, we have defined criteria for what to be excluded while transcribing, as well as how to handle spoken language and unfinished sentences. Due to collecting data through think aloud and interview, we chose to transcribe with two different approaches. The think aloud session has been transcribed with a purposeful mindset, which means that only relevant sections have been transcribed. The transcription criteria formed for think aloud can be seen below:

- Avoid interjections and pause fillers like 'ahh', 'mhhh', 'uhm' etc.
- Laughter and other reactions or tone of voice are omitted as they are not considered relevant.
- Enhanced language is used for grammatical accuracy.
- Words from the website read out loud are written in italics, to visualize the context of action.
- Relevant actions through clicking or pointing on the screen are written in brackets to contextualize the spoken word.
- Contextual notes from the authors will be written in brackets: '[]'

The conducted interviews have been fully transcribed, however as mentioned, criteria have been defined, which can be seen below:

- Avoid interjections and pause fillers like 'ahh', 'mhhh', 'uhm' etc.
- Laughter and other reactions or tone of voice are omitted as they are not considered relevant.
- Enhanced language is used for grammatical accuracy.
- Comments from the writer are written in brackets.

- Thought pauses are shown as three dots: ...
- Contextual notes from the authors will be written in brackets: '[]'

It is important for us that the transcriptions represent the participants' testimonials as closely as possible since it is them who shape this project (Tanggaard and Brinkmann 2020). It should be noted that all interviews were conducted in Danish therefore, the quotes used in the project have been translated with the goal of meaningful accuracy. During testing and evaluation, two conversations were not transcribed but notes were taken along the way. This was done due to the informal conversation where the tool was evaluated.

2.10.2 Coding of Material

After transcribing the collected data, we coded the material to get an overview. The purpose of the coding process was to reduce the overall material to smaller and more applicable segments. Here it is important to mention that this process has occurred throughout a longer period of time to make space to revisit the material. This also means that we have had an agile mindset while coding the material, as well as letting the empirical data shape our outcome (Tanggaard and Brinkmann 2020).

Tanggaard and Brinkmann (2020) emphasizes that codes can be concept-driven or data-driven. Data-driven codes are based on the collected material where the coding is generated inductively which means that themes have not been defined before the coding process. Concept-driven codes are codes formed in advance for example from theory, insights, and others, which means that the coding has been generated deductively (Tanggaard and Brinkmann 2020). In this project, we have worked with the coding process both inductively and deductively. With the approach of action research, we have had this in mind, and it has therefore also shaped a part of the coding process. However, we have analyzed the data-material inductively, and the approach of action research has not defined the entire process. Additionally, as mentioned earlier we have worked with the data material iteratively by following UCD principles (Norman 2002).

Chapter 3

Analysis

In this chapter, we analyze the development of the DIYAPS-readiness tool to help with challenges presenting prior to starting Do-It-Yourself-Artificial-Pancreas-Systems (DIYAPS). We recognize post-phenomenology as our scientific framework through which we analyze and explore the community within DIYAPS through the term lifeworld. Firstly, we contextualize the positioning of this thesis and how it was inspired by our findings in our bachelor's project. Secondly, data from our think aloud session, questionnaire, and interviews are analyzed to represent the research stage of User-Centered Design (UCD). This leads to the requirements for what solution could be developed based on the research. Here we mapped out the complexity of the starting process, which became the inspiration for the first iteration of the design. Thirdly, the design of the DIYAPS-readiness tool is described based on the data, where the theoretical concept of self-efficacy is applied to the structure, appearance, and wording of the tool. Finally, the tool is evaluated with the aim of gaining knowledge on where there are issues and thereby reasons for improvements.

3.1 Presentation of Participants

In this chapter, the participants of this project will be presented. There are five participants involved who are anonymized and will be given a name to personalize their statements. Of the five participants, two have built DIYAPS for themselves, two have built for their child, and one does not have experience with DIYAPS.

- **Aimee:** Has T1D, does not use a DIYAPS. She was involved in the think aloud test, and an interview.
- **Mary:** Does not have T1D, but has built DIYAPS for her son. She was involved in an interview and a test of our result.
- **Charlie:** Does not have T1D, but has built DIYAPS for his son. He is actively involved the Facebook group 'Looped - Denmark' and has been our gatekeeper. We have had messaged with him about our thesis and the process.
- **John:** Has T1D and has built DIYAPS for himself. He was involved in our bachelor's project, where statements during this time were found to be relevant for this master's thesis.
- **James:** Has T1D and has built DIYAPS for himself. He was involved in our bachelor's project, where statements during this time were found to be relevant for this master's thesis.

The participants from the questionnaire are referred to as 'person' or 'participant'. In addition, we will test our result with four peers from our network, who will be presented as 'peer'. They do not have T1D, and have some to no knowledge about T1D. Additionally, they have some to no knowledge about DIYAPS.

3.2 Understanding Empowerment in Relation to DIYAPS

As mentioned earlier, findings from our bachelor's project have contributed to this further research within the field of DIYAPS. During our bachelor's project, we became aware of the element of patient empowerment and how this relates to starting and succeeding with DIYAPS. We concluded that People With Type 1 Diabetes (PWT1D) should be empowered, have technological skills, an understanding of and reading skills within English, and the ability to be patient and motivated. Without this, we assessed that it would be challenging for them to initiate DIYAPS (Nielsen *et al.* 2022). Thus, empowerment has an important role in relation to DIYAPS requiring the citizen to be well-informed and capable of making decisions about their treatment. In addition, it is essential for PWT1D to be able to do it without assistance from a Health Care Professional (HCP), which was identified through our scoping review (see section 1.6.1). To get an understanding of the target group we researched at our bachelor's project and the target we are designing for in our master's thesis, we have included a figure by Botin *et al.* (2020) to visualize the different levels of empowerment present when living with a chronic condition. According to Botin *et al.* (2020) people with a chronic condition have different levels of knowledge, competencies, and skills. The figure divides people into four levels depending on the aforementioned, which can be seen below.

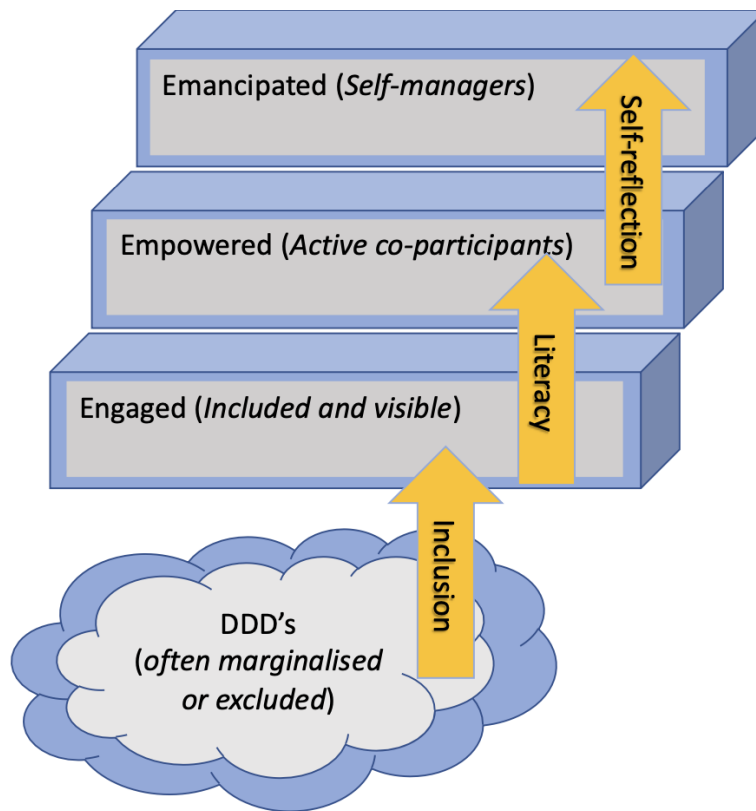


Figure 3.1: The four phases of empowerment developed by [Botin et al. \(2020\)](#)

In the figure people with a chronic condition are categorized into two different groups. They can be classified as People Like Us (PLU) and Disempowered, Disengaged, and Disconnected (DDD). The ladder classifies PLU, whereas the cloud classifies DDD. As [Showell and Turner \(2013\)](#) defines, PLU can be described as “... people who understand healthcare and health issues, take care of their own health, are literate, well to do, tech-savvy, and hold a tertiary qualification.” ([Showell and Turner 2013](#)). On the other hand, people categorized as DDD can be described as “... people disinclined to take exercise for its own (or their own) sake or to eat sensibly. They are not textually, technically, or health literate. They struggle financially, and may not have finished secondary education.” ([Showell and Turner 2013](#)). As seen in the figure, there are three different phases of PLU. Citizens in the *engaged phase* are encouraged to follow the service delivery and exhibit lower levels of self-efficacy and self-management. They are reliant on service delivery and have limited resources and understanding of their own condition and why the system works in the way it does. Citizens in the *empowered phase* are engaged and are supported with tools to support their position regarding the system and their personal health condition. This is promoted by their higher level of health literacy and eHealth literacy. Thus, the citizens are capable of using exciting and new personal solutions to transformation and the management of their chronic conditions in collaboration with a HCP. Citizens in the *emancipation phase* are self-reflected and have in-depth knowledge of their own health condition. Additionally, they have a high level of health and eHealth literacy and a detailed

understanding of why the system works as it does (Botin *et al.* 2020).

Through our empirical data from our bachelor's project, we determine that from these different categories people succeeding with DIYAPS are in the emancipated phase and can be called *self-managers* (Nielsen *et al.* 2022). Because this master's thesis is focused on those who have not started their DIYAPS journey, we aim to design and develop a DIYAPS-readiness tool for PWT1D in the empowered phase and can also be called *active co-participants*. The tool is supposed to create a sense of being more ready and prepared to start DIYAPS, which is also reflected in the name. At the same time, the tool can also create self-assessment at the recipient, to reflect if DIYAPS is something they want to move forward with. Based on the conclusion from our bachelor's project, we argue that those wishing to start DIYAPS are in an empowered state due to the necessary steps that are required prior to beginning DIYAPS (Nielsen *et al.* 2022). Additionally, Botin *et al.* (2020) argues that those in this phase have an understanding of the healthcare system and are able to manage their chronic condition independently however, are still collaborating with HCPs when necessary. We find it relevant to include the understanding of empowerment in this thesis, on the basis of the conclusion that those who use DIYAPS have achieved a level of empowerment. Therefore, we recognize that those involved with this thesis have also reached this.

3.3 Introducing Data From the Research Phase

In the upcoming sections, we will present the outlying challenges when starting DIYAPS, from our previous and current research. Afterwards, the beginning of the design of the DIYAPS-readiness tool is presented based on these findings.

