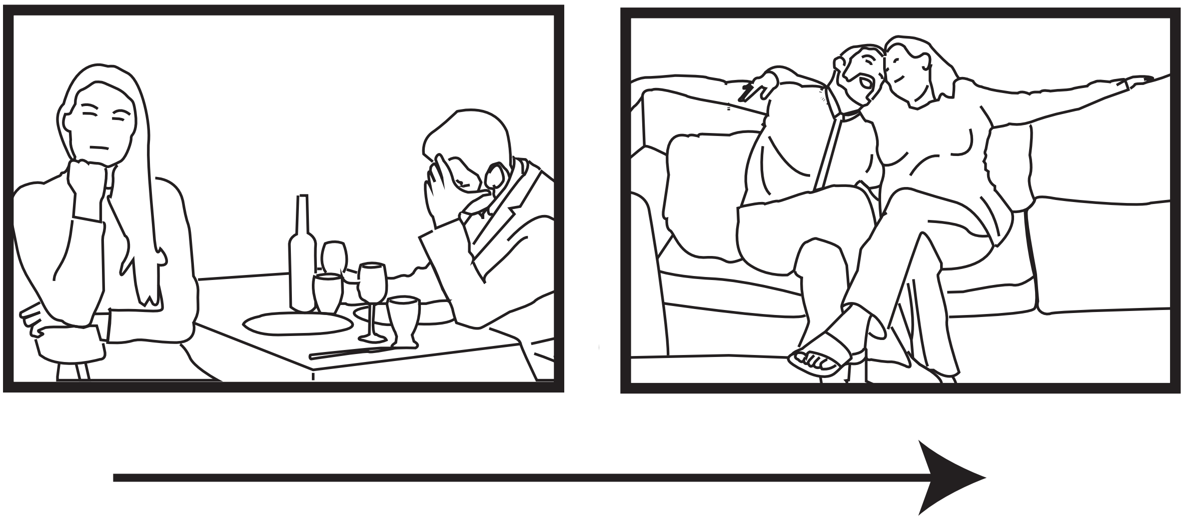
# D1Alemma

## A tool for relatives to support diabetes type 1 patients



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Master thesis

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# D1Alemma

## A tool for relatives to support diabetes type 1 patients

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# SUMMARY

The goal of this graduation project, conducted for the master science communication at the Delft University of Technology (TU Delft), was to design a tool to help partners of diabetes type 1 patients to come closer to the patient, by conversations about diabetes, to gain more insights in how the patients feels and how to support. The project is part of the Integrated Care Program for Diabetes type 1 patients (INCAP) in which ultiple partners are involved (SERMAS, Medtronic, Universidad Politécnica Madrid, TU Delft).

The addressed problem in this project is that partners of people with diabetes have difficulties how to support the patient, while the patients need this support in order to improve their self-management of diabetes. This is associated with the feeling of a partner of being excluded, because the partner does not know what it is to have diabetes, and is not able to grasp what is really going on regarding the diabetes of the patient.

To come up with a tool, several studies were conducted; a systematic literature study, context mapping, interviews and co-designing. The first two studies were conducted to gain knowledge about the topic to start designing a tool which benefits the user and solves a problem or at least starts solving the problem. The research questions answered using these methods were: How can relatives of patients with diabetes type 1 support the patient to improve their self-care management? Which elements of social support are desired from relatives for people with diabetes type 1 according to the literature? and How do relatives support the person with diabetes now? How can support be improved according to the patient and the relative? Co-designing was used as a method to involve the target group early in the process of designing a tool.

In the design phase two concept directions were created. The first concept direction is a tool which enriched the data of the blood glucose sensor with emotions and feelings. Adding emotions will make the data more comprehensible and more relatable for partners. The other design tool is DIAlemma, a digital application in which dilemmas and questions can be answered by both the patient and the partner to gain insights in how diabetes affects them, to reveal needs, expectations and wishes. This application stimulates conversations and discussions about diabetes. This is needed since partners can feel excluded from their partner regarding diabetes.

During the co-design sessions participants indicated that they value the design directions. It is a great addition to what is already out there. Based on a Harris profile, and the preferences of the target group a selection is made to further develop the DIAlemma tool.

The DIAlemma tool can supports in knowing and understanding what diabetes does to patient and partner in daily life. It does this by using real situations in which both the patient and the partner answer question about the situation, how they will act and how they expect the other to react. This way the partner is involved in the diabetes of the partner, and this can lead to a shared illness appraisal in which the problem is seen as a shared problem, rather than my problem or your problem. This is an important step in providing and receiving support. Eventually, better provided support will help the patient in their self-management.

# CONTENTS

# 1. INTRODUCTION

This graduation project for the master science communication at Delft university of Technology is about social support of relatives to diabetes type 1 patient to improve the effectivenes of diabetes self-management.

Diabetes is a known chronic disease. Around 422 million people are diagnosed with diabetes worldwide. It is a serious diseases, since 1,6 million people died in 2016 from diabetes as a direct cause. There are several types of diabetes, of which type 1 and type 2 are the most common ones. Diabetes occurs when the pancreas does not produce enough insulin or when the insulin produced by the pancreas is not effectively used by the body. This project is focused on type 1 diabetes only (WHO, 2016).

## Self-management

Self-management is a term that is used widely, it can be defined as the active participation of a patient in the treatment. Healthcare has shifted from a paternalistic traditional model to a collaborative model. In the traditional model the patient was seen as a passive recipient of care provided by healthcare professionals, while in the collaborative model the patient is actively involved and has a central role (Bodenheimer et al., 2002).

A definition of self-management in given by Barlow et al. (2001) and is as follows:

"Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established."

In diabetes, a condition which influences the patient constantly, it is necessary to take responsibility to manage the condition and to achieve the desired health outcomes.

According to Lorig et al. (2003) Self-management in diabetes consists of three tasks. Medical, behavioral and emotional management. With medical management the most important tasks are keeping blood glucose levels in range and good metabolic control. What should be taken into account to achieve good blood glucose levels are monitoring of the levels, food intake and counting carbohydrates, physical activity, and medication. Behavioral management involves lifestyle changes. Emotional management mainly involves accepting having diabetes and being motivated to take care of the it.

The effectiveness of self-management can be improved by different factors, like education, coaching or social support. In this project social support is taken as a focus to improve self-management behavior and outcomes, because most aspects of the self-care management takes place outside of the hospital and mostly with family members and friends are involved. Diabetes is therefore also known as a family disease since family interactions contribute to the self-management. The relatives of the patient are important to provide social support, which is associated with improved self-management and self-care behavior as well as better blood glucose control in the long term (Baig, Benitez, Quinn, & Burnet, 2015; Williams, Laffel, & Hood, 2009).

## Social support

Earlier research, performed for the course research methods in the master science communication at the TU Delft, was focused on the variables that are important to people with diabetes type 1. This study was performed with the aim to identify patients needs and wants and which variables are important to them. This study was done for the INCAP project, which will be described later in this introduction under "project partners".

The studied variables were:
- Self-care : Self-efficacy, reward, self-care management
- Professional support: Coaching, structured education, doctor-patient communication
- Social support: Social network, received support, perceived support

Social support was one of the variables that was mentioned by the diabetics as valuable and needed. "Regarding social network, about half of the respondents in this study indicated needing a social network. Received support was mostly wanted from family, other diabetics and friends. With regard to perceived support, the respondents preferred personal dialogue, going to diabetes events and social media." (Dirrix, Van Megen, Schouten & Smits, 2019).

Based on the outcomes of this study with 35 participants, I want to dive deeper into this social support phenomenon. This was the starting point of this graduation project.

The focus in this project is thus on social support, which is related to communication and the social and emotional aspect of diabetes. More specifically, the social support between patient and partner, since a partner is in general the closest to the patient and it is likely that is important to get support from the ones close to you. The project is focused on adults (18 years and older) with diabetes type 1. Children are taken out of the scope, because they treat diabetes most of the time with their parents.

## Problem

Social support is not always given in the right way, according to scientific articles. Statements from several articles are mentioned here.

Family members can feel distressed because they do not know how to positively support the patient due to a lack of knowledge. One out of three family members is frustrated because they did not know how to support the one with diabetes. (Baig et al., 2015; White, Smith, & O'Dowd, 2007).

In a study performed by Kovacs Burns et al., (2013), around 50% of the respondents stated they would like to help the person with diabetes to express their feelings and around 40% would like to be more involved in the care of the patient.

Diabetes patients also felt alone sometimes by a lack of understanding from their relatives. Also from the patients side good communication is required to indicate what is supportive and what is not (Kovacs Burns et al., 2013). It is important to support family members to understand the disease of the diabetic in the first place.

Next to knowledge, emotional support should be given. This is one of the most important ones, since feelings from diabetic patients can differ throughout the day from satisfaction to annoyance, from enthusiasm to sorrow etc. This is influenced by their glucose levels. The meaning of emotions and feelings have an influence on self-management (Rintala, Paavilainen, & Åstedt-Kurki, 2013).

## Goal of the project

The aim of this research project is to let relatives provide the right social support to the patient, or at least provide them with a tool to start providing this support.. This way the patient can improve the effectiveness of their self-management.  This will be done by letting the relative understand what diabetes is and how it influences the patient, and how the patient can be supported. This will be done by creating a tool.

## Research question

For this project a research question is formulated:

# How can relatives of diabetes type 1 patients support the patient to improve their self-management?

Sub questions related to this main research question are:
*Which elements of social support are desired from relatives for people with diabetes type 1 according to the literature?*
and
*How do relatives support the person with diabetes now.*
and
*How can this be improved according to the patient and the relative?*
and
*A tool will be developed to guide the process of providing better support. Can can this be achieved?*

## Project partners

This project is part of INCAP which stands for Integrated care program for type 1 diabetes mellitus patients with insulin pump. This project is funded by EIT Health, which has a core mission to accelerate innovation and entrepreneurship in healthcare to stimulate healthy living and active aging. The mission of INCAP is to improve the quality of life of patients with diabetes type 1.

The goal of INCAP is to develop an integrated program for patients with diabetes type 1 with digital technologies to improve clinical and healthcare outcomes.

The project is based on three pillars:
- The implementation of a remote monitoring support center
- The development of an educational program
- Establishments of a communication channel between hospital and primary care

INCAP sees education as the key to successful self-management.  The educational program is targeting its patients and their relatives. Goal is to empower them for better self-management of the disease, increasing adherence to treatment plans, and eventually improve clinical outcomes. It aims to educate patients and their cares through educational videos, information on nutrition and exercise, available on an application for their smartphones. They will also get feedback to improve adherence to the treatment.

Project partners of INCAP are Servicio Madrileño de Salud (SERMAS), which is taking care of the coordination of the project, Medtronic, which will be the service provider of the remote monitoring support center, Universidad Politécnica de Madrid (UPM) , which takes care of the user requirements, usability tests and health technology assessment, and the TU Delft, that is contributing to the education and communication part of the project (figure 1).

In this graduation project the focus is on the second pillar, the development of the educational program. To add to the educational movies, information etc, this graduation project will focus on the social support patients need from their relatives. Social support is found to be an important factor to improve self-management of the disease. This study aims to gain insights in how support from relatives can be improved to support the patient. These insights can be used to make the integrated care program even more integrated, by also addressing the relatives.

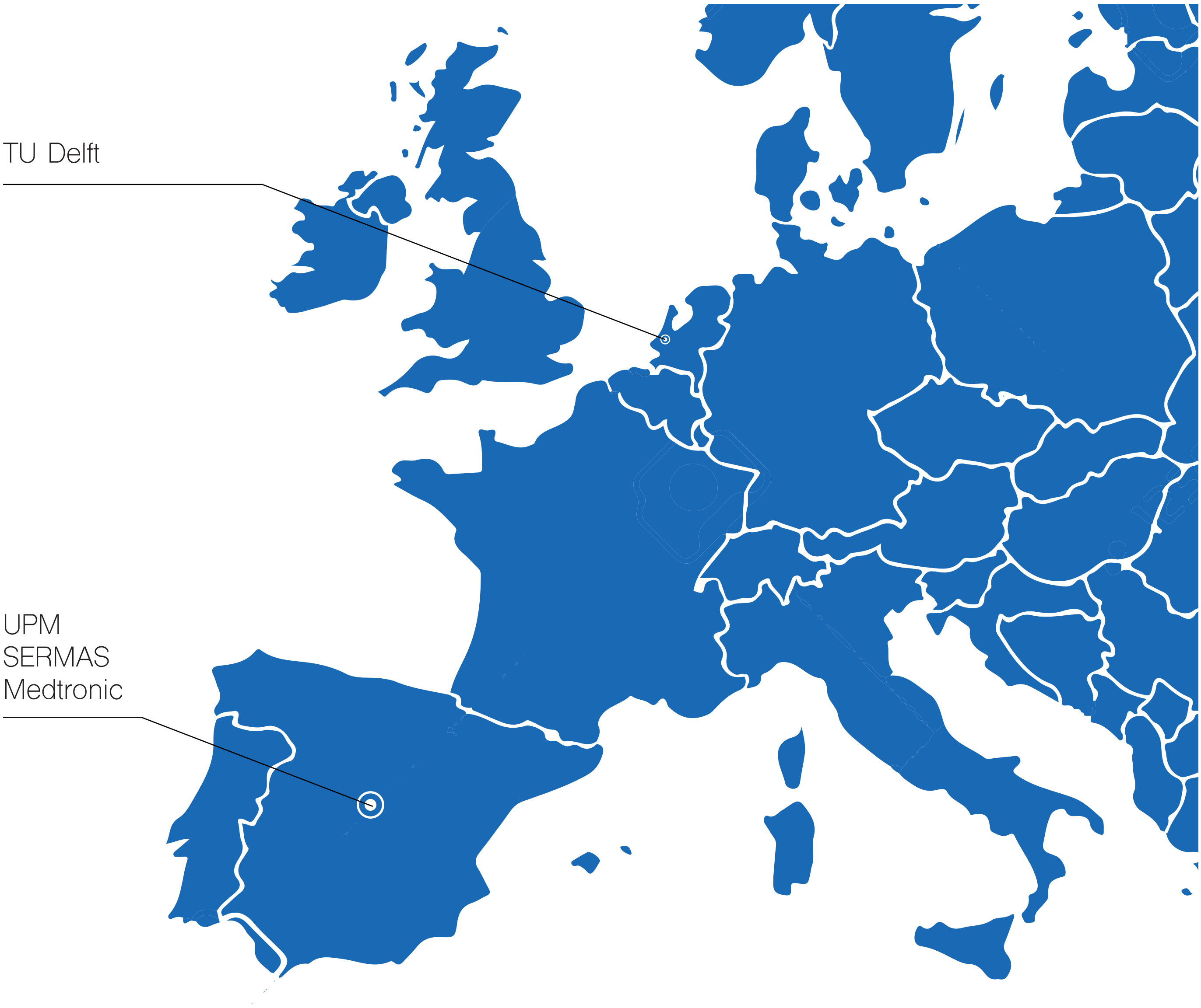


Figure 1: Project partners of INCAP located on a map of Europe

## How to read

This report starts with a chapter about the methodology used in this project. Later on the report is divided into four phases: the discover phase, in which the findings of the literature study and the analysis and findings of conducted interviews are given; the define phase, in which the requirements for the tool based are listed; the develop phase, in which the concepts are developed together with the target group; the deliver phase in which the design is evaluated and recommendations are given including a conclusion (figure 2).

| Discover | Define | Develop | Deliver |
|---|---|---|---|
| Systematic literature review<br>Context mapping (interviews) | List of requirements<br>Ideation<br>Concept directions | Co-design session<br>Concept choice<br>Iteration of design | Evaluation<br>Conclusion<br>Discussion<br>Recommendations |

# 2. RESEARCH METHODOLOGY

The main goal of this research is to support people with diabetes type 1 in their self-care management by receiving social support from relatives. For this a tool will be designed which helps the relative to gain more knowledge about the disease and to find ways on how to support the patient in the way he/she wants. This chapter describes the methodology of the research.

