

TALLINN UNIVERSITY OF TECHNOLOGY SCHOOL OF ENGINEERING Department of Mechanical and Industrial Engineering

DIASYMPHONY: A SET OF DESIGN INTERVENTIONS TO REDUCE DIABETES DISTRESS

DIASYMPHONY: DISAINILAHENDUSTE KOGUMIK DIABEEDIHÄIRETE VÄHENDAMISEKS

MASTER THESIS

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DiaSymphony: a set of design interventions to reduce diabetes distress

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THESIS TASK

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- 1.Conduct literature review and field research about diabetes distress
- 2.Utilizing design methods guided by the SDT to detect user pain points and needs
- 3. Utilizing holistic approach with co-design to propose design interventions

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2.	Qualitative field research: interviews, observation	15/02/24
3.	Definition of points to be explored	29/02/24
4.	Exploring concepts with collaborative design	21/03/24
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6.	Evaluation and conclusion	20/05/24

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ABSTRACT

Diabetes distress is a psychological condition resulting from the restrictive lifestyle imposed by the chronic disease, causing regimen-related distress, emotional burden, physician-related distress, and social conflicts. This study explores a holistic approach to ir, grounded in the Self-Determination theory (SDT), to enhance the integration and effectiveness of design interventions. Through extensive research, including interviews, observation, and collaborative design sessions with diabetics, this research identified key pain points, including the difficult process of estimating carbohydrates in a meal, which results in extra hours spent to balance blood glucose. Besides this short-term concern, the study also addresses long length diabetes distress matters, including the uncertainty about diabetes complications, and timeless distress, including needle anxiety and lack of integration of products. Utilizing techniques like User Journey Mapping, Persona Creation and Empathy Mapping, the design process focused on solutions that decrease complexity of diabetes management and integrate devices for extended usability.

The design solution is called DiaSymphony, an open-source diabetes assistant that integrates various resources to address identified pain points. DiaSymphony has a usercentred approach, reflecting the patients' perspectives on managing their own condition effectively. DiaSymphony's approach focused on autonomy, competence and relatedness fulfilment ensures that individuals will be motivated to face the challenges of diabetes, with the help of a platform that is built by other patients like themselves. The Design Thinking framework facilitated a dynamic and iterative development process, resulting in a final solution that is both practical and empathetic to the needs of diabetic individuals. This thesis highlights the potential of a holistic approach ion creating more integrated and effective diabetes management tools.

Keywords:

diabetes, diabetes distress, human-centered design, design thinking, holistic design approach, collaborative design, self-determination theory

KOKKUVÕTE

Diabeediga seonduv stress on psühholoogiline seisund, mis on põhjustatud kroonilisest haigusest tingitud piiravast eluviisist, põhjustades omakorda raviskeemiga seotud pingeid, emotsionaalset koormust, arstidega seotud stressi ja sotsiaalseid konflikte. Käesolevas töös uuritakse holistilist lähenemist, mis põhineb enesemääratlemise teoorial (Self-Determination theory), et edendada disainilahenduste integratsiooni ja tõhusust. Tänu põhjalikule uurimistööle, sealhulgas intervjuudele, vaatlustele ja diabeetikutega ühiselt läbiviidud disainiseanssidele tuvastati peamised valupunktid. Nende hulka kuulusid näiteks keeruline protsess süsivesikute hindamisel söögikordades, mille tagajärjel kulub vere glükoosisisalduse tasakaalustamiseks rohkem aega. Lisaks sellele lühiajalisele murekohale käsitletakse uuringus ka pikemaajalisi diabeediga seotud hädasid, sealhulgas ebakindlust diabeedi tüsistuste osas ja tähtajatuid hädasid, nagu näiteks nõelahirm ja puudulik integratsioon toodete näol. Kasutades selliseid meetodeid nagu kasutaja teekonna kaardistamine, persoona loomine ja empaatia kaardistamine, keskenduti disainiprotsessis lahendustele, mis vähendavad diabeedi haldamise keerukust ja kaasavad seadmeid laiapõhjalisema kasutatavuse tagamiseks.

Disainilahenduse nimi on DiaSymphony, mis kujutab endast avatud lähtekoodiga diabeediassistenti, millesse on integreeritud erinevad abivahendid, et tegeleda tuvastatud valupunktidega. DiaSymphony-I on kasutajakeskne lähenemisviis, mis peegeldab patsientide nägemust oma haiguse tõhusaks juhtimiseks. DiaSymphony lähenemine, mis keskendub autonoomiale, pädevusele ja sidususe loomisele, tagab, et inimesed on motiveeritud diabeediga seotud probleemidega toime tulema, kasutades selleks platvormi, mille on loonud teised samasugused patsiendid. Disainimõtlemise raamistik hõlbustas dünaamilist ja järk-järgulist arendusprotsessi, mille tulemuseks on lahendus, mis on nii praktiline kui ka diabeetikute vajadusi arvestav. See töö toob esile tervikliku, patsiendikesksete lähenemisviiside potentsiaali integreeritumate ja tõhusamate diabeedihaldusvahendite loomisel.

CONTENTS

ABSTRACT
PREFACE
List of abbreviations and symbols10
1. INTRODUCTION11
2. METHODOLOGY
3. RESEARCH: DISCOVER PHASE14
3.1 Background research on diabetes14
3.2 Diabetes distress15
3.3 Literature review about diabetes distress17
3.4 Self-determination theory19
3.5 Field research20
3.5.1 Research method and sources20
3.5.2 Contacts with patients: interviews and live observation21
3.5.3 Contacts with patients: observation of P2P communities23
3.5.4 Interactions with clinics, endocrinologists and nurses26
3.5.5 Contact with the Estonian Children and Youth Diabetes Association27
3.5.6 Interviews with opinion leaders
3.6 Defining design opportunities
3.7 Problem focus
3.8 Research question
4. DESIGN PROCESS: DEFINE, DEVELOP, DELIVER
4.1 Problem definition32
4.2 References of design application to help management of diabetes distress32
4.3 Description of the design-oriented evidence collection to guide the interventions
aiming to reduce effects of diabetes distress
4.4 Design research
4.4.1 Identifying pain points and mapping them by affinity35
4.4.2 Identifying pain points and mapping them by affinity
4.4.3 Empathy and decision-making mapping42
4.4.4 User/stakeholder requirements
4.5 Collaborative ideation
4.5.1 Imagining an ideal scenario for diabetes therapy
4.5.2 Analogous inspirations
5. DESIGN PROPOSAL: DIASYMPHONY, AN OPEN-SOURCE DIABETES CARE
PLATFORM
5.1 Metaphor53

5.2 Outli	ine of the concept	53
5.2.1	Definition of the diabetes AI assistant, the core of DiaSymphony	55
5.2.2	Auxiliary tools that can be personalized and utilized by peers	57
5.3 Prote	otype	60
5.3.1	Role-playing prototype of the diabetes assistant	60
5.3.2	Prototype of a 3D-printed insulin cannula	64
5.4 Prod	uct definition of DiaSymphony	66
5.4.1	Carbohydrate control manager	67
5.4.2	Diabetes follow-up	70
5.4.3	Ask your peers	72
6. C	ONCLUSION: ANALYSING GAINS TO THE USER JOURNEY	73
SUMMAR	Υ	75
LIST OF	REFERENCES	76
APPENDI	CES	80
GRAPHIC	C MATERIAL	90

PREFACE

The idea of exploring alternatives for better diabetes management comes from my own background as a diabetic since I was 5 years old. I spend most of my life trying to understand how to live with the disease, and always wanted to use my competence as a designer to address it. Over time, I have seen other diabetic patients struggle with the condition as well yet having different views on the problem. The best way I found to help came with this study, which focuses deeply on understanding the pain points of patients. As a designer, I had to empathize with individuals and stakeholders and focus on their needs and their experiences. Having diabetes helps me to empathize further with the individuals, which enriches the interactions with them.

The result of this work is called DiaSymphony, an open-source diabetes platform that presents resources to reduce diabetes distress in the daily lives of patients. It is composed of an AI assistant that helps diabetics to perform controls that reduce uncertainty in their journey and other physical products that help decrease the pain points of disease management. DiaSymphony integrates with existing technology to ensure more autonomy, competence and empathy towards patients. A maestro has a DiaSymphony to organize the actions of the musicians in reaching a common goal, so now have the diabetic patients have an option to gather resources to increase wellbeing and reduce diabetes distress.

I would like to express my gratitude to my supervisors Martin Pärn and Vladimir Tomberg, the Design & Technology Futures program tutors and colleagues, the Estonian Diabetes Children and Youth Association team and all the participants of my study. This research would not have been possible without their help, support and inspiration. Furthermore, I would like to acknowledge my family members, with the support that helped me to reach my final goal and also for sharing their network and expertise.

List of abbreviations and symbols

- DMT1 (Diabetes Mellitus Type-1)
- DMT2 (Diabetes Mellitus Type-2)
- DDS17 (Diabetes Distress Scale 17 Questions)
- CGM (Continuous Glucose Monitoring)
- HCD (Human-centered design)
- P2P (Peer-to-peer)
- DIY (Do it yourself)
- SDT (Self-determination theory)
- FDM (Fused Deposition Modeling).

1. INTRODUCTION

Diabetes is a chronic disease that afflicts millions of people worldwide. The disorder consists of a deficiency in production of insulin, a hormone that controls the balance of sugar in the bloodstream. This condition raises numerous problems for the diabetic patients in short-term and long-term, threatening their lives and decreasing well-being. Moreover, it has been documented in this essay that diabetes is linked to a wide range of issues that affect the whole society and economy.

Individuals with the condition are supposed to follow a restricted lifestyle in order to keep the levels of blood sugar balanced, taking time and resources to do so. They face negative feelings and pitfalls because of these stressful routines and compromises. As a result, patients face diabetes distress, a term coined by Polonsky et al. (1995) that describes a disease-linked psychological condition that affects the motivation of the patient to face diabetes.

In this study, the author investigates how this background can lead to a difficult environment to manage the disease. A framework based on the SDT (Ryan & Deci, 2022) was important to visualize the pain points placed in the user journey, a holistic approach rather than focusing on isolated matters to be solved individually. The aim was to develop a set of design interventions that act together reduce the influence of diabetes distress to patients. Active participation of diabetics was an essential part of the process, in a collaborative design process that resulted in a multi-layered concept.

The development process was grounded in the Design Thinking framework. This cyclical development methodology permits a dynamic way of work, with constant discover and validation. Research phase gathered literature about diabetes distress that were further investigated in the field, with conduction observation and interaction rooted in HCD.

As a continuation of the research, the design process focused on defining a problem that could be worked and framed it into possible approaches by mapping them, and later developing solutions with collaborative efforts. Then, the concept Symphony was proposed as an open source that gathers resources and integrate them together to build a diabetes assistant that addresses the pain points showcased. The design was developed in a collaborative work with patients who participated in the process.

DiaSymphony is a reflection on how the diabetic patients would like to manage their disease, as individuals who fit the best resources available to their own mental model.

11

2. METHODOLOGY

This study was developed with an integrated set of approaches oriented by the design thinking process (Brown, 2008) with the Double Diamond visualization by the Design Council (2014). This guideline is a cyclical development path that permits designers to discover a wild field of variables of the problem willing to create empathy with the user, before converging into a definition of the aspect to be focused on. Then, the development enters another phase of exploration, generating diverse ways to solve the target. The delivery step aims to validate a concept, and this process can be done several times with refinements informed by previous tests. In this study, the whole process was backed by an active collaboration of users to the result.

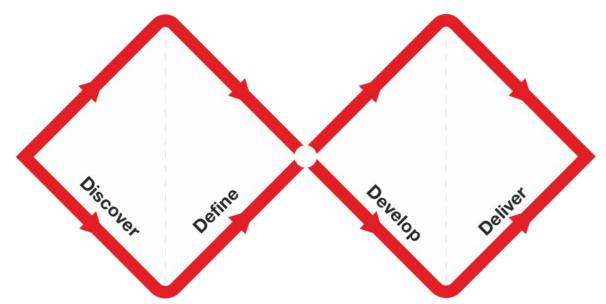


Figure 1 — The Double Diamond Design Thinking framework by the Design Council UK (2014)

During the Discover phase, the initial research was focused on finding literature that reflected the environment of emotional and psychological aspects of diabetes. In this phase, the term "diabetes distress" was selected to be the core of the study. Empathizing with the diabetic patients is an essential action of the Design Thinking process to conduct the process, which was done with observation and interviews with diabetic patients and other stakeholders. These interactions used HCD methods to place patients and their perspectives in the heart of the design process.

Following this exploration, identification of pain points and affinity map techniques were utilized in the Define step, with the participation of users, to filter their insights gathered into a set of problems to be worked on. These were grouped by different time spans, setting a definition of issues that must be addressed together. The creation of personas and their journeys are ways to place these problems in a timeline that helps the definition of the process. Lastly, a list of user requirements gathers all these points in a way that sets the upcoming creative process.

With a clear understanding of the needs to be approached after validation from patients, the Develop phase started with a collaborative session with the users. They were encouraged to imagine a better scenario for diabetes care and to remember services out of the diabetes care sector that solves a problem comparable to their pain points in the analogous inspiration exercise.

Lastly, the ideation generated concepts that were worked on and transitioned into the Deliver step. Prototypes were developed and went through tests. The prototype of an interactive platform counted with interaction with users, and their feedback was implemented to refine the concept. Another test was planned to check the viability of using the FDM 3D printing process as a part of the concept.

3. RESEARCH: DISCOVER PHASE

3.1 Background research on diabetes

Diabetes is a chronic disease that afflicts over 500 million people globally. In the next 3 decades, however, it is expected that this number will at least double (Lancet, 2023b). Despite its extensive presence in everyday life, historical significance and substantial improvements in therapy, individuals, societies and health communities still struggle understanding how to deal with diabetes. Statistics on depression (Centers for Disease Control and Prevention, 2023) and social issues, such as unemployment (Pedron et al., 2019) and lack of access to education (Akhter et al., 2016) indicate that diabetics experience rates that are significantly higher than those observed amongst individuals without the condition. The Lancet (2023b) claims that the future of healthcare, life quality and life expectancy will be defined by how the world can deal with diabetes in the next 3 decades. Hence, it is crucial to explore more effective strategies for addressing this condition by carefully comprehending overlooked problems in the background.

The disorder's name comes from a Latin term that describes sweetness, an attribute that may be found in the urine of diabetics as a result from the total or partial lack of insulin production. Insulin, a hormone secreted by the pancreas, plays a crucial role in balancing the body's sugar levels (Rahman et al., 2021). This sugar — more accurately referred to as glucose — keeps circulating through the bloodstream for rapid energy release when necessary. The human body needs to keep strict levels of glucose in the blood to function, hence acting many times a day to control its levels.

Without insulin and with a high amount of glucose in the blood, this excess will keep circulating through the body and will eventually enter the urinary system for elimination. The saturation of glucose in circulation can damage organs it passes through on the way, causing long-term damage also acknowledged as diabetes complications (Nathan, 1993). The lack of insulin also affects the production of glucagon, the opposing hormone providing quick energy to the body. Conversely, diabetics may experience low glucose in the blood, potentially leading to loss of consciousness and fainting. Understanding this risky journey sets the stage for comprehending complex challenges faced by individuals.

Diabetes is a chronic disease because it cannot be cured, and persisting medical therapy combined with follow-up of the condition is the only way to deal with it. In the last 20 years, the advent of CGM technologies improved possibilities for a healthy life with diabetes. Nowadays, the most advanced insulin pump therapies can simulate the behaviour of a pancreas with continuous subcutaneous infusion of low volumes of insulin (Saarinen et al., 2014). Combined with CGM, this therapy can decrease the low and high glucose episodes and ensure safety for long periods of time.

Since there is no better solution than life-long therapy for diabetes, monitoring the disease full-time is highly desirable to avoid complications. There is a strong dependence on the devices that must be carried along most of the time. A normal journey of a diabetes patient requires a routine planned around glucose control, day and night. There are desirable behaviours for diabetes, including maintaining strict control of blood glucose, having a diet that controls the consumption of carbohydrates and being always ready to react in time if these other activities don't go as planned.

However, diabetes is not only about maintaining the glucose in good levels and having a healthy and disciplined routine. The disorder requires compromises by the patient that are often connected to downfalls. For this reason, patients may suffer from a psychological condition that is exclusively linked to the pain points of daily management of diabetes, called diabetes distress (Polonsky et al., 1995).

There have not yet been meaningful studies that correlate diabetes distress and complications. Skinner et al. (2019) attributes this to lack of inclusion of diabetes distress long-term research. Conversely, Rock (2003) clarifies the influence of the environment in elevating glucose rates, which may indicate the role of diabetes distress in complications.

3.2 Diabetes distress

Diabetes distress refers to negative and emotional effects experienced by individuals with diabetes due to the challenges imposed by the condition in their daily lives (Polonsky et al., 1995, Skinner et al., 2019). This terminology proposed by a group of psychologists and psychiatrists from the Joslin Diabetes Centre has gained relevance in the diabetes environment since its introduction in 1995. According to a study, a person with type 1 diabetes may be forced to make 180 important decisions a day about the management of the disease, while type 2 diabetics may have to make 60 decisions of the same nature (Peyrot et al., 2005). This pressure, often combined with other factors such as stigma, difficult relationship with health insurances, fear of complications and pregnancy (Balfe et al., 2013), can lead to an environment of demotivation to take care of one's own disease.

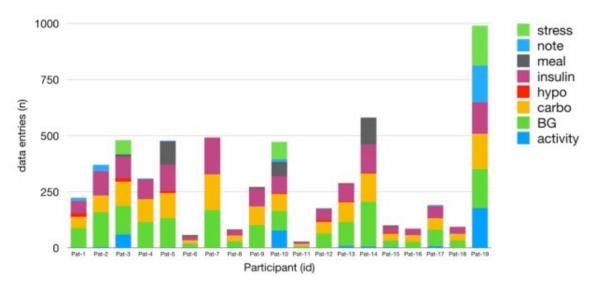
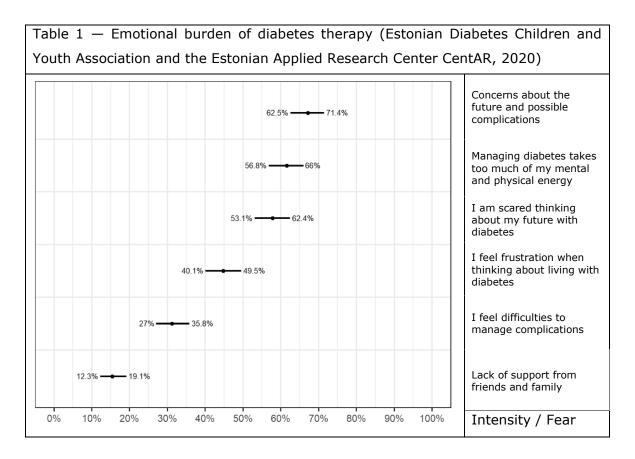


Figure 2 — Adult patients used an application to report diabetes decision-making in a period of 6 weeks. The median number of entries was 272 (Tack et al., 2018).

The impact of this condition can be measured and analysed. The DDS17 (Polonsky et al., 2005) is an evaluation tool designed by Polonsky et al. (2005) for assessing intensity of diabetes-related pitfalls among DMt1 and DMT2 patients. It comprises 17 items on various factors that potentially disrupt therapy. The items can be categorized as follows: 5 inquire about stress caused by the strict routine; 4 focus on doctor's competence; 5 explore the emotional impact; and 3 address social conflicts. Notably, it is possible to frame some items in more than one category. In essence, 13 out of 17 items comprise topics under daily life, emotional and social stress previously exposed in this essay.

Other tests, including PAID (Welch et al., 1997), DAWN (Peyrot et al., 2005), can measure frustration with diabetes. Stigmatization can be assessed with DSAS-1 and DSAS-2 (Liu et al., 2017). A holistic approach observed in these methods serves the purpose of comprehending underlying issues that patients face.

In 2020, the Estonian Diabetes Children and Youth Association and the Estonian Applied Research Center CentAR conducted a survey on Diabetes in Estonia. This survey was answered by 411 adults with diabetes type 1 and, alongside the topics, addressed emotional aspects of diabetes management. More than 50% of the participants expressed concerns about the future and possible complications, frustration regarding the mental and physical energy taken to manage the condition and feared thinking about their future with diabetes (see Table 1). In the meantime, between 12% and 19% of the participants reported lack of support from family and friends. All these answers can be connected to diabetes distress.



These survey findings offer valuable insights into the emotional aspects of diabetes management, alongside serving as a concrete example of challenges faced by diabetics in the real-world. The emotions are linked directly to the diabetes distress and disturb the therapy of individuals. It is necessary to understand behaviours that are influenced by these factors and frame them under psychological behaviour theories. With the help of the patients in a co-design exercise, it was possible to understand what kind of desirable behaviour is cancelled by diabetes distress. After that, experiences that they face were framed in a psychological framework, transitioning to understanding how to change behaviours attached to them to motivational factors like autonomy, competence and relatedness as presented in the SDT (Ryan and Deci, 2022).

3.3 Literature review about diabetes distress

Diverse fields of study researched the link between diabetes and negative trends to the quality of life of patients. According to the Centers for Disease Control and Prevention (2023), diabetics are 2 to 3 times more likely to be depressive, if compared to people who do not have any long-term or chronic disease. Diabetes distress adds up to the pitfalls as an extra layer that brings complexity to mental health management, being separated from depression (Skinner et al., 2019).

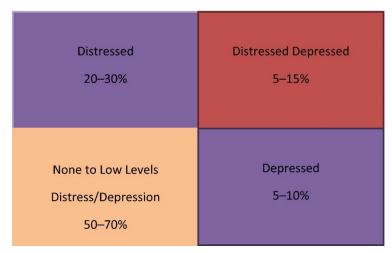


Figure 3 — Estimation of distribution of patients affected by diabetes distress, depression, by both or none of them, based on analyses of previous studies (Skinner et al., 2019).

Diabetes distress still lacks specific research and approaches to it. Skinner et al. (2019) claim that limited data focus on the study of diabetes distress and its effects on long-term care. A few studies about diabetes distress happen in Europe, and normally these publications are not following a common methodology that makes it possible to compare them with other European scenarios (Berry et al., 2015).

Yet, evidence traces a connection between the disease and its negative impact on the participation of diabetic workers in the labour market (Pedron et al., 2019). Absence of work of employed diabetics and their reduced productivity caused indirect losses in the order of US\$30 billion in 2017, while diabetes-related disability of people who are not in the labour market reached a cost of US\$37 billion in the same year (American Diabetes Association, 2017). As previously identified, one of the main factors of diabetes distress is the fear of diabetes complications and how they will affect futures prognostics.