3.3.1 Barriers When Starting DIYAPS

During our bachelor's project we became aware of the barriers when starting DIYAPS. All participants at the time mentioned different factors for starting DIYAPS and were in agreement that it could be an overwhelming process for some people. Here technical competencies and a language barrier were mentioned: *"You need a bit of technical insight [...] and above all patience. Then there's the language barrier, if you're not good at English then it's not that easy."* (John - Appendix D). Additionally, motivation and the understanding of your treatment were mentioned regarding starting DIYAPS: *"You have to be motivated to get invested in your own treatment. If you're not, then it's [DIY-looping] definitely not for you."* (James - Appendix D). These findings became relevant as the literature in section 1.6.1 also highlights barriers for starting DIYAPS, and how it leads to people being more aware of their self-management when starting DIYAPS. In section 1.6.1, it is mentioned that when the HCP distance themselves from DIYAPS, DIY-loopers have to take charge of their treatment in a new way, because they do not get the technical support and help with management of their T1D as they normally would. This leads to DIY-loopers carrying more self-management as they do not have support within the healthcare system. The term lifeworld can be used here since it highlights how individuals' perceptions, interactions, and cultural contexts shape their experiences in this context with their diabetes management and use of diabetes

technology (Ihde 1990). Furthermore, the shift in self-management emphasizes the impact of DIY-looper's lifeworlds.

From the aforementioned, it can be interpreted how advanced and difficult it can be to start DIYAPS in a Danish context. As mentioned in section 1.5, we identified multiple themes within posts regarding the starting phase of DIYAPS. Because of this, we became more curious about the process in a Danish context, and how to make a change for those starting DIYAPS.

During our research, we found the different guidelines (see section 1.3.1) interesting, as these are the only ways to build DIYAPS for a smartphone. Through the webnographic research it seemed that newcomers had trouble finding information in the different guidelines, and not understanding the process due to the language barrier or technical issues. Therefore, we chose to dive further into this through a think aloud interview.

Through a think aloud session with a person with T1D who was not familiar with DIYAPS, we gathered information from a first-hand experience with the online guidelines. Despite people with diabetes interacting with their diabetes technologies, DIYAPS requires a deeper understanding of the technologies. The individual's lifeworld will affect how they perceive the beginning of the first phase of DIYAPS. As she was an iPhone user, she was led to the LoopDocs website. While doing the think aloud test we prepared different prompts for her to complete, to get a sense of the website from her perspective. After the think aloud test we talked to her about the guide, where it became apparent that it was not a simple and easy task for her to navigate on the website.

"Very confusing. [...] I don't think the headlines create the overview I need. I think you need a lot of background knowledge to be able to navigate around. [...] There's no doubt in my mind that it's unfortunate because it's in English. It's not my strongest area."

(Aimee - Appendix C)

Aimee pointed out that the website was confusing and that the headlines did not help her get an overview when looking for something specific. At the same time, she also pointed out that there was a language barrier for her because English is not her strongest skill. This also aligned with our empirical data from the bachelor's project and the literature from the scoping review. Additionally, she also mentions that she would seek knowledge elsewhere to find information: *"I would definitely try to seek help elsewhere. I would probably be more prone to look for a YouTube video, for example."* (Aimee - Appendix C). Here she mentions video as a way for her to learn about the DIYAPS process. However, something Aimee also mentioned in the conversation was *"the need for background knowledge to be able to navigate around"* (Aimee - Appendix C). For us this was interesting due to the webnographic research on the Facebook group 'Looped - Denmark' and the identification of trouble when starting. Some of the posts were regarding the building process or finding the right components, which is also mentioned in section 1.5. Shortly after, while talking about 'background knowledge' Aimee mentioned:

"I feel like you must have a lot of background knowledge on this before you can navigate this website. I think that could definitely be a big advantage. Something that catches you a bit more before you step into the guide."

(Aimee - Appendix C)

She mentioned that she would like something to help her gain more knowledge before visiting the website. This was also something that caught our attention and led us to create a questionnaire for the Facebook community 'Looped - Denmark'. Since Aimee was not a DIY-looper herself, we wanted to investigate if people in the DIYAPS community had the same thoughts. As mentioned in section 2.7, the questionnaire was developed with three different branches to adapt questions to different phases of doing DIYAPS (seen in figure 2.1). As we shared it with the DIYAPS community on Facebook, it was important for us to make a questionnaire that different members could resonate with to keep up their interest when answering. At the same time, we were also aware that the Facebook group 'Looped - Denmark' was not as active as other groups compared with the number of members. This was taken into account and we therefore focused on the questionnaire as a way of gaining more insight, since we were still curious and wanted to explore the field even further. Through the questionnaire, we received nine answers from people in different phases of their DIYAPS journey. Out of the nine answers, seven were DIY-looping for themselves or their child, whereas the last two did not DIY-loop but were interested in starting. The results from the questionnaire can be seen in Appendix B. The overall consensus on starting DIYAPS was to achieve better blood regulation, as well as receive and control diabetes-related information directly on their phone. One of the participants further elaborated on this:

"I felt that there had to be a way to get the different assistive devices to connect with each other. I didn't want to wait for various companies to get their devices approved and then be 'lucky' to be granted exactly the one system that might come on the market. Furthermore, I wanted more control than the existing systems offered."

(Questionnaire Participant - Appendix B)

In this comment, it is expressed that the person did not want to wait for an approved system, and at the same time wanted to be more in control of their treatment. This is also aligned with the findings in the scoping review, where multiple articles argue that DIYAPS promotes self-management. Therefore, it can be interpreted that the customizability of DIYAPS is important to those who are using DIYAPS. At the same time, it can be questioned if DIYAPS is a more adjustable and applicable solution for PWT1D compared to the existing AID-systems. However, this will be further discussed in chapter 4.

Regarding competencies, four out of nine felt that their technical competencies were challenged during the starting process. Here it was elaborated that the Facebook group 'Looped - Denmark' was a help to complete the building process. The persons who were not DIY-looping answered that it was mainly

because they did not have the time to get acquainted with the process. Additionally, one answered that they found the guidelines too complicated and challenging to start the DIY-process, which was also Aimee's experience when she did the think aloud test. Similarly, in the questionnaire, there was a comment about the guideline being confusing: *"... But the guide is really confusing. I think a step-by-step system would help."* (Questionnaire Participant - Appendix B) This aligned with Aimee's perception of the guide as being confusing, but here the person is also suggesting a step-by-step system, which the person would find helpful. At the time, this was not something that caught our interest. However, after going back to the data it became aligned with new findings, which will be further elaborated in the upcoming sections.

Through the questionnaire, it was shown that some had difficulties navigating the guidelines, whereas others were comfortable with the open-source information. Here it can be highlighted that people in the questionnaire who perceived themselves with high technical expertise, were also those who did not have any issues or challenges when navigating, building, or setting up the system. Similarly, those who perceived themselves with low technical expertise were those who found it difficult to start the process and navigate around all the different information. At the end of the questionnaire, we had different proposals for initiatives to support people, prior to starting their DIY-journey, since we had previously observed that this was the moment when most sought out help. Interestingly, most answers were placed on the two suggestions regarding 'physical meeting with one or several persons to build DIYAPS together'.

This was a perspective, that we found intriguing. However, we assessed that we did not have time to research this area, because of the lack of interaction from users online. We included it as an option in the questionnaire, due to the social aspects that are interwoven in DIYAPS, since there is an existing community online. It is important to mention that we acknowledge the participants' answers and needs and that human interaction can not be replaced with technology. If we were to exclude human interaction as a possible initiative to follow, the next most answered suggestion was a video. This was also interesting for us since there are videos available for the building and setup process when DIY-looping. Moreover, it was something that was mentioned by Aimee in the think aloud interview, which made us aware of some people needing a visualization of how to get started to understand the guidelines even better. As this was a popular answer, we kept this in mind further on in the research process. Other suggestions that were also chosen were a 'digital handbook' and a 'tool to get you started'.

Following the iterative process of UCD, gathering data from the users was a part of our strategy which can be seen above. This process can be categorized as the stage called 'research' ([Interaction Design Foundation 2024](#)). Here we are collecting relevant data through the DIY-community, to be involved in our thesis. In addition, the principles of action research can also be identified through this process of involving the community. Due to our digital approach within action research, the questionnaire can be seen as a way to create collaboration between participants and researchers and thereby include the

participants in the research process. Therefore, the digital suggestions above were aspects we chose to continue working with.

3.3.2 Insights on the Starting Process of DIYAPS

We were aware that we wished to contact and talk with people who had gone through the process recently, and therefore had asked for people to reply to a post on the Facebook group if they wished to participate in an interview. Through this, we gained contact to Mary. She started building and using the Loop-app for iPhone, for her son in September 2023. She explained that they chose DIYAPS because the available insulin pumps without a tube did not have the ability to loop. She went through the process by herself, and described her experience as *"a bit uncomfortable and you feel very alone with it..."* and *"there isn't so much help to find any places. There are these Facebook groups but when you're sitting with it, it is a bit tough."* (Mary - Appendix D).

Several of the included persons in this project brought attention to the need for technical competencies, in line with the section about technical competencies in the scoping review in section 1.6. Mary mentioned that she did not believe anyone could sit down and just do it, she highlighted the need for some language and computer skills *"If you have the English and know it and have some computer skills, then I think it works."* (Mary - Appendix D). This was also evident from the questionnaire, where it was featured that something in Danish to prepare for starting was necessary. While talking with Mary, we were also interested in finding out what questions she had prior to and while building the DIYAPS. We wished to create an understanding of her lifeworld, and how technology is a part of that. The reason for this was to understand what direction we should be moving regarding the DIY-readiness tool. When asked about what could have helped her, she said that *"The settings are so individual, so it's difficult to create a tool that advises on this."* (Mary - Appendix D). However, something that could be useful prior to starting DIYAPS she mentioned *"...sort of an overview"* (Mary - Appendix D). This would become interesting for us later on because it gave us an indication of what type of solution we could design. Additionally, she mentioned:

"Well, it took some time before I could figure out if I could use Dash [Insulin Pump] without a Rileylink [Radiolink]. So maybe if you can spell it out. If you have this, this, and this, then you should do this. I definitely think that would be helpful for some."

(Mary - Appendix D)

In the set-up of the guidelines one must for example find the pages detailing all of the insulin pumps and CGMs you can use. According to the participants, this is not instinctual, which design should be according to (Norman 2008). We had previously discussed whether developing a completely new guideline or something similar would be the way this project would develop. However, none of our data pointed towards this being necessary. Additionally, through messages with Charlie, it was clear that those helping others on the Facebook group 'Looped - Denmark' wished to lead people in the right direction with the guidelines. This is also evident in the literature (see section 1.6.3), where they use

the term of peer-mentoring to describe how they guide people through the process. Those seeking help are encouraged to post online, where experts or other users then are available to help them. The use of the Facebook group for help is also prevalent in the data, which would be disadvantageous if we were to divert attention from the available guidelines.