## Methods

The research question in this project is: How can relatives of diabetes type 1 patients support the patient to improve their self-management? This will be achieved by making a tool.

The methods used to execute this research and to answer the research question are a theoretical study and design based research, with context mapping, interviews and co-design sessions. These two methods are chosen because it highlights the problem from two different perspectives. The literature study will answer which elements of support are important regarding earlier studies. The empirical study focuses on the experiences of patients and their relatives with diabetes type 1.

First of all a systematic literature study will be conducted. The main purpose of this systematic literature review is to answer the first sub-question: Which elements of social support are desired from relatives for people with diabetes. This literature study will be focused on adults with type 1 diabetes and which role their partner plays in their life dealing with diabetes. Findings from this literature study will be used as an input for the other sub-question: How do relatives support the diabetes patient at the moment and how can this be improved according to the patient and the relative? This question will be answered using generative methods, such as context mapping and semi-structured interviews.

The results of the literature study and the interviews with diabetes patients will be used as an input for designing a tool to help partners providing the support the patients wants to receive. Co-design sessions with diabetes patients and their partners will be used in the development phase of the tool.

This design based research approach is used to involve patients as early in the design phase as possible. This prevents designing tools that do not fit with the wishes or beliefs of the target group.

## Phase 1: Discover

The discover phase starts with answering the sub research question: Which elements of social support are desired from relatives for people with diabetes?

To answer this research question a systematic literature study was conducted. The insights from the literature study are used to formulate design requirements and to formulate interview questions.

Interviews were conducted with 11 people with diabetes type 1 and 5 partners of a person with diabetes type 1. A semi-structured interview was conducted. Before the interview took place an generative research tool was used to discover insights into the life of people with diabetes and their surroundings, feelings and emotions. The generative tool used for this was a sensitizing booklet. The interviews covered the assignments made in the booklets.

Data analysis of the interviews were done using transcribing of the interviews verbatim. Coding of the interviews were done by highlighting relevant quotes relating to the research question. After coding all the quotes, themes were created. This was done by creating a condensed meaning unit from the quotes and coding these units, creating subcategories and categories according to the method of Graneheim.

The outcomes used form these two studies delivered of input, in the form of design implications, for the design requirements for a tool. The theoretical insights and the insights from the interviews serve as a basis for the next phase of the project. The design of a tool which helps giving support to diabetes patients by their relatives. The next phases are related design-based methods.

## Phase 2: Define

In the define phase a list of requirements is created for a tool, which is based on the insight from the discover phase. The tool will be designed to provide a way for relatives and patients to provide social support in a way the patient want. This tool will be focused on diabetes type 1 patients in the beginning of a relation.

Ideas are generated for several sub-problems by using brain-writing techniques and using so called How-to questions. Two general concept directions were created from these ideas. In the next phase these will be further developed using co-design sessions with the target group; people with diabetes type 1 and its partners.

## Phase 3: Develop

In the develop phase two concept directions were presented to the target group, in this case diabetes type 1 patients and partners. The method used here is a co-design session, based on the generative research methodology described by Sanders and Stappers (2013). Participants were asked to draw and to write down how these concepts would be working in their ideal situation. Extra questions to help them started were listed. After generating ideas, they were asked to explain what they had written down. This could lead to an interesting discussion with other participants during the session if they were present. The involvement of the users in this phase of the design process, helps to design a tool relating to the wishes and needs of the target group. After co-designing, developing ideas for the two concept directions, participants filled out a form in which the opinion and necessity of the concepts was tested. The recommendations and suggestions from the participants are used to choose one concept direction and to further develop the tool.

## Phase 4: Deliver phase

This phase is about evaluating the tool. The tool is linked and tested to the design requirements created in the define phase. Recommendations on how to improve and develop the tool are given.

## PHASE 1

# DISCO

# OVER

## Introduction

This chapter is about the insights gathered form the research activities performed in the first phase of this project.

## Methodology

First of all a literature study is conducted. Afterwards people with diabetes and partners are involved in this study. Generative methods are used, in which the participants filled a sensitizing booklet and were interviewed after. All research was focused on the social and emotional context of the patient with diabetes.

# 1.1 DIABETES TYPE 1 EXPLAINED

The discover phase starts with an explanation of what diabetes type 1 is.

## Diabetes type 1

In diabetes type 1 the pancreas produces little or no insulin anymore. This leads to limited transportation of glucose from blood to cells in the body. Insulin is needed for the uptake of glucose in the cells from the blood. In the cells glucose can be used as energy. When glucose cannot be taken up by the cells, because there is no insulin, the blood glucose level in the blood will rise. High glucose levels in blood cause damage to tissues and cells (figure 3a&b).

The acute symptoms of diabetes are increased urination, thirst and tiredness, weight loss. Long-term complications because of raised blood glucose levels consists of nerve damage, blood vessel damage, heart disease, kidney problems, eye problems, diabetic food and pregnancy problems. Up till now there is no way to cure diabetes. Treatment options to slow down the process or to prevent the problems exists.

Treatment of diabetes has as goal to reach near-normal levels of blood glucose in the blood. In order to reach this, patients need to get insulin on a daily basis to regulate the amount of glucose in the blood.

Insulin can be injected by using pens or a pump. If pens are used, the patient needs to inject insulin multiple times a day by hand. In case of a pump, the pump is attached to the body and injects insulin constantly. There are mainly two types of insulin; rapid acting and long acting. The long acting insulin functions as the base level of insulin and is also called the basal. Rapid acting insulin is needed after peaks of glucose, for example after eating a meal, and is called a bolus.

The amount of insulin that needs to be injected is influenced by eating carbohydrates and physical activity. For every patient the amount of insulin needed differs. Patients have to monitor the blood glucose levels themselves during the day, this can be done by finger pricks or a continuous glucose monitoring sensor. This sensor is attached to a body part, like an arm, and can measure the blood glucose levels during the day.

A good blood glucose level is generally between 4.0-8.0 mmol/L. If the blood glucose level is higher than 8.0 mmol/L then there is a so called hyperglycemia, also known as hyper. If the blood glucose level is lower than 4.0 mmol/L it is called an hypoglycemia, also known as hypo. This can happen when the patient injected too much insulin. A hypo causes acute symptoms like dizziness, shakiness and hunger. If no action is taken when a hypo occurs (eating or drinking something with sugar), then it can happen that a person falls into a coma.

Source for this part WHO, 2016.

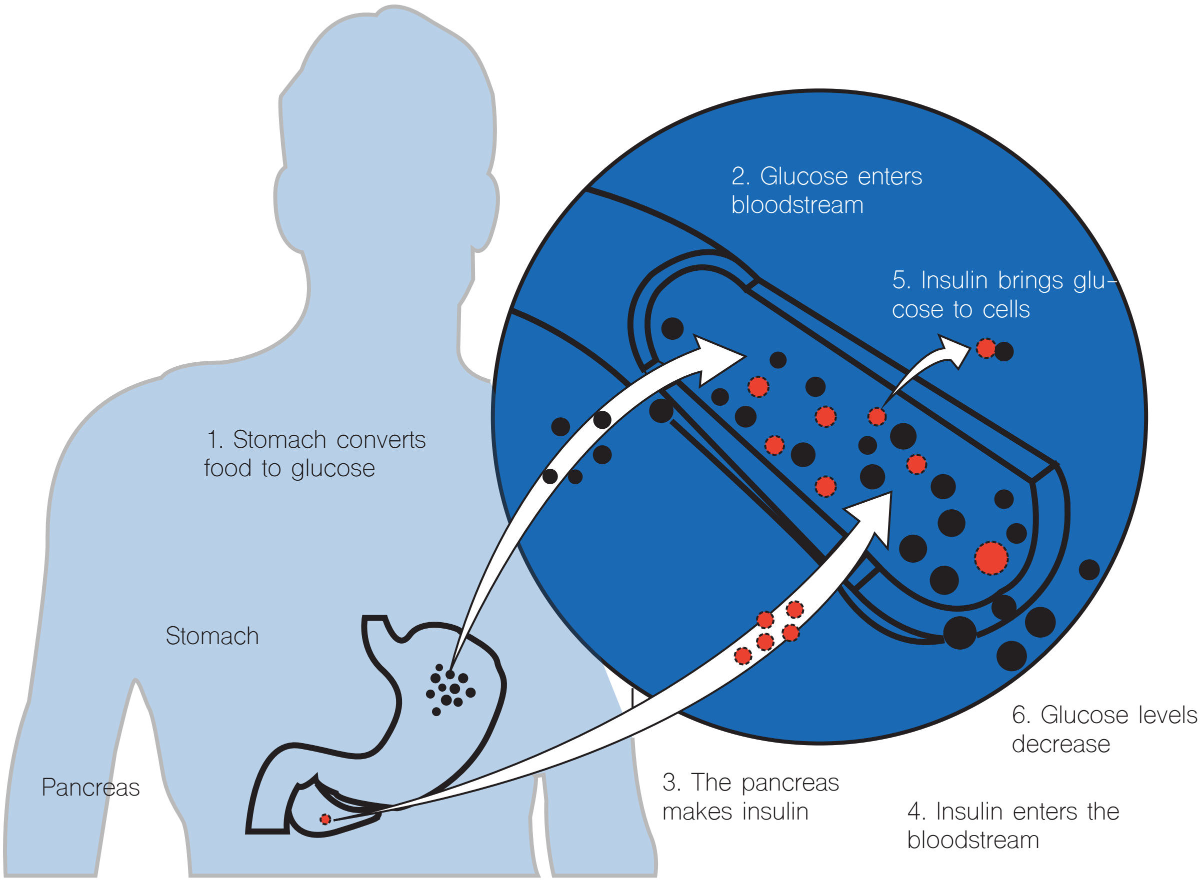


Figure 3a: Healthy person. Stomach converts food to glucose. Glucose enters the bloodstream. Pancreas produces insulin. Insulin brings glucose to the cells for energy. Glucose levels in the bloodstream decrease.

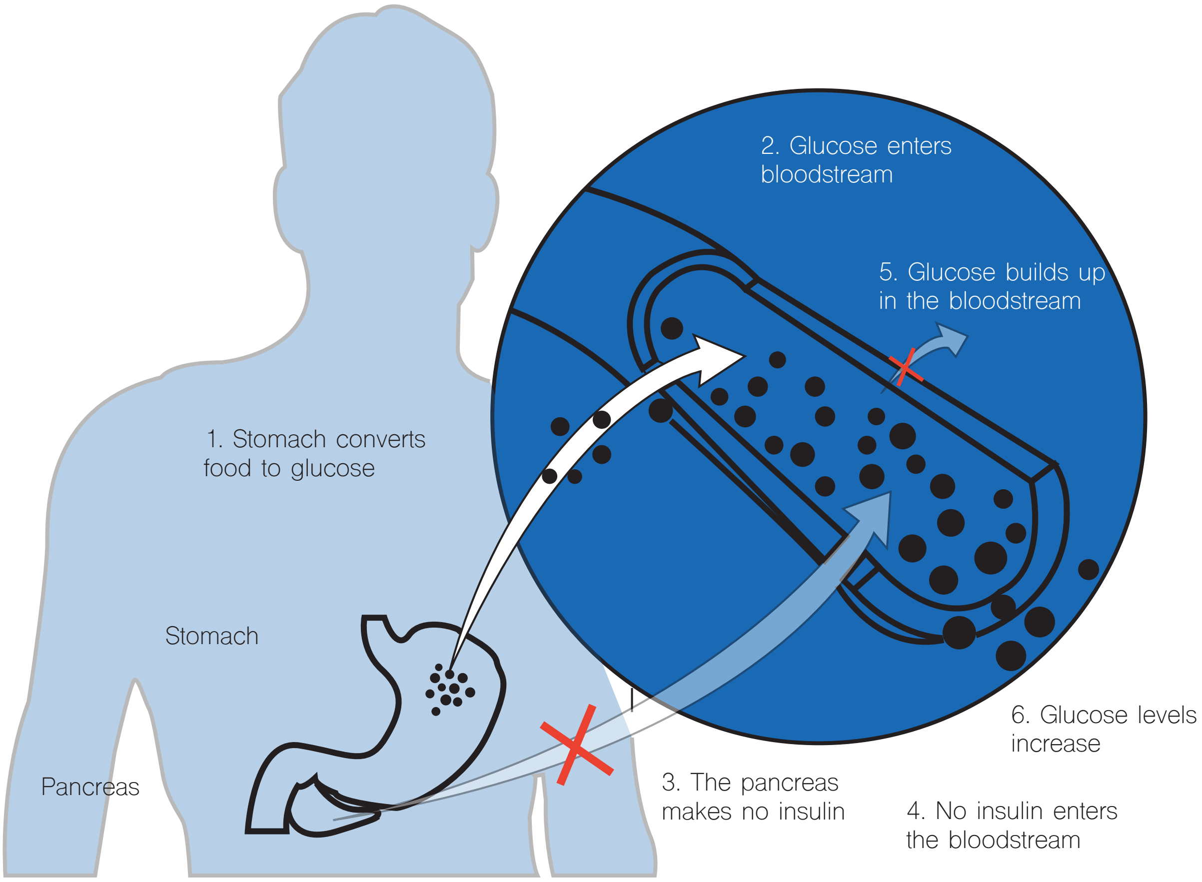


Figure 3b: Person with diabetes. Stomach converts food to glucose. Glucose enters the bloodstream. Pancreas does not produce insulin. Glucose builds up in the bloodstream and glucose levels in the bloodstream increase.

# 1.2 LITERATURE STUDY

The discover phase continues with a systematic literature study answering the sub research question: *Which elements of social support are desired from relatives for people with diabetes?*

To answer this research question a systematic literature study was conducted using the database Scopus and PubMed with the goal to find out how relatives of people with diabetes deal with the disease of their partner and which elements of support are desired for people with diabetes.

The search terms used in these databases were: (Diabetes type 1) AND (family OR friends OR relatives OR spouse OR partner OR marriage) AND NOT type 2 AND NOT (children OR child OR youth OR teens). Searches were limited to journal articles published between 1999 and 2019 in English or Dutch. This search resulted in 1862 documents on Scopus and 2514 documents in PubMed.

For the systematic review articles were included if the research was focused on adults with diabetes type 1 and their family members. First a selection was made based on title reading. Duplicates from both Scopus and PubMed were removed. This resulted in 26 review articles.

Articles were excluded if the article was cited less than 5 times, exceptions were made for the articles published in 2018 and 2019. These articles were included also if those were not cited. If a full text article could not be found, this article was also excluded. After this selection, 20 articles remained.