Triggers to diabetes distress can also be found in society. In research about the correlation between glucose levels to the social and cultural environments, Rock (2003) states that the environment can play a key role to increase the average values of blood sugar. Access to an incompatible income, lower access to education, housing and nutritious food are social determinants that lead to increased progression of diabetes (Akhter et al., 2016). One quarter of participants in a study in Switzerland claimed that stigmatization of diabetes was the main reason for being denied life insurance and supplementary healthcare (Gredig and Bartelsen-Raemy, 2017).

Access to specialized medical assistance is essential to address diabetes distress. Balfe et al. (2013) points out that lack of continuous care with the same endocrinologist and

limited amount of time of appointments can be a source of frustration. Talking about diabetes distress may become a secondary subject during appointments. Furthermore, emerging evidence shows that the communication between healthcare professionals and patients may contribute to increased distress (Skinner et al., 2019). Yet, diabetes distress hasn't been dealt with as part of the condition management.

To conclude this section, it is possible to affirm that the diabetes distress is a key element to the management of diabetes. The control of the disease still relies heavily on the patient, but the environment around effectively plays a significant role to disbalance the management. Finding the areas of conflict and addressing them can help diabetics in better management, leading to the reduction of diabetes distress.

3.4 Self-determination theory

The SDT (Ryan and Deci, 2022) offers a framework to understand the motivation of an individual in engaging in certain activities. The analysis is mainly based on 3 factors: autonomy, competence and relatedness (empathy). When there is the presence of these conditions, individuals are more likely to be motivated to fulfil a role in the society. If the person does not feel satisfied in these 3 aspects, the motivation to perform the same role diminishes. The opposite to the core values necessary to build motivation are: dependence on external factors, which negates autonomy; being uncertain about a topic, which reveals lack of competence; and lack of empathy or isolation, missing any relatedness.

Research on diabetes shows that the lack of fulfilment in these areas can lead to distress, affecting one self's ability to manage the disease. Based on the problems found in the environment of the diabetic individuals and the subdomains of DDS17 (Polonsky et al., 2005), they can be framed under the SDT (Ryan and Deci, 2022). This process served as a guiding framework to inform design interventions. The process was necessary to visualize what points must be addressed and then implement a solution.

The use of the SDT applied to diabetes management has proved successful in recent studies. Among the benefits listed, it is worth mentioning that the behaviour change theory has potential to improve adherence to the therapy, self-management, and overall quality of life (Sarfo et al., 2023). However, Mathiesen et al. (2021) mention that the success of the model does not depend on the application of one exclusive framework, but rather on the combination of different resources.

3.5 Field research

3.5.1 Research method and sources

The field research consisted of finding real life examples of diabetic patients facing diabetes distress, interacting with them, and perceiving their pains through a holistic view. Collecting qualitative evidence to guide the discovery step of Design Thinking was the main goal, willing to generate interventions that address the diabetes distress situations. Therefore, this step is naturally human-focused, investigative and interactive.

To reach the desired anthropological base for this research, contacts were established with patients and clinics in Brazil and Estonia, an association in Estonia, alongside interacting with opinion leaders and online P2P communities. Observation was conducted in contexts that individuals would need to manage diabetes and how they would react to it, aiming from an external and neutral perspective. This variation in sources provided a rich background that allowed a wide, yet detailed overview.

Interviews were made with patients, opinion leaders — whether diabetics or not —, besides contacts with a diabetes association and doctors. In total, 8 interviews were conducted: 3 with diabetic patients; 2 with diabetes-specialized nurses who are also diabetic patients; 1 with an opinion leader who is a diabetic patient; and 2 with parents of diabetic patients who act as opinion leaders. All the conversations were conducted in distance, except one that was held live during the Diabetes Day event. They happened in a context where the researcher provided a context about diabetes distress and motivated the interviewees to remember cases and detail their view on them.

This sample gathers views from different profiles that are important to consider, including in the medical field. The research is limited in terms of reaching DMT2 patients, who did not manifest interest to participate. Two endocrinologists, who were not interviewed but agreed to talk informally about the subject during medical appointments, also corroborated that it would be difficult to convince patients to participate.

Interactions with the Reddit community¹ and WhatsApp groups have access to a broader audience and were also important in the process to understand situations that cause or increase diabetes distress. All these interactions revealed different sources and different backgrounds that are regardless of specific types of the disease. Later, a collaborative session was conducted online in March/2024. During this time, the researcher and the

¹ r/diabetes: <u>https://www.reddit.com/r/diabetes/wiki/index/</u>. Accessed on 21.10.2023

groups reflected on situations that cause diabetes distress, the reasons behind this condition and how they deal with the situations. The most common citations were selected and further investigated. The network of participants was built together with collaborators from the Estonian Children and Youth Diabetes Association and Brazilian online P2P communities. A reflection on these interactions as follows:

3.5.2 Contacts with patients: interviews and live observation

Patients who are affected by diabetes distress are the focus group to define the problem space to be worked. The goal of the interactions with them is to find how the 4 subdomains of diabetes distress impact patients and analyse why this happens. Observation, interactions and interviews were the main activities performed with this goal. In a later stage, collaborative sessions were hosted to involve them in the design process, strengthening the validation of the process.

The first round of observation and interactions happened during the "Diabetes Day" event organized by the Estonian Children and Youth Diabetes Association to raise funds and awareness for diabetes. The philanthropic gathering happened on the 18th of November 2023, on Kadriorg Park, in Tallinn, featuring a 3,5 km run. Around 100 people were at the event, among diabetic patients and their families, corporate service providers and the staff of the organization. Many of the diabetics were DMT1 children and teenagers, alongside adults with the same condition. Unfortunately, DMT2 patients were not present, reflecting an understanding of organizers on their low engagement.

It was possible to see that most of diabetic individuals do not compromise their therapy management if they are around other people who empathize with their situation. Participants were talking about their devices and sharing tips, but overall, they wanted to enjoy their time together and the support they received. This is a positive sign, showing that they feel supported in this event, a relief in the stressful routine. They otherwise must face the emotional burden of diabetes management alone.

The purpose of the event itself had a goal of decreasing diabetes distress in children. An example of this context was a mascot distributing sweets to the people in case any of them would have a low glucose episode. This enhances security and support to the patients coming from a friendly character, while they perform a physical activity. These interactions caused a positive effect, inspiring guidelines for design interventions. When it was possible to approach individuals, an adult man holding a dog on a leash was an interesting choice. The pet wore a vest with the message "Diabetes Alert Dog". This is a dog trained to smell when the owner has hypoglycaemia and to alert the person by intensive interaction. The man and his family provided a rich content about the relevance of the pet in diabetes management. It was mentioned that the companionship of the animal is not only effective as a functional way to prevent low and high glucose episodes, but also provide a sense of security and emotional connection. The man also mentioned that the dog insists on the interaction with the owner if the level of glucose is critical, avoiding more serious outcomes. Diabetes alert dogs is a unique approach to deal with diabetes distress, increasing the sensation of relatedness and reducing the uncertainty.

During the conversation, the man reported his long experience as a diabetic patient. He did recall his first years as a patient during the independence of Estonia, and there were not many options of therapy. At that time, there were few resources to control diabetes in a long span. Despite considering the whole range of improvements made available since then, he thinks there is a lot to be improved.

After the event, more interactions were conducted. New observations and conversations revealed different aspects of diabetes distress. A young foreign man living in Estonia reported his experiences traveling around the world. He could not predict a low blood glucose during a short trip and struggled to raise the level of sugar again. The decision to eat sugar did not change the situation for the next few hours, which caused a fear that something out of control would happen in a foreign country. Fear of hyperglycaemia (low blood glucose) is also the reason behind the diabetes alert dog. Within this conversation, the man reported being concerned about food habits and avoiding long-term complications, being grateful for receiving support on this from local peers.

Another individual interviewed revealed that a diabetes community raised his awareness about open-source platforms and DIY systems that integrate products from different brands to control diabetes, improving his well-being. Diabetics feel comfortable to share their experiences and tips with other peers. However, apart from these groups, diabetics typically find it difficult to share their anguish and fears with other people. "It is like a prison", said one of them when asked about sharing diabetes struggles. According to this and other testimonials collected through this study, patients were afraid that no one else could understand what they have been through. In this context, interactions organized by diabetes associations and P2P communities are the only safe places for them to reach others and to understand their journey, removing barriers that increase distress. Lack of empathy from others may lead diabetics to give up valuable therapies due to social embarrassment. A man in his 40s shared a though about insulin pumps not fitting his expectations. During his brief experience using the device, he reported making a customization of his clothes to hide the insulin pump. When asked why, he mentioned that he was doing this purposely to avoid showing the device when surrounded by people. He wants to keep his diabetes a secret, in a clear sign of social discomfort. This act can be framed as a symptom of diabetes distress generated by a social conflict, and decreases the effectiveness of diabetes management.

Certain cultures can affect the openness of patients with diabetes. Developed nations with easy access to management tools tend to be more accepting of visible devices. In the P2P communities, the United States is often mentioned as a place where diabetics are comfortable wearing devices and performing glucose control in public. Conversely, lack of testimonials about other places may hide that diabetic individuals there are not having access to a good therapy or are hiding their condition.

In this round of interviews and observation, it was possible to discover that diabetic patients feel vulnerable and exposed to low blood glucose. They are also aware and afraid of the danger of high glucose for a long time, without monitoring it. Most of the people agree that support from groups is beneficial, and sometimes even raising awareness about new resources.

3.5.3 Contacts with patients: observation of P2P communities

P2P communities gather different backgrounds and patient profiles, a rich environment to explore. Observation-oriented research of such environments has the potential to uncover valuable insights that more precisely reflect user's needs (Brown, 2008). Two communities have been observed: a Reddit group called r/diabetes and a WhatsApp group of Brazilian insulin pump users. In the first community, there are DMT1 and DMT2 individuals, following a variety of therapies, each with different devices. On the Brazilian WhatsApp group, the focus is on a specific model of insulin pump, hence only gathering DMt1 patients and parents of children and teenagers with diabetes. The interaction of these groups was focused on following members talk about their issues.

The Reddit group allows users to post questions and stories about their diabetes management, and other users have the chance to comment on the post. Several topics address diabetes distress, with people asking for advice or reporting uncomfortable situations. Examples of these posts are: people who were anxious about traveling abroad safely with medications and devices; individuals who did not find doctors that can help with the distress caused by life with diabetes; persons who suffered rejection specifically due to their diabetes. Despite this rich background, the community does not accept interactions for study purposes. The interaction was then limited to observation.

Other topics that have been reiterated discussed were the adherence to the therapy and what meals are adequate for better management. Patients complained that it is unrealistic to follow perfect care due to the environment they live in. It can be easy to forget to manage diabetes during a busy workday, stated participants. They also agreed that forgetting to count the amount of carbohydrates ingested can lead to a difficult day, as it strongly affects blood glucose. An adult participant mentioned that he shares CGM numbers to his parents because he was afraid of collapsing because of low glucose in the blood. Other dependence on others to manage diabetes were common.

On the other hand, there are users with experience in those problems that could share their own successful stories and failures during their process. In all the cases previously mentioned, there have been more than one answer that shows valuable ways to approach the issues. The post authors immensely value the opinion of other users, as such feedback was not found in real life. The person who is answering is in equal conditions to the inquirer, meaning that the answer has added context and relevance. In this way, they help to address diabetes distress.

It was possible to observe DMT2 patients participating in some topics, but they were underrepresented considering the proportion they have on statistics. They looked for support in finding better food options, the effects of diabetes in the long term and about daily disease management. A considerable number of interactions, however, were from other stakeholders surrounding the diabetic. The reason could be a recent diagnosis or a result of a test that seems out of the target, with the posters showing a concern on the commitment of the patient to perform enough fingersticks and keep a balanced diet.

As a more exclusive group, the insulin pump community features questions about the use of the device. Most of them could have been answered by the customer support of the device supplier, but here the prompts are answered in a matter of seconds or minutes by members of the community. As mentioned previously, diabetics face the disease 24 hours per day, meaning that a quick answer can guarantee peace for a night of sleep, or a safe time during a weekend. Hearing from a person who has been through the same situation before seems to add relatedness, also derived from the human factor present in this interaction rather than contacting the customer service.

24

Inquiries about the best battery to be used with the pump may have an obvious answer from the device supplier: they have their official version and will only recommend it. But in an environment that individuals may not have access to a specific brand, another solution must be found. People in the WhatsApp group promptly shared their thoughts and experiences on the best products, and even how to make a battery last longer than usual. If the tip does not work, however, the person who asked in the first place will not think that the answerer lied or took advantage of the situation, because "it may not work every time". If the failure came from the device supplier, however, it would not be accepted as easily, as some complaints on the brand made clear.

Although the vast knowledge available within the groups, some concerns appear to be unclear to all of them. Diabetes complications pose a main issue for patients and users of the community. A young diabetic man in the Reddit group inquired about feeling his feet burning, as this can indicate complications caused by bad diabetes management. Being diagnosed for only a couple of years, his first months featured long times exposed to high glucose. Lately, he took better control of management. In his inquiry, he presented glucose rates that were considered good by the community, but he felt guilty about the first months and concerned that he was on a no return path of complications. Other users who commented made assumptions to help him, saying that this may have happened due to other reasons that are not related to diabetes, but they cannot really confirm their impressions. Some participants also reported that, after years of bad management, they finally managed to reach desirable indicators, but then the complications rose.

The P2P communities fulfil a role that cannot be played by any other stakeholder in this environment. They are not technical or medical specialists, but they have appeal with the diabetic individuals because they own experience, credibility, empathy to other diabetics and are almost immediately available all the time. Even if sometimes they do not have precise answers, they help people with doubts to reflect and search for alternatives to solve their concerns. With their work, they seem to effectively help diminish the effects of diabetes distress.

Following the research method proposed, the interviews, observations and interactions with diabetics provided a rich background and valuable insights on their lives and the challenges they face. They form rich fragments of a story, and the means to connect them is the distress related to their condition. Yet, many other situations have not been placed here, giving an impression that the complexity of the disease cannot be underestimated. Analysing these testimonials lead to fitting them into degrees of diabetes distress and framing them under the aspects of the self-determination theory.

25

3.5.4 Interactions with clinics, endocrinologists and nurses

Endocrinologists are among the most important stakeholders in diabetes care. These doctors are specialized in the endocrine system and, consequently, the deficiency of insulin. Together with nurses, they become the educational figures that instruct diabetes patients and follow up the positive and negative trends of the disease through the years, making decisions to protect and improve the life quality of patients.

Despite the importance, the competence of doctors is one of the topics addressed in the DDS17 (Polonsky et al., 2005). According to the questionnaire proposed, there is a chance of the diabetes distress being connected to issues in the doctor-patient relationship. The DDS17 mentions 3 struggles of patients that may be attributed to the doctor: frequency of interactions, lack of clarity in instructions and not taking concerns of patients seriously enough.

An endocrinology specialist from Brazil and another one from Estonia were consulted. Since these doctors found limitations in their schedules to collaborate, the interactions were conducted as normal medical appointments with the researcher. The endocrinologists agreed to talk informally about the topics during 2 appointments with each of them, and other facilities of the clinics were observed as well. During the interactions with the doctors, it was possible to see that they are really dedicated to helping their patients. They reported asking their patients to present short-term and long-term tests that could unveil diabetes complications and address the issue at its origin, increasing chances of better assistance. There is a clear instruction on the results of the tests and the possible complications. Some of them even share mobile phones for conversations after appointments, if necessary.

However, the doctors and clinics visited are only a small sample. In many situations, interaction with patients is mainly limited by the time of the appointment, and by consequence, the focus of the appointment may fall to the basic measurable metrics. Other important aspects, such as diabetes distress, may be a topic that is not directly discussed in every appointment. And it is not possible to confirm the lack of clarity of instructions and the other claims.

A testimonial from a nurse who works for a private company reveals that doctors from the public healthcare system may not follow these profiles previously mentioned. It was claimed that they prescribe obsolete therapies by modern standards due to the lack of other options, otherwise the patient will not have any therapy. When the patient is willing to take a more advanced therapy, these same doctors may discourage the person to do so.

Other conflicts emerge in the doctor-patient relationship, highlighting different priorities of both sides. A patient that has been interviewed reported that his approach to blood sugar control challenged doctor's warnings. He feared possible diabetes complications and kept glycaemia constantly at a low level. He trusted that it was possible to revert risks linked to his approach by quickly eating carbohydrates. In the end, the patient had an episode of conscious loss and was rescued by an emergency team with injuries on his head. If the rescue did not come in time, he could have died. His fear of facing longterm diabetes complications lead him to make mistakes that put his life in danger.

Shared-decision making could benefit both patient and medical stuff, but there should be room to discuss situations that contradict both sides. If the system is restricting interactions from the part of the doctors, the empowerment of patients could diminish this issue. The empowerment makes it necessary for the patient to be more competent on the subject, and this can lead to more autonomous decision-making. At the same time, different educational tools may provide doctors better options to help reduce variation in glucose levels without need for increasing interaction with patients. Consequently, diabetes distress would impact individuals less.

3.5.5 Contact with the Estonian Children and Youth Diabetes Association

Alongside the findings in scientific literature, it is important to find local examples and trends about diabetes distress and its disruption to the lives of the individuals. For a broader view of the local Estonian context, an interview with an opinion leader was conducted to detect situations that reflect the environment reported previously in articles. A member of the Estonian Children and Youth Diabetes Association, that also manages the Diabetes School, provided a testimonial about the context of Estonia.

The association is a non-governmental institution that aims to have a dialogue with society about diabetes and advocate for the rights of diabetics. The interviewee explained that the foundation of this organization dates to the context where Estonia had just joined the European Union in 2004, yet to reach levels of other OECD countries. Back in 2009, kindergarten institutions could claim that their teachers were not able to take care of children with diabetes. The European standards of healthcare hadn't been available for diabetes care in Estonia, and people only had access to a fraction of what was needed to manage the disease. Between 2008 and 2009, there was an economic crisis that brought financial instability and attenuated the difficult situation of people who needed to purchase these items.

In this context, a group of parents created the association to focus on the needs of children with type 1 diabetes in Estonia. The interviewee was one of these parents and described in detail what they aimed for. At first, the most essential goals were to make sure that people can have subsidized supplies for disease management and that kindergartens and schools would accept all children with diabetes. Being successful in the first task, they also found ways to fulfil the second one. Yet, they acknowledged that a strong stigma was making every achievement in the social field much more difficult to reach. This was one of the reasons why Diabetes School, an institution that educates people about diverse dimensions of diabetes, was founded by the same group.

It was possible to see in this testimonial that society does not seem to be particularly interested in addressing social topics related to diabetes. Referring to the context shared by the interviewee, if someone has the correct supplies and advanced technological tools, this would be enough for a person to reach a normal life with diabetes. Both the Estonian Children and Youth Diabetes Association and the Diabetes School address this disregard by promoting campaigns and participating in public debates.

3.5.6 Interviews with opinion leaders

Opinion leaders are individuals who are engaged in promoting improvement in diabetes care. For instance, they clarify patients' questions and promote new technologies in their social media groups. In total, 2 individuals with this role were interviewed. The first interview revealed new aspects to the research. The woman has had diabetes for more than 20 years and started YouTube and Instagram channels to talk about the management of disease. Later, she also covered different aspects of diabetes management, including the medical system and its vision from the patient side. The Brazilian healthcare system may not provide easy access to the devices and technologies, and patients must file lawsuits to acquire supplies necessary to an advanced diabetes management system. This opinion leader became an influential consultant and expert, and started clarifying questions from other diabetic individuals.

It was mentioned during the interview that technology can be great, but depending on it all the time makes diabetic individuals lack autonomy. The insulin pump of the interviewee was broken by the time, and she does not have a substitute pump. A temporary replacement product was from a previous generation, not compatible with the set of supplies that the person already had, being necessary to purchase new products. This leads to high levels of diabetes distress, since this means a back step in the therapy. Using the words of the interviewee, "we can be hostage to the situation".

28

From this part of her testimonial, it is possible to connect these issues with further financial burdens of a patient. According to the interviewee, many people will only have access to the public healthcare service and the Brazilian government only guarantees subside to the most basic therapies, which does not really help prevent diabetes distress nor long-term complications. These therapies normally consist of a long length effect of insulin and blood glucose stripes. Examples of cases have been mentioned that people did not know how to use these resources, ranging from people who overuse the insulin and had constant low glucose to people who had dangerously high glucose rates.

Table 2 — Insulin pump costs compared to median incomes in Brazil and Estonia				
	Brazil	Estonia		
Median incomes in the 4th quarter of 2023	R\$3.063,00**	€1.904,00***		
Monthly costs of a Medtronic 780G pump, excluding insulin*	R\$3.456,75	€436,22		

*Costs researched in local distributors, based on 1 box of CGM sensors, 1 box of insulin cartridges, 1 box of infusion sets, 1 AA battery and 1 AAA battery, following the specifications of Medtronic, as of 02.04.24. **According to IBGE - Brazilian Institute of Geography and Statistics, as of 19.04.24 <u>https://t.ly/CEFa9</u> *** According to Statistics Estonia, as of 19.04.24 <u>https://t.ly/6NcSK</u>

Table 2 shows insulin pump costs compared to the local median income. In Brazil, they surpass the median income, while in Estonia, it may take almost a quarter of the income to purchase the necessary items. It is essential to remember, however, that subsidies were not applied to this analysis. However, these policies are not widely available for the whole diabetic population, according to the testimonial of the opinion leader.

The interviewee also connected this negative trend to the doctors' openness to the most advanced systems. According to her, it is typical to hear from doctors of the Brazilian public healthcare system that diabetes can be well managed by a restrictive diet mainly, without the need of CGM. The reasons, however, must be further researched at the local level, which is not the goal of this essay.

The second interviewee is a father of a DMT1 teenager, being also the administrator of a WhatsApp group. In the community, he promotes donation and distribution of supplies to peers that don't access adequate supply chain. Moreover, he shares his expertise with other parents whose children were recently diagnosed. The group had 200 members at the time. This testimonial focused on the moment that the patients first receive the diagnosis and unfolding, followed by the uncertainty that makes every decision much more difficult. While his child was participating in parties or other social gatherings, the man mentioned that it

was possible to see frustration when his daughter had not been offered the sweets that other children had. According to him, his daughter had enough knowledge and autonomy to accept or refuse the offering, so it was not necessary for the other to avoid it.

He reported that his child does not want to share many details about the diabetes management, and that they have a silent understanding that this is acceptable. Most of the other members of the community are parents of diabetics like himself, showcasing an engagement of this group of stakeholders. The overall wish of the peers is, according to the interviewee, to offer a healthy, happy and autonomous life for their children.

3.6 Defining design opportunities

The field research performed in Brazilian and Estonian contexts builds a rich background to understand diabetes distress. Relevant aspects mentioned in the DDS17 (Polonsky et al., 2005) were approached and observed, allowing the researcher to understand the roots of the issues. Moreover, there are findings that can be framed under the SDT (Ryan and Deci, 2022), in a way that diabetic individuals can relate.