Simultaneously, the guidelines are well-represented in several places, which we did not wish to divert attention away from. We are aware that the current guidelines are complex however, they are made out to be instinctual since it is possible to follow them chronologically. Although it could be discussed if this is the reality, since we have observed and talked to several who did not have that experience. Additionally, the community surrounding the guidelines as mentioned in the literature compiled in section 1.6.3, highlights that our approach should not be something new, but instead an addition to what is available. This is also evident in Mary making it a point to say that although she frustratingly built the DIYAPS without much help, she still appreciated the Facebook groups since she used them for help with the app. Being a part of a community relates to how PWT1D experience and perceive DIYAPS. These influences are then interwoven with and shape their lifeworld.

Since we follow the principles of action research and UCD, we went back to the data we had collected, where the previously highlighted quote, as well as the previously mentioned wishes from Aimee and comments in the questionnaire, became the starting point for our further development. From here, we go from the research phase of UCD into the requirements phase, because we have identified several problems that need solving ([Interaction Design Foundation 2024](#)). The data presented above provided us with the argument to develop something that could be useful prior to building DIYAPS, especially because we acknowledge that everything after the apps are downloaded, is subjective. Therefore, we aim to develop a DIYAPS-readiness tool that is relevant within the lifeworld that is present in the DIY-community.

3.4 Design and Development of the DIYAPS-readiness Tool

Inspired by the results of our research thus far, we started discussing what would be beneficial for those who wish to start a DIYAPS, but are experiencing the challenges explained in the previous section. Thus, through the observed problems from our data collection, we researched how this can be solved as well as how it can be developed.

3.4.1 Visualizing the Identified Steps to Begin DIYAPS

When looking into what struggles people had prior to starting it was the perceived lack of technical competencies, as seen in the scoping review (see section 1.6.2), and not knowing where to start. As mentioned in section 1.5, components is a topic questioned often in 'Looped - Denmark', which is also in line with Mary's statement about not knowing if a radioLink was necessary. Therefore, by changing the narrative from guiding them by saying what they need, we aim to guide them with the information they have already possessed. We decided to start designing a way of gaining this knowledge, to then provide them with an answer to how they could proceed. To break down the process and visualize the different steps, we created a flowchart, which can be seen in Appendix E. Here one could go through the steps of finding the information by following the line, and by the end depending on what lines were followed a result would be given on what is possible to do. This was the second iteration of a separate flowchart. The flowchart was inspired by was one we had created, to map the complexities of the necessary components prior to starting the DIYAPS process, which can be seen in Appendix F. In this flowchart, we color-coded the different combinations as well as the different insulin pumps and glucose sensors for each system. This made it easier for us to work further when creating the second iteration of the flowchart.

The second iteration of the flowchart was inspired by Aimee's question of where to begin when she entered the guidelines. Additionally, the questionnaire data showed that having a one-pager in Danish to help with gaining an insight on what to acquire and do prior to reading the guidelines would be beneficial. Therefore, we would argue that the results of the DIYAPS-readiness tool could be the one-pager in Danish. The results will be further elaborated in section 3.4.2.

The beginning of the flowchart asks what type of phone one has, this is inspired by the two different guidelines, LoopDocs and AAPS. This then opens up to the question of which insulin pump the user has. There are 17 possible choices because that is the amount of possible insulin pumps to DIY-loop with however, not all are compatible with both types of phone. The argument for providing all possible DIY-options in both branches of the flowchart is because we wanted to let the users know that it is possible to DIY-loop with their insulin pump if they decide to make changes. It is not necessarily easy for them to change insulin pumps, but it may be acceptable for them to change phones or the other way around. One of the choices is a 'none of the above' option. After choosing an option from the insulin pump row, the next question is what type of glucose monitor is in use. Here there are 10 options, with the same argument as the aforementioned and also with a 'none of the above' option. Depending on what answers they have given they are led to different results. Because there are several ways of building DIYAPS for an iPhone, there is a question regarding which computer system one uses. The development of the flowchart can be identified as the beginning of the design phase of the UCD process. In this phase, we compiled the empirical data from the participants through the think aloud session, questionnaire, interview, and webnography. The process of this was to solve the problems that had been identified through statements and observations through a solution ([Interaction Design Foundation 2024](#)).

While developing this flowchart the amount of options and the need for something that directs the person instead of looking for answers became clear. However, while assessing the flowchart we also understood that this could become overwhelming to follow because of the amount of branches, as well as the excluding elements. Were the flowchart to be shown to participants, following the lines may seem too complex. As mentioned in the previous chapter, [Norman \(2008\)](#) aims towards a non-complex design where tasks should not require too much training. With the flowchart as the underlying structure, we decided to develop a DIYAPS-readiness tool, which will be elaborated in the upcoming section [3.4.2](#).

We chose Microsoft Forms as the platform due to the ability to branch answers, as well as it being available to use for free. By using Microsoft Forms we could create branches, which means that each choice the user makes leads to a specific result. The goal with this was to make the design more instinctual, because it then became something to answer without much forethought, thus following the aforementioned goal with UCD. We argue, that it is important to explain the development of the results that users will receive. These are designed by following the concept of self-efficacy, and based on the statements from our participants, which will be elaborated in the next section.

3.4.2 How the DIYAPS-readiness Tool Can Support Self-Efficacy

We aim to design and develop a DIYAPS-readiness tool for active co-participants to promote their self-efficacy and to support their empowerment to become more empowered and self-managed. The layout of the tool and the results that people receive when using the tool are based on the data we have collected throughout this process. Therefore, the tool is shaped to guide the person through a set of questions that are relevant to the starting process of DIYAPS. Additionally, the tool asks the same questions that are present in the flowchart described earlier, and the same options are available. However, the branches are hidden within the settings of the tool.

Firstly, the person is met by the question of which phone they have. The reason for this question is to separate between what is possible for them to use and DIY-loop with. The choice of this is based on the differences between what you can DIY-loop with based on the guidelines, it therefore became a convenient way of separating them through the branches. Once they have chosen a phone, the next question is revealed: "What type of insulin pump do you have?" This question is chosen due to the aforementioned differences, as well as the webnographic data that showed the theme of what components to use and Mary's statement of not being able to figure out whether she needed a radiolink for the insulin pump her son has. The insulin pump questions have four to five branches because it is relevant to know whether it is necessary for them to have a radiolink and whether the chosen insulin pump is compatible to use with the chosen phone. Then the next question is revealed to them: "What glucose monitor do you have?" The reasoning for that question is related to the same as the above-mentioned. Based on what phone has been chosen the questionnaire either ends there with a result provided, or if they have an iPhone a third question is revealed to ask what type of computer they use. As men-

tioned in section 1.3.1, there are two different ways of building for iPhone. Once they have answered this question they will then receive a result depending on the aforementioned. We aim to develop the result as a one-pager in Danish, which was requested in the data.

There have been developed 26 different results overall for iPhone and Android answers, where 15 of them will result in a 'possible to DIY' outcome. The wording of the results are all aimed at being positive and encouraging the person to continue working towards DIYAPS, even though they receive one of the 11 drafts that state that they cannot DIY-loop with the answers they have provided. Due to the element of discouragement and weariness mentioned in the literature and our data, we found that understanding how self-efficacy is affected and controls the way people start a task would be interesting for the development of this tool. Therefore, the wording of the results is inspired by how self-efficacy is built in persons (Bandura 2014). Our choice of self-efficacy stems from wanting to encourage people, by changing the way they can start DIYAPS. Therefore, the goal is to design this DIYAPS-readiness tool with a motivational aspect to encourage higher self-efficacy. The tool is not meant to assess their current self-efficacy, because there is not a one-size fits all for measuring self-efficacy (Bandura 2014). Simultaneously, it is not something we argue should be done without providing well-argued answers as well as personalized feedback. Consequently, we wish to create a sense of encouragement through the results that are given to the person completing the tool. The upcoming sections will describe the first iteration of the results provided after a person has answered the questions in the tool. An example of four different results can be found in Appendix G.

3.4.3 Result Type: Possible to DIY-loop

Based on the participants mentioning the need for a clear approach and a step-by-step guide, the structure of the result is to open up with whether the person is able to DIY-loop with the answers you have given. This section will focus on how the 'possible to DIY-loop' results are structured. The person is firstly met with *You have a compatible insulin pump and glucose sensor to DIY-loop with [system for the chosen phone]*. The goal throughout the results is to have a positive tone, which follows the influence of social persuasion on self-efficacy as described by Bandura (1995). Additionally, through the results, we aim to empower the receiver to achieve higher self-management.

Components

The next part of the results highlights whether it is necessary for them to acquire extra devices for their systems before building the DIYAPS-app. Based on what they have chosen, they will be provided with links that provide further details on what is necessary for them. The reason for providing these links is based on Aimee and other participants' comments regarding trouble with navigating information on the open-source guidelines. Our aim is that they can access the necessary guidelines directly through the results, without experiencing the letdown that Aimee had when trying to find relevant information. Since we are aware that lack of success with a task can result in lower self-efficacy, we seek to avoid such an experience through the results (Bandura 2014). This is the continuous argument for providing

links in the results. Therefore, each time new information is provided the link to more information is also provided.

How to Build DIYAPS

The next information provided is to be aware of what version of phone and computer system one has, since there are some caveats (see sections 1.3.1 and 1.3.1). For the phones, there are links to the lists provided on the guideline websites.

If the person has chosen iPhone they will be presented with the description of what it means to build on the chosen computer system. Those who have chosen Mac will also be provided with a text stating that: *If you have an older Mac or do not wish to build on the Mac you can build on a browser.* This is because there are some requirements for the Mac a person has (see section 1.3.1). In addition, there is also a description of what the differences are, and what it means to use the two different methods for building. If the person has chosen the Windows computer option, they only receive information about what it means to build with a browser. For Android, there is not any similar information to provide, besides the previously mentioned points of attention regarding the version of ones systems.

Essential Information Before DIY-looping

The next section describes different elements such as what to be aware of when choosing to DIY-loop, referrals to a Danish safety guide and available Facebook groups in case they wish to seek help. The chosen awareness points are based on the participants' statements, the literature, as well as different encouragements to read the guidelines thoroughly. It is a section where it states the following:

Building this app can be time-consuming, which you should be aware of. It is recommended to go through the guide and the links included here thoroughly. The app requires attention, as does type 1 diabetes in general. It is your own responsibility when you choose to build the app. It is also possible to read the loop safety guide here: [link to type1.dk who has made a safety guide to DIY]. Help is available on Facebook in the group Looped - Denmark, and there is also a Facebook group 'Looped' where users post in English. [Additionally In Android version: For AndroidAPS there is also a Facebook group "AAPS users".]