From these 20 articles the abstracts were read. Articles were excluded if the study was focused on adolescents or focused on diabetes type 2 or focused on only the person

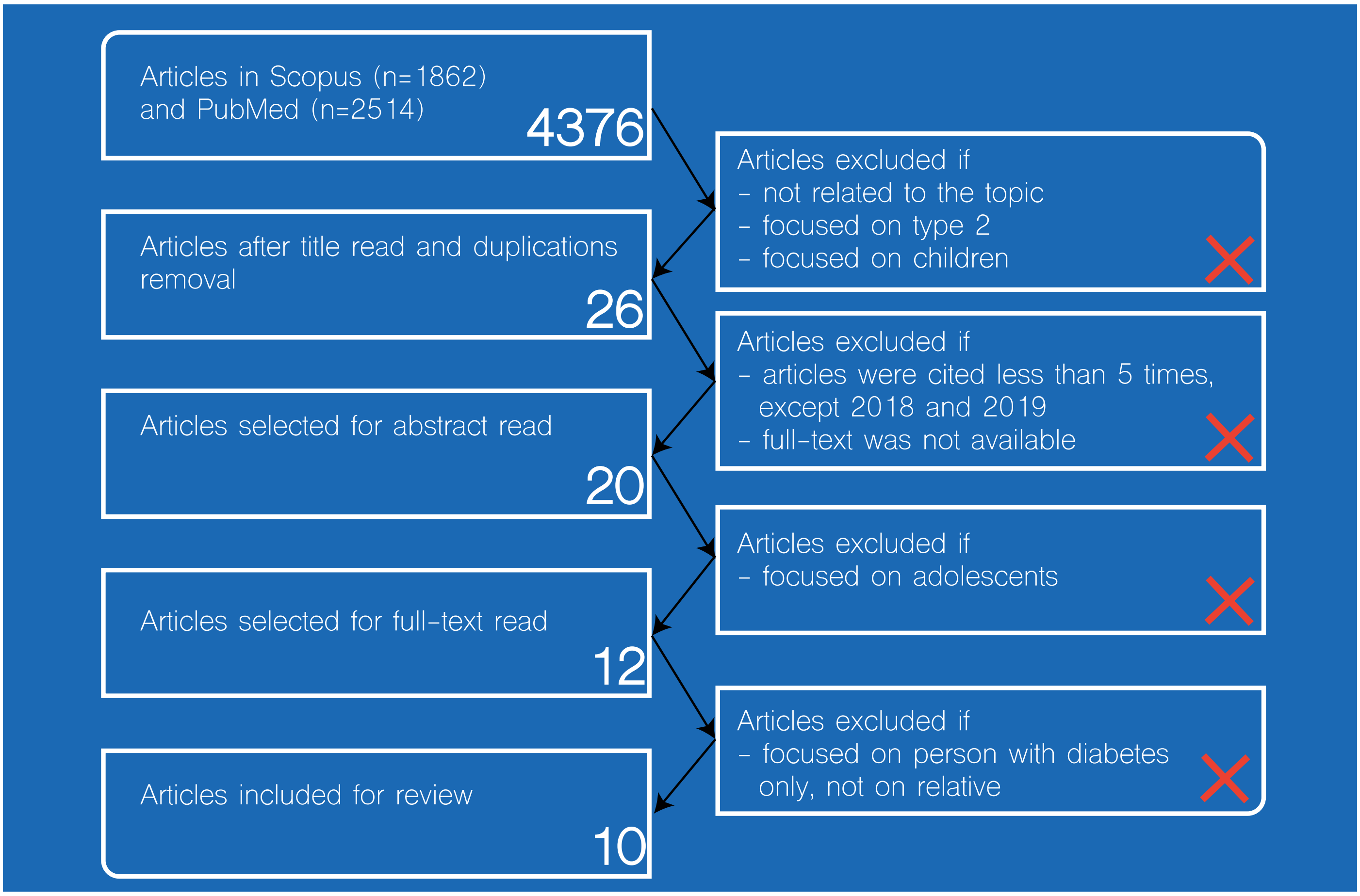


Figure 4: Overview of selection of articles in the systematic literature study.

with diabetes and not the relatives. 12 articles were selected for full-text review, of which 10 articles were included in the final review (figure 4).

## Results

Included articles were read completely. Afterwards the text was analyzed using codes to create overarching themes. This was done according to the Bryman coding. First the text of the 12 articles was read as a whole, notes were added and major themes were observed these were highlighted in the text using yellow. In the next step text relevant to answer the research question was highlighted and accompanied by notes and labels for codes. This was done by coping all the highlighted text and to highlight the sentences again by using different colors for groups. In the step after the text was systematically marked with colors, the text was indexed. This was done by hand. Codes were reviewed and grouped (appendix 1)
The groups created are:.

- Missing elements in support
- Diabetes distress in patients and partners
- Emotional support and active engagement
- Appraisal and collaboration

Those four themes will be described in more detail.

## Categories

### Missing elements in support

Diabetes patients do not always feel supported by their environment. According to the study conducted by Joensen, Filges, & Willaing (2016), people with diabetes felt being on their own in daily life situations. They feel that they do not have anyone to talk to and that they have to do everything themselves regarding diabetes management. They also feel a lack of connectedness and communality; they have a feeling of being excluded from society, they are different, and feel worth less.  Another aspect is the lack of feeling understood. Participants of this particular study indicated that family and friends can only listen to them, but they do not really understand the diabetes patient, or what the disease does. A real dialogue about diabetes is missing in their opinion. This is especially important in big changes in life, such as in their family or work situation. Which may cause a lot of worries and distress. However, not only diabetes patients indicated a lack of understanding from their surroundings, also the partners indicated this. They lack support from family and health care professionals, which was studied by Polonsky, Fisher, Hessler, & Johnson (2016).

### Diabetes distress in patients and partners

It can happen that the partners of diabetes patients worry or have distress about diabetes. This worry of the partner is then an extra concern for the one with diabetes. The worry or distress can be caused by a knowledge deficit or not knowing how to deal with the patient (Helgeson, Vicki, 2017). Partners explained that these negative feelings arose because of a lack of involvement in the self-management of the patient. This lead to increased frustration and feeling of not being able to help when things go wrong (Morris, Parker, Booker, & Johnson, 2006).

It can happen that the partner becomes overinvolved, this resulted in great support, but also in controlling and overprotective behavior, which was not seen as pleasant and resulted in negative associations with relationship satisfaction.  On the other hand, it can happen that the partner lacks giving emotional support, due to failing to understand the disease or being insensitive. This can result in poorer health outcomes, which can increase diabetes distress (Helgeson, Vicki, 2017; Morris et al., 2006).

Partners of diabetes patients can be distressed, sometimes even when the patient is not. In the study of Polonsky et al. (2016), diabetes distress is found to be relatively common in partners. Distress about hypoglycemia was reported most (64%), followed by emotional distress, which means that the partner feels overwhelmed by the demands of the diabetes patient. Role distress is also mentioned, partners have uncertainties how to be involved in the disease management. Management distress is also reported (the least with 28,4%) which indicates that the partner has uncertainties about the way the patient is managing its disease.

Hypoglycemic distress, which was mentioned mostly is further studied by Jørgensen, Pedersen-Bjergaard, Rasmussen, & Borch-Johnsen (2003). They show that patients generally reported a lower rate of severe hypoglycemia than their partner. This was mainly for partners of a patient with hypoglycemic unawareness. Hypoglycemic unawareness is dangerous, since the person with diabetes is unaware of a deep drop in their blood sugar level. For people with this unawareness the involvement of the partner is significantly higher than for people with normal hypoglycemic awareness, 70% and 45% respectively. In the same study, 44% of the partners reported disturbed sleep, because they have a fear of their partner getting a severe hypoglycemic episode while sleeping. This disturbed sleep pattern has an influence on daily diabetes stressors of the patient, since sleep quality of couples are interrelated. This was researched by Tracy et al. (2018). The results of this study indicated that on days that the sleep quality was better than the average, the next day fewer diabetes stressors were reported.

### Emotional support and active engagement

Not in all cases patient distress is a problem, and even if it is, there are some ways to lower this distress. In a study by Helgeson & Vicki (2017) participants indicated that emotional support in the form of listening to problems of the diabetic and providing encouragement was perceived as positive. Participants who indicated that their partner was involved in the right amount had lower levels of psychological distress than participants for which the partner was less involved. This was mainly due to emotional support, since instrumental support is not related to psychological distress. Patients may differ in the way they desire instrumental support, however for emotional support this is more uniform across patients, according to Helgeson & Vicki (2017).

Trief et al. (2017) conducted a study on relationship factors and outcomes for diabetes patients. Results of this study show that greater active engagement, the better the relationship satisfaction. Active engagement includes open communication and solving problems together. Another way to create a positive support between the patient and the relative is to play, researched by Van Vleet, Helgeson, & Berg (2019). On days that diabetics did a play activity with their partner, they reported better mood and they talked more about issues related to their diabetes. They also felt more support from their partners and they could handle diabetes stressors better on those days compared to days they did not play. It even strengthens problem solving abilities of the patients. This could be explained by the unconscious thought theory, in which unconscious thought is related to being more adaptive to making complex decisions. A distractor activity, such as a play, can be seen as an opportunity for unconscious thinking. This suggests that play can have a positive influence on the emotional and relational atmosphere. However, play did not have an effect on the self-care of diabetes.

### Appraisal and collaboration

Helgeson et al. (2019) performed a study on how patient appraisal was perceived as shared or individual and how this was related to supportive behavior. “A shared illness appraisal is an individual’s perception that the illness is our problem rather than my problem or your problem.” Patient shared illness appraisal leads to better supportive behavior and better collaboration between patient and partner. If an illness is perceived as shared, it is easier to ask for support from partners, since they both know that they play an active role in the management of the disease. The reception of the support given by the partners might also be received better since the management is seen as teamwork. In the study people in longer relationships show more shared illness appraisals. Shared illness appraisal can be seen as a lens through which the partner can see the patient's behavior and the other way around, in which the patient sees the collaborative and supportive behavior of the partner. When people in relationships approach diabetes communally, they benefit most from the support given by partners.

It is interesting to note, according to Helgeson & Vicki (2017) that the participants in their study reported the problem of having diabetes as shared, and the responsibility of dealing with it as individual. This indicates that patients know that the disease affects their partner, but that they also know that it is their own responsibility to take care of it.

These results suggest that relationships are important especially for diabetes patients, since their disease also affects the partner. Helgeson et al. (2015) examined whether romantic relationships and friendships of people with diabetes differed from diabetes patients from the same age group. They found that the diabetics received less friend support than the ones without diabetes, but no differences were found in friend conflicts. Women reported less romantic support than the control group. This study also indicated that it might be more difficult to talk about diabetes with a romantic partner than with a friend, since a higher level of investment is expected in these types of relations.

## Interpretation

The aim of this literature study was to find out how relatives of diabetes patients deal with the disease of their partner and which element of social support are desired. The search in Scopus and PubMed resulted in ten suitable articles that are included in this study. Articles included in the study were focused on people with diabetes type and/or their partners. During the analysis of the literature four categories were made: missing elements in support; diabetes distress in patients and partners; emotional support and active engagement; appraisal and collaboration.

Findings indicate that partners are indeed important to diabetes patients. However, not all relationships are the perfect environment for the patient. Patients can feel alone, because they feel they are different than others. The others do not have the expertise to feel the way they feel. This is due to a lack of understanding and knowledge Partners can therefore not provide the best support (Polonsky et al. 2016; Joensen et al. (2016)). On the contrary, they can worry about the one with diabetes, causing distress. Partners' distress is not desirable for the patient, because the patient will worry about it. Diabetes distress arises mainly in partners of patients who have hypoglycemic unawareness. This seems logical, because when a patient gets a hypoglycemic episode, the patient needs help, because the patient cannot function well. For a partner this can be seen as a hectic event. The distress and worry of happening again is therefore higher (Polonsky et al. 2016; Jørgensen et al. 2003)).

Overinvolvement and over protectiveness can be caused by this diabetes distress, because partners lack knowledge about the disease and are not involved enough in the management of the disease. On the other hand, the partner is involved which is a positive attitude. It can happen that partners are not involved, which is even worse for the patient, since this results in poor health outcomes. An equilibrium between overinvolvement and uninvolvement should be found (Morris et al., 2006).

In this study it is found that people in longer relationships have a shared illness appraisal and have a greater active engagement. A shared illness approach and active engagement are seen as involvement in the patient disease and is reported to have a positive effect (Helgeson et al. 2019). Since people in longer relationships show this behavior more, it seems logical to intervene in older couples, since they are more amenable towards a change in this direction. On the other hand, younger couples might benefit more from an intervention towards creating shared appraisal and more active engagement. It should be taken into account that people have different preferences, involving should fit with those preferences.

In order to involve the partner more, it is important that the partner is considered in the management of diabetes by health care professionals, without increasing the burden of the partner, since this can cause diabetes distress for the partner. To achieve this, partners should be more knowledgeable to be of better help to the patient. This way the patient may worry less about partner distress. Effective communication between the patient and the partner can be useful, as well as an educational program and a support program (Morris et al., 2006). Doing play activities together has a positive effect on the mood of the patient and the communication between the partners. Communication was more open and more related to the issues they dealt with (Van Vleet et al., 2019). More research is needed to come up with an intervention to support both the patient and partner.

An answer on the research question: Which elements of social support are desired from relatives for people with diabetes can be given. According to literature the elements of social support that are desired for the partner are: Involvement of partners in self-management of diabetes; active engagement of the partner; seeing the disease as a shared problem; be knowledgeable to help the patient; play can support this active engagement.

## Input for next phase

The insights from this literature study will be used as input to create an interview protocol for the next research phase in which diabetes type 1 patients and partner will be interviewed. This literature study has indicated that elements as active involvement, shared illness appraisal, and knowledge are important aspects to provide the best social support. The interview questions will be focused on these elements. Main goal is to look at situations in which this all go well and in which situations not, and the reasons why this is going so well or not.

## Design implications

Design implications are formed from this literature study. Later on, requirements and wishes are created from these design implications. Indications which requirement is linked to which implication is shown.

### Support shared illness appraisal

It is important to create a shared illness appraisal in a relation to provide good support. The partner should be aware that he/she is also involved in the disease of the other. *(Wish 4, 5)*

### Younger couples

Younger couples might benefit more from an intervention towards creating shared illness appraisal and active engagement. *(Requirement 10, 11)*

### Adult focused

While searching for relevant articles, there seemed to be a lot of things designed for children with diabetes and its parents. There seems to be lack of support materials focused on adults. The design should be targeting the adults. *(Requirement 11)*

### Information for partners

Partners are not always knowledgeable on how to support the patient. A tool focused on providing information towards partner might be helpful. *(Requirement 1, 4)*

### Involve partner in self-management

It is important that partners are actively engaged in the self-management of the patient, they should be supported in doing this the right way. This could be done by providing clear indications on how to be involved. This could lead to less uncertainty on how to act and behave. Hereby a good environment and open communication can play a role. *(Requirement 2, 3, 4, 5, 6 wish 5, 7, 11, 12)*

### Play elements

Doing playing activities can be a step towards better support from partners. People doing playing activities reported better mood, better conversations and felt more support. *(Requirement 89 wish 2, 6)*

### Share feelings

Patients can feel alone, because they cannot express how they feel in a way the partner will understand it, since the partner will never experience how it is to have diabetes. A way to express these feelings might be helpful. *(Requirement 2, 4, 8 wish 11)*

### Equilibrium between overinvolvement and no involvement

An equilibrium in the amount of involvement should be found to provide the best support, this can be done by good communication or a tool that will help identify what people expect from each other. *(Wish 11, 12)*

# 1.3 CONTEXT MAPPING

The previous section provided an overview of what was written in literature about the supportive role a partner can play. This section aims to gain insights in real situations and experiences of diabetes type 1 patients and partners. The main goal is to get insights in how partners are involved and how this involvement started and has changed over time, how this involvement is perceived by the patient. Another goal is to identify in which relationships is social support optimally used and how is this achieved and in which situations is this not optimal. The sub research question for this part of the research is: *How do relatives support the person with diabetes now?* and *How can this be improved according to the patient and the relative?*

## Research set up

Context mapping sessions were held with sixteen participants, of which eleven were patients with diabetes type 1 and five were partners.

An in-depth interview was done using generative tools to discover the latent needs of the participants. In order to get deeper insights into the life of people with diabetes and their surroundings, feelings and emotions, a qualitative research was conducted.

According to Sanders and Stappers (2013) context mapping allows designers to access qualitative tacit knowledge. Multiple research methods were used to access different levels of knowledge; sensitizing booklets and interviews.