Interactions with individuals during the Diabetes Day event, alongside isolated contacts, highlight the need for a person to be comfortable in the environment. Individuals may use creative resources that help them to have an easier living in such places, including the patient who hides the insulin pump or the one who has a diabetes alert dog. Providing them with tools that are not invasive, but can still reflect their own lifestyle, can lead to improved chances of better diabetes management. Additionally, it was possible to see how positive social environments can help diabetics to reduce the effects of distress. The findings reveal that better user interaction and user experience systems can be discussed, alongside focusing on human point-of-view.

Connecting with online P2P communities revealed a wide universe of testimonials with diverse experiences and perspectives that emphasize good degrees of relatedness and autonomy, aspects of the self-determination theory. These support groups provide emotional support and a valuable point of view from other diabetics, who are knowledgeable and play the role of guidance to the ones in a weak position. Informal networks like these have an extra element of value and appreciation. Design interventions to reduce diabetes distress certainly must incorporate elements of these communities, which brings the possibility of co-designing solutions with the patients.

The role of doctors, nurses and medical institutions is crucial and can influence the increase of diabetes distress. Medical staff that served as reference for this document are dedicated to the cause and wish their patients to improve their health condition. However, other stakeholders claim that this is not always the situation they face. The healthcare systems are complex and change demand resources and many hours to adequate it to a new methodology. From this perspective, a different approach should focus on increasing the possibilities of the patient to plan their own goals for the disease management with the support of the doctor. A reframed vision should view patients as more autonomous and competent, following their desire detected in the field research.

A similar trend could be found in a wide social level. Interventions on the system seem complicated, as they address situations that are influenced by many stakeholders. Yet, it is always possible to suggest new policies and approaches. The example of the Estonian Children and Youth Diabetes Association shows that changes can happen if the institutions are presented to the issue. Empowering these associations can be a way to help them to reach their goals and to improve awareness.

Lastly, the experience of the opinion leaders revealed aspects from the human perspective to a wider system view. Dependence on technology is both creating more autonomy and increasing dependency of users to the devices at the same time. Access to technology is another problem due to the high costs presented. From this report, conclusion leads to alternatives that can provide more customizable tools to the patients, that will be developed with HCD creative tools.

Design interventions focused on integrated holistic approach are necessary. They must empower individuals and remove pain points. The opportunity for interventions presents itself as a reduction of complexity of systems, rather than adding more elements.

3.7 Problem focus

Understanding holistically the experience of patients affected by diabetes distress, later utilizing these insights to inform design interventions to reduce the influence of the reported issues in the lives of the individuals.

3.8 Research question

How to reduce diabetes distress through a holistic design approach?

4. DESIGN PROCESS: DEFINE, DEVELOP, DELIVER

4.1 Problem definition

Diabetic individuals experience emotional burden, physician-related distress, regimenrelated distress and interpersonal distress related to the condition. Despite evidence of the impact of these distress factors, a significant gap in addressing them exists. Design interventions with a holistic design approach informed by the SDT (Ryan and Deci, 2022) can improve overall well-being by reducing diabetes distress levels.

4.2 References of design application to help management of diabetes distress

Different strategies to address diabetes distress have been tried throughout the years. Berry et al. (2015) reviewed service design with educational approaches that address diabetes distress, in which patients are followed during the self-management of the disease. The issues detected in the systems are that the interest from patients and families is normally low, and improvement to diabetes management may work only in the short-term. In this scenario, efficiency improves if the educational approach is followed by motivational strategies and goal setting that generate indicators to the stakeholders. According to the researchers, most of the educational approaches lack the emotional component of diabetes management.

Considering that frameworks that use motivational aspects to improve efficacy of educational programs, psychological follow-ups would have to be part of them. In 2010, a program that utilized Cognitive Behavioural Therapy for Adherence and Depression (CBT-AD) managed to help type 2 patients reduce depression and improve self-management behaviours. This led to 3 out of 4 participants to reach better glucose levels post-treatment (Melkus et al., 2010). According to Berry et al. (2015), the integrative nature of the exercise is the main cause of its success, because it considers psychological, behavioural and educational aspects acting on each other. The researcher states that addressing practical elements of diabetes is still something that psychological therapies lack, hence the importance of integration.

Another successful integration of the educational, psychological and motivational spheres was the program called PRIMAS (Peyrot et al., 2005). By integrating self-motivation aspects, goal setting to reach milestones and diabetes distress evaluation to a traditional educational program, PRIMAS managed to reduce long-term blood glucose

levels of participants, compared to a control group who did not take part in the process. Berry et al. (2015) highlights the showcase of the efficacy of integrating cognitive, emotional and interpersonal factors to diabetes education.

The use of tech devices to manage diabetes and, by consequence, address diabetes distress, have increased in the last 20 years. One of the main achievements is the closed-loop system integrated into an insulin pump. These devices can inject insulin on demand by analysing the blood glucose trends through a separate sensor. If the patient presents a low amount of sugar in the body, the pump will stop supplying insulin until the patient reaches normal levels, while automatically injecting when there is insufficient insulin. This has the potential to reduce distress levels but does not eliminate the burden caused by a diabetes routine. Insulin pumps still request the patients to plan, have controlled diets, to test the blood glucose and to replace supplies from time to time. According to Fagherazzi (2023), diabetes distress may remain despite diabetes technologies. For each benefit the technology brings, there is a trade-off or a suspicion that the technology is not fully solving the problem.

A study named REDEEM (Fisher et al., 2013) aimed to utilize a computerized program to address the 4 subdomains of the DDS17 (Polonsky et al., 2015): emotional burden, physician-related distress, regimen-related distress and interpersonal distress. The diabetes distress was significantly resulted after the tests, especially increasing selfcare behaviours on those who previously had high regimen-related indicators. However, the long-term glucose levels did not improve much, which Berry et al. (2015) attributes to lack of integration of a holistic approach to psychological factors and lack of personalized user preferences to the performance software regarding long-term blood glucose levels.

Although it is not a designed solution, diabetes alert dogs fulfil very well the role of reducing distress. Based on the interview reported in this study, the pet somehow performs social and emotional assistance on top of the main duty of preventing low and high glucose. Elements of this experience may serve as insights to design devices with the same aim.

Based on the evidence collected, it is possible to reduce diabetes distress by addressing multiple aspects at the same time. Individual items have the potential to reduce the condition as well, however, integrated options have showcased much more significant returns. Therefore, thinking on different layers of design interventions was approached to reduce diabetes distress in this thesis.

4.3 Description of the design-oriented evidence collection to guide the interventions aiming to reduce effects of diabetes distress

Based on the problem presented and on the conclusion of the research, a coherent design approach to achieve the reduction of diabetes distress by addressing self-determination theory aspects requires a complex structure. It focused on the individual needs of the patient, transitioning to collaboration with other stakeholders until finally reaching layers of the system. Therefore, the methodology chosen has elements of HCD, collaborative creative design and design thinking.

These design frameworks are complementary to each other. This structure is comprehensive, because each model builds up on the patients' needs to generate concepts that address their behaviours linked to diabetes distress. As mentioned previously in the research, multi-layered concepts with focus on education, emotional and practical aspects have more chances of being successful.

The aim was to review complicated steps in the process and replace them by seamless and holistic alternatives, to add assistance to situations where the patients cannot find someone to help, to attenuate the burden of the diabetes management and create a more positive environment to take care of diabetes. In the design phase, opportunities to act were identified, with stakeholders being part and contributing with relevant insights to the final design. By the end of the process, the final goal empowered and engaged the diabetic individuals by offering an approach centred on them.

4.4 Design research

Design research aiming to a holistic view needs a framework that places the individuals on the focus, understanding their needs, motivations and pain points. HCD stands out as an adequate approach for addressing challenges related to diabetes distress, given its empathetic focus on the persons. Moreover, the qualitative data obtained was turned into solid evidence for a more accurate design ideation and implementation.

Considering the complexity of diabetes and its management, the construction of a design concept revolves around the direct engagement of diabetic individuals. Patients willing to share their narratives on diabetes management and contribute to a better environment for disease care should be given creative tools to participate in the design

process (Sanders and Stappers, 2008). Collaborative design sessions with them through identification of pain points was a fluid way to uncover the nuances of diabetes distress. This method involves diabetic patients into the design process and explores their vision to get closer to their needs and aims. The insights from the participants were grouped in topics, using the affinity mapping technique. Clusters of problems that need to be addressed together could be defined, making the complexity of the diabetes journey easier to understand.

Storytelling techniques allow the transformation of the complex background into a narrative that not only generates engagement, but also frames the situations where design can intervene. The development of personas is a HCD technique that helps to build characters that represent key needs and pain points of the diabetic individuals, while also keeping a detailed background that creates empathy. This is complemented by the journey mapping technique, which permits placing these elements into a timeline, allowing needed touchpoints to be envisioned.

Using the SDT (Ryan and Deci, 2022) as a foundational framework allows the HCD process to highlight the psychological component that affects the individuals. The combination helps to categorize the aspirations of the patient, whether they are needing a better fulfilment of autonomy, competence or relatedness, if not altogether, to address the challenge correctly. This analysis ensures that the diabetics are offered the desired insights to decide.

The persons around diabetic individuals are not only important stakeholders, but also essential to support the management of the disease. Therefore, their participation in the touchpoints was considered. Lastly, summarizing the pain points to focus gave a clear direction to the project. Empathy maps and decision-making visualization are tools that transform the insights into easy-to-comprehend design opportunity clusters. To understand if the scenarios visualized reflect the reality of the patients, the maps were discussed with them.

4.4.1 Identifying pain points and mapping them by affinity

A collaborative session was proposed to 4 volunteers, of whom 3 are Estonians and 1 is Brazilian, all of them adults between 22–36 years old. The activity was planned to gather all of them together in one session. Unfortunately, the participants had conflicts in their schedules to meet at a specific time. For availability reasons, the interactions with them were conducted individually and focused on identifying pain points.

In the first step of the activity, the participants were informed about the goal of the research and about the concept of diabetes distress, as this is not a widespread theory among patients. After that, it was asked if they understood the concept and if they were familiarized with this term.

With that background, they were introduced to the second step, when they had to recall personal experiences of diabetes distress. The participants were asked to report them, while the researcher wrote them in a Google Jamboard. Examples were given to make their understanding of the dynamic better. These inputs were placed under the different categories of the SDT (Ryan and Deci, 2022) combined with the subdomains of the DDS17 (Polonsky et al., 2005). The input from one user also influenced other users to report similar situations in their own lives. If one specific item was more frequent in their daily routine, the sticky note became larger. Besides that, subgroups that can be linked as part of the same topic were grouped using affinity mapping. This clustering technique arranges complex information with similar patterns in groups, and these links can generate valuable insights to the design process (Tschimmel, K. (2012).

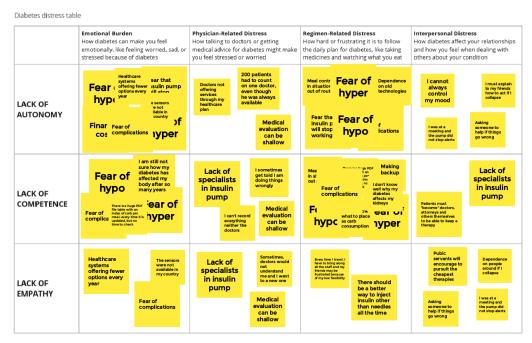


Figure 4 — Result of the collaboration session to map the issues faced by diabetic individuals

The insights from the participants showcase the complexity of life with diabetes. They can happen in short time windows, they can follow diabetic patients in their long journey with the disease, or they can be timeless, something that will be there regardless of the existence of an individual. Dependence on other stakeholders for both DMT1 and DMT2 is showcased among the concerns, as the patient wishes to manage the serious situations by themselves.

In their daily routine, patients may wish immediate action power compared to longterm disease management. At the same time, the chronic journey over months and years also seems to require detailed periodical follow-up, helping patients to keep track of their condition. Lastly, the timeless issues are also inserted in routine, but they bother the patients as frequently as the other situations. The main problems in each category that represent design intervention opportunities were summarized into common points.

Table 3 — Opportunities of design interventions categorized according to time matters		
Frustration with the management of one's own glucose control after meals, generating constant short length diabetes distress situations	 Fear of hypoglycemia (low blood glucose) and fear of hyperglycemia (high blood glucose) are the biggest concerns of patients in the daily management, and main causes of diabetes distress daily; Carbohydrate ingestion control is key to avoid them, but the current alternatives complicate the process: 85% of patients don't know how to do so or use a single metric for different meals; 	
Frustration with the management of one's own disease and its consequences, generating persisting long length diabetes distress situations	• The patients fear the long-term menaces that lead to other health conditions, and feel lost about how to control the triggers to them and current standpoint, being in a blind spot regarding their situation;	
Frustration with the status of the current alternatives of therapy options offered or the environment, and desire to change, which are timelessly presented to the diabetic patient	 According to one of the participants, distress directly related with the use of needles, mostly for the injection of insulin, affects 60% of the patients, which can also be confirmed in a study conducted by Tanenbaum (2016); The device options available in the market may not offer the flexibility that patients need; Lack of compatibility between brands; Costs of therapy and financial capability to afford it. 	

There is frustration with the management of one's own glucose control after meals, generating constant short length diabetes distress situations. Fear of low blood glucose, fear of high blood glucose and bad control of carbohydrate ingestion can be directly linked between each other, according to more detailed testimonials given by participants. Patients reported that a wrong input of carbohydrate consumption to an insulin delivery system, a dose that is described as bolus, can lead to low or high levels of blood glucose sugar in the aftermath of a meal. Sometimes, even a slightly small mistake can cost hours of concern and corrective measures. Some patients reported that they use an approach of the same amounts every day, regardless of what they eat, as they don't have the patience or knowledge to analyze the nutrients of their meals.

There is frustration with the management of one's own disease and its consequences, generating persisting long length diabetes distress situations. Patients declared that they miss an overview of the effects of long-term diabetes on their bodies. They only get information about this when they go to the endocrinologist and make tests, or they may go to a specialist in specific body systems that are affected by diabetes. Either way, they do not get a full picture, and tend to forget if the amount of recommendations is high. They feel that being in this blind spot can lead them to uncertainty about the future.

Moreover, there is frustration with the status of the current alternatives of therapy options offered or the environment, and desire to change, which are timelessly presented to the diabetic patient. There are elements in diabetes care that patients have no control over. Using needles to inject insulin and to perform fingersticks is considered highly annoying for some interviewees, but still remains the only «option for them since decades. If the patients feel highly bothered, they can even compromise their control to reduce distress of insulin injection or making blood tests. On another side of the same aspect, the equipment supplied, even the most modern ones, can create hassle for daily life and to increase diabetes distress. On top of that, they are not compatible with each other, in a scenario that makes specific sets of devices be unique and makes a patient dangerously dependent on it. This is increased by the approach of healthcare systems towards the equipment that is offered for the therapy.

Unplanned interactions with interviewees enhanced individual storytelling.

Organizing interactions between patients was a plan to add collective valuable insights to the project. The research plan included a focus group with 4 participants. Due to conflicts in their schedules, only 1 participant engaged in the main meeting. Later, it was only possible to schedule individual sessions with each of them.

This apparent issue has become a positive unfolding, giving more time to each participant to express individual stories, but still being influenced by the insights posted by previous interviewees. A Google Jamboard containing insights of previous individuals was displayed to the newer participants. Yet, the late interviewees mentioned completely different experiences compared to the previous ones, but they ended up enriching narratives within similar topics. There was also a difference in details reporting depending on the therapies each one followed, bringing different layers of complexity to the stories. In the end, the hindrance of meeting all the participants together caused trade-offs that may have affected the potential exchange of experience between themselves. However, the adapted research method reached relevant feedback and enriched the overall storytelling experience. As reported, the new approach still allowed important insights provided by the patients, which can be used to proceed with the research.

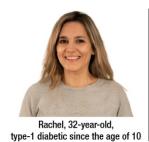
4.4.2 Identifying pain points and mapping them by affinity

Creating personas for this project is a crucial step to understand the aspirations of individuals within their contexts (Cooper et al., 2007). By compiling the insights from the research phase and interviews into a user profile, a relevant understanding of needs, pain points, preferences and behaviours is formed. These aspects allow designers to take the position of a diabetic individual and to approach the problem with an empathic view that should result in a user-friendly solution.

Visualizing the journey of the diabetic persona in the environment where the experience with the disease happens enriches the impact of the design intervention. As diabetes is a full-time care condition, these experiences are spread through the whole day, including the sleeping time, and in long-term. Valuable insights about the distress faced by diabetic persons and mostly situations that are not reported can unfold into a real reflection about the core of the difficulties, rather than just providing slightly better solutions. How should people react to the restrictions of diabetes, at the same time trying to fit their condition into a normal life? Mapping the journey of a diabetic may not answer this, but the answer comes from the reflection on that.

For a better representation of the challenges of the research, it is necessary to focus on 2 different profiles: a DMT1 patient and a DMT2 patient. These 2 different conditions affect individuals differently, meaning a different approach towards the disease. Therefore, different traits and pain points influence details on the formulation of the design. See appendix for a full profile of the personas.

DMT1 persona: Rachel



A day in Rachel's life

"Rachel went out with her friends last night and could not find an easy way to make carb control. As a result, she spent most of the night trying to lower her glycemic. However, she did inject much insulin, which caused on her a risk of low glucose. This was very bad news to her, as she is organizing an important meeting in the office. She thinks about calling her boss and ask to work at home in the morning. Eventually, she manages the glucose well and gets better, ready to go to the office. During a lapse in time, she does not manage to eat what she planned despite have injected insulin for it, and has a difficult time. Later at home, she tries to find similar stories from peers."

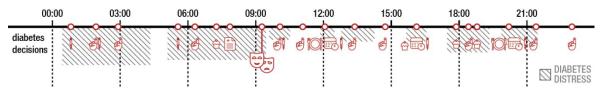


Figure 5 — The journey of the DMT1 patient, through the point of view of how many diabetes decisions are accumulated and their contribution to distress

DMT2 persona: Jeremy



A day in Jeremy's life

"Jeremy wakes up and goes for a walk in the morning, keeping a more healthy routine after the DMT2 diagnosis. Despite the effort, the food that he consumes is generous in carbohydrates, which makes his glucose to be high for a long time. However, he is not aware of this because he does not perform enough fingerticks because of needle anxiety. He also thinks that he can sense the high glucose. Two episodes of hyperglycemia in one day makes him and his wife reflect on other ways to control the blood glucose."

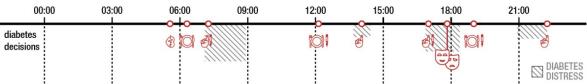


Figure 6 — The journey of the DMT2 patient, through the point of view of how many diabetes decisions are accumulated and their contribution to distress

Analysis of the personas reveal that DMT1 patients are more concerned about their condition. According to the interviews, this comes from the fact that their diabetes starts from an earlier stage in their lives, which makes it part of their routine. That also contributes to a more proactive effort of parents to comprehend diabetes and to partially taking control of management during the childhood of the patient. Consequently, these individuals focus more on full-time disease management and normally have a better-informed network.

The DMT1 persona is a young person who has career plans, appreciates spending time with family and friends, and would like to build a family. However, uncertainty brought by the management of diabetes creates obstacles for these plans. The persona has created a routine with strict management willing to avoid unpredictability, but this does not completely solve the issues. In the short-term, that can affect the sleep hours and the performance in the work environment. On the other hand, the fear of complications may hinder long-term plans. A DMT1 persona feels that there is a lot of dedication to the management of the condition, which takes time, and yet this is not enough.

Following this, a comprehensive analysis of the daily journey of the DMT1 person reveals cyclical patterns influenced by the challenges of diabetes management. The after-meal hours express the main issues of the management of diabetes, claiming many hours of attention if the carbohydrate control goes wrong. The decision-making process is quite important, but there seems to be not enough information to make the right choices. In this scenario, the design methodologies must aim for better conditions in decision-making journey to patients, allowing them to prevent wrong measures. Future plans are compromised not only by these short run downfalls, but also by uncertainty on diabetes complications, mining the autonomy of the individual.

The DMT2 persona is a senior individual who has discovered diabetes later in life. A daily routine with well-divided windows has been consolidated for many years. Adding habits to ensure a stricter control of diabetes becomes a hard intervention. That scenario reflects on not performing blood glucose control as often as desired by the doctor, which leads to long periods of unknown situations. Needle anxiety also contributes to reducing the willingness of performing frequent fingersticks, as the high blood glucose symptoms are somehow possible to detect, according to the persona. At the same time, this individual feel that if there were other ways to control the glucose that did not demand constant finger punctures, the control would be easier and more frequent. The vision of the person about long-term plans features plans for retirement and has clearer goals, but has a shorter length compared to the one visualized by the DMT1 patient.

The journey of the DMT2 persona traces a connection between the lack of better resources to control the disease, an underestimation of the consequences of the condition and bad management of diabetes. Inserting diabetes control into the routine is a challenge for these patients, and it is often difficult to leave established habits acquired over years or decades. One of the main diabetes management points rejected by the DMT2 patient is the excessive use of needles and the difficulty in accepting the need for better control. Eating and injecting insulin is taken as a closed loop to achieve the correct glycaemic range, rather than differentiating between foods that have potential to elevate blood sugar. The main challenge to design tools for this persona lies in addressing needle anxiety and alerting about the diabetes complications.

4.4.3 Empathy and decision-making mapping

After the previous steps of persona creation and journey mapping, it was possible to contextualize the emotional burden and downfalls faced by the diabetics. The design process was strengthened with a link between these pains and the consequences they generate, with the aim of removing these fears from the experience. The empathy map is an important HCD tool that allows the organization of the reactions of users to perceive them better, providing anthropological background that helps to define relationships with social groups or social tools (Tschimmel, K. (2012).

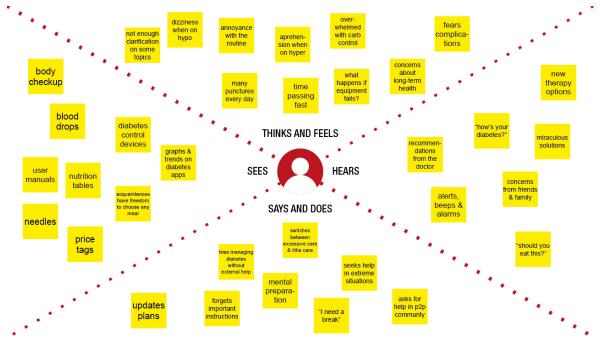


Figure 7 — Empathy map

There is frustration with the management of one's own glucose control after meals, generating constant short length diabetes distress situations. The carbohydrate control is a crucial part of diabetes management: knowing the content of a meal can make someone efficiently control the ingestion of insulin, and by consequence, the levels of glucose most of the time. A simple concept, but a rather difficult application, makes patients commit mistakes and release the wrong amounts of insulin into their bodies. The outcomes of these decisions can be explained as follows:

1. A person will conduct a precise control of carbohydrates and will inject the correct amount of insulin bolus. Therefore, the insulin will not disbalance the blood sugar in the following hours after a meal. This is, according to participants and doctors, the ideal scenario. However, other factors external to the

carbohydrate control can still contribute to a disbalance in the levels, but they are not frequent, as patients reported.