A section of text from a result in the tool.

Translated from Danish to English

This section was written due to the data from participants showing that it can take time to build the systems, as well as the literature regarding how a person takes responsibility for themselves when building DIYAPS (see section 1.6.1). We aimed to provide them with an understanding of what is required to build a DIYAPS, while also giving them options to seek help. Within the influence of social persuasion in self-efficacy it is important to meet the person with realistic expectations. For a person's self-efficacy if they already have low expectations of themselves, these awareness points could result in wanting to halt the process. However, we hope that the mention of the Danish safety

guidelines and different Facebook groups will motivate them to continue reading. Especially because the following section is a link to a video on other people building the systems. This, as well as the link to Facebook, relates to the influence of vicarious experience to affect self-efficacy described by Bandura (1995). Because they can watch someone else build the system, or see the success experiences of others in the group this should lead to them having a perception of their own capability. Our data also shows that several of the participants wish to use videos to help them with the process. Mary also mentioned during the interview: *"...I saw a video on youtube before I started. That was while I was also reading the documents."* (Mary - Appendix D). This, in turn, can also be characterized under the influence of vicarious experience, due to the process of watching others build the systems (Bandura 1995).

If the person has chosen Android, there is a section regarding the objectives (see section 1.3.1), which highlights that these are completed while using the app and is there as a help for the person to learn the functions of the app.

Finishing Section

The final section can be categorized as a well-wishing section and is inspired by social persuasion and physiological and emotional state from self-efficacy described by Bandura (1995). The section states: *"You're ready to start building once you have read the above and purchased the necessary equipment. Remember that it's okay if you need breaks. Follow the guide here: [link to guideline]"*.

In regards to social persuasion, it is in relation to the encouragement from others, where we attempt to convey positivity by writing that they are ready to continue further by reading the guidelines and building the DIYAPS. In addition, the reminder to take breaks relates to physiological and emotional state (Bandura 1995). We argue, that this is to prevent the person from letting their stress or frustration overrule their capability. Finally, the way the results are built in this step-by-step system should reduce the stress of not being able to find information in the guidelines, as the data showed most found this part difficult.

3.4.4 Result Type: Not Oossible to DIY-loop

This section will describe how the 11 not possible to DIY-loop results are structured, they have between five to seven sections based on the person's answer. The person is met with a sentence that states what compatible or incompatible diabetes technology they have, which leads them to not be able to DIY-loop. An example of this is *"You have an insulin pump for [guideline for chosen phone system], but unfortunately, your glucose sensor is not compatible with [guideline for chosen phone system]"*. In some results, if someone with an iPhone has answered only Android compatible devices, they will receive a notice that their system is compatible with Android. Through this, it is possible for them to figure out if they wish to change their phone to have DIYAPS.

Components

After this, they are met by a link to the compatible pieces of technology based on their phone choice. The argument for this is to provide them with details on what choices they have if they wish to continue researching DIYAPS. If their insulin pump or sensor is compatible, but needs additional artifacts like a transmitter or a radiolink this is also stated. Are they then to change one or the pieces, then they know that they would need extra artifacts to DIY-loop.

The aforementioned awareness elements and building videos in section 3.4.3 are in these results as well. Because of the same argument it is necessary for them to be aware of what expectations there are if they choose to DIYAPS with new components. Mary mentioned in her interview that she would have been interested in using a tool that would give her an idea if it was the right fit for them: *"I had used it to see if it was something that was compatible with me and our skills and capabilities."* (Mary - Appendix D) We wish to keep them encouraged in exploring DIYAPS, and not have a sense of letdown that they are not capable of DIYAPS because of this set-back. Simultaneously, the result provides them with a clear overview of what possible steps they can take.

How to Build DIYAPS

The second to last line is a link to the building process of the system they have chosen. Once again, we aim to provide this to give them an idea of what they would need as well as setting expectations. It could be argued that this would possibly affect their self-efficacy because we are aware that the guidelines can be confusing for people. However, we argue that by reading these results they still have a sense of positivity when reading and clicking the links. They are not obligated to follow any of the links, but for those who may be curious we wish to provide them with the choice. By providing the receiver with the choice, we meet different levels of empowerment and give the opportunity to self-assess their capabilities. Those who are more empowered can then explore further through the provided links.

Finishing Section

Finally, we conclude by stating: *"You are welcome to use the DIYAPS-readiness tool again if you change your diabetes equipment. Have a great day."*. Once again, this is inspired by the positivity that is necessary in the influence of social persuasion on self-efficacy by Bandura (1995), because they are invited to continue their search and thus maintain a sense of positivity and motivation.

The first iteration of the DIYAPS-readiness tool will be shown to and tested by a participant from the 'Looped - Denmark' Facebook group, as well as our peers since we also wanted to gain insight from those who are not familiar with DIYAPS. The choice of our peers was because of the lack of access to users who were contemplating DIYAPS, despite our attempt at finding them through posts on the Facebook group. Additionally, we were limited by time constraints during our thesis. The evaluation and test of the DIYAPS-readiness tool will be described in the upcoming section.

3.5 Evaluation and Test of DIYAPS-readiness Tool

To follow the UCD process we conducted evaluations with a DIYAPS-user and four peers. During evaluations, we hope to identify issues or lack of usability within the tool. We aim to provide a tool that people can resonate with, as well as utilize.

While testing our DIYAPS-readiness tool the theme of simplicity became apparent. First, the participants agreed that the questions were easy to go through. In addition, they mentioned in some capacity that the results gave them a good overview of what to do prior to starting: *"It gives a quick overview over what I have to do with this in regards to the technology I have"* (Mary - Appendix H). This was also mentioned by one of our peers: *"You can use this information at the end to get an overview. There are many different links that refer to different places. It provides a kind of overview, step-by-step. It makes it more manageable."* (Peer - Appendix H). One peer had a result of not being able to DIY-loop, where they said they appreciated the information given to them: *"Even though it does not work for me, there is still something else that works. I can find a way to make it work."* (Peer - Appendix H). They had a sense that it was manageable. However, the participants mentioned the need for a type of categorization or headlines: *"This invites me to read everything through. If you made some categories, it could invite me to just read just the part that is necessary for me"* (Peer - Appendix H). Another peer mentioned: *"Perhaps you can give the different steps a headline to create a better overview"* (Peer - Appendix H). Because some of the results were more text-heavy than others, some participants perceived their results as less simple than those participants who had shorter answers. This gave incentive for us to rethink the structure of how the result was built, especially due to the comment from one participant who said: *"I would need the categorization no matter what, so like this is step one, step two or a type of headlines"* (Peer - Appendix H). We acknowledged this because it was mentioned by the majority of the participants, so although they gained an overview they recognized the need for structure. Furthermore, one person mentioned that they *"need an experience that I am taken care of, and led through this"* (Peer - Appendix H). Additionally, there was also mentioned a need for an introduction to the test, which stated what the purpose of the DIYAPS-readiness tool is and how the information could be used. This was in our mind however, it was not developed yet due to time constraints. Nonetheless, their comments benefit our further process: *"Will I be introduced to what the test is used for? Like an invitation: This is a free tool, there are no data being tracked. So how will I be guided so it seems more trustworthy?"* (Peer - Appendix H) and *"Could you have a why is this information important, to say this is to prepare you to Loop with LoopDocs"* (Peer - Appendix H).

This became an inspiration to how we could introduce the DIYAPS-readiness tool to a person choosing to use the tool. The feedback received on the overall look of the tool has been taken into account, to follow the UCD process of the evaluation stage, where one is supposed to identify any improvements or issues ([Interaction Design Foundation 2024](#)). Therefore, we chose to take the feedback into account and add three titles in the results to separate the sections based on the type of information, as well as add an introduction to the DIYAPS-readiness tool. The titles became; 'relevant to know about

your components', 'what you need prior to starting', and 'important information before you begin'. These changes were made because we recognized what the participants were saying since some of the longer results were overwhelming to look at. There was some feedback we could not fulfill. One participant mentioned that the links in the results were disturbing while reading. However, because they are necessary for the results we assessed that they should not be removed. Most of those testing the DIYAPS-readiness tool instinctively clicked on the links to begin with. This indicates to us that the introduction of the results should state that it is not necessary to do this on the first read-through of one's results.

3.5.1 Feedback: What You Need Prior to Starting

The participants also gave specific feedback to the first sections of the results containing information on what one needs. Because the participants received different results, they gave feedback on the result they received. Two of the participants received 'possible to DIY-loop' results. Mary, who uses DIYAPS, received the result of no necessary equipment due to her son's equipment. She appreciated the result they received and after reading through her result she said that *"you are more convinced that you have the right things and that you can actually start"* (Mary - Appendix H). However, our peer received a longer result where they needed extra pieces of technology for their pump. They commented *"what does transmitter mean? I like that you have links to everything."* (Peer - Appendix H). Here we became aware that you have to know the vocabulary when reading these documents even though you are a person with T1D. Because the receivers are people who are new to this phenomenon, we need to think of how we mention elements that are new to them. Therefore, transmitter (see section 1.3) could be the wrong word to use, and perhaps a word like 'sender' would be more beneficial wording. Especially because *what you need* is a question that we know is prevalent from people entering the community, as can be seen in our data from webnography and Mary's interview. Therefore, we added an explanation of the use of the transmitter, as well as a to the radioLink.

The two participants who received a 'not possible to DIY-loop' result were positive about the subjects mentioned in their results. They were both left with a feeling of having options on what to do and where to continue. Although their answers meant that they could not use DIYAPS. This indicated to us that the structure of the results did not affect their self-efficacy, since they did not feel discouraged. We aimed at providing information that would lead to this. However, because they both own an iPhone, their results gave them the option to research other insulin pumps for LoopDocs. In addition to this, there are links to research Android in the results. The reason for having this was due to some of the results being compatible only with Android and we wished to highlight this. In regards to this, one peer mentioned:

"There are a bunch of things to research and since I also have this with Android, it looks like there are even more links I should investigate. So it becomes more confusing. I think that would cut down the information. [...] Maybe you can move the android part to the bottom, not necessarily the whole text..."

The other peer with this type of result also mentioned the same problem, due to the overload of information: *"Can you move that about Android down to the bottom, because I don't have an Android..."* (Peer - Appendix H). This feedback was valuable while also assessing the structure of the results and text volume as mentioned earlier. To reduce the sense of the volume of text we choose to follow this feedback and push this information to the bottom, where we invite them to take the test again. We argue that it is necessary to have the information available because we want to let them know that it is an option.

3.5.2 Feedback: Important Information Before You Begin

For the last part of the results, there were different comments and feedback as to what could be changed to adjust it with usability in mind.