To get more knowledge and information about this research method, a company called Muzus, specialized in context-mapping is contacted. They helped me with setting up a research and gave examples on how such a sensitizing booklet could look like. They advised me to create a booklet with small assignments, such as who is important to you, and to let the participants create a timeline. Stickers would also work good, according to them. They advised me to read the book Convivial Toolbox from Sanders&Stappers. I took their advice with me, and I was grateful that they were willing to help me and made time for it.

The participants of the research were provided with a sensitizing booklet in which small assignments are given about living with diabetes. They answer several questions revealing their personality. Thereafter they identify who are the most important people in their lives and why they are important. The goal was to map out the social network of the patient and to analyze how those people are involved in their diabetes and what support they provide. In the booklet the participants maps the most important people in their lives onto a circle, in which they are located in the middle. The closer the mapped person is to the center of the circle, the closer the relation with the patient. This exercise is followed by an assignment in which the map all activities they performed on a particular day, in which activities diabetes play an big role, how they felt, why they felt that way and who are involved in that stage. This was done to get an understanding on how patients deal with diabetes and how it influences their lives and to discover everyday problems regarding diabetes. If the partner was willing to participate, questions about the involvement in diabetes were asked.

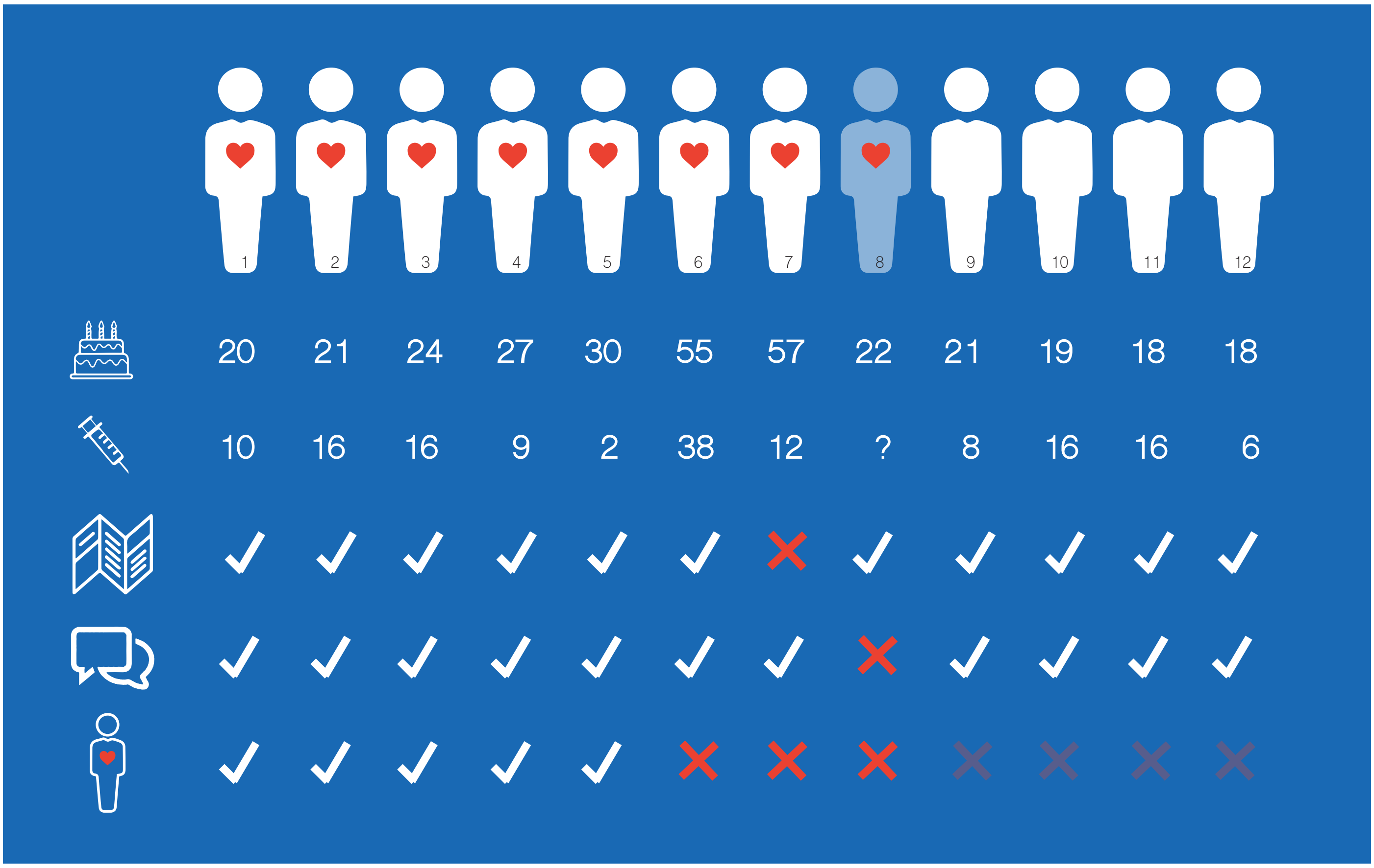
This booklet was send to them days before the interview via mail. They were requested to return the booklet to the researcher's address before the interview took place. This way the researcher got familiar with the participants, and could adjust the questions to gain deeper insights in the life of the participant. The participant got already familiar with the topic and had thought about several aspects beforehand.

A semi-structured interview with open questions was prepared using a list of questions (appendix 2) The interview was categorized into 4 themes: Diagnosis and influence in daily life; social network with a main focus on support of the partner; contact with other diabetics; contact with health care professionals.These categories were made to get insights in the network of support from different parties.

## Participants

A total of seventeen people participated in this study. Twelve were diabetes type 1 patients and five were partners of a diabetic. People were gathered via an earlier survey that they filled out and via diabetes trefpunt of the diabetes vereniging nederland. Selected patients were between 18 and 57 years diagnosed with diabetes type 1 and living in the Netherlands (figure 5 and 6). Informed consent was given by all participants, before they participated in the research activities.

Given the privacy and the location of the participants, the interviews were done in private settings. Since diabetes is also a very personal disease and everyone deals with it its own way, was also a reason to do the interviews in separate sessions. The interviews took place at a location of the participant's preference, either at their home, at a public place in their hometown or at the Delft University of Technology, or via skype or phone. In case the partner of the diabetic was willing to join, he/she was involved as well. The interviews took about 45min-2hours and were recorded.



| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 20 | 21 | 24 | 27 | 30 | 55 | 57 | 22 | 21 | 19 | 18 | 18 |
| 10 | 16 | 16 | 9 | 2 | 38 | 12 | ? | 8 | 16 | 16 | 6 |
| ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ | ✓ |
| ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ |
| ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ |

**Figure 5: Overview of participants in this study.** First row indicated participant number, heart means that the participant is in a relationship. Second row indicates the age of the participant. Third row indicates the age on which the participant was diagnosed with diabetes type 1. Fourth row indicates if the participant has filled the booklet. (One person did not do this, because the interview was scheduled before the booklet could have reached her). Fifth row indicates if the person was interviewed. (One person is not interviewed, becasue she dropped out of this study, no reason mentioned). The last row indicated if the partner of the participant participated in the research.

Figure 6: Overview of residences of participants in this study.

## Analysis of the results

To preserve the richness of the results, a qualitative way of interpretation is needed. The method described by Graneheim and Lundmann (2004) is used. The interviews are transcribed verbatim. A grounded theory approach is used to create themes. Condensed text will be abstracted for further analysis. It emphasizes descriptions and interpretations on a higher logical level. To do this, codes, categories and themes on varying levels will be created. Creating categories is the core feature of this qualitative research analysis. A category is a group of content that shares a commonality. After transcribing, the text is divided into meaning units, which are relevant quotes relating to the research question. The meaning units are then transferred into condensed meaning units, which makes it more abstract. Then the condensed meaning unit is labelled with a code. The various codes are compared on differences and similarities and sorted into sub-categories and main categories. Finally, the categories are grouped in a theme.

In order to maintain the credibility of the results, the way how meaning units, condensed meaning units, categories and themes are made will be illustrated. Meaning units will be created using representative quotations from the transcribed text. The intent is not the verify that the data in labelled and sorted in a way that another researcher can do it in exactly the same way, but to determine whether or not researchers would agree with the way those data were labelled and sorted.

Example:
Meaning unit: 3 Vannacht werd ik wakker met 20 bijvoorbeeld. Soms heb ik nachten dat ik heel hoog zit, dan weer heel veel hypo's. Afgelopen week zat ik heel veel hoog. Vannacht had ik wel zoiets van dat ik het even niet meer aankon dus toen zei ik X, ik zit op 20, wil je water voor me pakken. Ja natuurlijk. Toen ging hij gelijk. Het ging echt heel snel. Soms moet ik echt 3x X roepen, maar nu was het echt gelijk jaaaa. Dus nu pakte hij water voor me, terwijl ik naar het toilet ga. Maar het is echt fijn dat hij er dan even is en zegt ah wat kut. Meestal wil ik hem er daar niet voor wakker maken, zeker niet als ik hoog zit, maar vannacht omdat het de zoveelste nacht was dat ik wakker werd bij 20 dacht ik nu heb ik het even nodig.

Condensed meaning unit: Even tegen iemand praten en luisteren

Codes: Offer a listening ear.

Subcategory: Emotional support positive

All details on how to come fro quotes to categories can be found in appendix 3.

## Research tools

Sensitizing booklet
Interview questions

## Results

All participants were open to share their experiences regarding diabetes. Most of them stated that they were positive about the topic of the project, since they say that the emotional and social side of diabetes is underexposed. Prior to the interview the sensitizing booklets were filled and returned by mail (appendix 4).

All the participants mentioned that diabetes is always with them, it's in their mind, they think about it constantly. The impact of diabetes differs per person. Some were diagnosed with diabetes type 1 when they were young, they do not know any better, while others were diagnosed later in their childhood or even in adulthood. They know how it was before having diabetes, and the acceptance of having diabetes is difficult for them. All participants have found their way around diabetes, they do not let diabetes rule their lives, they have found a way to cope with it.

The analysis of the interviews resulted in seven themes.

- Social support from partner
- Motivation
- Collecting and sharing information
- Lack of recognition
- Peer support
- Relation with caregivers
- Personality differences

The theme that is most relevant to answer the research question is: the social support from partner. This is mainly related to sharing information; the lack of recognition; and motivation. The other themes are also relevant but are further away from gathering insights to answer the question.

## Interpretation

On the following pages, first the insight from the booklets are shown followed by a schematic overview of the codes and categories are shown including an interpretation of the results.

## Insights from booklets

Sensitizing forms are used in this study to get the participants already thinking about the subject before the interview took place. During the interviews more is asked about their social environment, in which the circle was used as a starting point. The timeline that they have filled indicates how diabetes influences their daily tasks. If partners were participating they filled out a small questionnaire at the end of the form.

## Circle

The diabetes patients wrote down the most important people to them in the circle, in which the most important people are closer to the middle of the circle. All participants have listed multiple people, with a short description. If the patient has a partner, this person is always closest to the patient. Also parents (in law) are close to the patients, especially mothers, followed by siblings and friends.

Reasons for stating specific people in the circle are:
They are always there for me
They know a lot about diabetes and about me
They help me when needed
I have a lot of fun with them.

Interview questions are used to gain deeper insights in the relationship with those important people.

## Timeline

The timeline is filled by all participants, including sticker usage. The stickers indicate when diabetes plays an essential role in their life, when people are involved, and which emotions they have.

Activities during the day are described. The emotions that people have written down are either linked to the activities, are they fun, stressful, annoying etc, or linked to diabetes influences, I have a hypo, so not feeling good. This provides insights in how much a person values the emotions linked to diabetes or more on the activities they do, without thinking about diabetes.

Diabetes is always there 24/7. Activities they do during the day are linked to diabetes, such as checking their blood glucose level. They have to check it before driving the car before eating a meal, before sports, before going out, etc. Sometimes it is not possible to stop doing an activity, while it would have been better if they took a break to correct their levels and to control the diabetes. Occasions in which this happens are busy days at work and are stressed. Next to that, they can never predict how they will feel during the day, since diabetes has an unpredictable behaviour.

Most participants indicated that the mornings are difficult, during the night their blood glucose level might have changed a lot and therefore they can wake up with a hypo or hyper. They have to check and correct, but they are also in a hurry. Partners help a lot in this phase of the day.

In the evenings, many of the participants indicate that they are very tired, and that doing many activities cost a lot of energy.

The participants have indicated with the stickers which people are involved during the day. It is analysed that people talk about diabetes during the day with people close to them or with colleagues. These are the people that know about their diabetes and take care of them.

## Partner information

Partners have indicated how much diabetes plays a role in their lives and how much knowledge they have to support the patient, how much they talk about it, if they want to be more involved, and the ownership of the problem.

Partners indicated that in the beginning of the relationship more conversations were held about diabetes than now. Most of them also see diabetes as a shared problem. One participant sees diabetes not as the problem of the patient, but as a shared problem, his problem (because he is involved) and no problem (if they work on it together there is no need for a problem).

One participant reacted this way: Diabetes plays a small role in his life, has insufficient knowledge, and does not know exactly how to support. Wants to be more involved. Sees it as a shared problem.

The answers given on these questions were later used as input for the interview.

Filled booklets can be found in appendix 4 and figure 7.

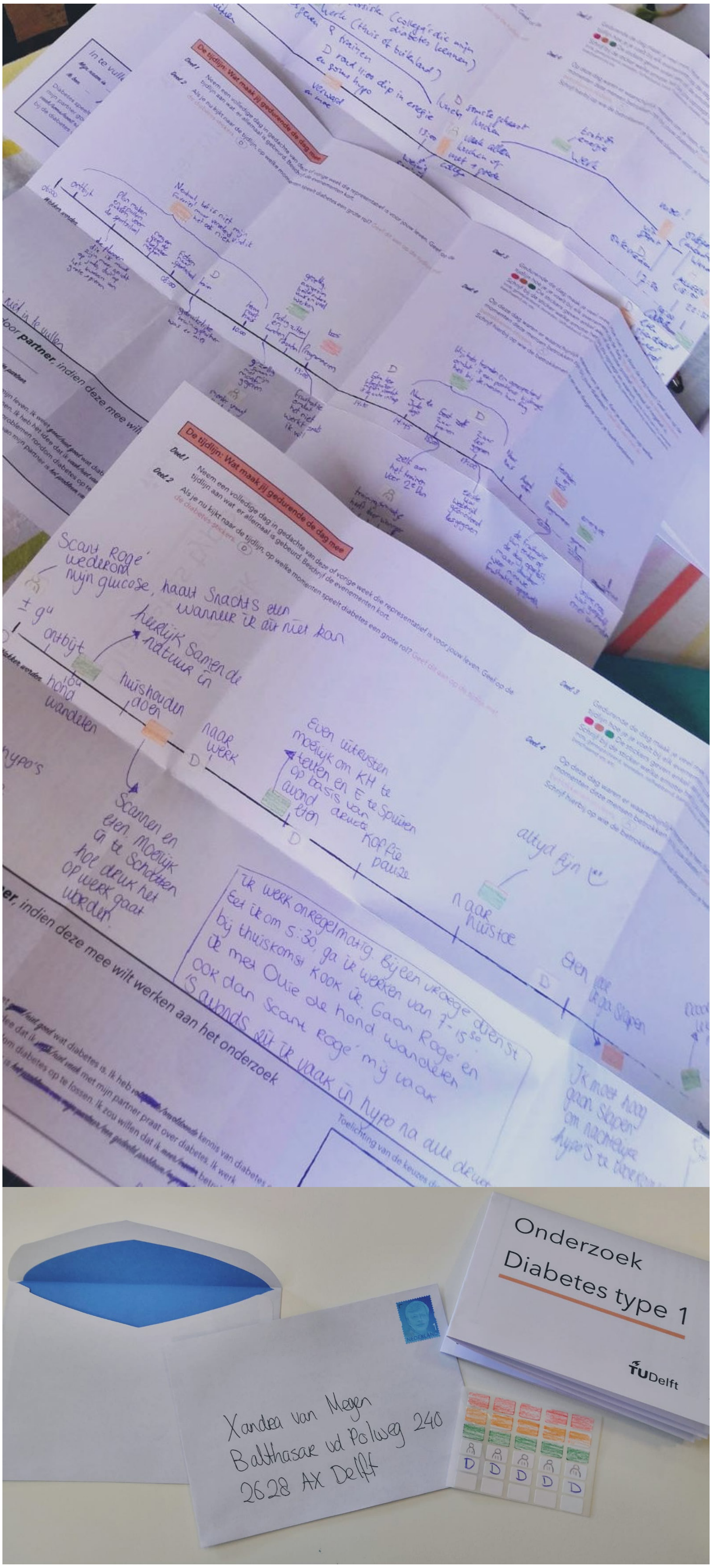


Figure 7: Pictures of sensitizing booklets

# Theme: Social support from partner

## Category: Managing the disease

| | | |
|---|---|---|
| Codes: | Not the feeling of being alone. | 3 |
| | Without support, bad decisions would have been made. | 3, 9 |