- 2. A person will exaggerate the amount of carbohydrates consumed and will inject an excessive amount of insulin bolus. Therefore, the insulin will overly lower the levels of blood sugar in the following hours after a meal, causing a dangerous outcome. The patients often reported that they can feel weak and sleepy. This requires immediate measures of compensation, mostly consisting of consumption of more carbohydrates in the form of sugar to quickly raise the levels of sugar, which not always, but often leads it to high levels after just a few minutes. The unstable glucose rates can persist for hours and disrupt the concentration of patients in other activities.
- 3. A person will underestimate the amount of carbohydrates consumed and will inject a low amount of insulin bolus. Therefore, the insulin will not be able to balance the levels of blood in the sugar in the following hours after a meal, causing a difficult situation. Patients may tend to inject bolus in excess when receiving constant high blood glucose alarms, disregarding insulin already in action (Garg and Jovanovic, 2006), which typically leads to low levels after a couple of hours. The insatiable glucose rates can persist for hours and disrupt the concentration of patients in other activities.

The decision-making is affected by the placement of board data about carbohydrate amounts and a complex functionality that calculates the insulin amount, comparable to the definition of Patti et al. (2020). Mapping these processes were important to reveal the complexity of the decision process and where the errors lie. The chart below shows the decision-making process and the reaction chains:

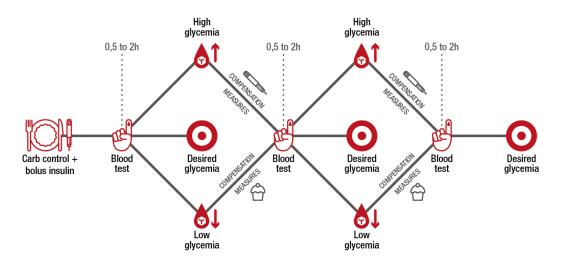


Figure 8 — General decision-making process of diabetic individuals after meals, inspired by the Design Council's Double Diamond model (2014).

Part of the distress is caused by the unknown, meaning that a situation could be out of control even with the best efforts of the patient. However, it is also possible that the patients will not perform blood tests to find out about glycemic. By doing this, they are probably reducing the amount of distress by ignoring the notification of a bad outcome, but ignoring their own may not eliminate this kind of distress. These patients will eventually have the symptoms of low or high glucose given by their own bodies, and may have to deal with even more extreme situations.

With the given qualified data, it is possible to conclude that the wrong control of carbohydrate ingestion is a key element in the diabetes distress, and the current options to deal with it are not being used by patients. Wrong inputs generate a chain of issues that are associated with diabetes distress, causing each patient to deal with the consequences of it during minutes or hours after the first decision taken. When asked, patients confirmed that the scenarios displayed in the decision-making flowchart are real, with one participant even saying that "carbohydrate control is always a gamble". The pain points that can be extracted from this context are:

- Difficulty in accurately estimating the amount of carbohydrates in a meal;
- Over correction or under correction, leading to more diabetes decisions;
- Dealing with the correction of glycemic rates hours after a meal bothers the patient, creating concerns and demanding attention;
- Fear of uncertainty, even after dedicating so much to correct the issues;
- Fear of more serious outcomes from these situations.

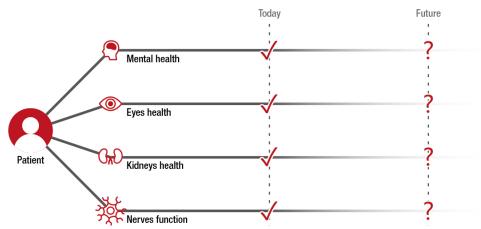
The key subdomains of the self-determination theory to be addressed here are competence and autonomy. Lack of competence induces the patients to commit mistakes, but this can also be associated with lack of suitable options for them to consult. The autonomy is taken because of the time spent dealing with the care of the low and high glucose, not allowing a patient to be available for other tasks.

There is frustration with the management of one's own disease and its consequences, generating persisting long length diabetes distress situations. A chronic disease is a persisting health condition that demands ongoing and long-term attention throughout the entire lifespan of an individual. Diabetes not only falls into this category, but also plays a significant role in prompting additional health conditions because of its bad management. Diabetes can induce health issues like nephropathy, retinopathy, and neuropathy, among others.

It should be a priority of patients to be informed about such issues. However, testimonials revealed that they miss information about the progress of consequences

that may be affecting their health systems, either by lack of own interest or by external issues. And that creates a scenario where the side effects may be already in the initial phase or advanced development, and these issues are not being detected and treated.

Everything starts from the patients' own care. Self-care is essential in medicine, let alone in diabetes management. However, the tools that can be used for the follow-up are not always a consent between patient and doctor. It was reported that it can be difficult to find a common ground with the specialized doctors about the adequate therapeutic options. Individuals also claim that sometimes, they cannot recall exactly what the doctor recommended. In addition, the healthcare systems may not offer the services that patients need. This scenario described by patients makes them fear that there are currently no viable alternatives for them to self-check their condition.



The chart below shows the uncertainty that patients face, based on their testimonials:

Figure 9 - Uncertainty on diabetes complications can cause diabetes distress

The pain points that can be extracted from this context are:

- Insufficient relevant information about personal long-term self-care;
- Uncertainty (or underestimation) about the stage of the diabetes complications;
- Information is lost or forgotten on the way;
- Concerns about shallow external evaluation;
- Difficulty to build the ideal feedback loop.

All the key subdomains of the SDT (Ryan and Deci, 2022) were identified in the claims of the patients and have the possibility to be addressed in this project. Lack of competence induces the patients to feel lost regarding their long-term condition and to miss important feedback loops. They consider that the options offered by external agents to face it are few, amplifying the lack of competence, which makes patients have a feeling of lack of support from their system. They mention that they can only gain access to specific feedback loops after insistence, if they know what they are talking about. However, the ground-level knowledge of a big portion of patients will influence them to not persist to reach these advanced therapy options. Therefore, a patient's desire of aiming for more autonomy by having more control of self-care is limited.

Finally, there is frustration with the status of the current alternatives of therapy options offered or the environment, and desire to change, which are timelessly presented to the diabetic patient. Diabetic patients can gain benefits to make the management of the disease more seamless with development of innovations in the sector. For instance, a Japanese technology introduced in the beginning of the 21st century reduced the duration of the glucose test process from 1 minute to 5 seconds (Yamada, 2011). Considering the user journeys described previously in this essay, this improvement may have improved the ease for patients to test themselves. Allied with other developments, this possibly contributed to reducing diabetes distress by that time. There are elements in diabetes care, however, that neither the patients nor the medical bodies or the suppliers can yet improve.

Using needles to inject insulin and to perform finger-sticks is considered highly annoying for some interviewees, but still remains the only option for a considerable number of patients. Following the journeys mapped in this essay, and based on the reports provided by patients, the need of testing themselves constantly is related to better diabetes management, hence the introduction of CGM technologies. This solution may be the answer to this user need, but not all the patients have had access to this management tool yet.

However, when talking about insulin intake, the use of needles or cannulas is still the only way to get the insulin to perform its function. If the patients feel highly bothered with this process, they can even compromise their control to reduce distress of dealing with needles. A cannula is a tube that accesses deeper layers of skin, allowing delivery of medication over a period of hours or days. It appears as a good option for reducing the need for injection, giving freedom to a more precise control.

On top of that, patients reported that they face problems with the lack of compatibility of the devices. Sometimes, even devices that are supplied by the same brand are not compatible with each other. This scenario creates specific sets of devices to be unique, making a patient dependent on spare parts that may not be easy to find every time and everywhere. This is increased by the approach of healthcare systems towards the equipment that is offered for the therapy. The map below shows the lack of flexibility caused by the current environment:

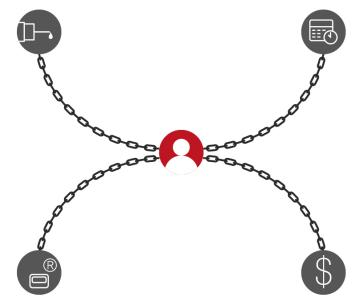


Figure 10 — Involuntary commitment of patients to external agents caused by the lack of options

The pain points that can be extracted from this context are:

- Excessive dependence on use of needles to inject insulin and perform blood glucose tests;
- Excess of devices needed to keep diabetes management;
- The devices available on the market may restrict too much the lives of individuals;
- Lack of compatibility between systems/brands;
- Concerns about affordability of the supplies.

When categorizing the pain points under the self-determination theory, lack of empathy appears as a strong factor perceived by patients. However, the limits imposed by several factors do not allow better products to be created now. New technological approaches and change of paradigms can trigger positive changes soon. The patients also feel a lack of autonomy to change a set of devices with the fear that it will not be always available, then combining a lack of knowledge.

4.4.4 User/stakeholder requirements

Based on the analysis of the pain points, the user requirements for the project determined the main areas of intervention, as follows:

Table 4 $-$ Conversion of pain points into user/stakeholder short length requirements				
Pain points	User requirement			
Difficulty in accurately estimating the amount of carbohydrates in a meal	More accurate and user-friendly ways of evaluating amount of carbohydrates in a meal and/or ways to prevent intake of disproportionate amounts of insulin			
Over correction of glycemic out of range, leasing to fluctuation in the opposite direction				
Dealing with the correction of glycemic rates hours after a meal bothers the patient, creating concerns and demanding attention Fear of uncertainty, even after dedicating so much to correct the issues	Further-detailed reports about the progress of glycemic rates during the critical lows and highs, while also preventing overcorrection by not triggering instinctive reactions			
Fear of more serious outcomes from these situations				

Table 5 — Conversion of pain points into user/stakeholder long length requirements				
Pain points	User requirement			
Insufficient relevant information about				
personal long-term self-care	A user-centered system to follow up			
Uncertainty (or underestimation) about	long-term diabetes specific complications			
the stage of the diabetes complications				
Concerns about shallow external evaluation	Increasing the level of awareness of			
	users about specific issues			
Information is lost or forgotten on the way	A way to attach temporary/permanent			
Difficulty to build the ideal feedback loop	information to a personalized feedback loop			

Table 6 — Conversion	of pain	points into	user/stakeholder	timeless requirements

Pain points	User requirement	
Excessive dependence on use of needles to inject insulin and perform blood glucose tests	Preventing the excessive use of needles by restricting it to the minimum needed	
Excess of devices needed to keep		
diabetes management	Integration of devices, allowing longer	
The devices available on the market may	range of use	
restrict too much the lives of individuals		
Lack of compatibility between systems	A system that allows compatibility	
Concerns about affordability of the supplies	A more affordable set of devices and supplies	

The user requirements were formulated to assist patients reaching better autonomy, competence, and empathy levels, corresponding to the subdomains of the SDT (Ryan and Deci, 2022). Approaching the scenario with this vision allows the design process to provide tools that enhance motivation and decrease the influence of factors that undermine well-being. The strategies to apply the principles are explained below.

Short length situations

- Autonomy support: providing tools and resources to individuals, allowing them to make well-informed and quick decisions about their diabetes management. This support can come as an assistant that relieves the mental load of making the carbohydrate counting and insulin dosage. Individuals would be able to have a wider range of food options and make better decisions about the management of their glycemic.
- Competence support: offering awareness about the impact of each decision, avoiding a mistake that can lead to a sequence of diabetes distress. The amount of carbohydrates consumed and the time that the body normally takes to manage them is important, therefore it is the main information necessary in the process. If they learn patterns, this can result in a seamless management in the future.
- Relatedness support: increasing the sense of empathy that patients struggle to find in their daily routine. A good example would be to fulfill the same role that the "Diabetes Alert Dog" provides, but in a way that is more accessible to more people. The connection with the P2P communities can be strengthened to create a sense of empathy.

Long length situations

- Autonomy support: helping individuals to follow up and better understanding the long-term diabetes-related complications on their health. This can be done by integrating existing platforms, such as CGM, to other services that can be complimentary. Furthermore, putting together procedures that can be performed by the patients themselves with more frequency allow the self-empowerment necessary to take better care.
- Competence support: increasing individuals' awareness about their condition is not an easy task. It requires a personalized medicine approach, with tailored information that allows accurate decisions. CGM is important as a centralizing tool, and it can provide relevant feedback on trends. In this new scenario, the doctor could be involved more than the current situation, by agreeing with patients on subjects on interactive means, including maintaining critical reminders. The strengthening of the current information flows of patients and

their P2P communities could provide individuals with more relevant cases and outcomes.

 Relatedness support: increasing the connections between diabetic individuals and healthcare professionals is a key point to address empathy. New means of communication should provide ways for both doctors and patients to monitor recommendations from previous appointments, and how they are followed. P2P communities should be enhanced and new means of consultation among the members should be created. The individuals can receive clarification and encouragement.

Timeless situations

- Autonomy support: integrating devices and making them compatible among brands can make individuals choose their preferred ones. Individuals can decide on products that are affordable over the expensive ones that are the only option, or the most durable over the one that lasts shorter, thus decreasing the distress of managing the condition. The conduction of this process could be partially made with the support of open-source communities that offer DIY systems. These interventions can also come in the form of new products tested and introduced.
- Competence support: raising the awareness of individuals that there are ways to decrease the interaction with needles, to better manage the devices needed to manage diabetes, and to find alternatives in the market that fit different profiles of persons. Increasing the integration of data received is also important, as much as the spread of these scenarios. P2P communities already welcome open-source systems, therefore both should be part of the plan to increase the reach of such solutions.
- Relatedness support: the same open-source communities can be the key to successfully developing these products. They are basically made by diabetic individuals and their families and friends, who advocate for better solutions, thus willing to develop better conditions. These are the ideal development platform for interventions.

4.5 Collaborative ideation

Collaborative design is a process that involves cooperation of designers and other significant stakeholders. The aim is to develop a design together, distributing the roles of designing the solution more equally, considering the indispensable background that all the agents involved offer to address the challenges imposed. In this scenario, the designers work with patients mostly, but also healthcare professionals and opinion

leaders to generate solutions. Sanders and Stappers (2008) describe the person who is contributing to the design process as the "expert of his/her experience", and the designer has to provide means for ideation and expression to this contributor. Including them in the design process is decisive for validation of the project.

Two techniques were used to get insights from participants: brainstorming and analogous insights. Brainstorming allows participants to express their vision on how the system would work to reduce diabetes distress. The analogous inspirations technique inspires participants to think of resources from unrelated fields that somehow can be brought to diabetes management and fulfil functions needed to solve the pain points.

4.5.1 Imagining an ideal scenario for diabetes therapy

A collaborative session was held to get insights from the participants about a desirable future of diabetes management, where they could propose a better environment for disease care. They were motivated to reflect on situations they faced along their lives and what could be improved to avoid the same issue happening again. Later, they described fields that could be better explored or improved. The aim was to imagine an ideal scenario for diabetes care, and they came with the following ideas:

Increasing duration of CGM systems and their functionalities. The potential of CGM systems currently available in the market have potential to be further explored, say the participants. They supported the idea of making them last longer and costing less, which would allow more comfort with the therapy.

Personalized-medicine devices. Most of the participants shared their fear of not understanding exactly their own condition. According to them, the devices should reflect their personalized needs, meaning that it would contain their history in diabetes management. With that approach, participants would be able to better control their goals.

Insightful advice system by P2P communities. As identified during all steps of the project, participants value interaction with P2P communities to improve their expertise on managing the disease. One participant suggested that any kind of intervention would benefit from allowing constant interaction between patients. This is already done in different ways, such as message applications, social media, internet forums or local P2P networks, so any intervention in this regard must consider this environment.

4.5.2 Analogous inspirations

Another part of the mentioned collaborative session was set to encourage participants to think of resources from unrelated fields that can be applied to diabetes management, with the overall goal of reducing pain points faced in the disease care. Their insights can be used as a reference of a role that can be fulfilled by an existing service, meaning that a solution does not have to be created from scratch, but rather from something that users feel comfortable with.

Photo recognition of meals and conversion of that into carbohydrates. Photo recognition was one point that all participants of the creative collaboration talked about. This would be used for recognition of ingredients in one meal, which would be converted into a sum of carbohydrates. The participants stated that it would automate the count and allow them to simplify the process.

Diabetes knowledge database and awareness testing. Among the participants, it was common to hear that a diabetes platform with general knowledge about the disease is needed. One participant suggested a Wiki-like structure, where the own audience of the website can contribute with the information by adding topics and editing the content. It would work as a source of information available to everyone for free, containing verified information and credible sources that would be checked and approved by the website's community. Other participants suggested that there is a need to test the knowledge of the patient from time to time, which would lead to better decision-making.

Products that would be compatible with other brands. An example of a product that faces different sets of standards and still performs its function was a tire. One participant mentioned that one could choose a set of tires that would fit many car models and brands, and they could function well regardless. So this participant proposed that some devices to manage diabetes would be like them.

5. DESIGN PROPOSAL: DIASYMPHONY, AN OPEN-SOURCE DIABETES CARE PLATFORM

5.1 Metaphor

Building metaphors is a creative exercise that helps developers to frame design problems. They open possibilities for non-obvious design solutions, as they frame the problems with another perspective (Casakin, 2007). Metaphor helps to organize the outcomes of the design thinking process. The following metaphor was created in the context of this study:

Diabetic patients wish to manage their condition as it was a symphony

Symphony is a good metaphor for the wish of diabetic patients to integrate the use of resources available to reflect their own needs and mental models. DiaSymphony is a name construction that approaches diabetes management to patients in the same way.

5.2 Outline of the concept

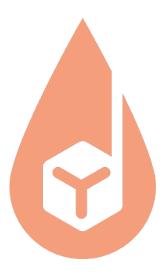
DiaSymphony is an open-source diabetes platform that presents resources to reduce diabetes distress in the daily lives of patients. It is composed of an AI assistant that helps diabetics to perform controls that reduce uncertainty in their journey and other physical products that help decrease the pain points of disease management. These interventions integrate with existing technology to ensure more autonomy, competence and empathy towards patients.

After evaluation of the ideas generated in discussion with diabetic patients, the design process culminates in the setting of an open-source platform that helps individuals to have access to resources that can improve care and decrease distress. The design intervention consists in the organization of systems that gather the resources available, integrate them into one platform and distribute them according to specific needs of patients. This decision was a consequence of evaluation and selection of the ideas and principles desired by diabetic patients, alongside trends happening in the field. The system also works as an information source to patients who do not depend on external insulin and other stakeholders who help patients, providing a search mechanism for carbs.

Starting with the point of view of the patient, the process of controlling blood glucose after meals was the main pain point in short-term windows. It was found out that the ways of doing carbohydrate control are not fulfilling user needs, and they are not integrated with other diabetes management tools. DiaSymphony addresses this pain point by creating a seamless process by using AI resources to simplify carb counting. However, if there is still an issue that could not be solved, it informs the user what should be avoided to generate a new chain of diabetes events that lead to distress.

Integration of existing self-care platforms and DiaSymphony allows patients to be informed about personal long-term health trends. Data from CGM systems and smartwatches can play an essential role in increasing the awareness of the patient about diabetes complications, while decreasing levels of anxiety. The users can make better decisions if they know that specific habits contribute to worsening the condition of one organ, and they can avoid it by working solutions with their specialized doctors.

P2P communities act nowadays as information cores to individuals. They have been an essential stakeholder to spread better diabetes therapies and decrease diabetes distress. They are places to find tips on how to deal with specific situations and frustrations, where vulnerable individuals find a chance to finally achieve a satisfactory feedback loop. In the platform conceptualized here, peer participation is integrated into diabetes care. Young DMT1 patients may be more motivated if talking to peers that have the same age, and they are able to filter these profiles. On the other hand, DMt2 patients may not be dependent on external insulin, and their profile will identify this to show only relevant information. The assistant will be able to find previous discussions in the database, creating a permanent content.



DiaSymphony

Figure 11 — DiaSymphony logo proposed

For instance, if the patient will travel somewhere and feels insecure about the devices in the context of the destination, testimonials of individuals who faced the situation previously can help with the preparation. The AI system will analyze the inquiry and will filter the most applicable cases, giving a glimpse to the patient if approach options are possible. To allow less language barriers, the local communities who already contribute to their own open source systems would be the center. That would also allow users sharing diverse kinds of information, including sharing goals, strategies, contacts and useful information. A place to buy specific foods is precious information that raises interest on the diabetics, therefore this specific experience is more likely to be found there. Another important item would be access to specific governmental or private institutions and their policies to provide diabetes care, that can be shared to decrease the complexity in the process of a new patient. As mentioned previously, the design interventions become more relevant if they are made in different levels that support each other. The diabetes assistant will achieve its aim to reduce diabetes distress if connected to other fields that influence the disease care. The idea is an open source system that access P2P channels with stories that have relevance to the patient. Moreover, P2P communities would be able to spread these design interventions to a broader audience.

5.2.1 Definition of the diabetes AI assistant, the core of DiaSymphony

The main design intervention integrated to the open-source platform consists of a diabetes management assistant that uses artificial intelligence to guide a patient into a seamless disease care. As highlighted by research, diabetes management can be very complex, and the patients feel overwhelmed while performing all the tasks necessary to ensure good health. This generates diabetes distress, which reflects the amount of time dedicated every day to manage the disease. That background led to the creation of DiaSymphony, a system that uses a holistic approach to address core and surrounding issues connected to the disease, improving motivation and opportunities to improve and preventing rash decisions. As a part of the collaborative approach in the open-source platform, the diabetes AI assistant will be available to the public to use, while IT specialists can contribute with new features that can be later on aggregated.

The main function of DiaSymphony is to help patients to manage their carbohydrate intake more wisely. The system focuses on the prevention of mistakes in this step, rather than notifying patients of mistakes. Prevention is a key factor here, because it provides an important function that most patients struggle to perform. The assistant presents carbohydrate control as a seamless task, in opposition to the current situation presented. Furthermore, the CGM systems already correct blood glucose based on trends, and can also benefit from a more precise register of carb consumption. Integrating these features to an existing solution is the ideal scenario, removing complexity to patients.

Every time the user has a meal, DiaSymphony will be prompted to count the carbohydrates in a meal by photo, written description or voice description. These 3 different input means are necessary to give flexibility to patients, addressing different mental models to ensure more accessibility and an intuitive experience. Eventually, they can use all of them at the same time, or only 2 of them. The system will recognize the amount of carbs and give an input to the user how to handle insulin intake based on the effects caused by that meal. To fulfill different scenarios in the lifestyle of the patients, DiaSymphony will take into consideration their favorite meals and local ingredients. It is important to approach carbohydrate counting as personalized as possible to reach better results in preventing diabetes distress. The AI can work with geolocation to select a list of meals that will be more likely available in a region, decreasing the number of options that cause doubts to the user. Within this framework, the users will be more likely to learn and remember the amount of carbohydrates in their favorite meals.