Concerning the wording used in the results on of our peers mentioned: *"I think it's quite considerate written. you've written you have to take breaks, and that's time-consuming. We invite you to sit down and take an active part in this whole process. You invite interaction between the user and the system".* (Peer - Appendix H). They expressed how and why they think our wording is considerate and thoughtful. They paid attention to the way we had prioritized to draw awareness to the process, and that breaks may be beneficial to keep people motivated. Additionally, one of the other peers mentioned that they liked the part about responsibilities when DIY-looping: *"I love the part about 'the app requires attention in the same way that type 1 diabetes generally does". I think that's nice'"* (Peer - Appendix H). In another evaluation with a peer, it is mentioned to include more information about the process, when expressing responsibilities when DIY-looping.

"As for responsibility, I would add "In addition, one must assume to take on more responsibility regarding the healthcare providers". Then emphasize more what it means in terms of how the collaboration works with healthcare providers. [...] I think I need to know what this means for my treatment. Because I assume I'm taking control of some treatment to a certain extent."

(Peer - Appendix H)

With this in mind, we acknowledge the need for more information regarding what type of responsibility this leads to. Despite that, we did not want to overload the receiver with too much information and we therefore, had to assess what information we categorized as "need to know" and "nice to know". However, we added a sentence to the section about how DIYAPS can change the cooperation with the HCP, to keep the receiver aware of this. This is also in alignment with the findings in the scoping review in section 1.6.1.

In other evaluations, something that especially caught our interest was the need to save the results in the end. During two different evaluations, this was mentioned: *"Maybe also the option to save the summary. So you have the links saved. They probably disappear as soon as you hit 'submit'"*. (Mary - Appendix H). *"Otherwise, I would take a screenshot or put it in my notes. I think it would be good to be aware that you can save it. Down here where you write, "You are welcome to take the test again", you could add a comment that if*

you want to save this information for another time, you can press save..." (Peer - Appendix H). It is expressed that due to all the information delivered in the end, there is a need to save the information, so it is possible for them to revisit the information without completing the DIYAPS-readiness tool again. Here they both mentioned a feature to save the result in the end. The peer person adds that it would be helpful to guide the receiver through the text in the end, so that they are aware that the result can be saved or downloaded if necessary. At the same time, Mary also mentioned the different links to click on, which she found helpful to seek further information: *"I don't know if you want to go directly into them when you do this test, because then you are in the process of answering the tool. But these are some good links to have collected in one place. So the option to save it could be very good. Or possibly to have it sent by email"*. (Mary - Appendix H). However, she was in doubt if she would use the links right away, which led to the importance of having the results saved. Here she suggested that it could be done through mail. So instead of downloading the document, the document could be sent through email to access the information when needed. These comments regarding the opportunity to save the information were something we had in mind while redesigning our DIYAPS-readiness tool, as it was something we assessed to be necessary for the final iteration. Therefore, we added a sentence regarding options to save the result afterwards. This was the only option available with the chosen platform. In addition, one person in our peer expressed confusion about the 'submit/send' button as the last thing to see after reading the result. *"Why does it say "send", can it be changed? I think maybe you should explain what send means, I think a lot about whether the answer is saved for some statistics"*. (Peer - Appendix H). They suggested changing or removing the button if it was possible. They got more confused about the button, and if it had any significance when completing the tool. However, due to the chosen platform, the bottom could not be removed and will be further discussed in chapter 4.

3.6 Creating a Change in the Danish DIYAPS Community

To follow the principles of action research we aim to make a change within the DIYAPS field and for this community. For this reason, we have included reflections and thoughts from all participants and peers to assess if our DIYAPS-readiness tool would make a change for people in this community in near future. Due to our timeline with our thesis, we did not have the time to redesign our tool, beyond the feedback mentioned above. Our goal was to publish the tool within the Facebook group 'Looped - Denmark'. However, due to our time frame, we did not have the time to do this, prior to this thesis' completion. Following the iterative design process according to UCD, it would be relevant to assess and evaluate the DIYAPS-readiness tool again once it has been published to investigate if the tool has been helpful in the DIYAPS community.

Participants and peers had different comments envisioning the DIYAPS-readiness tool as a helpful initiative within the DIYAPS community however, all comments were positive and optimistic. They indicated that they would be encouraged to start DIYAPS, which can be interpreted that their self-efficacy is positively affected by reading their results:

"Sometimes if you need to install something, and you haven't had the process explained to you, you can be confused throughout the whole process. But then you have removed some of the confusion from the start (through the tool). I 100% think that would make me feel more prepared to get started".

(Peer - Appendix H)

"I think it was a great help to get some basic information, but I would have liked to have that knowledge before I started. So you know what you need. It's all about guidance, so I get the feeling that I'm being taken care of".

(Peer - Appendix H)

"I still feel there are different things I can do to learn more about it and get closer to being able to use it. But of course, it takes some time, and there's a lot to familiarize yourself with, also to set aside time to read up on the links".

(Peer - Appendix H)

The comments from our peers indicate an interest and a sense that it would help them if they were in a situation where they wanted to start DIYAPS. However, they all agreed that our DIYAPS-readiness tool could support with basic information and help to be more prepared for the building and set-up process. In the last quotation, it is also mentioned that our tool initiates learning more about the phenomenon of DIYAPS and creates an understanding, that it takes time to read up on the different links to be prepared for the starting and building process of DIYAPS. Here we also found it relevant to ask Mary, who reviewed and tested our tool, as a person who started DIYAPS not long ago. She also had a positive experience with the DIYAPS-readiness tool and expressed: *"I think it's definitely something that you can use when you want to start. At least those were some of the questions I had that are answered".* (Mary - Appendix H). She also stated, as the peers did, that the DIYAPS-readiness tool would be a good starting point, and could help the receiver with the decision to start or not to by completing the test and get oriented in the result: *"...but I think if you take this as the very first step before you're further into the decision-making process, then it's as I believe something where you can at least be convinced that it's something you can get started with. I think it works well".* (Mary - Appendix H).

Based on these comments, we assess that the developed DIYAPS-readiness tool could create a change in the DIYAPS community. Through the inclusion of members from the community, we have created a tool that can be relevant to use for those interested prior to starting DIYAPS.

3.7 Summarization of the Analysis

Through our findings, we have identified challenges within the starting process of DIYAPS. In our webnographic research presented in section 1.5, the topic of components and what systems could be used for starting DIYAPS was prominent. Therefore, we chose to conduct further research to understand these issues. With a think aloud session with Aimee, we recognized how the guidelines can be overwhelming for a person researching DIYAPS for the first time.

With the involvement of the community, through a questionnaire and interviews, we researched the challenges further to achieve a better understanding of their lifeworld. In addition, the research gave indications of possible solutions to benefit their process. As a result, we were inspired to design a DIYAPS-readiness tool to prepare and help those who are interested in starting DIYAPS, with the focus of providing an overview of the components based on the available systems as mentioned earlier. Inspired by Norman (2008) we followed the principles of UCD when designing and developing the tool with the iterative design process in mind. A flowchart was developed where the complexity of the choices were discovered. Based on this, we transferred the structure of this flowchart to a digital tool. This tool took the branches of the flowchart and provided a result based on a person's answers to each branch. Through the theoretical concept of self-efficacy, we developed the DIYAPS-readiness tool with an element of encouragement, which could in turn affect their self-efficacy towards a sense of self-motivation. We identified this by testing and evaluating the tool as well as different results with participants and people from our network. From the evaluation and testing, we determined that this tool could create a change for newcomers to DIYAPS.

However, with the involvement of our peers, it could be questioned if the DIYAPS-readiness tool we have developed will be applicable to the DIYAPS community.

Chapter 4

Discussion

Through our analysis, we have emphasized the development of a DIYAPS-readiness tool based on insights from the participants. In this chapter, we wish to discuss the last iteration of our tool as well as the relevance of the outcome. Additionally, we will discuss if Do-It-Yourself-Artificial-Pancreas-System (DIYAPS) could become a stable part of the Danish healthcare system due to the benefits that are perceived surrounding DIYAPS.

4.1 Discussion of Our DIYAPS-readiness Tool

We developed a DIYAPS-readiness tool with the focus of preparing newcomers in the DIYAPS community to start building their own system. The goal is to create better access to DIYAPS, while also helping those who may not know where to begin. Therefore, we aim to help them prepare for starting the building process. It could be questioned, if we make it more available, which could lead to liability issues as mentioned in the literature in section 1.6.2. However, we argue that our tool aids them prior to starting and it is therefore still their own responsibility to build and maintain the application and follow up with their healthcare team. Additionally, our goal is to have the DIYAPS-readiness tool available in the Facebook group 'Looped - Denmark', which means they must be a part of this group also. Because of this, it could be argued that they have some prior knowledge of DIYAPS or have done some type of research before using our tool. We aim to engage them in the DIYAPS-readiness tool as soon as they enter the Facebook group, which our data shows that this is the first step to learning about DIYAPS. We recognize that DIYAPS is a system that could result in a lack of help from Health Care Professionals (HCPs) which is also the reason for editing our tool to make the users aware that they must discuss any changes with their healthcare team. The addition of this line should create more transparency, while also providing them with the understanding that it is possible to start DIYAPS if one is up for the task. However, we argue that this must be tested in further iteration, following the principles of User-Centered Design (UCD). Our results showed that most who started DIYAPS did this without help from their HCPs both in the literature and in the interviews *"When it isn't approved they don't wish to be involved, but they can see that it works when we sit with them"* (Mary - Appendix D). However, the HCPs recognize the results that DIYAPS provides them, whereas the literature shows that the HCPs are not necessarily interested in how the people reach good results.

There are strengths and weaknesses in the DIYAPS-readiness tool we developed however, the tool emerged from the data that we collected and therefore, represents the statements from the participants of this project. The tool could have looked differently if we had proceeded differently. However, we

wish to discuss what our choices have meant for the tool. We chose to keep the wording of the results as simple as possible, which means the results could not be too personalized. On one side, if we were to personalize the results more, we could have added more details on the role of the recipient. This could for example be their technical competencies or their confidence in themselves, which would be in line with self-efficacy. On the other side, if we did this there was a chance that we would make it seem more or less difficult than it would be for them.