## Category: Supportive behavior

### Subcategory: Practical support

| | | |
|---|---|---|
| Codes: | Counting carbohydrates. | 3, 5 |
| | Grabbing food or drinks. | 2, 3, 4, 5 |
| | Brings extra stuff. | 3, 5 |
| | Scanning of the blood glucose levels. | 2, 4, 5, 12 |
| | Taking over tasks, so I can take more rest. | 2 |
| | Fill reservoirs. | 3, 4 |
| | Intervene in emergency situations. | 2, 3, 4 |

### Subcategory: Emotional support positive

| | | |
|---|---|---|
| Codes: | Offer a listening ear. | 3 |
| | Telling other people what the patient deals with. | 1 |
| | Practicing how to deal with the disease in social events. | 2 |
| | Thinking along about solutions. | 3, 5, 6, 9, 10 |
| | Showing gratitude. | 2, 11 |
| | Only helping in case it is needed and knowing what to do. | 6, 12 |
| | Sobriety. | 7 |
| | Providing feedback to the patient on how he/she behaves. | 6 |
| | Show curiosity and interest, be caring. and show empathy. | 3, 4 |

### Subcategory: Joining the patient during hospital visits

| | | |
|---|---|---|
| Codes: | Not always possible due to busy work schedules. | 2, 4 |
| | Both the same information. | 2, 4, 7 |
| | Be sure not to forget any questions I have. | 7 |

### Subcategory: Emotional support negative

| | | |
|---|---|---|
| Codes: | Worrying. | 5, 7, 12 |
| | Not knowing what the disease is. | 2, 7 |
| | Lack of empathy. | 2, 6, 9 |
| | Using diabetes as an excuse. | 6 |
| | Micro managing. | 6, 12 |

### Subcategory: Adjusting life of both to the disease

| | | |
|---|---|---|
| Codes: | Not willing that partner does not do things because of me. | 7 |
| | Change of job, to be at home during the nights. | 2 |
| | Accepting that it is a shared problem from both parties. | 2, 7 |
| | Try to find a balance in what to share with each other. | 2, 6 |
| | Accept changes in character of the patient and the relation. | 6 |

| | | |
|---|---|---|
| **Subcategory:** | **Recognizing characteristics of diabetes indications.** | |
| Codes: | Recognizing low blood glucose levels/hypos and act on it. | 1, 5 |
| | Verbally aggressive. | 6 |
| | Over-assertive. | 2, 6 |
| | Not being able to cope with criticism. | 6 |
| | Looking for a fight, but not noticing it. You act outside of yourself. | 6, 9 |
| | Become more withdrawn. | 6 |
| | Angry. | 12 |
| | Irritated. | 12 |
| | Grumpy. | 2, 5, 12 |
| | Slow. | 11 |
| | Hyperventilation. | 11 |
| | Sweating. | 5 |

## Theme: Social support

As already read in the literature, social support from relatives is important. This also came back every time during interviews. One participant said that after she was diagnosed at the age of 16 she did not get any support from her parents or other family members. When she had to inject insulin they said to her: Go to the hallway, we do not want to see that. The lack of support resulted in bad management habits. She neglected the fact that she had diabetes, she forgot her pump on purpose and she did not take good care of the disease. This resulted in more complications, like infections throughout her body. The turning point to take better care of herself and the diabetes came when she met her boyfriend. He provided her with the support she needed. He was interested, listened to hear,  he was helping with counting carbohydrates, he helped in cases of hypos and hypers, etc. For her the feeling of not dealing alone with the disease, but having someone to help and support her, motivated her. Now she is managing her diabetes well, as they reap the benefits. She feels way better now. This story, told during one of the interviews, was a good practical example of how social support of a partner is valuable and stretches the importance of it. Other participants also emphasizes the value of social support, because if this was not present a lot of bad decisions would have been made.

Supportive behavior of mainly partners, and in some cases friends or family members consists of practical support and emotional support. Practical support can consist of counting carbohydrates, grabbing food in drinks in case of a hypo especially helpful during nights, taking care of extra equipment when going outside, scanning of blood glucose levels, filling insulin reservoirs, intervene in emergency situations.

Emotional support consists mainly of offering a listening ear when the patient needs it to for example express frustration or worries, thinking along about solutions when the patient is stuck finding the right way to handle it, showing gratitude, sobriety and not worrying in case it is not needed, show curiosity and interest, be caring, create empathy, join hospital visits. Another aspect is providing feedback to the patient to tell them how they behave, since most of the time they do not know it themselves when they have high or low blood glucose level. People can become verbally aggressive, over-assertive, angry, grumpy, irritated, looking for a fight, but not noticing it. It feels like acting outside of yourself. It is important to know how you behave and thereafter tell others that the personality changes are due to diabetes and not due to them.

If diabetes is seen as a shared problem, management of the disease is better, according to the literature found earlier. Participants in the study also indicated that the disease highly affects the partner and that he/she adjust life too. One partner of a participant has changed jobs, because he wanted to be home during the nights to help her if she will get a hypo. Another participant indicated that she had bought a new kind of recumbent, because biking on a normal bike was not possible anymore. Her partner bought the same bike, so they could still travel together and have nice conversations. Patients preferably do not want that the partner does not do things because of the diabetes, they do not want to restrict them. A balance has to be found in how to deal with it for both of them. Therefore it is important that both the partner and the patient accept that it is a shared problem. The patient should also realize that the problem is shared and the partner wants to help. This can sometimes lead to conflicts, said one partner of a participant.

Negative supportive behavior consists of worrying, not knowing what the disease is, using diabetes as an excuse and micro managing the partner. There are always sides of the same coin, no matter how difficult it is for the patient to be micro-managed, how difficult it is for the partner that the illness is also an extra burden on him/her. They also notice that sometimes the patient need some supervision or support. And that is difficult.

It helps if the patient knows that the partner understands what the patient is going through. It does not help to micro-manage a diabetic as a family member on how to manage the diabetes management. If there is anything that annoys patients then it is when someone says: you need sugar, or what is your value now, and then minutes later again, or did you scan already. Instructing a patient how to manage the disease does not work. What works is giving feedback in a general sense. For example; Well you get very agitated or restless or tired.

Over-concern can be stifling, no matter how well-intentioned. Everyone has their own character. You have to deal with is as a partner, you can't get around it. The partner must understand what it means. What can go wrong and if he or she really needs to help. But should not act if it's not necessary.

Worrying because the partner has heard stories about other people having diabetes that ended badly is unwanted. They know how to take care of themselves, and worrying questions or too much interference does not help.

Support of a partner is most valuable since this person is most of the time together with the patient, they have a lot of contact together and they know their personality characteristics and daily routines.

Do not try to micro-manage the patient, or providing advice as a partner. The patient is the one with the disease, and know how to deal with it. It is better to let them explain their choices than providing advice or saying what they have to do.

Do not compare the patient with patient from stories on television, that is always an extreme case.

*Quotes from patients*

*6 "Ik denk dat het helpt dat ik weet dat ze snapt wat ik doormaak. Het helpt bv niet om als familielid een diabeet te gaan micromanagen op hoe die zijn diabetes huishouding regelt. Als er iets is waarmee je mij op de kast krijgt dan is het als iemand zegt: je hebt een suikerklontje nodig. Maar partners die elkaar op die manier gaan instrueren hoe de ander zijn ziekte moet hanteren, dat werkt niet. Niet van wat is je waarde en en tien minuten later weer, wat is je waarde nu. Heb je toch wel goed gedaan, heb je wel de KH geteld. Daar word ik zo ontzettend moe van."*

*6 "Maar het zijn natuurlijk altijd kanten van dezelfde medaille, hoe moeilijk ik het ermee heb dat ik gemicromanaged wordt hoe lastig het voor haar is dat mijn ziekte ook een extra belasting voor haar is. Zij merkt ook dat ik soms wat toezicht of ondersteuning nodig heb. En dat is lastig."*

*5 "Ik heb altijd het idee gehad vanaf het begin dat jij je er meer druk om maakt dan ik. De maat van bezorgdheid die ik soms wel overmatig vind."*

*7 "Die nuchterheid is heel, voelt heel ontspannen. Overbezorgdheid kan verstikkend werken, hoe goed bedoeld ook. Iedereen heeft z'n eigen karakter. Je moet wel als partner, je kan er niet omheen. Je partner moet wel begrijpen wat het betekent. Wat er mis kan gaan en als het echt nodig is dat hij of zij wel bijspringt. Maar niet als het niet nodig is."*

*3 "Mijn vriend staat het dichtst bij mij en weet denk ik ook alles eigenlijk wel. Hij steunt me altijd, dus hij kookt vaak en zet het bord neer en heeft dan koolhydraten al geteld. Voor mij maakt dat een heel verschil. Voor hem is dat waarschijnlijk niet heel boeiend, maar voor mij maakt het wel heel veel uit, omdat ik het heel de dag ook al doen."*

*3 "Afgelopen week zat ik heel veel hoog. Vannacht had ik wel zoiets van dat ik het even niet meer aankon dus toen zei ik X, ik zit op 20, wil je water voor me pakken. Het is echt fijn dat hij er dan even is en zegt ah wat kut. Meestal wil ik hem er daar niet voor wakker maken, zeker niet als ik hoog zit, maar vannacht omdat het de zoveelste nacht was dat ik wakker werd bij 20 dacht ik nu heb ik het even nodig."*

### *Quotes from partners*

*2 "We hebben nu een huisje gekocht en toen heb ik gezegd Ik ga van baan veranderen omdat ik bij jou thuis wil zijn. Dat is echt door de diabetes. Ik wil nu een baan van 9 tot 5."*

*3 "Eigenlijk wel eigen interesse inderdaad. Dat versterkt eigenlijk ook je band wel, dat je er voor elkaar kan zijn als er iets. Voor mij echt heel simpel is, maar grote impact heeft. Dat vind ik wel nice."*

*4 "Nou dat is een lastige vraag, omdat ik niet voel wat zij voelt. Ik heb wel een keer gehad dat ik zeg maar een hypo had, slecht gegeten en was ik actief bezig en opeens ging ik bijna onderuit. Dat was heel interessant in de auto terug. Dan snap je wat het is."*

*2 "daar is zij weer zo eigenwijs in. Ze blijft haar eigen ding doen.Maar zij moet leren dat ze sommige dingen niet kan of dingen uit handen moet geven. Ik ben daar nu mee bezig om dat bij haar binnen te brengen. Ze wil niet altijd luisteren daarnaar."*

*In the undesired situation the partner does not understand how the patient is affected by diabetes and how this relates to the values. In this situation the partner is also asking questions, gives unwanted advice etc, which the patient does not want.*

*In the desired situation patient and partner do understand each other, both know how to tell each other what they feel, can find the right words to support, and they both feel satisfied.*

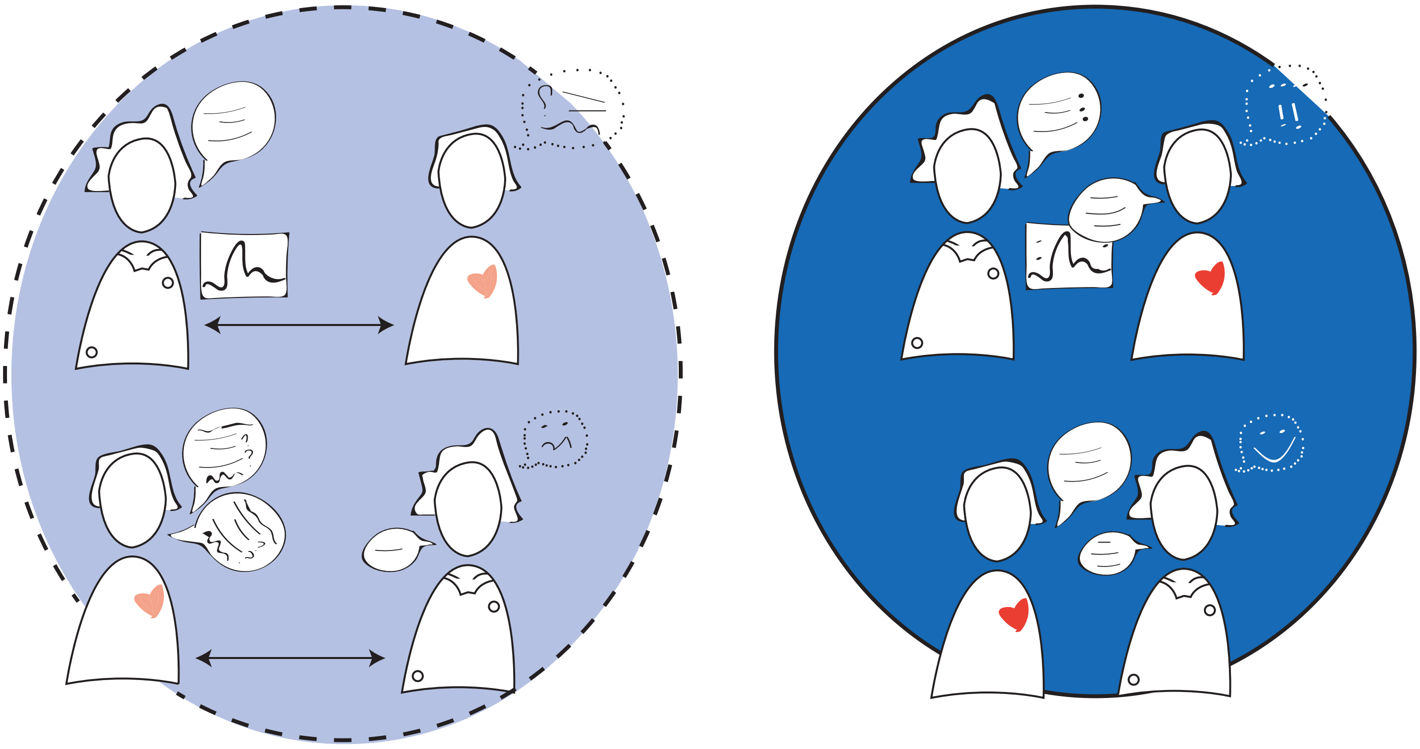


Figure 8: Visualization of an undesired situation and a preferred situation, regarding social support.