By creating this smooth connection with the individual, this system will also be able to track preferences over time and analyze long-term consumption. An overview of carbohydrates consumed will be produced, suggesting a list of goals to improve in the patient's diet. Given the background provided by the patient, the assistant can be propositional to help individuals taking a new approach on dietary options. Logically, the patients can set their own goals to improve their diabetes management.

The long-term follow-up will also produce key indicators to support the patient in their disease care. They could be even more effective if the CGM technology owners allow integration to their databases. For instance, there is a partnership of integration between Abbott (Freestyle Libre CGM supplier) and Snaq (carbohydrate counting assistant), which showcases that companies are willing to work together to offer an overall better product. The main information produced here is a follow-up of the insulin's effect on the meal informed by the patient, creating a system to prevent reactions to the trends and thus avoiding desperate measures by the patient.

Lastly, this diabetes assistant will also remind the patient to keep track of medical appointments. It is normally required for diabetic individuals to visit specialized doctors at least once a year, which is crucial for measuring the impact of the diabetes and its possible complications. According to the demand, the user can adjust the level of notification needed to meet the plans. In these appointments, the doctor can enter recommendations of diabetes management to the system, keeping track of them for future reference and inserting them in the routine of the patient.

Key features of the diabetes assistant summarized:

- AI assistant that counts carbohydrate intake;
- Multiple prompting options to increase the precision of analysis and follow different mental models of use;
- Recommendation of bolus patterns for each meal;
- Follow-up to support users in not making wrong decisions;

- Collection of long-term data to create an overview to patient and doctor;
- Management of the schedule about the main medical appointments;
- Suggestion of dietary options and management goals;
- Integration to other diabetes management tools.

There are open questions that need to be monitored after the introduction of the system. DiaSymphony's assistance has the potential to reduce diabetes distress, but wrong usage can also contribute to increasing the condition. The prototype stage focuses on specific steps and its effect is punctual, and more testing is still necessary.

DiaSymphony may have started as an organic idea to fulfill a goal, but its future depends on engagement of the communities who will support it. Working in collaboration with other stakeholders demands an organizational structure, a leadership that can manage and coordinate resources to continuously achieve innovation (Faridian, 2023). At the same time, Gallegos et al. (2018) stresses that there are currently limits to intellectual property and regulation linked to open-source healthcare systems.

5.2.2 Auxiliary tools that can be personalized and utilized by peers

The design intervention proposed addresses the lack of compatibility between products in the market, both with digital and physical means. Patients reported that most products only function with a specific setting, generating extra distress brought by their costs and supply challenges. In this thesis, it was conceptualized as an alternative for this bottleneck with the application of principles of mass customization to the production of diabetes supplies.

Open-source platforms already represent a fertile ground for such developments. For instance, biohackers from the Open Insulin Project have the goal of producing insulin independently of the so-called big pharma industries to provide diabetic patients more affordable medication. These DIY initiatives, supported by a global network of local peers, may enable patients to have conditions of reaching medical products previously inaccessible to them (Gallegos et al., 2018).

Taking advantage of this scenario, a set of supplies that can be 3D-printed will be made available through open-source platforms. Supplies that are basic to diabetes management or to reduce diabetes distress can be quickly reproduced in small labs that have 3D printers available, thus increasing the reach of these products. Another advantage of having an open-source cannula is the 3D model can be personalized and printed quickly. Considering individuals using different diabetes management systems, they would have the possibility to customize products to fit their own set of devices.

Regarding fear of needles, it is possible to insert a solution into this open-source platform concept. The proposition is to use a cannula to transfer insulin into the body, minimizing the interactions with needles to the lowest level. A cannula is a thin tube inserted into the skin to reach a specific layer of the body, being still accessible from outside and allowing the injection of medication for a period of hours or days. In the market, there are cannulas available to inject insulin, with the recommended usage time being up to 3 days to ensure effectiveness of the medication (Pfützner et al., 2015). Therefore, the cannula has the potential to reduce interaction with needles to a fraction when considering a person who needs multiple injections every day.

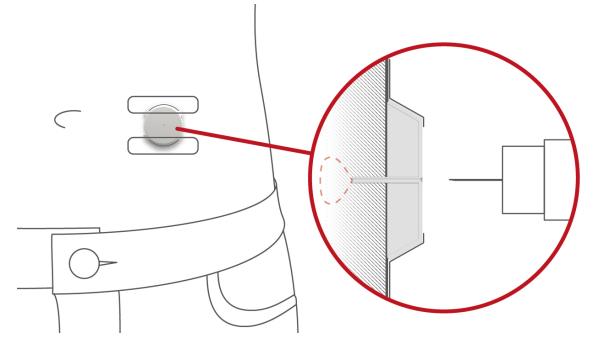


Figure 12 — Cannula proposal for insulin intake without the need of constant injections

These items may be accessible to patients if they purchase from specific suppliers. However, not all the patients have access to them through their networks and supply chains. Sharing information about therapies is a significant feature of the P2P communities. It should be an important place to reach patients who are open to trying new solutions for problems that some have no idea about better outcomes. Open-source cannulas are available to more patients, allowing them to test if this option would fit their needs, a cannula developed for an open source platform becomes a reliable alternative. During research, it was detected that DIY platforms are on the rise in the diabetes care environment, being Nightscout (open CGM project) and OpenAPS (open artificial pancreas system) 2 notable examples. An open-source cannula has the potential to integrate with one of these initiatives.

To ensure that a cannula can be produced without significant expenditure dedicated to industrial processes or supply chains, the most reliable alternative is 3D printing. The advantages of this process lie exactly on the fact that it does not require any mold for production, as a printer can replicate parts precisely with just the input provided by a 3D model file. And the replicability of parts anywhere can overcome logistic chain challenges that main suppliers may not be able to currently go around.

Overall, the cannulas have to reach some indicators to be considered safe to use. Research shows that cannula produced by Medtronic, one of the main players in the market, presents a leakage rate of 2,2%. This probability still ensures a trustworthy function of the cannula while delivering insulin. Regarding specificity of the process chosen to produce open-source cannulas, there have been success cases in printing 3D parts of this kind for other medical uses (Lussenburg et al., 2022) other than diabetes care. It is possible to reproduce the same conditions of successful experiences to the diabetes-oriented cannula. The material of the part must provide both safety regarding contact with the body and reproducibility though the 3D printing process. Therefore, the safest choice for the prototype is PTFE (Polytetrafluoroethylene), given its successful application in both cannulas to inject insulin and in the 3D printing process.

The ideal scenario would feature a cannula that integrates CGM, with the same puncture occupied by an insulin tube and a glucose sensor tube. Tschaikner et al. (2019) found success in integrating a commercial cannula produced by Medtronic with a CGM sensor supplied by Dexcom, with little modification to the parts. However, while Medtronic's cannula has a lifespan of 2 to 3 days, the duration of the Dexcom G7 sensor is estimated at 10 days. This difference would create an unfavorable outcome for the insulin injection performance. Therefore, such a concept is feasible and requires more integration of both functions into one product, possibly with the participation of the producers to assist the development.

Further developments inside the open-source community would emerge from this scenario, depending on the initiative of members and developments in technology. Extra DIY products can be developed and shared in DiaSymphony. This initiative shows that the wish for a better quality of life without diabetes distress is something that can come from the partnership of diabetic individuals and corporations, as they can support each other in reaching the necessary requisites for products.

59

5.3 Prototype

The prototyping step was divided into 2 areas of interest. The first one aimed to test the AI assistant concept. In this stage, the researcher interacted with volunteers to test AI alternatives that could possibly be used to perform carbohydrate control, and what were the main issues found on the way. The second focus area was to check the possibilities of using 3D printing services to produce parts that can reduce the interaction of patients with needles and reduce the dependence on standard supply chains from manufacturers, yet considering the standards applied by products available in the market.

5.3.1 Role-playing prototype of the diabetes assistant

The role-playing prototype aimed to test principles that can reduce pain points found in the journey of the patient. This prototyping step focuses on ephemeral pain points that happen daily, afflicting the individuals during a short span after meals. During the previous interactions with patients, it was identified that they may have a better time if they have a more precise carbohydrate control for individual meals during the day.

The solution to approach the execution and management of carbs control system that aims to prevent wrong insulin involves prompting AI to identify the amount of carbs in meals using complementary communication means. The answer provided by the system was analyzed together with the individuals and compared to current alternatives of carbohydrate control, and the accuracy of each mean was tested. Combinations of prompting options that fit better the convenience were evaluated.

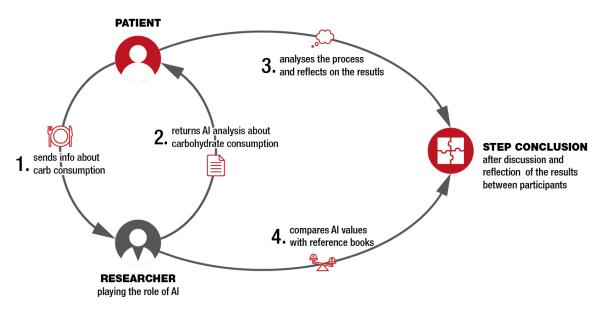
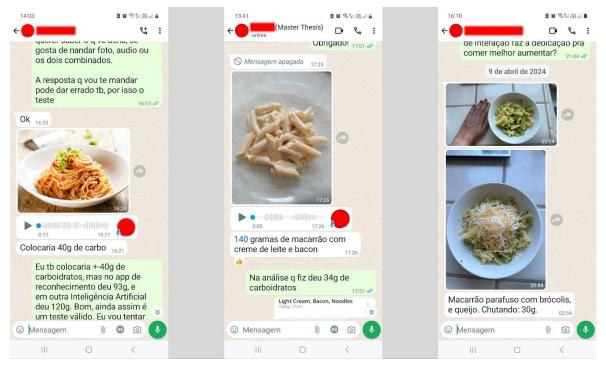


Figure 13 — Interactive prototype workflow

The prototyping step consisted of a role-playing simulation, and the researcher played the role of the AI conversion tool to several interactive systems. Levels of interaction level and satisfaction of users were tested, evaluating if individuals can fulfill their needs when using AI to manage carbohydrate ingestion after meals, thus reducing related distress. Every time the user has a meal, they prompt the researcher about what is the content of carbohydrate of their meal. Information required from the participants is summarized below:

- Sending a picture of an imminent meal, or if not possible, a frequent meal;
- Recording a voice message that describes the content of the meal;
- Sending a written message detailing the content of the meal;
- Sharing the carbohydrate estimation for the food.



Figures 14, 15 & 16 — Prompt from 3 participants to the researcher via WhatsApp message

With this feedback, the researcher uses different means available to evaluate the given input on how much carbohydrate is consumed to the user, based on the description provided. Moreover, the individuals had to provide their own carbohydrate intake calculation, and these were compared with the AI answers. One of the individuals has large experience doing carbohydrate control compared to the others. It is important to highlight that the participants are informed that the answer provided by the AI does not replace their own analysis, as this is only a study. Based on this step, it was possible to understand what requires further attention. Below, it is possible to see the different profiles of individuals participating in this prototyping stage, and in table 5, the results of it. Individual 1: DMT2, 56-65-year-old female;

Individual 2: DMT1, 13–18-year-old female, with the contribution of her father; Individual 3: DMT1, 9–12-year-old female, with the contribution of her mother; Individual 4: DMT1, 26–35-year-old female;

Table 5 — Results of prototyping a carbohydrate calculation system with help of AI					
	Estimation of consumption made by the individuals	ChatGPT	Snaq		
Individual 1, meal 1	63 g*	89 g ~ 116 g	78 g		
Individual 1, meal 2	55 g*	50 g ~ 70 g	65 g		
Individual 1, meal 3	49 g*	56 g ~ 72 g	39 g		
Individual 2, meal 1	42 g	36 g ~ 44 g	34 g		
Individual 2, meal 2	-	33 g ~ 35 g	42 g		
Individual 3, meal 1	50 g	50 g ~ 60 g	61 g		
Individual 3, meal 2	32 g	37 g ~ 39 g	36 g		
Individual 3, meal 3	30 g	49 g ~ 56 g	31 g		
Individual 4, meal 1	40 g	100 g ~ 120 g	93 g		

*The individual did not have exact values of the carbohydrate consumption, therefore the researcher used a reference book of carbohydrate measures published by the Brazilian Diabetes Society (SBD Monteiro et al., 2008)

This prototyping step revealed that the results generated by the AI were not reflecting the expected consumption by the participants, and even the ranges of values were too broad and not precise enough for utilization. Most of the audio files and the written messages describe carbohydrate rich ingredients as simply as "pasta" or "rice". After discussion with one of the participants, it was found out that the same ingredients have been labelled differently in value reference tables, mostly labelling the way of cooking. This can include "cooked", "boiled", "baked" or other kinds of preparation, and already considers the percentage of water added to the recipe. It was identified that this missing label may have induced AI to use nutritional values of raw ingredients rather than cooked ones, generating unrealistic carbohydrate content for a meal.

Another fact that can be concluded from this study, there was a great variation of meals. There have been participants who focused on a constant diet, while others had variations in their choices. It is not the goal of this thesis to find out the reasons behind the variation exposed, but to help patients build a better relationship with their meal choices.

Alongside the issue, it was also raised how local ingredients and preparations make an impact on carb counting. For instance, while the National Health System from the United Kingdom recommends 30g of carbs for each 100g of cooked rice, the Brazilian Diabetes Society - SBD considers an amount of 33g for each 100g (Monteiro et al., 2008). This can be traced to the local preferences and availability of ingredients, which leads to an absence of regional dishes being absent from global lists.

Participants highly appreciated the support and dedication presented by the researcher and the feedback given, even if they were alerted that they were not valid for diabetes management purposes. Some participants asked questions in return, and returned appreciation when their conclusion was validated. They have different preferences on the input forms, and the photo option was their favourite, followed by voice interaction and written messages.

The prototyping stage unveiled a positive outcome. Patients who completed the steps were more interested in making a precise carbohydrate counting after some time, making adjustments to their upcoming meals willing to decrease consumption of carbohydrates. While other participants who were willing to participate, but didn't manage to, evaluated the potential of the prototype to increase their quality of life and reduce the diabetes distress on the daily routine.

Different mental models were evaluated to allow users from different backgrounds to use the assistant. Independent DMT1 patients, DMT1 children assisted by their parents and inexperienced DMT2 patients concluded the role-playing test to find out about their carbohydrate consumption and displayed different needs. While the core experience of using the assistant was to provide a fast way to count carbs and more autonomy to patients, it was found out that parents of DMT1 were interested in a more detailed process. Parents assisting their children are aware that a process that empowers the patients to be less dependent would be essential, but they still find it necessary to keep some control. One of the parents that participated in the process supported this idea and would prefer to assist only in case of necessity. Since the diabetes assistant works within the framework of SDT (Ryan and Deci, 2022), gradually increasing autonomy of patients is a plausible way to decrease dependence on other stakeholders.

5.3.2 Prototype of a 3D-printed insulin cannula

With the aim of addressing needle anxiety, a version of an insulin intake cannula that can be 3D-printed was also tested. According to Berry et al. (2015), integration of practical experiences is crucial to address diabetes distress successfully. Therefore, decreasing the impact of using needles has an potential positive contribution to any diabetes management system.

According Lussenburg et al. (2022), cannulas can be successfully 3D-printed for medical uses. This resource ensures that patients can try an insulin intake option that decreases the use of needles, with the advantage of not being stuck to any specific product set. The printing machine must, however, be able to reach strict settings to print the parts with correct properties. Expert users can modify the master file to become compatible with any alternative available in their environments. An expert group is necessary to ensure that the new product is safe to use and performs well delivering insulin.

The prototyping step of the cannula started with research about the minimum requirements to reach a viable product. A list was based on the following principles:

- The 3D modeling platform must be open-source;
- the cannula has to be a single 3D body part to be printed;
- the part has to be printed without support material;
- the material of the cannula has to follow the ones used in the production of other products already available in the market;
- a similar gauge to other insulin infusion cannulas must be achieved;
- the printing process must be FDM, allowing widespread and multiple suppliers to produce it;
- the costs need to be competitive with other cannulas in the market;
- the cannula must be sterilized for use and reuse;

Alternatives of software considered to be used in the prototyping stage consist of free versions or open-source CAD tools. FreeCAD stands out as a software that has been gaining popularity recently, besides being open source. Moreover, it has a more technical approach needed to deal with healthcare products.

The process of building a virtual cannula for the DiaSymphony platform started with the creation of a 3D file. All the measurements were taken from standards in the markets, such as gauge size of the needles, combined with ergonomic measurements to allow a comfortable usage and handling. Moreover, limitations of the FDM process were considered to adjust the final dimensions.

The cannula was modeled from a flat surface in a diametral format that converted into angled walls, which allows the FDM 3D printing process to deposit material without the need of supporting material. On these walls, there are two side recesses to fit other products that may be necessary during the usage. They will be customized by developers according to the variety of products available in the market and the function required. An intake tube connects the top of the cannula, where the injection will take place, to the bottom of the part, thus delivering insulin to the correct layer. To insert the cannula, it will be possible to use a common insulin pen needle to insert the cannula tube under the skin, as it will pierce through prior to conducting the insertion.

One of the limitations spotted is that a FDM-printed part may not reach a standard 25 gauge needle found in commercial cannulas, that has a diameter of 0,515 mm. Due to the limitations in the FDM extrusion, the diameter of the 3Dprinted needle must be at least 1 mm, which falls closer to a 19 needle gauge. The bigger gauge means a more painful application to the skin, but also opens the possibility of inserting a sensorial filament in the tube that could be connected to a CGM system. This is a relevant way to compensate for a competitive disadvantage, while the technical evolution of the FDM process becomes precise enough to allow a smaller needle diameter.



Figures 17 & 18 – prototype of a 3D-printed cannula

Despite the availability of PTFE 3D printing processes for industrial and commercial purposes, it is not possible to find suppliers widely available. The technology has been developed as recently as 2019 by 3M, and it still has limitations due to the properties of the material. Alternatively, a more commercial material called made of a mix of PC-PTFE is more widely spread, but it has yet to be tested for medical purposes.

The costs of one 3D-printed cannula, on the other hand, are aligned with the expected results. Printing them can reach competitive levels of price, compared to standard suppliers. The printing of 2 prototypes costed \in 10, compared to a cost of \in 113 for a box of 10 units of Medtronic cannulas.

These results are limited by not testing the application of the cannula to a patient. A medical test of the properties would need to be conducted in a specific lab environment, with the help of a specialized team of doctors, nurses and technicians. Among the unknown properties, sterility of the FDM parts remains as a potential threat to the

concept. Initially, it was raised the possibility of sterilizing through steaming the part, which has potential to modify the properties and compromise its function. However, Guerra et al. (2018) concludes that using ethanol for sterilization of 3D-printed bioresorbable stents — devices that allow bloodstream flow to the heart — is an efficient method that does not compromise material properties. The use of this sterilizing substance may or may not be restricted in different locations, however, this is a common material used for disinfection worldwide, as seen during the Covid-19 pandemic.

Other issues that remain to be tested are the flexibility of the cannula tube in contact with the skin, the pain perception of patients with a needle that has a lower gauge and the accessibility to the hole of the cannula. For the first topic, it is expected that continuous improvement in FDM 3D printing technology could allow flexibility of materials after the process is finished. As mentioned previously by Lussenburg et al. (2022), material properties that must be followed to reach specific goals, and further exploration is needed.

The perception of pain is very important to a patient who has needle anxiety. Studies found mostly focus on the pain perception of needles with higher gauges, therefore not applicable to the results found in this research. It is critical to highlight, however, that the primary goal of this prototype was to conceptualize an alternative of which development can be shared by the open-source community, further progressing to make it usable.

Accessing the hole of the cannula with a needle is possible, but it could have been easier. There have been features that tried to guide the needle to the infusion tube in the 3D modeling process, but they always compromised the capacity of the FDM machine to print without supporting material. It was concluded that this part will remain as it is, and the user does not need to be concerned about the sharpness of the needle, as it does not touch the skin. In the future, developers can create an accessory that helps the patient to insert the needle inside the cannula hole, for instance with the use of a plastic hose that can extend the reach of the cannula.

5.4 Product definition of DiaSymphony

After the simulation of the features decided in the concept selection, the diabetes assistant can go to a stage of refinement. The points observed in the role-playing prototype were converted into an interactive system that reflect the steps the user should take to make the carbohydrate control easier. As a result, it was decided that an assistant available on mobile phones and personal computers would be the best way to reach the most users from different age groups, with the possibility of using the system

elsewhere depending on technologies available. Additionally, CGM systems operate in these systems, which facilitates the integration with them.

DiaSymphony AI assistant focuses on 3 main areas: **carbohydrate control manager**, **diabetes follow-up** and **ask your peers**. The "carbohydrate control manager" mainly addresses pain points seen on the short-term management, ensuring a potential reduction of anxiety and increasing well-balanced post-meal management. Long-term pain points are mostly approached by the tools of the function "diabetes follow-up", allowing patients to forecast the management of side topics of diabetes. Additionally, "ask your peers" will focus on the issues that are timeless, including the extension of contact with local diabetes groups. Next, it is possible to see the functions grouped under each of these items.

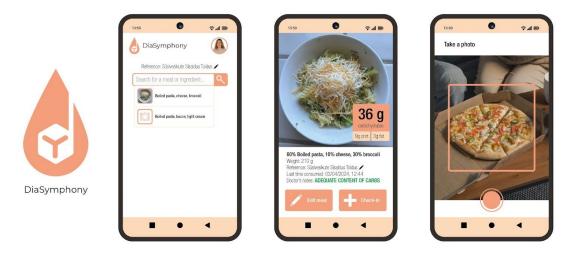
5.4.1 Carbohydrate control manager

The carbohydrate control manager will be based on reference databases, referred to as the safest options in measuring food consumption. They contain a list of food items followed by their carbohydrate content, evaluated by nutritionists and other doctors. Examples of such materials published by local diabetes entities include "Süsivesikute Sisaldus Toidus" by Pärnu Haigla and "Carbohydrate Counting Reference Tables" by the NHS Trust. These lists are already used by diabetic patients, mostly in the forms of a physical book or a PDF file. The same databases will be used to quide the carbohydrate control manager on top of using the AI evaluation of the meals. Values generated by the AI will always have the book as the guideline to show the values. The AI will learn and make its own estimations over time, increasing the range of possibilities. It is important to mention, however, that each book has a limited number of items, and they may be insufficient to cover all the meals demanded. It will be necessary to find more than one book to cover different local demands around the world. To cover this, one reference book will be chosen, which can either be done automatically by geolocation reference or personalized by the user. Moreover, this list will become searchable in the software, making it easier to quickly consult the content of carbohydrates of a specific ingredient. If the internet connection is not available, individuals can still use this to guide their carb control.