Barriers With the Chosen Platform

Due to testing the DIYAPS-readiness tool with different types of participants, we received different types of feedback. We were able to accommodate most of the feedback however, some could not be realized due to the format we chose to build the tool in. The chosen platform, Microsoft Forms, had some limits that led to some elements that we could not change although it would be more convenient to those using the tool. Therefore, it could be questioned if the chosen platform would result in a less actionable tool. As mentioned in the previous chapter, those who tested the DIYAPS-readiness tool requested the ability to save their results or were in some ways confused about what to do after finishing the test. The way it is set up, they can click submit, which sends their answers to be saved to our Form. They are then met with the choice of saving the result to their own Microsoft account. We had wished to provide them with a PDF or have the result sent to their e-mail however, this is not possible. As our peer mentions, this can then become a question of reliability in terms of how we use the results of those who answer. Because we do not wish to use their specific answers, we have decided to inform them of how their data is handled. Additionally, they are told how they can save the result if they wish to do so differently than having to submit the answers. We are aware that this means we may not be able to see if the DIYAPS-readiness tool is used however, we argue that they should have the right to not send their data to us. Had we chosen a different platform, we may have had other choices like those we originally wished to explore. On one side, we wished the tool to be available after we leave the university, which is why we had to choose something free for us to use afterwards as well. Furthermore, other platforms we researched were limited to respondents or in the capability to branch answers. On the other side, the platform affects the look of the DIYAPS-readiness tool both aesthetically and in terms of the flow of the questions. This was also something pointed out by our test participants. By choosing something different, we could have explored a different way of introducing the results for example by splitting the sections up, so they received it in smaller doses, which one peer pointed out *"Do you know those pop-ups, where you can skip or push next, and then you get small bites of information. Maybe you could do something like that, but without skipping because it is important information"* (Peer - Appendix H). However, because we wished to have the results collected on one page for them to save this may not have been beneficial for this purpose.

Another thing that could have benefited from the choice of a different platform was the presentation of the links. As it is now, the links are pasted directly into the results. It is essential for the DIYAPS-readiness tool to have the links, so there is direct access to the necessary information on the correct part

of the website. Therefore, we could not remove them. As mentioned in the previous chapter, a peer suggested that we could have created a word as the link. However, because of the chosen platform to develop the tool, this was not possible. This was also an idea we had prior to the choice of Microsoft Forms but had to vacate once it became clear that it was not possible. It could be discussed if the way the links are presented, leads to a more confusing read-through of the results. There is an indication from our empirical data that this may be correct nonetheless, with this platform we are forced to keep the links there due to our prioritization of accessibility. Several peers mention that it seems as if there is more to read than there actually is with the length of the links. Moreover, there were a few whose first indication was to click on the first link they received. Therefore, we argue that the way we combat this is to indicate in the introduction that it is not necessary to click on the links while reading it the first time.

Challenges When Referring to the Guidelines

Besides the way the links are presented, there is also the question if leading the person to the guideline websites that we have observed some have problems with, complicates the usefulness of the tool. Because the DIYAPS-readiness tool is not made to replace the guidelines, we aim to deconstruct the complexity by describing what information is found on the specific link that is followed. At the same time, we still argue that building DIYAPS requires a certain level of empowerment, and thereby is not a system for all People With Type 1 Diabetes (PWT1D). Through our data, we are aware that the guidelines can be confusing the first time they are entered. In spite of that, we argue that they are the only places that are reliable for the building process, which is why we have chosen to refer to these websites. Since the participants mention the need for something to ease them into the process, we argue that our tool should provide that, due to the information given in the results and thereby navigation.

We hope that providing information on what they find on each link that this alleviates some of the confusion of going through the guidelines to find the information. Especially since this is the goal of the DIYAPS-readiness tool we developed. Alternatively, we could have developed something different, which as we have mentioned does not align with the focus of the Facebook groups and experts of DIYAPS. However, other perspectives and further research will be presented in chapter 6.

What Value has Involving Our Network Generated?

Due to time constraints, we tested the DIYAPS-readiness tool with our peers, to achieve feedback and evaluation of the tool. However, for the development of further iterations of the tool it could be relevant to test and evaluate the tool with people in the DIYAPS community to a greater extent to include the community to make the DIYAPS-readiness tool more applicable. Despite testing with our peers and other participants, we would still argue that the tool has been enhanced with comments from them. The one participant included from earlier interviews has contributed with knowledge about the starting process and elements, which she would have found useful at that time. During that evaluation, we focused both on the content of the DIYAPS-readiness tool as well as the layout, as she knew the

different components and necessary information when starting DIYAPS. The involvement of our peers contributed to the layout of the tool, and if they found the tool intuitive to use. Most of the peers could not evaluate on content within the tool as they did not have knowledge about the DIYAPS field. In spite of this, they could comment on whether it is understandable and if they believed it could aid those without much knowledge about DIYAPS. Therefore, we can not determine whether this would create an obvious change within the DIYAPS community. However, we argue that because the participants stated a sense of helpfulness from the DIYAPS-readiness tool during the evaluation stage, it would make a change in the future for the DIYAPS community, as mentioned in section 3.6. Working with the principles of UCD, we find it relevant to follow the iterative design process, to make the DIYAPS-readiness tool as applicable as possible for the DIYAPS community. Therefore, future research should focus on the involvement of the community to a greater extent and thereafter, create new and improved iterations before finalizing the tool.

For Whom is the DIYAPS-readiness Tool Useful?

We are curious as to who will benefit from this DIYAPS-readiness tool as it is designed for a target group with a certain level of empowerment. As mentioned in section 3.2, we argue that people who are interested in and who want to start DIYAPS can be categorized as empowered, also called active co-participants. They are therefore in one of the three stages of PLU (Botin *et al.* 2020). For that reason, we state that the empowered people who have been involved have given relevant feedback, in line with people who potentially will make use of the DIYAPS-readiness tool in the future. At the same time, we have focused on not involving emancipated people, also called self-managers, as they can be assessed as being "too" self-managed for using the tool, and would thereby not provide relevant feedback.

Through our questionnaire, we enabled the opportunity for all who wanted to be involved in our thesis to be included. As mentioned in section 3.3, two of them were not DIY-looping yet, but were interested in starting. In their case, they both found the process too complicated and assessed that they did not have the time or competencies to start right away. However, we would argue that these would benefit from our tool, even though they assessed that they did not have the competencies to start right away. We state that through the tool, other PWT1D in different stages of empowerment could benefit from the tool, due to the information given in the results, even though the DIYAPS-readiness tool is not intentionally designed for all stages of empowerment. One commented in the questionnaire that: *"I am too busy right now to focus on something so new, and so distinctively different"* (Questionnaire Participant - Appendix B). We reached out to specifically these two participants, as we found it relevant to explore their experiences with the starting process. However, we did not get any response and had to proceed with the thesis without them. For future evaluation, we argue that it would be relevant to include the DIYAPS community to a greater extent, who experienced difficulties with the guiding material or who has not started yet due to difficulties navigating around. Although we would also argue that people being empowered at a certain level can be tough to capture within the Facebook group, as it is dif-

difficult to assess people's empowerment on initial appearance. Therefore, we state that finding relevant people to test with can be time-consuming, and is something we already experienced during our thesis.

But what do we enable with the DIYAPS-readiness tool in the DIYAPS community? Through our tool, we aim to create a more manageable opportunity for those who are empowered and are interested in DIYAPS to support their self-management and self-reflection. Presumably, the tool helps and supports navigating information about DIYAPS and by that contributes to newcomers being more self-managed when reflecting upon DIYAPS prior to starting. This can also be seen in relation to 'lifeworld' by Ihde (1990). The DIYAPS-readiness tool provides the opportunity for interested people to enter into this community and change their current lifeworld, by engaging them in whether this change is possible for them. DIYAPS requires attention as much as T1D would do without it. Therefore, their lifeworld is not changed in a way of letting go of the control but is changed by the system helping automate some of the practices that exist when having T1D.

Ethical Reflections

It could be questioned if our DIYAPS-readiness tool encourages people to do something that is not acknowledged within the healthcare system. We would argue that our tool supports the process prior to starting DIYAPS, thus helping to reflect on whether DIYAPS can be a choice of treatment or not, through the different components and systems. We acknowledge that people should have the choice to DIY-loop if they want to however, we state that our DIYAPS-readiness tool is not a direct encouragement, but a way of navigating easily through information about the process and components that are required to start DIYAPS. Here it is important to mention that we do not recognize the DIYAPS-readiness tool as a replacement for the already existing guidelines. In spite of this, it can be discussed if we indirectly affect people in the community by making the decision to DIY-loop easier through our tool. Since the tool provides more accessibility to the knowledge that is necessary to begin, due to the amount of information in the results. However, this can not be assessed without further investigation. Because we are aware of this, we have prioritized to indicate in the results that DIYAPS requires time, care, and independence, in concurrence with their T1D. It is important to mention that we are aware of the ethical elements within this context. Being in the DIYAPS field and supporting the community can be a gray area and thus create challenges. As mentioned earlier, the DIYAPS-readiness tool is meant to be available on the Facebook group Looped - Denmark. Therefore, we argue that those utilizing the tool have discovered DIYAPS separately from our tool. For that reason, we would highlight that the DIYAPS-readiness tool is meant to aid and encourage them to assess if DIYAPS is suitable for them.

4.2 Has DIYAPS Come to Stay?

As mentioned in section 1.4 the geographical 'zip code lottery' affects the distribution of diabetes technology for PWT1D. We argue, that because of the challenges when allocating diabetes technology, people in the empowered phase seek other ways in order to meet their own wishes. This also means that PWT1D in the empowered phase are willing to commit to other systems such as DIYAPS, which are not acknowledged by the healthcare system to achieve better health and more self-management. You could say that the evolvement of diabetes technology has come a long way however, politically we can not keep up. At the same time, as mentioned in section 1.4, if the economy is not prioritized for these citizens through the supply list, we could argue that this is also an incentive for citizens to seek other alternatives. It can be questioned if DIYAPS is a temporary system because PWT1D can not wait for AID-systems to become more prevalent. If the AID-systems became more accessible, would people then over time shift to these authorized and acknowledged systems? It is difficult to predict when this will be possible because you can not count on the development being affordable enough for the government to prioritize the supply list. It may already be concerning that not all the regions have prioritized allocating sensor-based glucose monitors to all adults primo 2024 as The Danish Health Technology Council recommended (Festersen 2023a). However, from our empirical data, it seems that PWT1D are done waiting and taking matters into their own hands. Here is an example from the questionnaire:

"I felt that there had to be a way to get the different assistive devices to connect with each other. I didn't want to wait for various companies to get their devices approved and then be 'lucky' to be granted exactly the one system that might come on the market. Furthermore, I wanted more control than the existing systems offered."

(Questionnaire Participant - Appendix B)

The citation from the questionnaire expresses the challenges with AID-systems, and that it was not an option for them. They wished for more control and did not want to wait for various companies to get their devices approved. Thus, this person sought other possibilities and chose to DIY-loop.