# Theme: Motivation

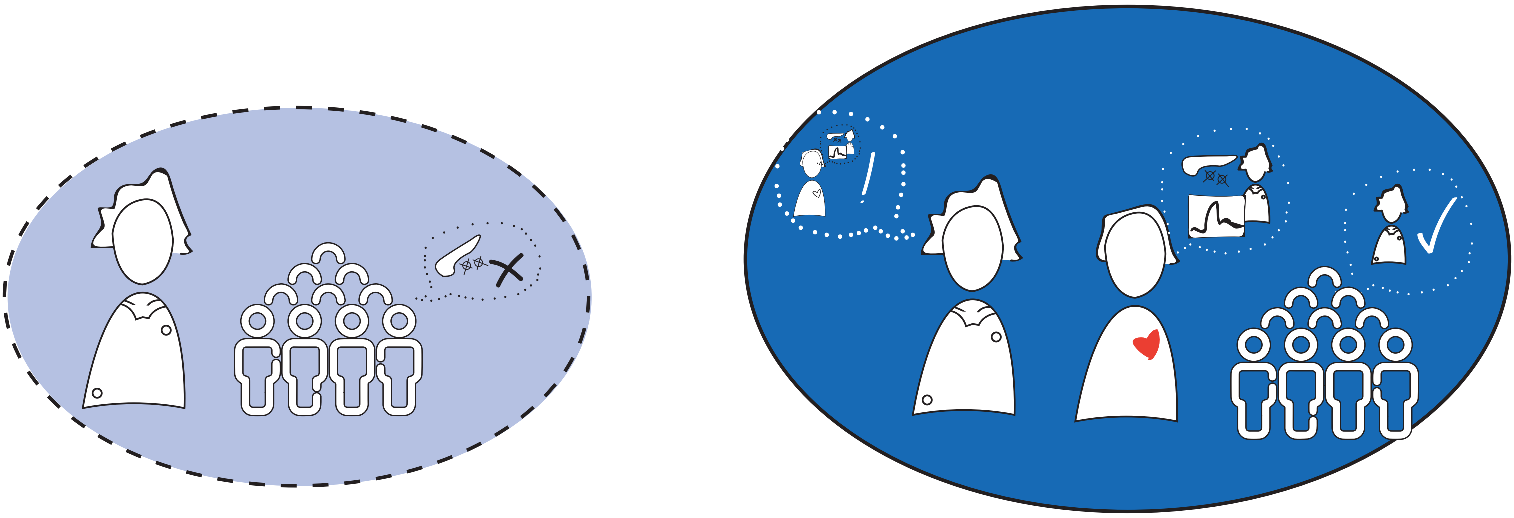
## Category: Motivations

### Subcategory: Positive influences

| | | |
|---|---|---|
| Codes: | Wish to have children. | 2 |
| | Other things than diabetes itself. Have fun at work, know that handling your medical condition contributes to this. | 6 |
| | Reach goals in life that were set before diabetes diagnosis. | 10 |
| | Improve values. | 3, 5 |
| | Want to do well for others who help you. | 3, 11 |

### Subcategory: Negative influences

| | | |
|---|---|---|
| Codes: | Frustration. | 3, 6 |
| | People from outside have no knowledge, a lot of misunderstandings and disappointment. | 6, 7 |
| | Not getting chances in life because of diabetes. | 6 |
| | Knowing what it's like without diabetes. | 3, 6 |
| | Loss of confidence in doctors. | 3 |
| | Complications and consequences of diabetes. | 7 |
| | Influence of blood glucose determines mood. | 1, 6, 10, 12 |



*In the undesired situation there is frustration, disappointment, loss of trust and confidence in society, feeling to be set aside and not seen as a full person.*

*In the desired situation patients will be understood by society, to get the same chances in life as anoybody else.*

Figure 9: Visualization of an undesired situation and a preferred situation, regarding motivation

## Theme: Motivation

As stated before a partner can be a reason to be motivated to take care of the disease in a good way. They want to do well for the other who is helping. If they put effort and time in it, even if they do not necessarily have to do it, than I have to do it as well, says one participant. Other motivations to manage the disease well or even better than before are the wish to have children. When a woman wants to get children the hba1c level should be good for at least one year. This is a good motivation to keep the value at the right level. Another way is to just improve this hba1c level after a reduction of the value. They are motivated to keep the value more steady. One participant had a clear goal in life, this goal was already set before the diagnosis of diabetes, he still wanted to achieve this goal, and therefore it was necessary to manage diabetes well. Another participant does not get motivation from the values related to diabetes, but from things other than diabetes. For example having fun at work, and by knowing a good medical condition contributes to this he is motivated to manage it well.

Decreased motivation can occur due to frustrations, misunderstandings from outside people who do not get what diabetes is, not getting the chances in life you would normally get because of diabetes and loss of confidence in doctors. For people who are diagnosed at a later stage in life, they know how their life was before having diabetes. Next to that the complications and consequences of diabetes can also lead to frustration, disappointment, anger, which demotivates them. Another aspect is the influence of blood glucose levels, that can determine the mood of the patient.

Positive motivation arises from perseverance and doing it togehter with other. Negative motivations arises from frustration and disappointment.

*Quotes from patients*

*10 "Omdat ik toen ik in het ziekenhuis kwam wel echt een doel had, ik wil mijn zwarte band nog halen. 1 week voordat ik in het ziekenhuis kwam had ik het examen net niet gehaald. Ik wil iets, en ik heb wel echt een doel in mijn leven wat ik wil bereiken."*

*5 Maar wat ook speelt is dat bij mijn laatste controle bij de internist was mij hba1c iets hoger. Een gemiddeld waarde van hoe je de afgelopen 3 maanden heb gezeten. Dat was wat opgelopen, dus nu wil ik het extra goed doen om het wat lager te krijgen.*

*3 "Eigenlijk is het omslagpunt geweest dat ik met X een relatie kreeg, en dat hij mij is gaan helpen een beetje. En het idee dat ik er niet meer alleen voor stond. Dat hielp mij heel erg om er weer mee aan de slag te gaan. Inmiddels gaat het eigenlijk wel oke. Toen dacht ik als hij, terwijl hij geen diabetes heeft en het eigenlijk niet hoeft te doen, dit wel alsnog voor me wilt doen, dan moet ik ook mijn aandeel brengen. En nu merk ik ook hoe fijn het is om wat stabieler te zijn, dus dat zorgt er ook voor dat ik gemotiveerd ben om ermee door te gaan."*

*6 Een dag later kreeg ik te horen: nee we nemen je niet aan want je bent diabeet en dat staat op de rode lijst. Geen discussie over mogelijk.*

*6 "Maar ik vind het anticiperen en voorbereidingen treffen en organiseren van werk minder lastig dan omgaan met tegenslag als je te horen krijgt we nemen je niet aan, omdat dat je zelfbeeld ondermijnt. Die andere dingen kan je zelf regelen. Maar iemand die de kwalificatie ongeschikt op je plakt, geeft een hele andere vorm van teleurstelling."*

*6 "Ja ik weet hoe het was om geen diabetes te hebben. Emotionele kant nog belangrijker omdat je geconfronteerd wordt met het gemis. Dat gecombineerd met een aantal expliciete afwijzingen omdat je diabetes hebt, dus we kiezen niet voor jou maar voor iemand anders."*

*6 "Suikerhuishouding is toch heel subtiel in het bepalen van je stemming. En hoe je op dit moment in je vel voelt zitten."*

# Theme: Sharing information

| | | |
|---|---|---|
| **Category:** | **Partner gets information** | |
| **Subcategory:** | **Information given by partner itself** | |
| **Codes:** | Sharing information from hospital visits to keep partner up to date. | 1, 2, 6 |
| | Show partner what I do all day, show values, explain feelings and emotions. Explain what to do and why. | 2, 3, 4, 11 |
| | Talking about practical stuff, learn how to inject, where are the items in case of emergency. | 5 |
| | Provide documents with characteristics of hypos and hypers and how to act on it and what it means to them. | 1, 7, 12 |
| **Subcategory:** | **Information given by others** | |
| Codes: | Event about diabetes. | 1, 3 |
| | Education. | 5 |
| | Internet to look up how it works, medical information only. | 3, 11 |
| | Joining hospital visits with internist and diabetes nurse, to gain trust and be sure about things. | 4 |
| **Subcategory:** | **Moments of sharing information** | |
| Codes: | Information is shared if it is needed in that moment, sometimes this is too late. | 2 |
| | Information is shared when the condition get worse. | 2, 3, 4, 7 |
| | In the beginning of the relation more information is shared than now. Most information we both know already. | 4 |
| **Subcategory:** | **What to share with whom** | |
| Code: | Choosing who to tell what. Partner knows more than others. | 4 |
| | Explaining to strangers is difficult, they do not know what it is. a perfect moment can never be found. | 1, 7, 9 |
| | Terminology differs between people. | 1, 10 |
| | Using humor to tell what the complications can be. | 6 |
| | Using pump as conversation starter with strangers. Tell them when they ask. | 12 |
| | In case of emergency there is a document in my phone for every one to read. | 7 |
| **Category:** | **Patient gets information** | |
| **Subcategory:** | **Not personal contact** | |
| Codes: | Searching on DVN/diabetesfonds website. | 6, 10 |
| | Tv-programs, such as Klokhuis. | 4 |
| | Diabetes information folder. | 10, 11 |
| **Subcategory:** | **Personal contact** | |
| Codes: | Learn by experience, what is happening to me. Experiencing an hypo. | 6 |
| | Health care professionals, personal contact, calling or mail. | 10, 11 |
| | A course in which I learned what to do in the beginning of the diagnosis. | 11 |

## Theme: Sharing information

The way how partners get the information when starting a relationship and how they gain more knowledge over time differs per person. All participants with a partner stated that the partner mainly gets information through the patient itself. In the beginning this could be handing documents with basic knowledge about diabetes and what it means specifically to the one with diabetes. The partner mainly learns about diabetes by living together with a diabetes patient. They will use their equipment often and experiencing a hypo or hyper provides a lot of insights of what the disease involves. The partner receives soon in the relation information about what to do in an emergency situation. They learn where the equipment is and how to use it. Later on in a relation, information of hospital visits is shared, if the partner cannot join, to keep him/her up to date.

Other sources of information for partners are diabetes events, knowing other people with diabetes, having basic knowledge because of education. Some of the partners also look actively on the internet, there is a lot of information about diabetes online. However, this is mainly biological orientated only. In some cases the partner also joins hospital visits, to gather information, interpret information and to think along with the patient.

The moments of sharing what type of information differs. Some of the participants mentioned that they talked about diabetes when the condition gets worse or explained how to use certain equipment when it was needed to use. So in the moment. According to a participant's partner this was too late, since the patient had trouble explaining it while she was experiencing a hypo. In general in the beginning of a relation more information is shared than later in a relation. Most information is known to both. When new things, or complications pop up, more is spoken about it.

For patients with diabetes it is sometimes difficult to know what kind of information to share with whom at what moment. In most of the cases the partner knows most information, and they know much more than others, like friends. Some people do not know what the disease is and then a lot of misconceptions will arise, different terminology needs to be used. Explaining what diabetes is to strangers is difficult, because the perfect moment can never be found. Some use the insulin pump as a conversation starter, because people always ask or stare at it. Most of the participants are open and willing to explain what diabetes is. Two participants also say that they use humor to explain their situation and the complications that can occur. This was mainly after some years, when they accepted their disease.

Patients themselves need to gather information as well, since they do not know everything. They learn mainly by experience, what is happening to me when I get a hypo. It is learning the hard way. The health care professionals, mainly the diabetes nurse, is a valuable source for information at any time. Courses are also given in which a lot is explained about for example a new type of insulin pump, when you will get one and of course right after diagnosis. Other sources of information do not involve personal contact, like the Diabetes Vereniging Nederland or diabetesfonds website, television programs, or information folders.

The need in this regard is that information is shared at the right time in the right siutation. The information should be personalized and related to the context of the patient and partner.

### *Quotes from patients*

*7 “Heel globaal wist hij wel iets, niet veel. Ik heb hem van tevoren een paar a4tjes gegeven over mijn ziekte, dat hij ook wel weet waar je aan begint. Bleef daar vrij nuchter in. A4tjes was gewoon wat diabetes voor mij inhoudt. Dit is diabetes type 1. Elk mens is uniek. Dit is mijn diabetes. Dat is breed en er kan veel gebeuren. Laat het maar op je inwerken en heb je nog vragen.”*

*6 “Via mij, is in de eerste fase ook meegeweest bij gesprekken met de internist en DVK. ook omdat ik in die fase niet zelf kon autorijden of kon fietsen. Ik koppel wel terug wat er met de DVK of met de internist is besproken.”*

*6 “Mensen met wie je dagelijks omgaat kan je vertellen dat als ik erg laag zit dat ik overassertief wordt, dat ligt aan mij niet aan jou. Die stap zet je om dat open en bloot te vertellen, dat kost tijd. Ook al zit je 5jaar lang in een patroon, soms kom je periodes tegen die tegenslag oplevert.”*

*12 “Maar ik draag mijn pomp in het zicht, en vragen mensen wat is dat, en dan leg ik het uit. Het is niet heel veel minder of meer dan dat. Maar ik ga niet uit mezelf vertellen heee ik heb diabetes, fijn kennis te maken. Ik gebruik mijn pomp als gespreksstarter.”*

*3 “Ik ben ook bij een psycholoog in het lumc voor mijn diabetes en die zei ook je moet echt je mensen uitkiezen wie je meer wilt vertellen dan anderen. Dus mn vriend vertel ik meer, andere vrienden niet super goed vertel ik minder, want het helpt mij ook niet per se.”*

### *Quotes from partners*

*3 “En van leren, vallen en opstaan, meemaken, ja wat voel je nu. Zijn kutvragen, maar daardoor leerde ik het ook. Nou dit is kut, dit is belangrijk, dit boeit niet, en dit wel. Algemeen wat het in je lichaam doet.*

*2 “In die situatie was ze al behoorlijk ver weg. Het was beter geweest als we dat eerder hadden besproken.Het komt eigenlijk alleen ter sprake als het al te laat is. Van de ene kant vind ik dat jammer. Aan de andere kant denk ik als het niet nodig is en het gaat goed zoals het nu gaat dan is het ook vanzelfsprekend ook voor haar.”*

*In the undesired situation information booklets, or information on the internet is mainly medical oriented, not personalized and not clustered, leading to the partner not knowing what to do in case the patient needs help.*

*In the desired situation partners gain knowledge by experience and via the patient itself. But also by tailored information to partners specifically, since they do not know what is important to the patient. They also should get practical information.*