Users can recall a frequent meal, as they can make their post-meal blood glucose management easier by repeating a process linked to a specific meal, and use for future decision-making in future. The response to a habitual behavior (meal) is an automatic response (Aarts & Dijksterhuis, 2000). If the diet consists of only a few choices by option or by recommendation, therefore the patient can perform carbohydrate management in an

automatized way. However, given different contexts reported by interviewees, it is not always possible or wanted to only rely on the same food options every time. Acknowledging the consequences of different meals for the blood glucose can help individuals to understand better diabetes management. Even if the meal is not that frequent, they can later on be converted into valuable information that helps patients to develop an automatic reaction chain to certain kinds of ingredients. A command called "recall a frequent meal" allows individuals to use a food previously eaten in the past as the reference again if the person happens to make the carb control of the dish repeatedly. The command allows changing the number of grams of the dish, but in this case, it would require the person to confirm the proportion of ingredients. Users may learn patterns of carb consumption and will create acknowledgement, decreasing the diabetes distress caused by decision-making.

Taking a photo of the meal and have AI to recognize carbohydrate sources in images of their meals was highly desired by participants. Such a concept has been already implemented in systems like Snaq and Figwee, among others. This feature has become possible thanks to the wide spread of smartphones with cameras, vast internet connection availability and the fast development of AI capabilities recently. Technologies like these are welcome to help diabetics manage their meals. Yet, there are concerns regarding wrong diagnosis by the AI. During the previous prototyping step performed, it was confirmed that individuals may find challenges in prompting the system to generate a precise answer. Since the goal of taking a photo is to simplify the recognition of carbohydrates on the food, there is still a wide tolerance for mistakes. For these reasons, the "take a photo" command uses photo recognition by AI to count the carbohydrates in a meal. The user has to use the assistant to take a picture of the meal just before eating, or enter a photo stored in the files. The AI will then analyze and inform the user about the expected amount of carbohydrates in that meal. However, the system works with a safety margin: the analysis of the AI will always be compared to the current carbohydrate content table used as a reference database. As stated in the previous "reference database" function, these indexes are the safest option to guide diabetics into carb control. The feedback provided by the assistant is based on the amounts detected, reflecting the references in the database, and AI will learn from this process. As perceived in the roleplaying prototype, extra prompting to the software is necessary to avoid mistakes. This can be done with a voice or written message. Whether more details are added or not, the AI will then create a suggestion of insulin pattern to be injected. The AI will learn how to be more precise over time, and to adapt to the tastes of the patient.

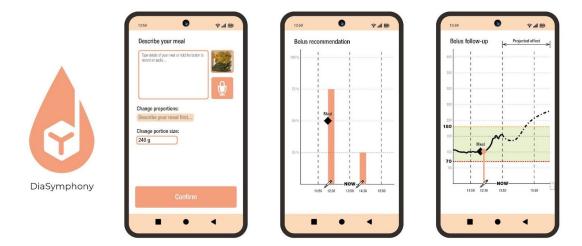


Figures 19, 20 & 21 - DiaSymphony's interface of reference database, recall a meal & take a photo

Describe a meal or entering ingredients by writing or audio record are other prompt options, without image input. This is a way to make sure that the system still functions if the camera is not available and gives more options to individuals. Having 2 options of prompting offers options for different mental models. In case of audio prompting, the content will be converted into text and then presented to the user. DiaSymphony will use AI to recognize the items and will perform a search on the database, thus summing up the total of items. The system will request more input from the user if there is not enough information. These questions will refer to amounts (either weights or measures), or the cooking process. For the ones who want to understand better the role of each ingredient in the carbohydrate counting process, this is a reliable alternative. The user can explore the ingredients before eating them, The AI will calculate the sum and give the total amount of carbohydrates. This command works optimally for meals made at home and takes more time than the other options and has a potential to be educational.

Bolus recommendation after analysis of meals is an important feature of DiaSymphony. The system provides orientation to the patient in taking the correct amount of insulin at the correct times, thus avoiding distress related to wrong carbohydrate counting. DMT1 and DMT2 users will receive different recommendations based on their insulin-dependency status. The calculation of the post-meal insulin dose comes from the integration of information collected by DiaSymphony and the CGM system. These data will be placed into the carbohydrate control formula published by Schmidt and Nørgaard (2014), and later updated if necessary. If the CGM system is not integrated into DiaSymphony, the assistant cannot make a recommendation in terms of units, but rather in percentage distribution. For instance, by eating a food rich in fat and protein, the person will either be informed that most of the bolus is needed at the moment they start the meal, and the remaining amount of bolus will be added 2 hours later.

Bolus follow-up is an analysis of the effect of the insulin on the blood glucose in the upcoming hours. It will display the evolution of glucose rates projected for the next hours with the goal of providing a reference to avoid unnecessary correction, or to highlight the need for early correction. This feature will be displayed with meal analysis and must be connected to the CGM system to be in effect. Following most of the chart-oriented visualization provided by CGM systems, the layout of bolus follow-up will feature similar design: the range of good glycemic limited by a lower red line and a higher orange line. Since modification to existing CGM systems is a remote possibility, the diabetes assistant will count on importing and integrating the data from the brands which have interest in cooperation. The bolus follow-up feature will be set in a conversation between doctor and patient and the settings will be added to the user profile.



Figures 22, 23 & 24 — Interface of describe a meal, bolus recommendation and bolus follow-up

5.4.2 Diabetes follow-up

Integrate your CGM system is a function that allows individuals to connect this glucose monitoring tool to the diabetes assistant. It allows crossing information and obtaining important feedback loops that help to improve diabetes management. The glucose timeline can be visualized as an important element of the insulin action, and DiaSymphony will be able to make projections and recommend avoidance of harsh measures as a consequence. Therefore, the previously mentioned "Bolus follow-up" function will be fed by this integration. Alongside, the results of specific lengths in the period of long-term glucose rates can give essential information to doctors about the diet.

Integrate your smartwatch is a function that gathers all sorts of information about health can be beneficial to diabetes care. Data about trends of blood pressure can significantly contribute to a better diagnosis of diabetes complications, and levels of other substances present in the sweat can also provide indicators that can be useful. The smartwatch can also show the impact of physical exercise on the glucose rates. Moreover, it was identified in research that disregard of long-term health trends is a major concern to patients.

Check your bolus recommendation patterns is a command that is co-designed by the doctor and the patient, this allows post-meals insulin doses to be calibrated. The doctor can set the anticipation necessary for the patient to inject the bolus and also the correct doses, with the aim of reducing uncertainty of insulin action. This will be displayed when the patient enters a meal, and the graph will show the correct timing for bolus intake.

Upcoming appointments reminds patients of periodic doctor appointments and tests requested to keep control of the diabetes care. According to diabetes care associations such as Diabetes UK, patients should visit a diabetes-specialized clinic at least once a year, where they will have access to different healthcare professionals that can check complications' development. Depending on the stage of complications, the frequency needs to be even higher. Users can set, together with their doctors, a time window for upcoming appointments. The individuals can enter data themselves about their schedule, and within the normal expected timelines there will be requests for more scheduling. The doctor can also enter information to guide patients about other kinds of medical tests expected. Tests are also something important to consider. Endocrinologists can make patients aware of other specialties that must be checked. And if there is a need for other tests, the overview presented by DiaSymphony will help with organizing the demand.

Self-examination tool function indicates means to patients to perform self-tests that can contribute to a better management of diabetes complications and reduction of uncertainty. For instance, a tutorial about how to check the health of the feet is included. Ketosis tests will also be featured. The user can tick this from the list of tasks when it is done, giving an overview of the frequency these tests are made.

Your goals function allows the patients to access the recommendations given by the doctor. If the notifications are activated, the individual can be informed if the carbohydrate content of a specific meal is within the tolerance for the therapy, or if it is lower or higher. It is expected that this reminder helps patients to follow orientation. If it is not followed, this can be discussed with more efficacy in the upcoming meeting. This command addresses the lost information on the way, and in principle does bring more trade-offs to the routine. However, the patient can reduce diabetes distress if following the routines planned.

5.4.3 Ask your peers

Contact your local community section gathers information about the local communities to be presented in the diabetes assistant. Addresses, working times, key persons, important contacts and others will be available to allow individuals to access the local networks, if available. Events can be published here as well, if existing. This information will be filled by the peers. Opinion leaders can present themselves to other patients as a local reference to navigate through difficult matters, which reflects what has been seen in current environments.

Ask questions to peers allows users to inquiry about diverse situations that they are facing and are not sure how to deal with. There are many topics that individuals may find a more empathizing vision and reflection about from peers (Balfe et al., 2013), especially if the subjects do not require any medical consent. Since this is an open-source environment, there will be participation from a diverse range of users, and it is up to everyone to filter the profiles that they empathize more with. Questions that may not find an answer in the local community can be researched in the worldwide community for similar prompts. These will be in each local community, and opinion leaders or volunteer doctors can contribute, as it happens currently. The role of the AI is to search and find the best references for these interactions.

Accessories to improve your well-being allows users to access a directory with files that can be 3D-printed with FDM process, designed to reduce pain points of diabetes therapy. These files are designed by expert users and will be revised and tested by a team within the community, before being released. For the users to download it, there is a disclosure informing the user about the potential risks. This will also follow instructions of how to use the part. The further implementation of this function also requires a development of security protocols to avoid abusive usage. Moreover, printing technology of materials must advance in order to implement this feature, finally allowing users to overcome supply chain and financial issues.

6. CONCLUSION: ANALYSING GAINS TO THE USER JOURNEY

DiaSymphony reduces diabetes distress by creating a seamless process to manage diabetes. It starts with the carbohydrate counting and management during mealtimes, a main concern of the patients because of its potential to disbalance blood glucose. The assistant helps by simplifying a complex calculation, and the multiple prompts increase the precision of the analysis. As previously exposed, the correct carbohydrate counting will avoid the cyclical path of short length distress after meals.

Taking the example of Rachel, the representation of a DMT1 persona, it is possible to see that she makes great effort to keep her glucose under control. However, she fails to perform carbohydrate counting and manage her blood glucose after a night out with friends, due to the lack of knowledge about the meal and the social context she was in. With the interventions proposed by DiaSymphony, she will eliminate the knowledge barrier by having an assistant to perform the carb calculation for her. The fact that the system features an option of downloading lists from other locations allows her to eat typical foods of other countries without making a complex calculation. The same picture she takes to post on social media, she uses to prompt the assistant for results, alongside with a written description. Meaning that this action is something that she is used to doing already, besides not raising any possibility of stigma On the way home, the projection of glycemic allows her to plan a whole night of rest.

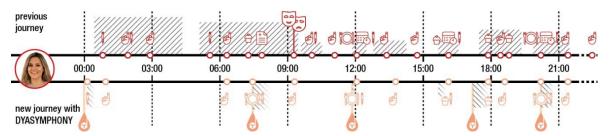


Figure 25 — A comparison between DMT1's journey before and after DiaSymphony, potentially

She may still be exposed to mistakes, but DiaSymphony addresses this possibility by helping her make precise decisions. With the projections of glucose rates, she knows what to do to avoid overcompensation. The day without big surprises allows her to dedicate more to her work and her plans. Moreover, the support of peers is useful to increase her knowledge about diabetes, given that there are people who faced similar issues available to talk to her. For Jeremy, the representation of a DMT2 persona, DiaSymphony helps him to acknowledge that his approach of feeling the effects if the glucose is high is not enough for keeping a healthy life. He sees that his morning walks have a great effect on his glycemic, but after having breakfast, he realizes that blood glucose changes much quicker than he originally thought. By using a CGM system integrated with DiaSymphony, he can now watch the projection for the next hour and take only one insulin shot. At lunchtime, Jeremy finds out that complex meals require injections spread through a longer period, instead of one shot that will be short on effect. Jeremy acknowledges that knowing his glycemic better allows him to reduce the need to perform fingersticks and insulin injection, thus decreasing his levels of distress. Furthermore, he has a possibility of using the insulin cannula to make a more spread control.

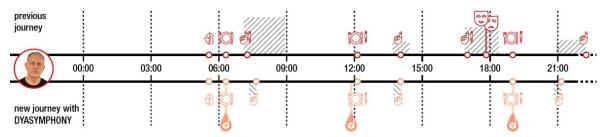


Figure 26 — A comparison between DMT2's journey before and after DiaSymphony, potentially

DiaSymphony increases the possibilities for its users to make choices. They have autonomy to make better plans for their lives based on the support given by the AI assistant, acknowledging the outcomes of their actions for better decisions. They can also make better connections between habits and consequences for their health, learning specific paths by repetition. Lastly, the support from the peers helps them to navigate in this process where they previously had little support.

There is also a great potential for new technologies adding up to the platform. Dexcom, one of the world leaders in CGM devices, has officially announced start selling a monitoring system that does not require prescription for DMT2 patients in the summer of 2024. This can possibly popularize fulltime monitoring among more patients. The technology of smartwatches still has potential to englobe more aspects of healthcare, allowing further integration with DiaSymphony. Patients will have plenty of options to build their own management systems with resources that follow their needs and mental models. The holistic approach of DiaSymphony benefits the individuals who want to put these technologies to work together for fulfilment of custom needs.

SUMMARY

This study discusses the influence of diabetes distress in the life of the patients, causing negative trends and pitfalls that affect mental health and motivation to manage the condition. Diabetes is a chronic disease that can be worsened without constant care, causing social and economic impacts. The focus on the diabetes distress demands a holistic approach to the individuals, offering integrated solutions that allow them to follow their own mental models, rather than aiming individual tasks to manage the disease. With the context presented, DiaSymphony is an open-source platform that features an AI assistant that empowers the aspects of SDT (Ryan & Deci, 2022) to decrease diabetes distress.

After literature review about diabetes distress, it was possible to find more layers of complexity during the field research. Observations and interviews with diabetic patients, medical bodies and peer communities generated rich qualitative data that was used to define problems and to map the design processes. Contribution with patients was further extended to the development phase, where they interacted with the design team to conceptualize a better environment for diabetes care using creative techniques.

During the prototyping step, participants experienced the interaction with a diabetes AI assistant proposed by DiaSymphony. Their feedback indicates that these design interventions have the potential to decrease diabetes distress. Participants were grateful and enthusiastic with the empathetic approach taken during the role-playing prototype step. The holistic visualization of users and the integration of peer communities to DiaSymphony reinforce this feature. Usage of DIY potential in open-source communities through 3D-printed supplies goes together with desires of patients to customize their therapies to their own mental models.

Reflecting on the exploration conducted in this research, it is possible to conclude that diabetes distress can be reduced with the integrated design interventions proposed through DiaSymphony. Limitations were also found through the research, including in the capacity of the AI, intellectual rights, legislation for the AI assistant, and material availability, reproducibility and lack of medical testing for the cannula. These topics must be further discussed prior to the implementation of DiaSymphony. The development of new technologies can overcome these issues and be integrated into DiaSymphony.

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APPENDICES

Appendix 1A – Affinity mapping after collaborative session: short length distress

	Emotional Burden How diabetes can ma emotionally, like feel stressed because of	ing worried, sad, or	Physician-Related Distress How talking to doctors or getting medical advice for diabetes might make you feel stressed or worried	Regimen-Related Distress How hard or frustrating it is to follow the daily plan for diabetes, like taking medicines and watching what you eat	Ir H a
LACK OF	Fear of hypo	Fear that insulin pump will stop working		Meal contr in situatior out of rout	
AUTONOMY		Fear of hyper		Fear tha insulin p will stop working Fear of hypo	
LACK OF	Fear of hypo		I sometimes get told I am doing things wrongly	Meal control Making in situations plans is out of routine stressful	
COMPETENCE		Fear of hyper		Fear (hypc as carb consumption byper	
LACK OF EMPATHY				There should be a better way to inject insulin other than needles all the time	

Diabetes distress table

Interpersonal Distress

How diabetes affect your relationships and how you feel when dealing with others about your condition

> I was at a meeting and the pump did not stop alerts

> > Dependence on people around if I collapse

I was at a meeting and the pump did not stop alerts

Appendix 1B – Affinity mapping after collaborative session: long length distress

	Emotional Burden How diabetes can make you feel emotionally, like feeling worried, sad, or stressed because of diabetes	Physician-Related Distress How talking to doctors or getting medical advice for diabetes might make you feel stressed or worried	Regimen-Related Distress How hard or frustrating it is to follow the daily plan for diabetes, like taking medicines and watching what you eat	Inte How and othe
LACK OF AUTONOMY	Fear of complications	Medical evaluation can be shallow	Fear of complications	
LACK OF COMPETENCE	I am still not sure how my diabetes has affected my body after so many years	I can't record everything neither the doctors	Fear of complications	
LACK OF EMPATHY	Fear of complications	Sometimes, doctors would not understand me and I went to a new one Medical evaluation can be shallow		

Diabetes distress table

terpersonal Distress

ow diabetes affect your relationships nd how you feel when dealing with thers about your condition

> Asking someone to help if things go wrong

Asking someone to help if things go wrong

Appendix 1C – Affinity mapping after collaborative session: timeless distress

	Emotional Burden How diabetes can make you feel emotionally, like feeling worried, sad, or stressed because of diabetes	Physician-Related Distress How talking to doctors or getting medical advice for diabetes might make you feel stressed or worried	Regimen-Related Distress How hard or frustrating it is to follow the daily plan for diabetes, like taking medicines and watching what you eat	Interpe How dia and how others a
LACK OF AUTONOMY	Healthcare systems offering fewer options every year	Doctors not offering services through my healthcare plan	Dependence on old technologies	l c al cc my
LACK OF COMPETENCE	There is a huge PDF file table with an index of carb per meal, every time it is updated, but no time to check	Lack of specialists in insulin pump	There is a huge PDF file table with an index of carb per meal, every time it is updated, but no time to check	Patieni "becon attorne others to be a therap
LACK OF EMPATHY	Healthcare systems offering fewer options every year	Lack of specialists in insulin pump	Every time I travel, I have to bring along all the stuff and my friends may be frustrated because of my low flexibility	

Diabetes distress table

rpersonal Distress

diabetes affect your relationships how you feel when dealing with rs about your condition



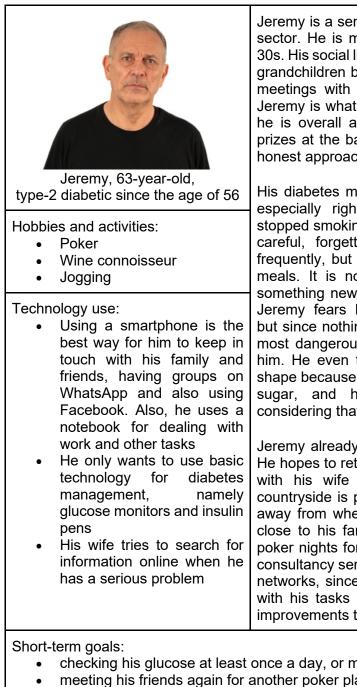
Appendix 2A – DMT1 persona creation

Rachel, 32-year-old, type-1 diabetic since the age of 10 Hobbies and activities: • Fashion	Rachel has been diagnosed with diabetes mellitus type-1 at the age of 10. This was a difficult time for her, but thankfully she had great support from her parents and friends from the neighborhood. This created a great bundle with these people, and she still enjoys organizing social gatherings with them whenever possible. Rachel is dedicated to her career and works as a marketing coordinator, and has recently concluded online courses in digital marketing and AdSense. Her diabetes management is responsible, but not perfect, managed with long-term basal and bolus insulin pens. She feels that it is quite difficult to	
TravellingBouldering	control her boluses, especially after meals. Once, she had a serious low glucose episode, and is	
Technology use: • Alongside using the main social medias for keeping in touch with friends and family (Instagram), Rachel also follows peer-to-peer diabetes communities (Reddit)	afraid of this happening again during her work. Rachel visits an endocrinologist every year and reports these situations, but she feels that she is just a number. Rachel fears long-term diabetes complications, and is not sure where she stands right now. But she hopes she is doing well, although she is not sure how to follow it nor the appointments to make to control it.	
 Rachel keeps her glucose under control with the traditional finger blood test method, followed by a PDF file that helps her to count carbs, but she has to search each item in the list She was not enthusiastic about CGM in the past, but she is considering it after low glucose episode 	Planning long-term life is difficult. Rachel wants to have children but is concerned about being there for her children with her chronic disease. Her past relationships possibly could have worked, but she felt as a burden to her partner. She then focuses on her current relationships with family and friends, but feels that everything would be easier if she was not diabetic.	
 Short-term goals: 80% of time in the planned blood glucose range going bouldering if she finds a time window preparing for a weekend trip with her friends Long-term goals: 		

ong-term goals:

- •
- •
- finding out more about her blood pressure issues being promoted and reaching a managerial position she desires to become mother within the next 6 years •

Appendix 2B – DMT2 persona creation



Jeremy is a senior financial analyst in the banking sector. He is married and has 3 children in their 30s. His social life combines family life, with his first grandchildren being born recently, and also a few meetings with friends, especially to play poker. Jeremy is what someone would call stubborn, but he is overall a good person. He has got a few prizes at the bank branch he works at due to his honest approach towards the tasks.

His diabetes management has seen better days, especially right after the diagnosis, when he stopped smoking. But recently he has not been so careful, forgetting to check his glucose rates frequently, but still taking fixed bolus doses after meals. It is not like he will learn to deal with something new at this point of his life, he thinks. Jeremy fears long-term diabetes complications, but since nothing is happening, he considers that most dangerous consequences are not affecting him. He even thinks it is a bit better to keep in shape because his body does not absorb so much sugar, and he did not gain much weight considering that he is also jogging every morning.

Jeremy already has some plans for the long run. He hopes to retire in the next 5 years, and moving with his wife from a flat to a house in the countryside is planned. But only a few kilometers away from where he lives, since he wants to be close to his family and also to host many other poker nights for his friends. Jeremy plans to offer consultancy services to his professional and social networks, since he feels that he still likes to deal with his tasks and wishes to inject resources in improvements to his new residence.

- checking his glucose at least once a day, or more if he feels like
- meeting his friends again for another poker playing night
- spending the weekend with his children and grandchildren

Long-term goals:

- retiring in the next 5 years
- becoming a consultant and offering services to friends and small companies
- moving to the countryside with his wife

Appendix 3A – DMT1 persona full journey mapping

"A day in Rachel's life is typically dependent on the quality of the diabetes management. Being an active person at her workplace, she has only a few windows to take care of this and takes every chance to make the control work as good as possible. Her days look much better when she does not deal with low or high glucose situations, but to achieve this, she must be accurate and strict.

To make sure that this will be possible, she wakes up early in the morning to check if her blood glucose is within the limits. Everything becomes better if she can make the carb counting of lunch and dinner correctly, avoiding episodes of low and high glucose. However, she went to have dinner with her friends last night and came across an uncomfortable situation.

Rachel tried to make her carbohydrate control as good as possible, but she could not make sure if the ingredients she found on her portions reflect the ones on the PDF file that she stores on her mobile, containing information about more than 2.000 food items. It ended up happening that she also forgot to compensate for the excessive meat consumed, meaning more long-term nutrients to digest, something that is not widely known by all diabetics. Having to take care of it, her sleeping hours were taken away due to this peak of blood glucose, for which she injected more insulin than required in order to go back to sleep.