On the other hand, as shown in the quote above and the scoping review, we can also assume that empowered PWT1D choosing to DIY-loop may want to achieve not only more self-management but also more customizability through DIYAPS. It can be argued that having a chronic condition such as Type 1 Diabetes (T1D) is subjective and that wishes for treatment can be different from person to person, thus a 'one size fits all' model can be doubtful. Therefore, the purpose of doing or wanting DIYAPS can be based on the opportunity to accomplish customizability as well as self-management. Thereby, the choice of DIYAPS alters their lifeworld to heighten their sense of connectivity with their diabetes technology and everyday life. Each person choosing to DIY-loop has their specific view of how their technology should be a part of their lifeworld, which then enhances the outcomes of DIYAPS. This is a factor that many can not comprise on (Ihde 1990).

Through our scoping review, we became aware of how important these factors can be for PWT1D when starting DIYAPS. In the article by Schipp *et al.* (2022) it was expressed that "Some participants in-

licated that they would never swap to a commercial device.” (Schipp et al. 2022). They assessed that DIYAPS was the best option for them and that several features were perceived as more unique with DIYAPS compared with the commercial companies. Here compatibility, user-led design, ability to evolve faster, customizability, and community were mentioned as valuable benefits of DIYAPS. At the same time, they also expressed their appreciation for the choice to combine insulin pumps and sensor-based glucose monitors despite them being from different companies (Schipp et al. 2022). In another article, a participant also elaborated:

“I will never, never, ever consider looking at a commercial based system. The algorithm that I use is updated weekly. We add patient led innovation. We’re able to customise, personalise and add additional features and benefits every day. And, we can keep improving upon a system without the need for clinical trial, testing, evaluation and then approvals.”

(Schipp et al. 2021)

Here customizability is again mentioned and is among others a reason for not going back to commercial based system. In the articles by Schipp et al. (2021) and Schipp et al. (2022) it is highlighted that DIYAPS was created to fulfill the needs of the diabetes community, which could not be met by the commercial companies. So as commercial products become more accessible in the future, DIYAPS will meet new unmet user needs and thus remain relevant in the future for empowered PWT1D. We can therefore question if DIYAPS is not only temporary but has come to stay. From the scoping review and the DIYAPS community, we perceive the commercial products with a lack of user-led design. The DIYAPS community will be one step ahead compared to the commercial companies, due to the community being able to change and evolve fast. At the same time, it is uncertain to know whether the commercial companies will catch up, with all the things that have to be approved before the DIYAPS community has taken the next step. We assume that if the commercial companies are not collaborating with the T1D community and are not developing diabetes technologies that are based on their needs, DIYAPS may have come to stay.

Chapter 5

Conclusion

In this master's thesis we have investigated the following problem statement:

How can a DIYAPS-readiness tool be developed through a user-centered design approach with the Danish DIYAPS community, and how can it support self-management for empowered people with type 1 diabetes prior to starting DIYAPS?

Based on the elaborated analysis and discussion we can conclude that the development of our DIYAPS-readiness tool can support self-management, and encourage People With Type 1 Diabetes (PWT1D) who are interested in and wish to start Do-It-Yourself Artificial Pancreas System (DIYAPS). With the inclusion of the DIYAPS community through User-Centered design (UCD) we have developed a DIYAPS-readiness tool based on their insights, experiences, and suggestions to design a tool with relevance prior to starting DIYAPS. The tool provides an opportunity for the community to facilitate navigation of information that is available about DIYAPS and thus make a change by following the principles of action research.

Using the principles of UCD by [Norman \(2008\)](#), we have focused on the iterative design approach, which is also reflected in the development process and the DIYAPS-readiness tool itself. Therefore, this has affected the design of our tool by practicing webnography and with the involvement of participants through a think aloud test, interviews, a questionnaire, and testing of the DIYAPS-readiness tool. Through this involvement, we can conclude that the DIYAPS-readiness tool can have an effect on people's lifeworld, because diabetes technology becomes more prominent when using DIYAPS. Consequently, our DIYAPS-readiness tool supports their DIYAPS-journey prior to starting. The content of the DIYAPS-readiness tool is inspired by self-efficacy and has been written to support this. Through the testing of the tool, we can conclude that the results led to a sense of encouragement, and they thereby felt ready to research DIYAPS further. Additionally, based on the empirical data we can conclude that PWT1D who are empowered and interested in DIYAPS would benefit from the DIYAPS-readiness tool to assess if DIYAPS would be the right system for them to use. This can be emphasized through the information enlightened in the results. We can therefore, state that being empowered is required to gain valuable usefulness from the tool, due to the independence and the user being well-informed when DIY-looping.

Through our discussion, based on data from the scoping review, we can conclude that customizability is a prominent feature of DIYAPS, because of the constant evolvement of the system. Thereby, DIYAPS is a system where customizability is possible to a greater extent, where our DIYAPS-readiness tool can provide better access for those who wish to accomplish this.

Chapter 6

Future Perspectives

Regarding this master's thesis, it is possible to continue the investigation in different directions and perspectives.

With our findings from the analysis and the discussion, we find it relevant to further explore the iterative design process regarding the tool. From the tests and evaluation, it could be interesting to include more participants from the DIYAPS community and include their points of view. This could contribute to further adjustment of the DIYAPS-readiness tool, where revisiting the different stages from UCD would be relevant in this context. Through this, we wish to explore action research further by creating a closer contact between us and the practitioners, and thereby help the DIYAPS community. Here we also find it interesting to create more knowledge for the world, by creating awareness on this societal group and the challenges they are facing in the healthcare system. We find it important to enlighten the user perspective within the field of DIYAPS and share their experiences and perspectives. Continuing this thesis would create the possibility of making a change within the DIYAPS community to a greater extent.

Another continuation of this thesis could also process some of the suggestions from the questionnaire concerning 'physical DIYAPS building groups'. This was the most answered suggestion, which we find relevant to explore further. As mentioned earlier, the community aspect is important however, most of it happens online, since the healthcare system is not acknowledging the system and thereby does not facilitate any initiatives. We find it interesting to explore how physical meetings may help people who wish to start DIYAPS, and how these physical meetings can be designed and facilitated.

Since this thesis has been from a user perspective it could be interesting to involve HCPs and their point of view regarding consultations where PWT1D have questions about DIYAPS. As a HCP it can be difficult to consult PWT1D concerning DIYAPS as there are constraints from the HCPs' perspective. They are therefore in a gray area where we find it interesting to explore if we can help HCPs understand DIYAPS and the people who use it. In this context, it could be relevant to involve different HCPs within a Department of Endocrinology, to explore their experiences when consulting about DIYAPS. At the same time, it could also be intriguing to research if a digital booklet or pamphlet could be relevant in this context for the HCP to hand out when consulting about DIYAPS. However, as DIYAPS is a difficult field to navigate in, it would still be necessary to investigate the spectra of how much assistance the HCPs are allowed to deliver, and if a pamphlet for example would overstep an obligation.

Bibliography

- Albris, K. and A. Wahlberg, 2018 At være online: Webnografi og digitale metoder. In *Antropologiske projekter. En grundbog*, chapter 16, pp. 261–274, Samfundslitteratur.
- AndroidAPS Community, N.D.a Building aaps. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Installing-AndroidAPS/building-AAPS.html#install-git>.
- AndroidAPS Community, N.D.b Cgms/fgms configuration. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Configuration/BG-Source.html>.
- AndroidAPS Community, N.D.c Completing the objectives. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Usage/completing-the-objectives.html>.
- AndroidAPS Community, N.D.d Downloading the aaps code. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Installing-AndroidAPS/building-AAPS.html#download-the-aaps-code>.
- AndroidAPS Community, N.D.e Insulin pump choices. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Getting-Started/Pump-Choices.html>.
- AndroidAPS Community, N.D.f List of phones. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Hardware/Phoneconfig.html>.
- AndroidAPS Community, N.D.g Medtronic pump. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Configuration/MedtronicPump.html>.
- AndroidAPS Community, N.D.h Transferring and installing aaps. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Installing-AndroidAPS/Transferring-and-installing-AAPS.html>.
- AndroidAPS Community, N.D.i Welcome to aaps documentation. Last Accessed 23-02-2024 Link: <https://androidaps.readthedocs.io/en/latest/index.html>.
- AndroidAPS Community, N.D.j xdrip+. Last Accessed 23-02-2024 <https://androidaps.readthedocs.io/en/latest/Configuration/xdrip.html>.
- Bandura, A., 1995 Exercise of personal and collective efficacy in changing societies. In *Self-Efficacy in Changing Societies*, pp. 1–45, Cambridge University Press, United Kingdom.
- Bandura, A., 2014 Social-cognitive theory. In *An introduction to theories of personality*, chapter 16, pp. 341–357, Psychology Press, 7th edition.
- Bassi, M., D. Franzone, F. Dufour, M. F. Strati, M. Scalas, *et al.*, 2023 Automated insulin delivery (aid) systems: Use and efficacy in children and adults with type 1 diabetes and other forms of diabetes in europe in early 2023. *Life* **13**: 783.

- Botin, L., P. S. Bertelsen, L. Kayser, P. Turner, S. Villumsen, *et al.*, 2020 People centeredness, chronic conditions, and diversity sensitive ehealth: Exploring emancipation of the 'health care system' and the 'patient' in health informatics. *Life* **10**: 1–14.
- Brejner, M. L. S., 2019 Nye intelligente (og dyre) insulinpumper på vej. Last Accessed: 21-02-2024 Link: <https://sundhedspolitisktidsskrift.dk/nyheder/1919-nye-intelligente-og-dyre-insulinpumper-pa-vej.html>.
- Burnside, M., H. Crocket, M. Mayo, J. Pickering, A. Tappe, *et al.*, 2020 Do-it-yourself automated insulin delivery: A leading example of the democratization of medicine. *Journal of diabetes science and technology* **14**: 878–882.
- Chiang, J. L., M. S. Kirkman, L. M. Laffel, and A. L. Peters, 2014 Type 1 diabetes through the life span: A position statement of the american diabetes association. *Diabetes Care* **37**: 2034–2054.
- Christensen, B. S. and K. A. Nielsen, 2022 Aktionsforskning. In *Kvalitative Metoder: En grundbog*, chapter 5, p. 137–160, Hans Reitzel.
- Crocket, H., 2020 Peer mentoring in the do-it-yourself artificial pancreas system community. *Journal of diabetes science and technology* **14**: 1022–1027.
- Danske Patienter, N.D. Sundhedsvæsenet er ikke gearret til fremtidens sygdomsbillede. Last Accessed: 03-06-2024 Link: <https://danskepatienter.dk/temaer-projekter/temaer/sammenhaeng-i-sundhedsvaesenet/sundhedsvaesenet-er-ikke-gearet-til>.
- Diabetesforeningen, 2023 Diabetes i tal. Technical report, Diabetesforeningen.
- DIYPS, N.D. Dana lewis. Last Accessed: 16-02-2024 Link: <https://diyps.org/dana-lewis/>.
- EBSCO, N.D. Cinahl databas. Last Accessed: 13-03-2024 Link: <https://www.ebsco.com/products/research-databases/cinahl-database>.
- Elsevier, N.D. Scopus content. Last Accessed: 13-03-2024 Link: <https://www.elsevier.com/products/scopus/content>.
- Festersen, S., 2021 Nyt nationalt udbud af insulinpumper og glukosemålere. Last Accessed: 21-02-2024 Link: <https://diabetes.dk/nyheder/2021/nyt-nationalt-udbud-af-insulinpumper-og-glukosemalere>.
- Festersen, S., 2023a 3 ud af 5 regioner giver sensorer til alle voksne med type 1-diabetes i 2024. Last Accessed: 21-02-2024 Link: <https://diabetes.dk/nyheder/2023/3-ud-af-5-regioner-giver-sensorer-til-alle-voksne-med-type-1-diabetes-i-2024>.
- Festersen, S., 2023b Det store postnummerlotteri kalder på politisk handling. Last Accessed: 21-02-2024 Link: <https://diabetes.dk/nyheder/2023/det-store-postnummerlotteri-kalder-pa-politisk-handling>.
- Foreningen Type 1, 2022 Techguide: Skema over insulinpumper. Last Accessed: 21-02-2024 Link: <https://www.type1.dk/typels-techguide-viser-skema-over-insulinpumper/>.
- Foreningen Type 1, N.D. Spørgsmål og svar om looping. Last Accessed: 16-02-2024 Link: <https://www.type1.dk/udgivelser/looping/spoergsmaal-og-svar-om-looping/>.
- Garcia, A. C., A. I. Standlee, J. Bechkoff, and Y. Cui, 2009 Ethnographic approaches to the internet and