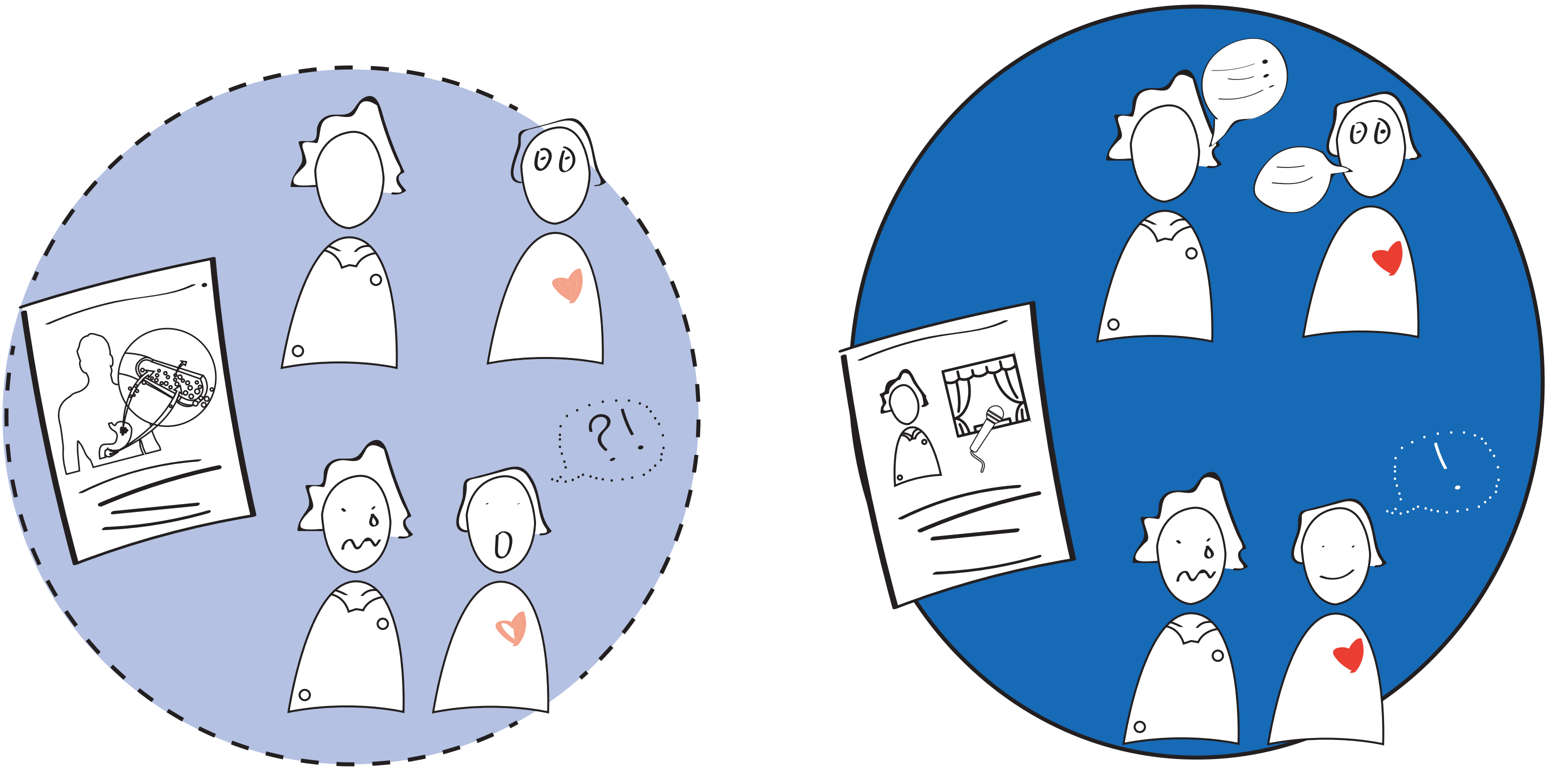


Figure 9: Visualization of an undesired situation and a preferred situation, regarding sharing information

## Theme: Lack of recognition

| | | |
|---|---|---|
| **Category:** | **Misconceptions** | |
| **Subcategory:** | **Confusion with type 2 diabetes** | |
| Codes: | They think you have type 2 and you have eaten too much sugar, they do not know the difference. | 2, 6, 7, 10, 12 |
| | I have to defend myself. | 12 |
| | Slight irritation. | 10 |
| **Subcategory:** | **Confusion with drugs** | |
| Codes: | People think I use heroin. | 3, 6 |
| **Subcategory:** | **People don't know what it is** | |
| Codes: | People ask weird questions. | 2, 6, 7, 10, 11, 12 |
| | People stare at me. | 3, 11, 12 |
| | People give unwanted advice. | 7 |
| | Don't know how to handle it. | 6 |
| | To be seen by society as incomplete. | 6 |
| | Complications of the disease are unknown. | 7 |
| | Even ignorance by doctors (other disciplines) | 7 |
| | Ignorance by teachers. | 9 |
| **Category:** | **Lack of empathy** | |
| Codes: | Don't know how I feel. | 2, 6 |
| | Cannot put themselves in the situation. | 2, 4, 5, 6 |
| | Does know the basis, but not the details. Try to understand it, but don't really get it. | 2, 4, 5, 11, 12 |

## Theme: Lack of recognition

The theme "lack of recognition" is based on the misconceptions existing around diabetes and the lack of knowledge and empathy. As stated already in the sharing information theme, some people do not know what diabetes type 1 exactly is. All participants have experienced that people confuse type 1 with type 2 diabetes. Reactions as, "have you eaten too much sugar", "oh you are not that fat" are common. It is perceived as very annoying that people do not know the difference. They do not want to receive unwanted advice. Some people think even worse, they believe or ask if I am using heroin when I inject insulin. People have to defend themselves, which causes slight irritation.

In some situations these misconceptions causes a lot of harm to the patient. A participant indicated that he was rejected from a job because of diabetes, while he could do the job in his opinion, but because people do not know exactly what the disease is and because there are a lot of prejeducises, he did not get the job. It is very frustrating and difficult to accept to be seen by society as incomplete.

A lot is unknown about the disease, also about the complications. There is even ignorance by doctors of other disciplines. Patients have to tell doctors what to do and how to deal with diabetes, which is not always possible. There is also ignorance among teachers. One participant told a story about high school. She was in class and her insulin pump gave an alarm, a sound, to remind of her of refilling the reservoir. She asked the teacher to leave the classroom to do this. The teacher did not allow her to do so. After a while the insulin pump made louder sound. The teacher became angry, walked to her and grabbed her insulin pump and pulled it off her, including the canule. The girl took her pump back, left the classroom and cycled home. The teacher was suspended.

Partners of diabetics know the basics of diabetes. However the details are mainly not known and the emotional value cannot be transferred. Partners do not know how the patient feels, they cannot put themselves in the same situation. They try to understand what it is like, but they do not really get it. This lack of empathy is difficult to deal with according to the participants.

An increased need of support is found for patients in moments of change, for example a new job, getting pregnant.

*7 "Ik heb nu een leeftijd dat mensen denken dat het diabetes type 2 is. Vaak krijg ik leefstijladviezen, terwijl ik toch niet helemaal overgewicht heb."*

*2 "Ja als ik er dingen over Vertel dan begrijpt hij het niet zo goed in die zin dat hij zich er niet in kan verplaatsen. Daarom snapt hij het niet. Daarnaast kan ik heel veel mensen die suiker hebben en hij kent er geen één. met hen kan ik wel over zaken praten en Zij snappen het direct. X zegt wel ja en doe maar rustig omdat hij zich daar niet in kan verplaatsen."*

*12 "Ik denk dat ze het altijd wel willen begrijpen en dat ze het wel snappen en begripvol zijn van moet je gewoon doen. Maar ik denk niet dat ze het echt snappen."*

*6 "Maar het is heel confronterend en heel kwetsend om te ervaren dat je door de maatschappij in groot verband wordt gezien als incompleet terwijl er niks aan je te zien is."*

*9 "En ik had toen ook mijn pomp en die ging af omdat mijn reservoir te laat was. Ik zei: mijn pomp is leeg, ik moet m even vullen. Kost hooguit 10 minuten. Mag ik dat even doen. Nee dat mag niet. Dat ding blijft natuurlijk piepen, want het is best belangrijk dat ik insuline binnenkrijg. Op een gegeven moment piepte die steeds harder. Toen pakte ze dat ding af en trok ze eraan en toen trok ze de canule eruit. Dus ja toen op haar bureau gelegd. Toen heb ik m'n spullen gepakt, opgestaan, mijn pomp van het bureau gepakt, en naar huis gefietst."*

*In the undesired situation partner and patient do not understand each other and do not know how diabetes affects each other. This creates a distance in the relationship. Also society lacks knowledge and is asking non related questions, leading to misconceptions.*

*In the desired situation partner and patient do understand each other, have recognition. For partners there is a need to come closer to the patient, in a way to understand what the disease is and how it feels.*

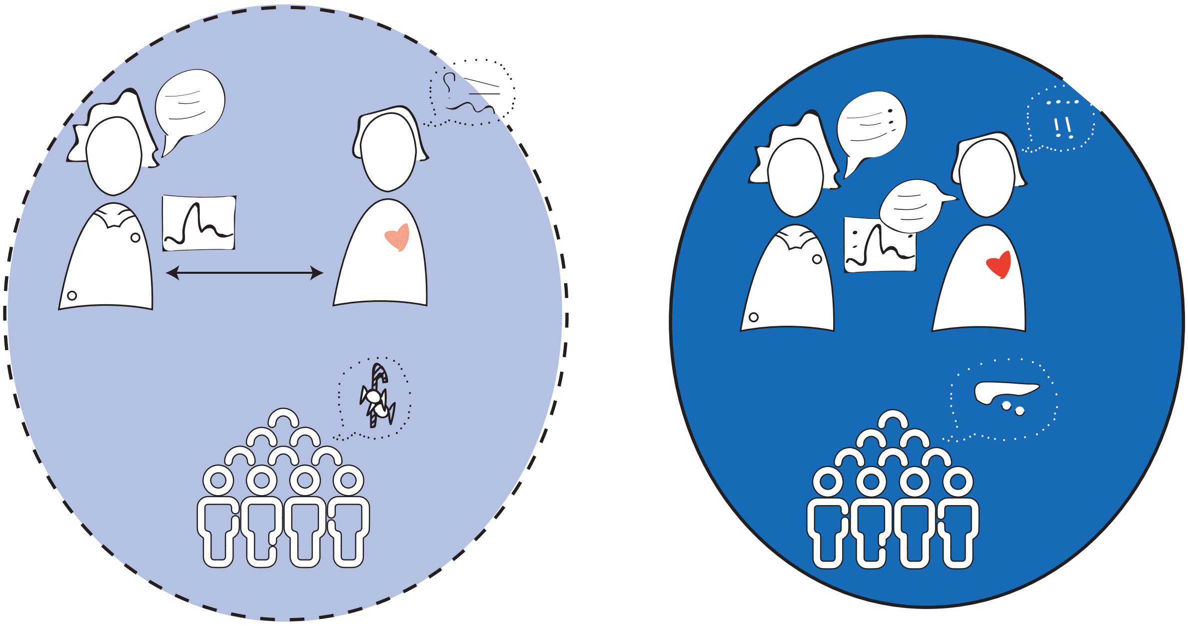


Figure 10: Visualization of an undesired situation and a preferred situation, regarding lack of recognition

# Theme: Peer support

## Category: Where do people meet peers

### Subcategory: Online

| | | |
|---|---|---|
| Codes: | Facebook groups/instagram. | 1, 2, 3, 4, 5, 9, 11, 12 |
| | Whatsapp groups. | 3 |

### Subcategory: Offline

| | | |
|---|---|---|
| Codes: | Events. | 1, 2, 3, 6 |
| | Camps. | 12, 4 |
| | Holidays. | 5 |
| | At school/sports. | 2, 9, 10 |
| | Going out. | 2, 11 |

## Category: Goals to meet peers

### Subcategory: Equipment

| | | |
|---|---|---|
| Codes: | Share equipment. | 2, 3, 4 |
| | Talking about equipment's performance. | 2, 6 |

### Subcategory: Recognition

| | | |
|---|---|---|
| Codes: | I am not the only one. | 1, 2, 3, 4, 11, 12 |
| | They know how I feel. | 2 |

### Subcategory: Helping and learning

| | | |
|---|---|---|
| Codes: | Using humor to deal with the disease. | 2 |
| | Share experiences, learn from each other, using different methods, come to solutions, complain | 1, 3, 4, 5, 9, 10 |
| | Giving tips to others, mainly practical. | 1, 3, 4 |
| | Help others offline. | 3, 5, 10 |
| | Share frustrations. | 6 |
| | Recognize patterns. | 5 |

## Category: No peer support

| | | |
|---|---|---|
| Codes: | Personalities differ too much. | 7, 11 |
| | Feels forced, threshold is too high. | 3, 11 |
| | Events are targeted to a too broad audience. Not my type of people or topics. | 6, 11 |
| | People are too negative. | 10 |
| | Knows already enough people. | 4 |

## Theme: Peer support

In contrast to people who lack empathy, other people with diabetes do know how it feels to have diabetes. Peer support is therefore important to most of the participants of this study.

Participants have found peers during events organized by diabetes associations, camps, holidays, at school, sports or from going out. They also look for peers online in Facebook groups, WhatsApp groups and on online forums.

Participants mention mostly that peer contact is handy for sharing and lending equipment. They also talk a lot about equipment or types of insulin for example to compare. Another main benefit of having peer contact is knowing that you are not the only one with the disease. Knowing other people with diabetes feels as a relief, they also know how it feels having diabetes. Sharing experiences helps and they learn from each other. They ask questions and receive suggestions. Mainly the tips they provide are related to practical issues. Issues you cannot find on the internet. Sometimes even the manufacturer does not know the answer, while patients do, since they have the practical experience. Sharing frustrations, complaining is also part of the support.

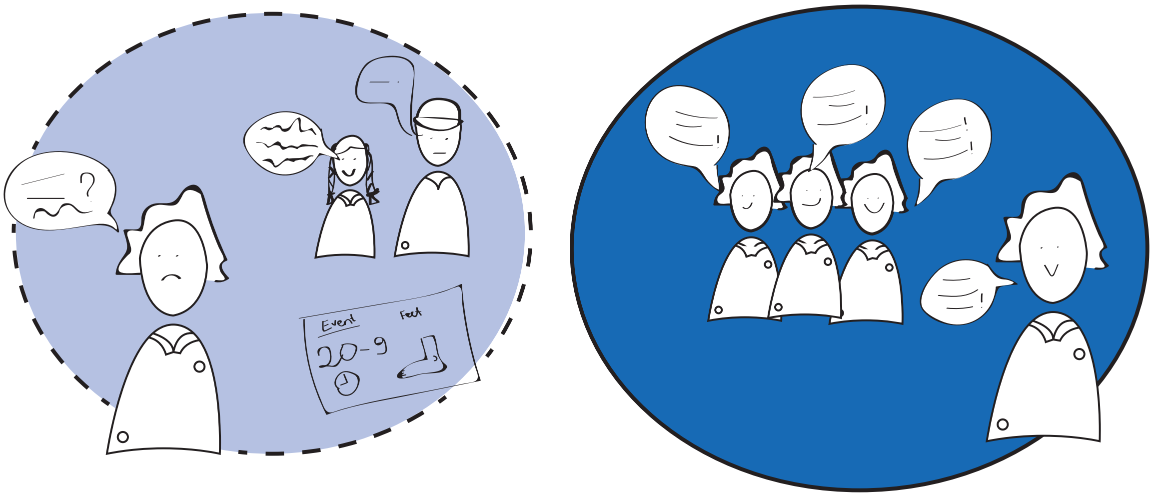
Three participants mentioned that they do not want peer support. Reasons for this were that other people were way too negative. Another reason was that the participant had already enough contacts, so new contacts were not needed anymore. Other participants also indicated that events are organized for people with diabetes, which is an opportunity to meet peers. However the threshold to go there is high, the target audience is mainly too broad and they do not want to meet people who are much older or have a completely different personality.