Injecting insulin is normally what reduces Rachel's blood glucose level. But since she was distressed and needed to sleep, she took an approach of injecting more insulin than necessary. That brought her levels down after one hour, but then, they decreased to a dangerously low level. One problem has then been converted into an opposite issue.

By this time, Rachel realized that she would not sleep that night. It was only a couple of hours until the sunrise, anyway. She needed to perform at least 3 blood tests in the meantime, and she finds it particularly annoying to picture her finger every time a new test is needed. Many diabetic patients do not feel good about the excessive need for interactions with needles, both for insulin injection and blood testing.

Rachel then decides to eat a sweet snack as an early breakfast. She would have fainted if not doing that, given the amount of insulin she injected to compensate for her glucose peak. Fear of low glucose and high glucose are among the biggest concerns of diabetics, and situations like wrong carb control potentialize these episodes.

By the time that Rachel realizes that it will take some extra time to recover, Rachel realizes that it is already morning. She has to get ready for work and decides that it would be better to stay at home and perform her tasks remotely. Luckily, she has an agreement with her boss in these situations, and she sent a message to confirm that.

With the extra time spent on following up her glucose rather than commuting, Rachel realizes that the sweet snack was almost too much, but still manageable. She feels relief after long hours of distress trying to handle her levels, but her mood is not very good. Moreover, she is concerned of what these hours with low and high glucose could be doing in the long-term.

The morning time flows quickly, while Rachel tries to organize her tasks before an important meeting in the afternoon. She decides to go to the office and her lunch at home allows her to better control the carbohydrate ingestion. She eats a small portion of rice, a small piece of salmon, lentils, and a salad, and water with lemon. After that, she then goes to the office. Being disciplined, Rachel knows that she can make the control easily if the portions are well-known and if she injects the bolus insulin. Yet, she realizes that there was no sufficient time in advance for the insulin to act correctly, which leads to a quick interval of high glucose, but she knows that after a while it will be fine.

During the process of organizing the meeting, Rachel feels that she needs a snack. A good thing is that she can try the food that will be available at the meeting, making sure that everything is according to what she planned. Rachel injects a bolus and bites the sandwich, and receives a call. She did not eat the whole sandwich as planned, meaning that the bolus given to the whole snack will lower her glucose beyond the consumed amount of carbs.

The meeting starts punctually. In the schedule, there was the marketing budget for key social media accounts that the company was considering very important, namely TikTok and Instagram. Rachel has quite some interest in this meeting, having a great chance to help the marketing team and to be considered for a future promotion. But suddenly, Rachel remembers that she did not eat the sandwich, and the bolus she injected was acting. She then eats some sweet snacks to avoid a drop in blood sugar.

Almost being caught by surprise, she decides to take a quick break and uses this time to perform a blood test: her blood sugar was quite low by that time. Feeling a bit weak, there is only one safe option of eating something sugary and dealing with the consequences later. The meeting goes well and she feels better by the end.

After a day of learning lessons on how diabetes can be an obstacle in her life, Rachel goes home and has dinner. She also searches in the peer-to-peer community about other users, if they had situations like this before. A topic with a similar story was found, and then another one, and another one... Meaning that this can affect everyone."

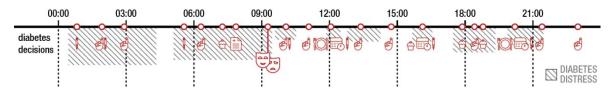
The summary of Rachel's journey in this day looks like this:



Rachel, 32-year-old, type-1 diabetic since the age of 10

A day in Rachel's life

"Rachel went out with her friends last night and could not find an easy way to make carb control. As a result, she spent most of the night trying to lower her glycemic. However, she did inject much insulin, which caused on her a risk of low glucose. This was very bad news to her, as she is organizing an important meeting in the office. She thinks about calling her boss and ask to work at home in the morning. Eventually, she manages the glucose well and gets better, ready to go to the office. During a lapse in time, she does not manage to eat what she planned despite have injected insulin for it, and has a difficult time. Later at home, she tries to find similar stories from peers."



Appendix 3B – DMT2 persona full journey mapping

"Jeremy starts his days early. After some morning rituals, he goes straight for a walk, or as he prefers to say, a jogging session. He has had diabetes type-2 for a few years, and incorporated some healthy habits to his routine. Alongside the physical exercise, Jeremy also stopped smoking when he received the diagnosis. Jeremy expects that these new habits will serve as a self-controlling measure, so he does not need to waste much time checking his blood glucose.

Then he goes home for breakfast with his wife, if she is still there when he arrives. It happens that she was not there, but she left the meal ready for him. Jeremy eats a portion that includes ham, eggs, bread and honey alongside a cup of coffee with sugar, which was carefully prepared by his wife. She placed a pack of sweeteners alongside the cup of coffee, but Jeremy prefers to add sugar or honey to his drink. Overall, he considers the meal to be light and knows that they never cause him to get thirsty after a while, one of the symptoms of high glucose.

This time seems to be an important time to do some blood glucose tests, as he had an activity that lowers the glucose right after another one that has the opposite effect. 'Perhaps they compensate for each other', Jeremy thinks. So then he does not bother performing the test. About one hour later, he started feeling the very same symptoms he knows very well: his blood glucose is high.

Jeremy then runs to the fridge to search his insulin pen. The value of his blood glucose may be high, and he takes a shot to compensate for it without even knowing what the level was. He felt sleepy at this time, and wonders if this has anything to do with his high blood pressure. After a while, he still seems to feel thirsty and decides to perform a test to realize that the glucose was still high. Another shot of bolus later on, and Jeremy hopes it will go down soon.

It is a critical situation, but Jeremy still thinks that, as a type-2, there will always be active insulin in his body, but maybe it takes more time to act. It would be a very stressful routine for him to check his blood sugar all the time, especially for the amount of fingersticks he would need for that. So he takes an approach to ignore the problem and to use these commitments to a new lifestyle as a justification for that. His wife, however, is more concerned and still asks him to do more blood tests.

Jeremy goes to work and starts his shift. There is a long day ahead of him, so he starts with checking his email and following market trends. Next, he attends a meeting with the team to discuss the priorities of the day and ongoing projects. Lastly, Jeremy analyzes a financial report and keeps control of the key performance indicators and market data. His commitment to the KPIs isn't applied to check his glucose levels.

By the end of the morning, he thinks about his next poker night with friends. It is his time to organize the place and snacks, and he has not had time to go to the supermarket yet. He saw an offer at the supermarket nearby, perhaps he can take the chance to buy the snacks and grab lunch nearby. Jeremy quickly checks the online map with the options of food nearby. He thinks that any pizza option at the Italian restaurant would be satisfying, before he goes back to his work tasks until midday.

The food stand is not that busy, so Jeremy sits and eats. Before leaving, he injects the bolus to compensate for his meal. Later, he buys the groceries and heads back to work. Jeremy will check his blood glucose in about two hours, which is the time that the insulin will take to make effect. His glucose was a bit high, but in principle, it was within the expected, he thinks. According to his own experience, the blood sugar will be lower in a few minutes.

After helping a colleague, he goes to the bathroom. He has been there a few times already after the lunch, perhaps this could be a hyperglycemia. A work routine made Jeremy only realize right now that he has been doing this, and that he needs to check his glucose again. It happens that the glucose was high, but he does not understand why. He injects insulin to reduce it and calls his wife. She said that she will look for it and will return soon.

The work ends without him understanding very well why his glucose was high for such a long time. He goes home and his wife mentions that nutrients on pizza are complex and not so easy to digest, taking up to a few extra hours for some proteins to be digested. This results in glucose peaks after the effect of the basal insulin. She suggests that he avoids eating pizza from now on, for which Jeremy says he will think about.

It was then dinner time and Jeremy said he would like to eat something lighter, given what has happened during the day. He had a salad and salmon, and his wife decided to join Jeremy to reinforce positive feedback towards this new approach. Perhaps he will not really extensively change his habits, but a situation like this showed him that he needs to be careful. All the good results that he reached after the diagnosis were because of his commitment to new diets and monitoring, not only because of isolated habits.

Before sleeping, Jeremy tests his blood glucose again, and it is within the desired levels. A few hours after dinner passed already, and there is nothing else to increase his glycemic. Then, he discusses with his wife ways that he can better control his blood sugar without the need for many finger-sticks. They will visit Jeremy's endocrinologist soon, and they decide to ask his help. Perhaps there is another device that suits his needs better."

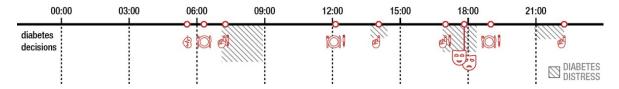
The journey of Jeremy's day described above looks like this:



Jeremy, 63-year-old, type-2 diabetic since the age of 56

A day in Jeremy's life

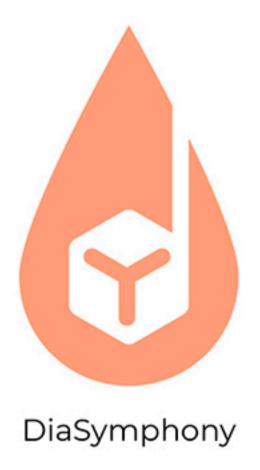
"Jeremy wakes up and goes for a walk in the morning, keeping a more healthy routine after the DMT2 diagnosis. Despite the effort, the food that he consumes is generous in carbohydrates, which makes his glucose to be high for a long time. However, he is not aware of this because he does not perform enough fingerticks because of needle anxiety. He also thinks that he can sense the high glucose. Two episodes of hyperglycemia in one day makes him and his wife reflect on other ways to control the blood glucose."

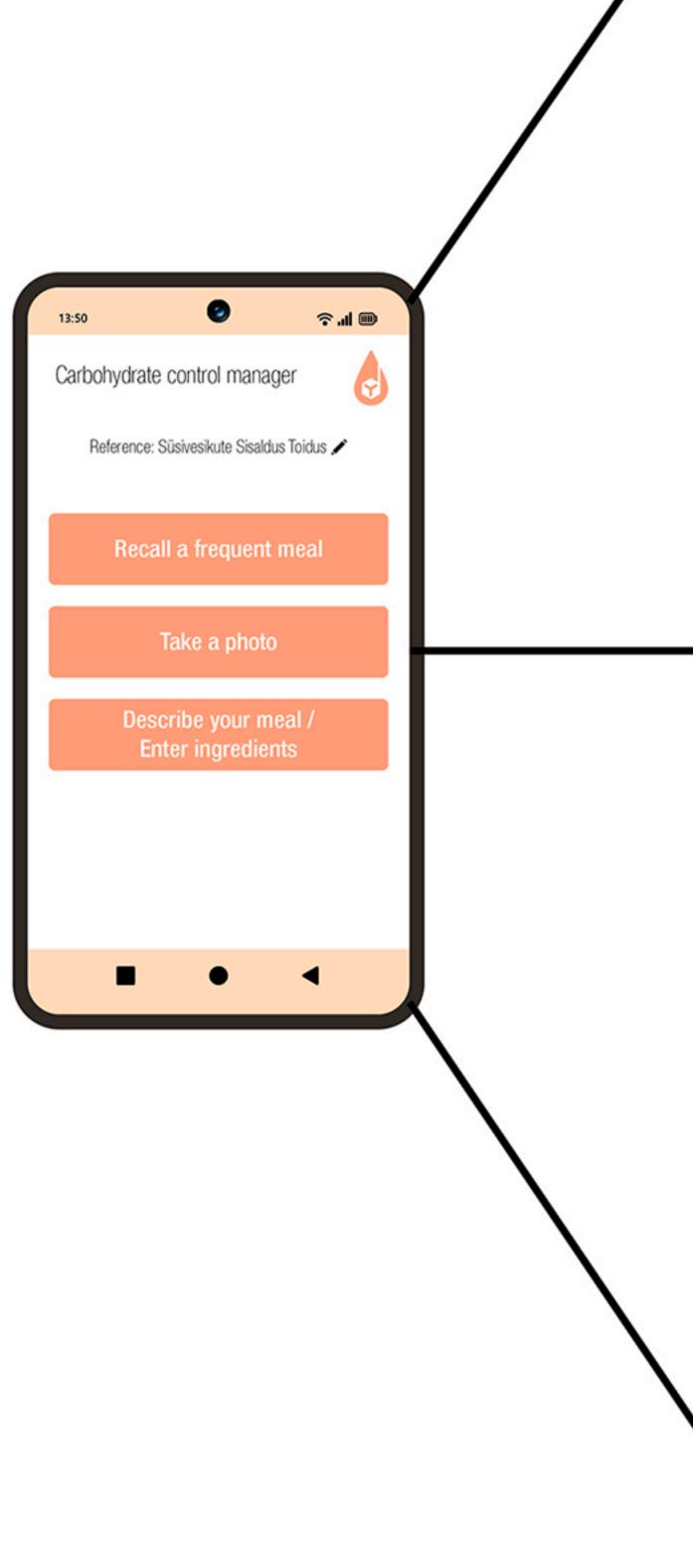


GRAPHIC MATERIAL

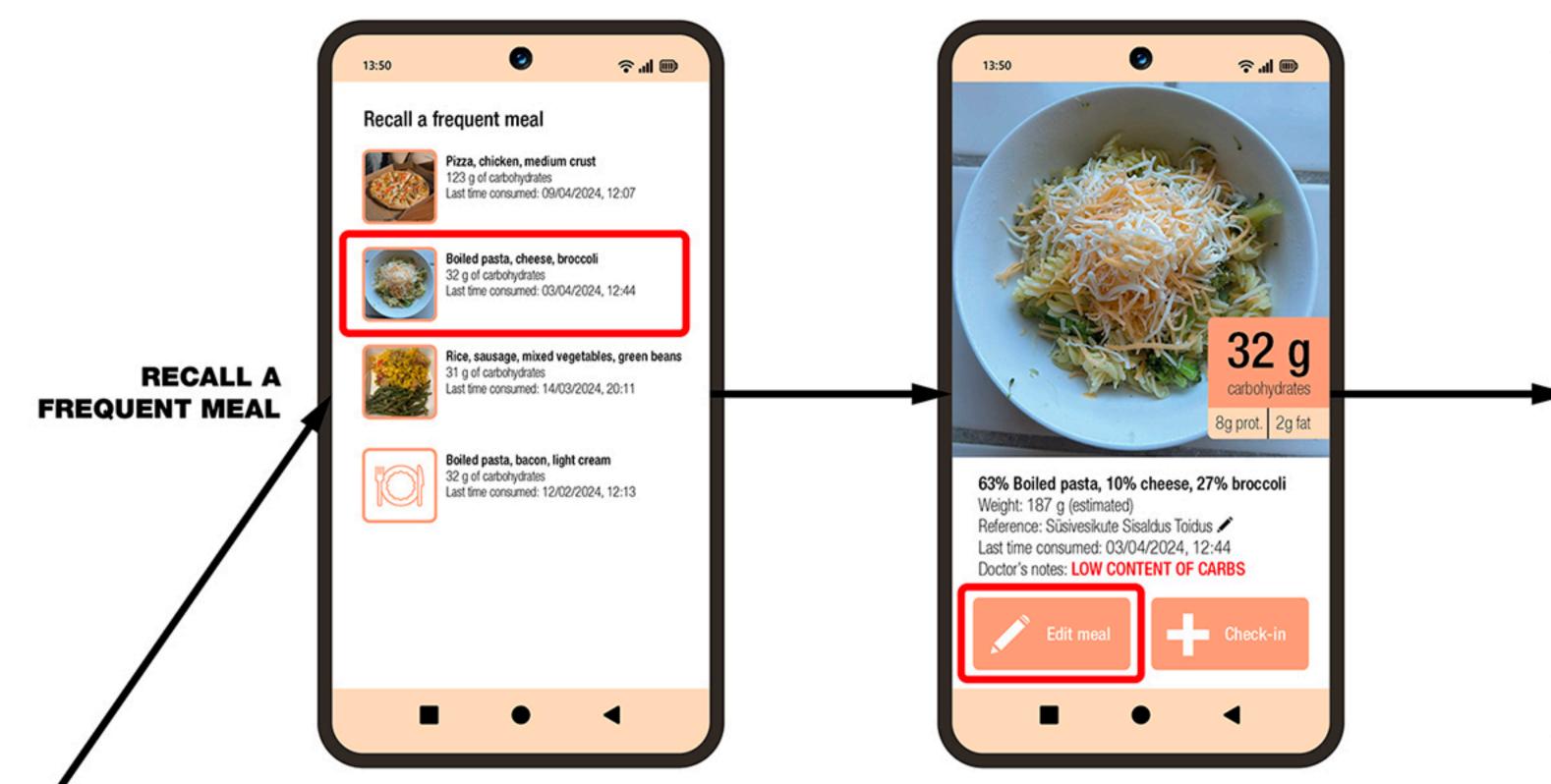
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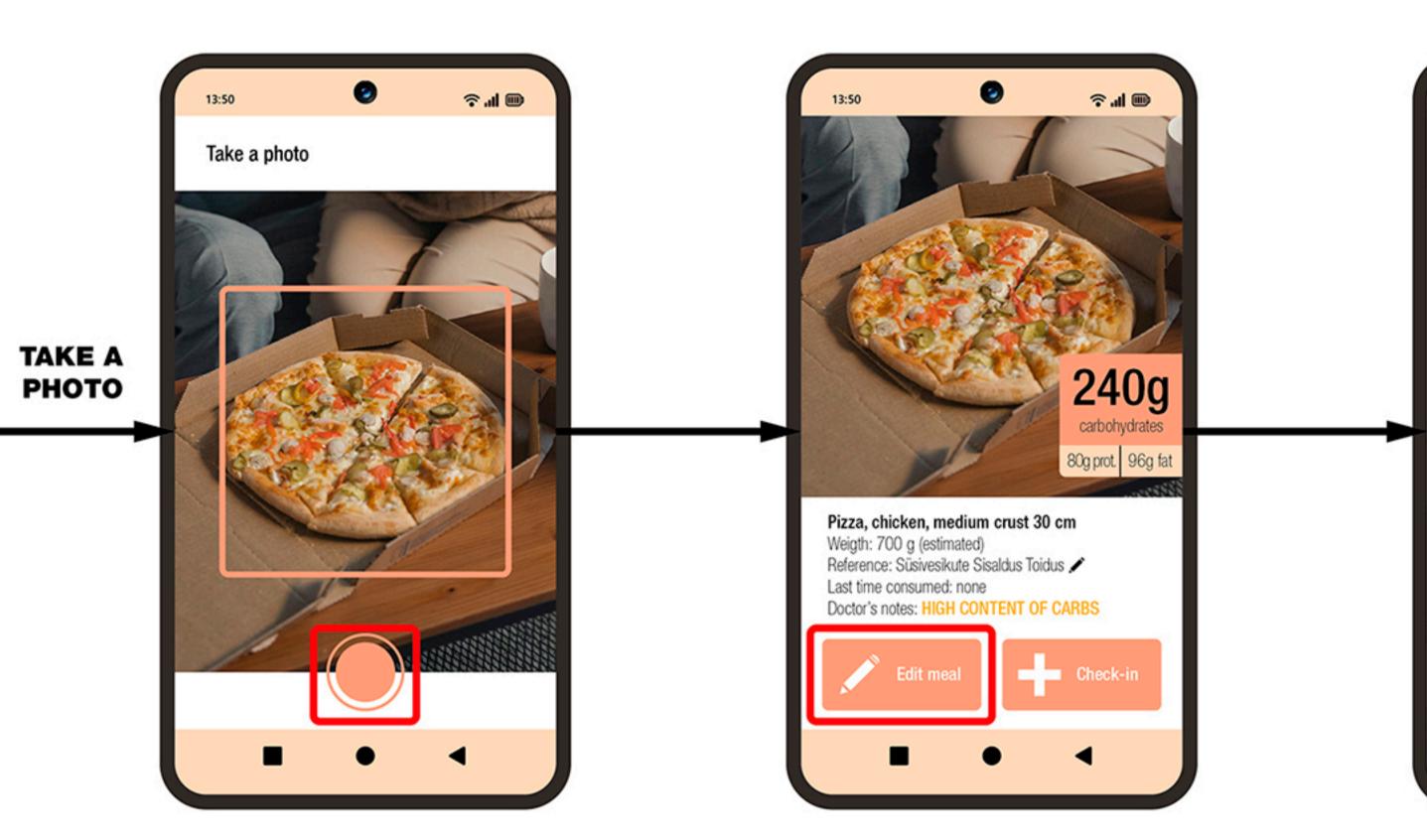
- 1. User journey inside the DiaSymphony platform
- 2. Technical drawing of the 3D-printed insulin cannula