- computer-mediated communication. *Journal of Contemporary Ethnography* **38**.
- Heinemann, L. and K. Lange, 2019 “do it yourself” (diy)—automated insulin delivery (aid) systems: Current status from a german point of view. *Journal of Diabetes Science and Technology* **14**: 1028–1034.
- Hesse, M., 2006 Om surveyundersøgelsen - fra virkelighed til data. In *Sociologiske Metoder: Fra Teori til analyse I kvantitative og kvalitative studier*, p. 31–48, Samfundslitteratur.
- Ihde, D., 1990 Technology and the lifeworld. In *Technology and Lifeworld: From garden to Earth*, chapter 2, p. 21–30, Indiana University Press.
- Interaction Design Foundation, 2024 What is user centered design (ucd)? Last Accessed: 01-05-2024 Link: https://www.interaction-design.org/literature/topics/user-centered-design#ucd_considers_the_whole_user_experience-3.
- Kesavadev, J., S. Srinivasan, B. Saboo, M. K. B, and G. Krishnan, 2020 The do-it-yourself artificial pancreas: A comprehensive review. *Diabetes therapy : research, treatment and education of diabetes and related disorders*. pp. 1217–1235.
- Kildedal, K. and E. Laursen, 2015 Professionsudvikling - udvikling af professionel praksis gennem aktionsforskning. In *Aktionsforskning: En grundbog*, chapter 4, p. 81–96, Samfundslitteratur.
- Laursen, E., 2015 Aktionsforskningens produktion af viden. In *Aktionsforskning: En grundbog*, chapter 5, p. 97–112, Samfundslitteratur.
- Litchman, M. L., D. Lewis, L. A. Kelly, and P. M. Gee, 2019 Twitter analysis of #openaps diy artificial pancreas technology use suggests improved a1c and quality of life. *Journal of Diabetes Science and Technology* **13**: 164–170.
- Litchman, M. L., H. R. Walker, C. Fitzgerald, M. G. Hoyos, D. Lewis, *et al.*, 2020 Patient-driven diabetes technologies: Sentiment and personas of the #wearenotwaiting and #openaps movements. *Journal of diabetes science and technology* **14**: 990–999.
- LoopDocs Community, N.D.a Loopdocs guide. Last Accessed 23-02-2024 Link: <https://loopkit.github.io/loopdocs/>.
- LoopDocs Community, N.D.b Loopdocs guide. Last Accessed 23-02-2024 Link: <https://loopkit.github.io/loopdocs/gh-actions/gh-overview/>.
- LoopDocs Community, N.D.c Loopdocs guide. Last Accessed 23-02-2024 Link: <https://loopkit.github.io/loopdocs/build/overview/>.
- LoopDocs Community, N.D.d Loopdocs guide. Last Accessed 23-02-2024 Link: <https://loopkit.github.io/loopdocs/faqs/loop-faqs/#is-there-a-cheat-sheet-for-a-school-nurse-to-use>.
- Nationalt Center for Etik, 2018 Retfærdig prioritering i det danske sundhedsvæsen. Technical report, Nationalt Center for Etik, Last Accessed 12-03-2024 <https://nationaltcenterforetik.dk/Media/637997316169817241/Udtalelse%20retfaerdig%20prioritering.pdf>.
- Nielsen, J., 1993 Usability testing. In *Usability engineering*, chapter 6, pp. 165–206, Academic Press, Boston.

- Nielsen, K. C., M. E. H. Rasmussen, and S. R. Lund, 2022 Brugen af diy-looping i et borgerperspektiv. do-it-yourself artificial pancreas som alternativ behandlingsmetode for borgere med type 1 diabetes i en dansk kontekst. Not Published - Available in appendix I .
- Norman, D., 2002 User-centered design. In *The Design of Everyday Things*, chapter 7, pp. 187–218, Basic Books, New York, second edition.
- Norman, D., 2008 Words matter. talk about people: Not customers, not consumers, not users. Last Accessed: 02-05-2024 Link: <https://jnd.org/words-matter-talk-about-people-not-customers-not-consumers-not-users/>.
- O'Donnell, S., D. Cooper, Y. Chen, H. Ballhausen, D. M. Lewis, *et al.*, 2023 Barriers to uptake of open-source automated insulin delivery systems: Analysis of socioeconomic factors and perceived challenges of adults with type 1 diabetes from the open survey. *Diabetes research and clinical practice* **197**.
- OpenAPS Community, N.D. Hardware overview. Last Accessed 23-02-2024 Link: <https://openaps.readthedocs.io/en/latest/docs/Gear%20Up/hardware.html>.
- Palmer, W., S. A. W. Greeley, L. Letourneau-Freiberg, and R. N. Naylor, 2020 Using a do-it-yourself artificial pancreas: Perspectives from patients and diabetes providers. *J Diabetes Sci Technol* **14**: 860–867.
- Rosenberger, R. and P.-P. Verbeek, 2015 A fieldguide to postphenomenology. In *Postphenomenological investigations: essays on human-technology relations*, Postphenomenology and the Philosophy of Technology, pp. 9–42, Lexington Books.
- Schipp, J., T. Skinner, E. Holloway, R. Scibilia, H. Langstrup, *et al.*, 2021 How adults with type 1 diabetes are navigating the challenges of open-source artificial pancreas systems: A qualitative study. *Diabetes Technology and Therapeutics* **23**: 546–554.
- Schipp, J., T. C. Skinner, E. Holloway, R. Scibilia, H. Langstrup, *et al.*, 2022 'we're all on the same team'. perspectives on the future of artificial pancreas systems by adults in australia with type 1 diabetes using open-source technologies: A qualitative study. *Diabetic Medicine* **39**.
- Showell, C. and P. Turner, 2013 The PLU Problem: Are We Designing Personal ehealth for People Like Us. *Studies in Health Technology and Informatics* .
- Spradley, J. P., 1979 Asking descriptive questions. In *The Ethnographic Interview*, Holt, Rinehart and Winston, 11th edition.
- Steno Diabetes Center Copenhagen, 2023 Loopere får bedre livskvalitet. Last Accessed: 16-02-2024 Link: <https://www.sdcc.dk/presse-og-nyheder/nyheder/Sider/Loopere-f%C3%A5r-bedre-livskvalitet.aspx?rhKeywords=time+in+range>.
- Sundhedsthyrelsen, 2023 Last Accessed: 20-02-2024 Link: <https://www.sst.dk/da/udgivelser/2012/notat-vedroerende-behandling-med-insulinpumper>.
- Suttiratana, S. C., J. J. Wong, M. S. Lanning, A. Dunlap, S. J. Hanes, *et al.*, 2022 Qualitative study of user experiences with loop, an open-source automated insulin delivery system. *Diabetes Technology & Therapeutics* **24**: 416–423.

- Tanggaard, L. and S. Brinkmann, 2020 Interviewet: samtalen som forskningsmetode. In *Kvalitative metoder - En grundbog*, chapter 1, pp. 33–63, Hans Reitzels forlag.
- Tingkær, E., 2023 Sæt politisk handling bag behandlingsrådets grønne lys til diabetesteknologi. Last Accessed: 21-02-2024 Link: <https://diabetes.dk/nyheder/2023/saet-politisk-handling-bag-behandlingsradets-gronne-lys-til-diabetesteknologi>.
- U.S. National Library of Medicine, N.D Pubmed. Last Accessed: 13-03-2024 Link: <https://pubmed.ncbi.nlm.nih.gov/>.
- Vaus, D. D., 2002a Administering questionnaires. In *Surveys in social research*, chapter 8, p. 122–141, Routledge.
- Vaus, D. D., 2002b Constructing questionnaires. In *Surveys in social research*, chapter 7, p. 194–121, Routledge.
- Vaus, D. D., 2002c The nature of surveys. In *Surveys in social research*, chapter 1, p. 3–8, Routledge.
- Videncenter for Diabetes, 2021a Blodsukkermåling og type 1 diabetes. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/behandling/blodsukker/blodsukkermaalning#kontinuerlig-glukosemaalinger-cgm--24>.
- Videncenter for Diabetes, 2021b Højt blodsukker og type 1 diabetes. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/behandling/blodsukker/hoejt-blodsukker>.
- Videncenter for Diabetes, 2021c Injektion af insulin. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/behandling/insulin/injektion-af-insulin>.
- Videncenter for Diabetes, 2022a Følgesygdomme og type 1 diabetes. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/foelgesygdomme>.
- Videncenter for Diabetes, 2022b HbA1c og middelblodsukker. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/behandling/blodsukker/hb1c-og-middelblodsukker>.
- Videncenter for Diabetes, 2023a Behandling med insulinpumpe. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/behandling/insulin/insulinpumpe#insulinpumpe-og-sensor-af>.
- Videncenter for Diabetes, 2023b Blodsukker og type 1 diabetes. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/behandling/blodsukker>.
- Videncenter for Diabetes, 2023c Lavt blodsukker og type 1 diabetes. Last Accessed: 16-02-2024 Link: <https://videncenterfordiabetes.dk/viden-om-diabetes/type-1-diabetes/behandling/blodsukker/lavt-blodsukker>.