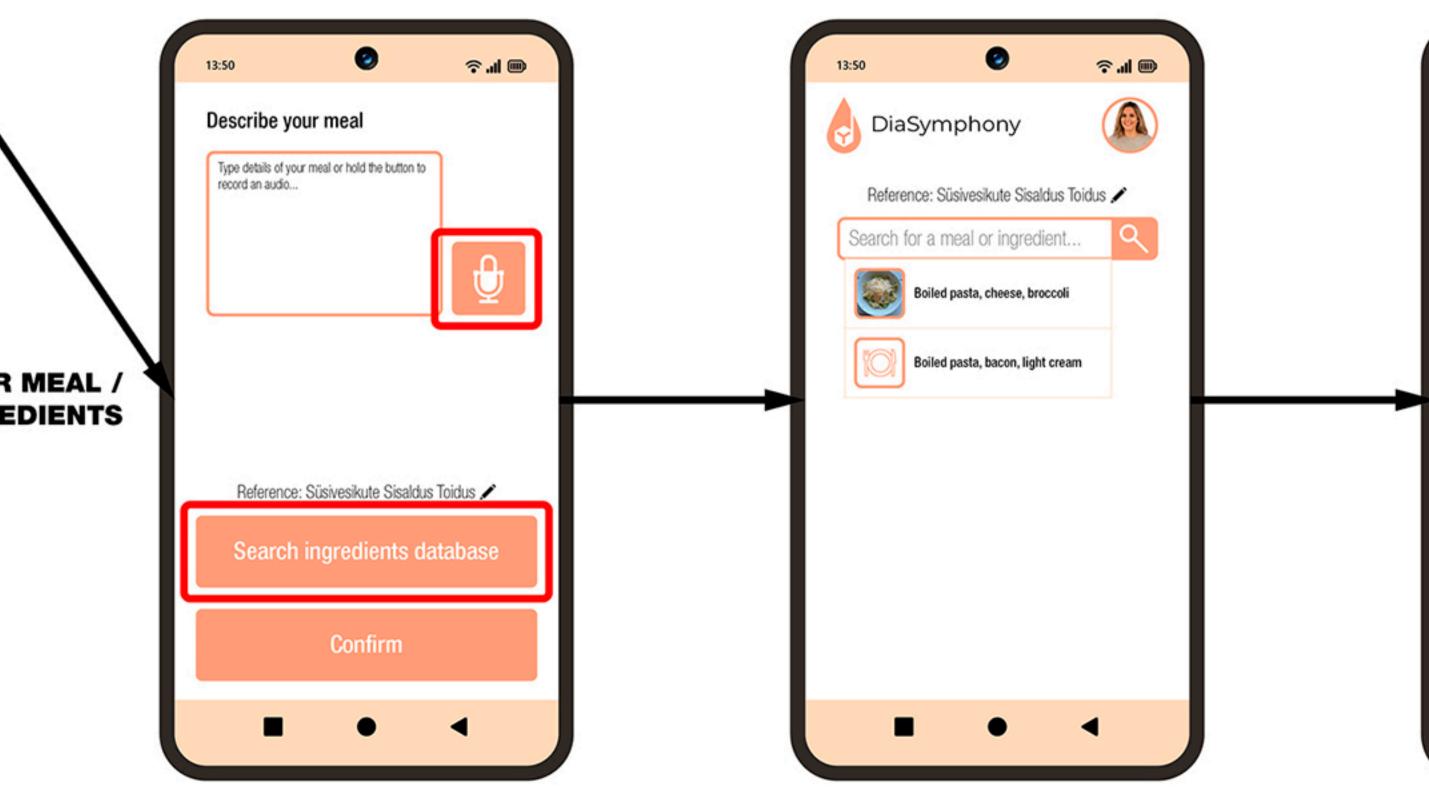


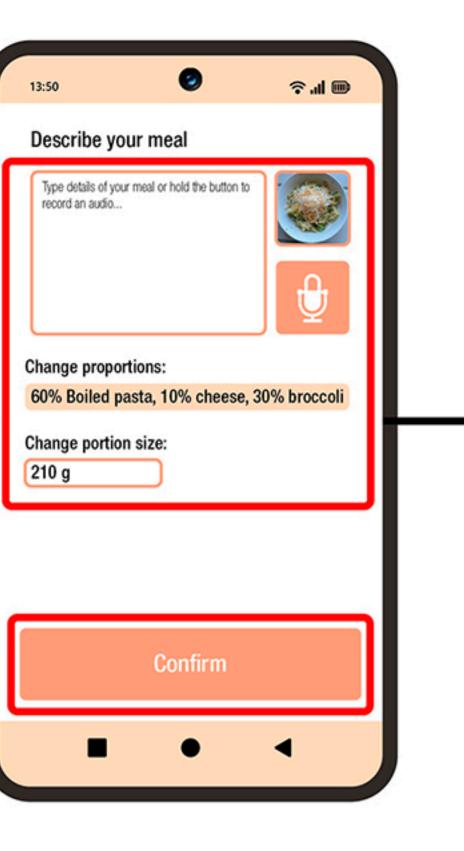


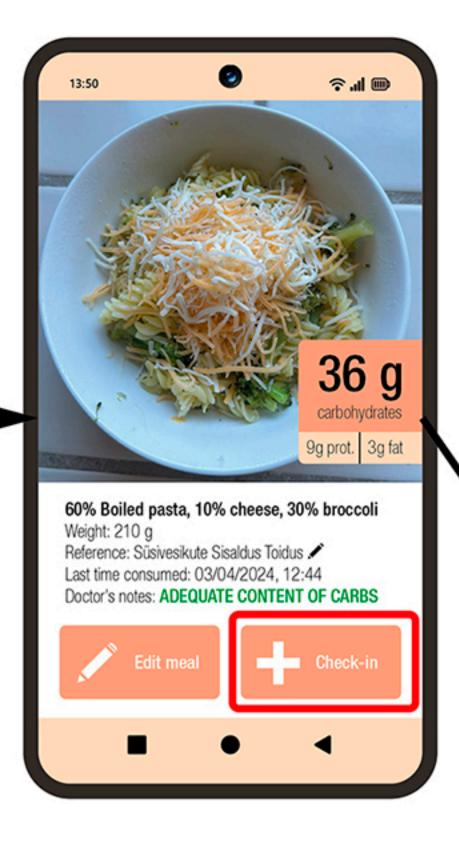
DESCRIBE YOUR MEAL ENTER INGREDIENTS

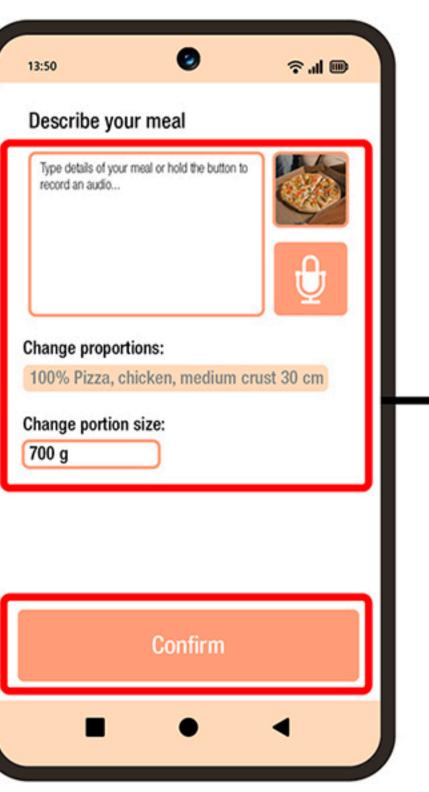






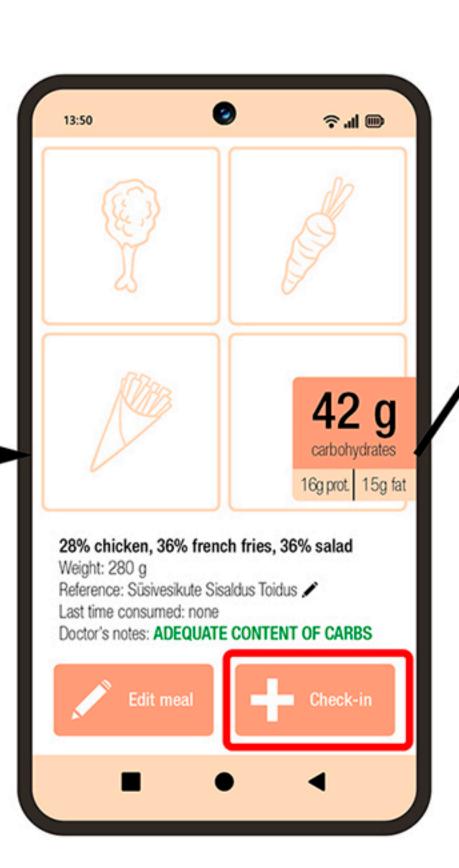


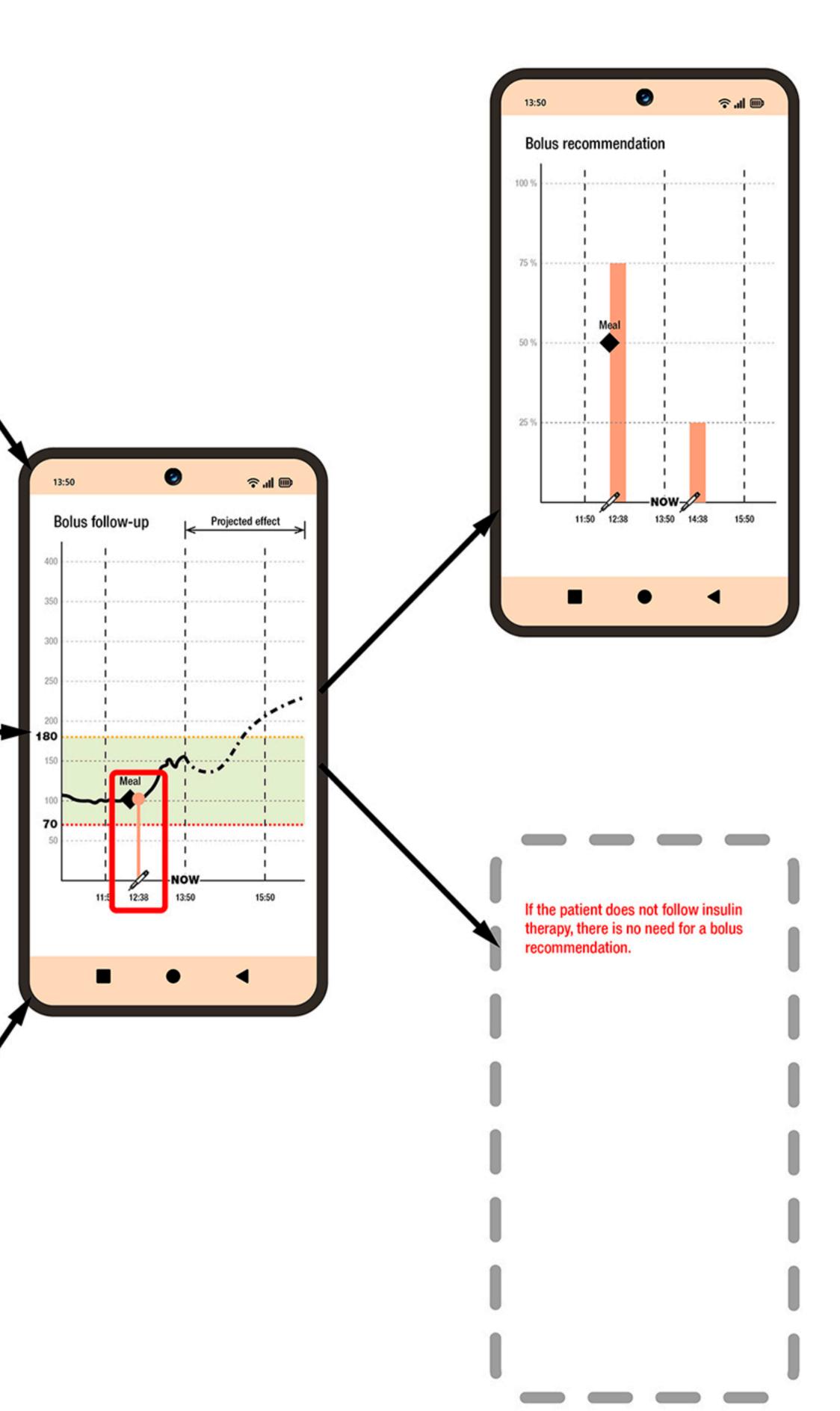




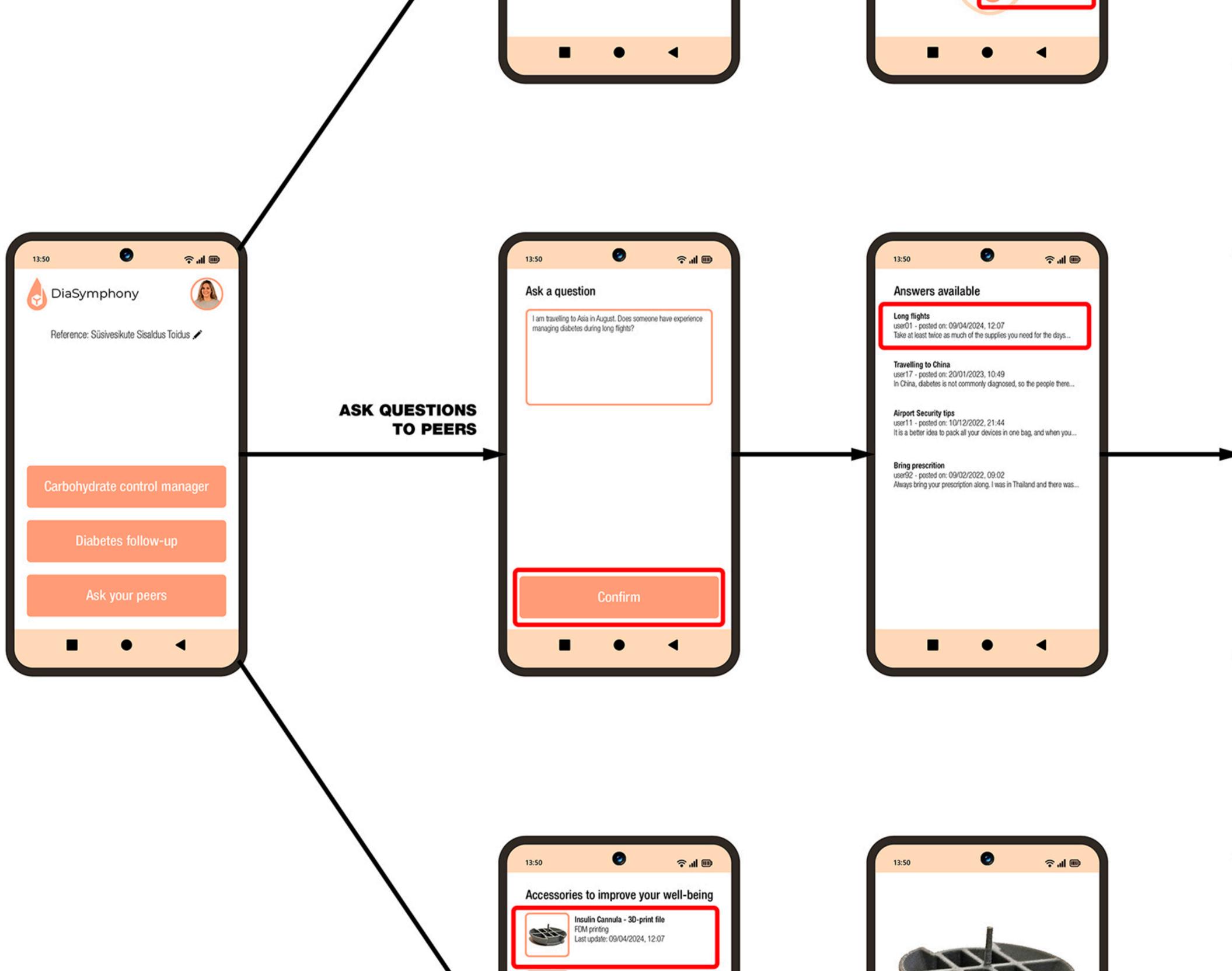


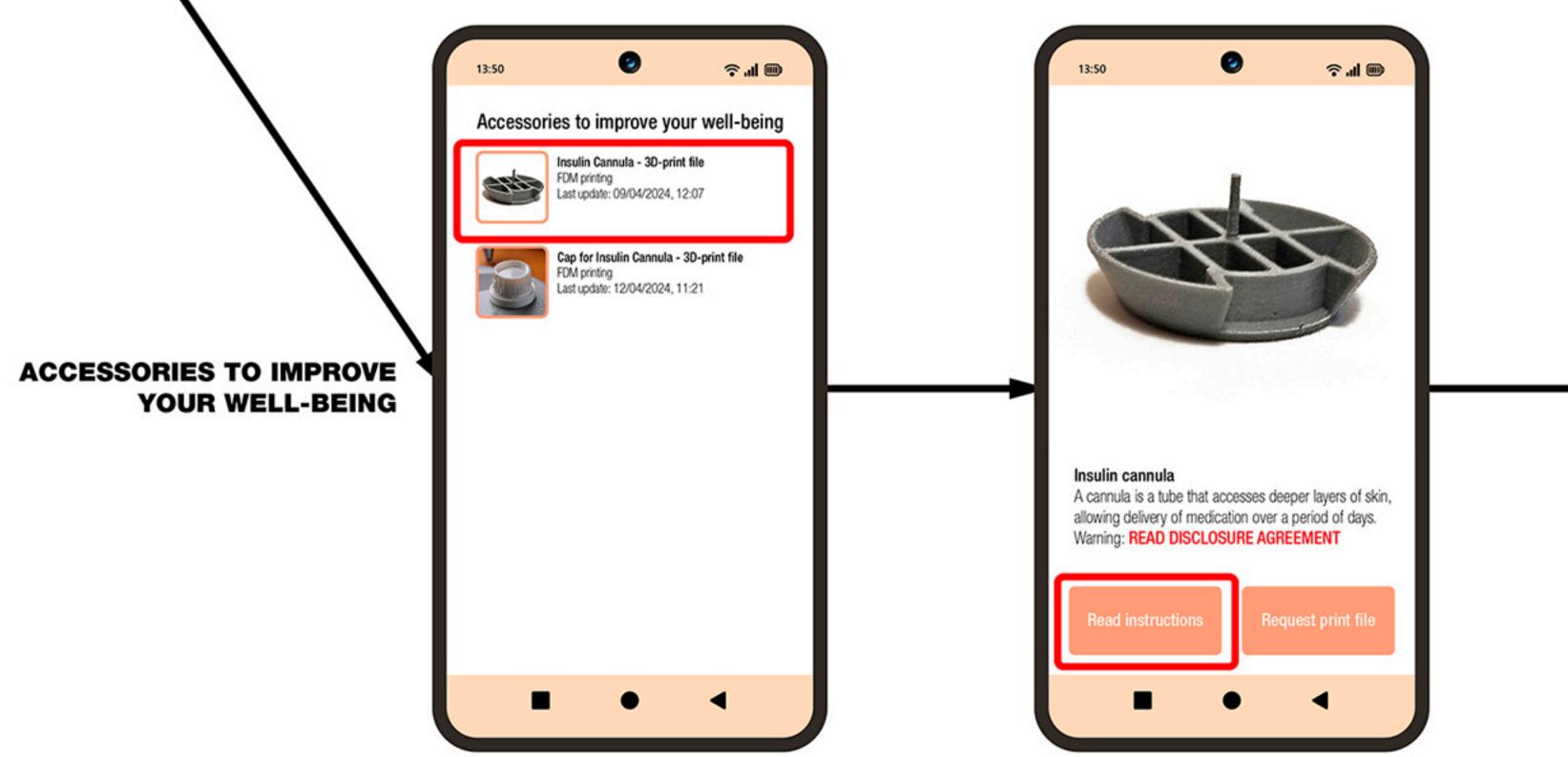


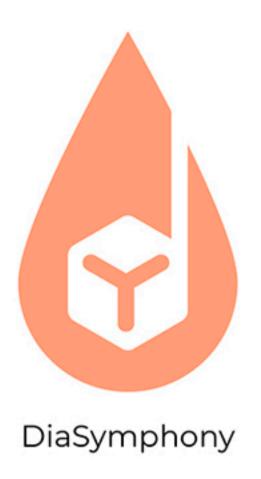


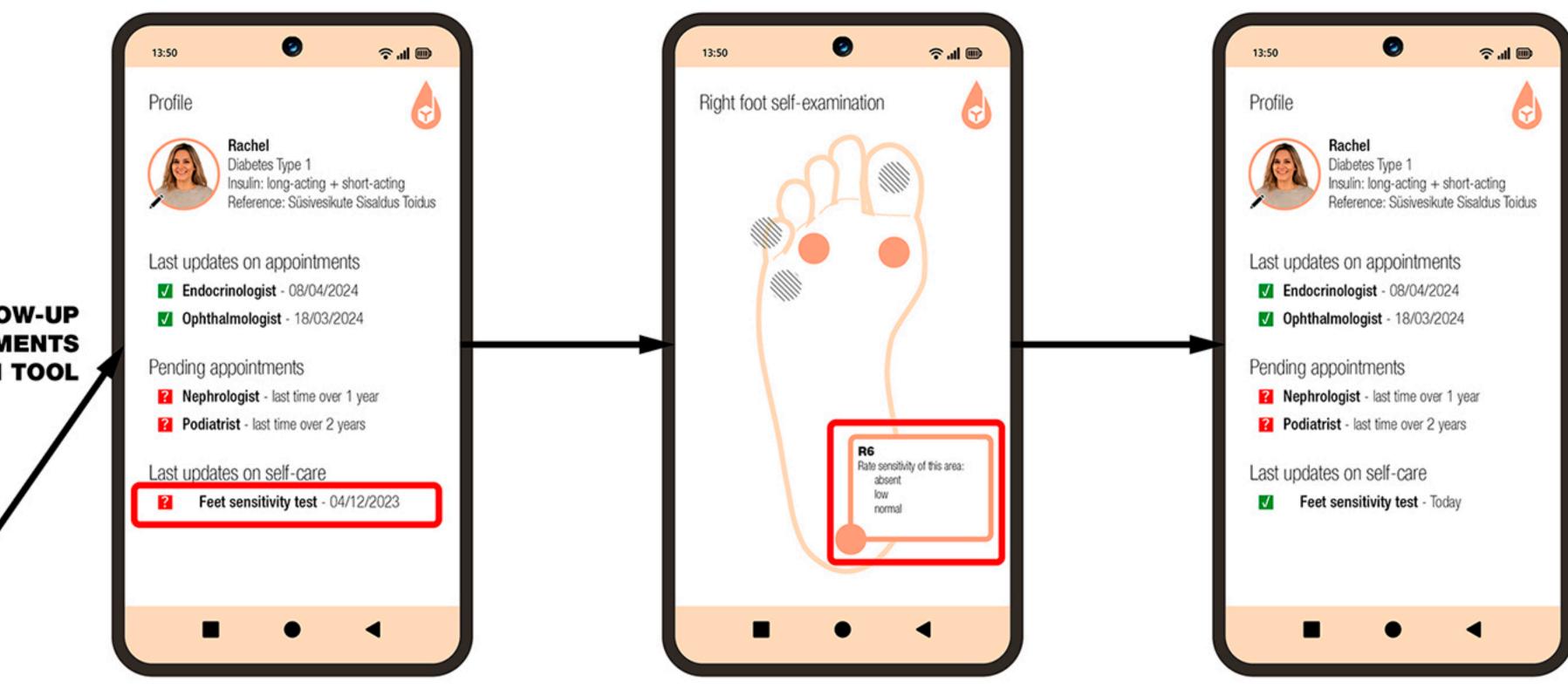


DIABETES FOLLOW-UP UPCOMING APPOINTMENTS + SELF-EXAMINATION TOOL









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Long flights user01 - posted on: 09/04/2024, 12:07

Take at least twice as much of the supplies you need for the days you'll be in the air and on layovers! Trust me, I learned that one the hard way. Last trip to Hawaii, my flight got delayed for hours, and of course, my snacks were all gone by the time we finally took off. Having those extra supplies saved me a major meltdown (and a potential sugar crash)!

Here's what my long-haul flight toolkit looks like now:

- Cooler bag with ice packs: Lets me pack healthy snacks like pre-portioned nuts, cheese, and veggies. Airplane food can be a sugar bomb, and you never know what kind of delays you might hit.
- Extra insulin/medication: This is a lifesaver, especially if you factor in potential lost luggage or changes in time zones that might mess with your dosage.
- CGM if you have one: This little gadget is amazing for keeping an eye on your blood sugar throughout the flight, especially when turbulence makes finger pricks tricky.
 Medical information form for the airline: Fill this out beforehand.
- It lets them know you have diabetes and might need specific things, like space for injections or a place to store your cooler bag.

Remember, every diabetic is different, so what works for me might need tweaking for you. But hopefully, these tips help make your next long flight a little smoother. Safe travels!