*6 "Je praat met elkaar over apparatuur. Over de emotionele kant is zelden het gesprek."*

*2 "Zij kunnen zich meer inleven in de situaties die ik doormaak. Zij kunnen zeggen Oh ja ik snap dat je daar heel moe van bent. In plaats van Oh ja oh ja snap ik snap ik. Het gevoel wat je daarbij krijgt is heel anders. Zij voelen meer wat ik echt voel."*

*3 "Ja sommige dingen staan niet op internet, bijvoorbeeld of je met een sensor in zee kan zwemmen. Er staat wel watervast, maar is er dan verschil tussen zout en zoet water. Soms weten alleen maar gebruikers dit, en de fabrikant niet eens. Dus dan is het handig om verschillende ervaringen van mensen te horen."*

*11 "Je kan ook wel naar evenementen gaan. Maar voelt geforceerd, voor mij moeilijker om mee om te gaan. Leuker om op een andere manier te vinden.Nu heb ik wel zoiets van ik kan het wel doen ,naar een diabetescafé ofzo. Maar nog niet echt dat ik er helemaal voor ga. Vooral het eerste jaar echt geen behoefte aan. Nu zou ik het wel leuk vinden om iemand tegen te komen. Je moet ook maar een leuk type tegenkomen, je weet het natuurlijk ook niet."*


*In the undesired situation patients with diabetes cannot find a connection with other patients, due to personality differences, or events organised with topics they are not interested in.*

*In the desired situation, patients find peers  with a matching lifestyle or same mindset to share information and expereinces with, since that is more practical and reliable and can cause relief.*

Figure 11: Visualization of an undesired situation and a preferred situation, regarding peer support

# Theme: Relation with formal caregivers

## Category: Contact with health care professionals

### Subcategory: Pediatrician

| | | |
|---|---|---|
| Codes: | Great guidance, warm and relaxed. | 2, 4 |
| | Bringing improvement possibilities in a subtle way. | 2 |
| | They take time for you. | 2, 4, 11 |
| | Was very negative, listed only negative points. | 1, 12 |
| | Too much talking. | 10 |

### Subcategory: Internist (adult)

| | | |
|---|---|---|
| Codes: | Thinking along with my situation. | 4 |
| | Always positive. I was a good patient. | 10 |
| | More freedom. | 10 |
| | Do everything yourself, waiting longer. | 2 |
| | Not interested, not answering questions. | 6 |
| | Too much following the protocol, no room for changes. | 4, 7 |
| | Made mistakes. | 3, 7 |

### Subcategory: Diabetes nurse

| | | |
|---|---|---|
| Codes: | More valuable than internist, more practical experience and more support. | 1, 6 |
| | Share more information with nurse. | 2, 6, 11 |

### Subcategory: Hospital atmosphere

| | | |
|---|---|---|
| Codes: | Use of automation, less personal atmosphere. | 2 |
| | Treated impersonal. | 7 |

*12 Maar ik heb wel eens ruzie gehad, omdat het altijd was dit doe je fout, dit doe je fout, dit doe je fout, dit doe je fout, en dan krijg je gewoon in een half uur alles over je heen gegooid wat je in heel je leven fout hebt gedaan. Bij mij schoot dat dan in het verkeerde keelgat, want ik ben er 24/7 mee bezig, ik doe hartstikke mn best en ik krijg een lijstje wat ik fout doe.*

*2 Bij de internist ben je veel meer op jezelf gesteld. Je moet veel meer zelf doen dan bij de kinderarts. Je bent ook meer zelfstandig. Je moet alles alleen doen. Als je problemen hebt kan je wel vragen stellen. Maar je moet vaak wachten tot zij tijd hebben.*

*3 Na drie maanden aan de bel getrokken, met ik voel me echt doodziek, dit gaat niet zo. Toen bleek dat ik nog geen insuline echt nodig had. Vanaf toen is het niet meer goed gegaan, vooral mentaal ging het heel slecht. Omdat ik dacht dat ik dacht dat de artsen hier meer vanaf moeten weten, en ik heb geen idee wat ik moet doen en zij maken best wel een belangrijke fout. Vertrouwen verloren in de ondersteuning die ik had.*

*6 De DVK in was echt top. Daar heb ik heel veel aan gehad. Eigenlijk zijn de contacten met DVK voor mij waardevoller dan met de internist. De internist is er eigenlijk alleen maar om het krabbeltje te geven wanneer ik aanvullend medicijnen nodig heb. DVKs hebben meer praktijkervaring. De probleem waarmee ik worstel zijn veel praktischer van aard.*

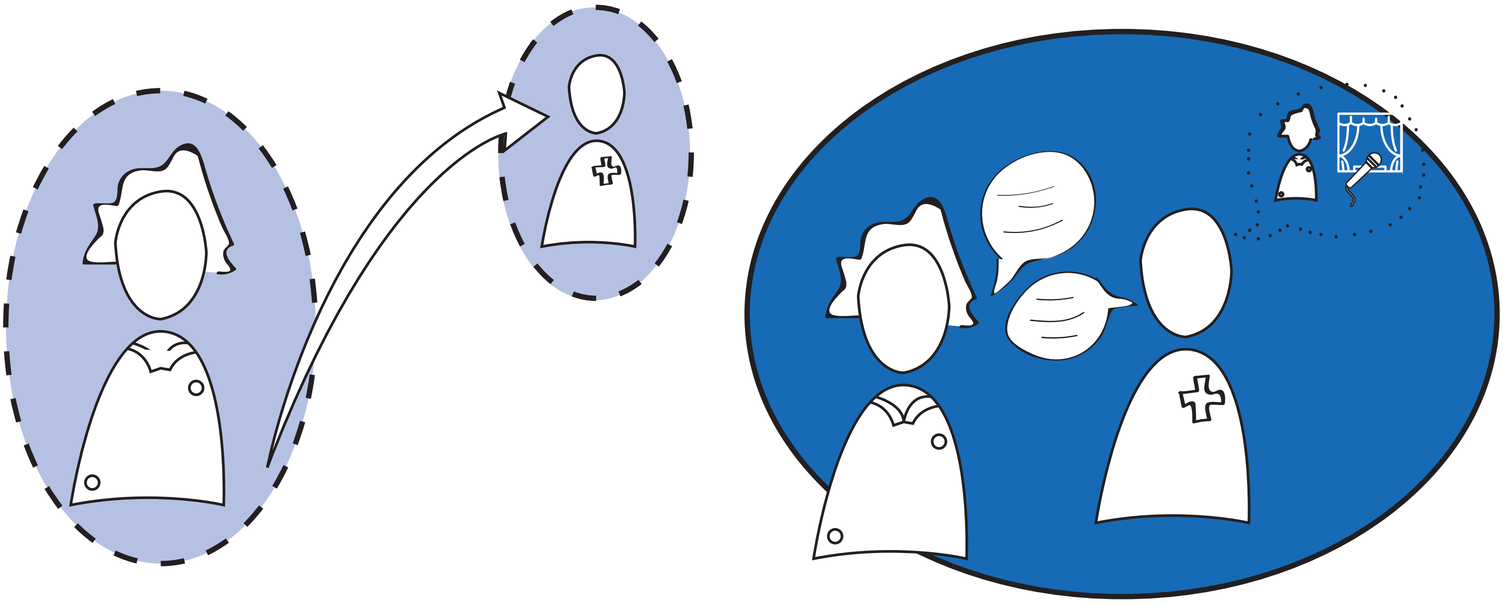
*11 Goede band met diabetesverpleegkundige, mail ook met haar, kan alles vragen. Reageren altijd meteen,. Ook als ik met haar in een sessie zit dan heb ik het gevoel dat ik alles kan vertellen. Meer met haar dan met mij dokter, dat is wat officieler.*

## Theme: Relation with formal caregiver

The relation with the caregiver plays a role in how to manage diabetes. Diagnosed as a child, you will go to the pediatrician. More than half of the participants had a good relation with their pediatrician, their bond was warm and relaxed. Improvements were made in subtle ways and they take time for you. Three participants indicated that the relationship with their pediatrician was not that good. The pediatrician was very negative, he/she listed only the negative things. This was very hard for them, since they are dealing with the disease 24/7 and they to their best to take care of it the best they can. Hearing only negative points, does not motivate them.

When they become adults, or are diagnosed as an adult, they go to the internist. Here they experience more freedom, they have to do everything themselves, and they have to wait a little bit longer than in the hospital. Also here the differences between the relation between partner and doctor changed per person. Some were really positive, the internist was thinking along with the patient to come to a solution or was always positive, while other participants mentioned that the internist was not interested, was only following protocols and did not leave room for personal experiences or situations or even made mistakes. The atmosphere in hospitals is by some participants considered as impersonal, because of the doctor or because of all the automation used nowadays.

Most of the participants had a better relationship with the diabetes nurse. They value the appointments with the diabetes nurse more, because the nurse had more practical experience, was able to answer questions and provided more support and was more open for questions. Patients share more information with the diabetes nurse than with the internist.



*In the undesired situation patients do not feel supported by caregivers, they feel on their own.*

*In the desired situation there is good personal contact with the doctor and nurse. It is thereby important the personal situation of the patient is taken into account.*

Figure 12: Visualization of an undesired situation and a preferred situation, regarding relation with formal caregiver

# Theme: Personality differences

## Category: Influence of diabetes in life

### Subcategory: Not changed

| | | |
|---|---|---|
| Codes: | Life has not changed much. | 2 |
| | I don’t know any better. | 4, 5, 12 |

### Subcategory: Positive points

| | | |
|---|---|---|
| Codes: | More aware of body and its limits. | 2, 10 |
| | Became more open. | 11 |
| | Became more mature. | 9, 11 |
| | Earlier developed responsibility. | 9 |

### Subcategory: Negative points

| | | |
|---|---|---|
| Codes: | Not seeing any positive points. | 5, 6 |
| | Denial phase, wanting to participate with others. | 3 |
| | All frustration. | 3 |

## Category: Keeping track of data

| | | |
|---|---|---|
| Codes: | Respond better to fluctuations. | 7 |
| | Able to anticipate in advance. | 6, 7 |
| | Analysing trends. | 5, 6, 7 |
| | Own settings. | 12 |
| | Only looking at the data when you want to look. | 12 |
| | Forgetting to take action when needed. | 4, 12 |

## Category: Acceptance

| | | |
|---|---|---|
| Codes: | Takes long. | 3, 6 |
| | Is emotional. | 3, 6 |
| | Plan ahead. | 6, 7 |
| | Not able to do everything anymore. | 6, 7, 11 |
| | Better to accept what you have now than to reflect on what can still come or what you had in the past. | 6 |
| | Don’t be ashamed. | 4, 9 |
| | Open attitude. | 2, 4, 12 |

## Category: Adaptation

| | | |
|---|---|---|
| Codes: | Find resignation. | 6 |
| | Not stating the disease as goal number one. | 5, 6, 7, 10, 11 |
| | Where there is a will there's a way. | 10, 12 |
| | More freedom now, than before. | 10, 11 |

Since everybody perceives diabetes in its own way and everyone has its own personality, many different aspects play a role per person. Some participants stated that diabetes did not play a big role in their lives, mainly because they do not know any better or they are used to it completely.

Some participants also value positive aspects of having diabetes, while others do not see anything positive, they see it is all frustration. People who mentioned positive things said things like: I am more aware of my body and its limits, I became more open, I developed a better relationship with my parents, I became mature sooner than my friends, and developed responsibility earlier.

Some participants took accurate care of their management by keeping track of all the data to respond better to fluctuations, to anticipate in advance on hypos or hypers, to analyse trends. They also used their own settings to make it more personal and to gain more insights into their own diabetes. Others show more slacking behavior, they forget to take action when they need to, they inject insulin after dinner instead of before or they do not check values before sleeping or driving the car.

Also acceptance plays an important role in diabetes self-management. People accept having the disease in several ways. Some ignore that they have diabetes in the beginning. Some participants said that accepting phase took long and is emotional. People who were diagnosed at a young age, have accepted it, they do not know any better. They are raised this way and they have learned not to be ashamed. For people who were diagnosed later, it limits them. They know what they had before. However they also realized now, at the moment of the interview, that it is better to accept what you have now than to look in the past or to reflect on what can still come.

For adaptation to the disease all participants said something like; diabetes is not my life, I am not the disease. Life should also be fun. They all have found resignation.

*3 Toen ik 18 was ging ik naar Leiden om te studeren, dat in mn eerste jaar echt ontkent dat ik diabetes had. Ik wil aan alles meedoen net als iedereen. En diabeet, ach ja, dat heb ik niet dacht ik. Toen zat ik altijd rond de 30, dat was voor mij normaal. En dat is jarenlang een beetje zo doorgegaan.*

*6 Je moet voor de diabetes heel veel regelen , doen . je bent beperkt in een aantal dingen. Altijd spullen bij je, dingen vooruit plannen, spontaan dingen eten of op weg gaan is er niet bij, zeker niet in het begin. Dat levert frustratie, boosheid, teleurstelling op. Het levert situatie op waarin je veerkracht en mentale belastbaarheid minder kan. Je leert bepaalde dingen te accepteren maar ook om bv die boosheid die je af en toe ontwikkeld om dat een plekje te geven*

*4 Nee, echt dat was het allereerste wat ik heb geleerd van mij DVK, echt een topwijf, schaam je niet voor je diabetes. Als je moet spuiten moet je spuiten, als je moet prikken moet je prikken, dus dat heb ik heel mijn leven zo gedaan. Nee, echt schamen nog nooit gehad. Of anders gereageerd of anders gehandeld.*

*11 Het is heel bepalend natuurlijk. Op het begin was het natuurlijk veel dominanter in mijn leven, want dan laat je echt alles. Ik moet alles perfect doen, ik durfde ook heel veel dingen niet meer aan het begin. Ander gaat mn bloedsuiker dalen of stijgen. Nu heb ik dat heel erg van me afgezet.*

*In the desired situation acceptance and resignation needs to be found in the disease. If this is found, it is easier to talk about it.*

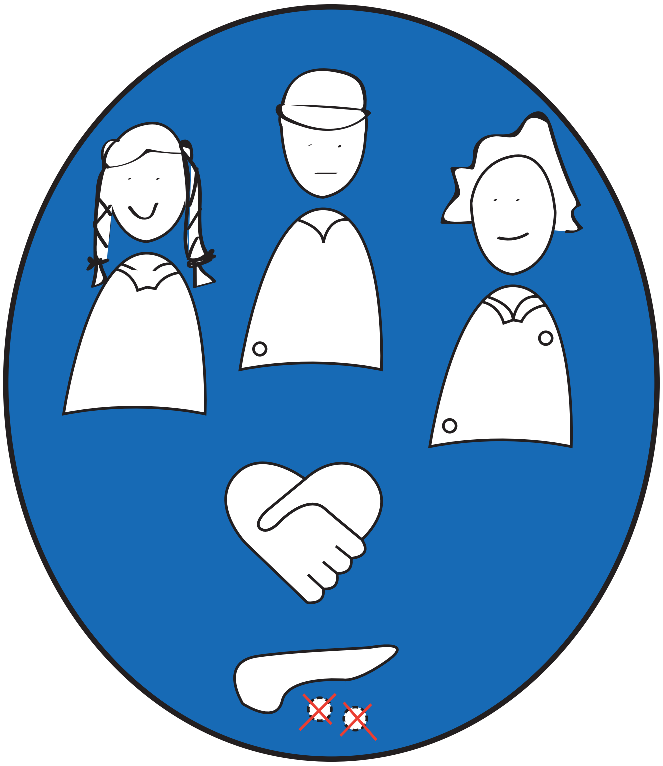


Figure 12: Visualization of an undesired situation and a preferred situation, regarding relation with personality differences

## Interpretation

A simple answer on the research question: How do relatives support the person with diabetes now and how can this be improved according to the patient and the relative cannot be given with a short and clear answer. Multiple aspects play a role. An interpretation of the results to answer the question is given.

Practical and emotional support is given to the patient. Valuable practical support is; counting carbohydrates, grabbing food in drinks in case of a hypo especially helpful during nights, taking care of extra equipment when going outside, scanning of blood glucose levels, filling insulin reservoirs, intervene in emergency situations. This works mainly well, and partners know in general what to do.

Emotional support is given by offering a listening ear when the patient needs it to for example express frustration or worries, thinking along about solutions when the patient is stuck finding the right way to handle it, showing gratitude, sobriety and not worrying in case it is not needed, show curiosity and interest, be caring, create empathy, join hospital visits and providing feedback. It is more difficult to provide emotional support, because it is more than just knowing the facts and do what is written down. It is important to understand the disease and how this affects the patient, including feelings and emotions, this is not simply read in a booklet or on the internet.

It is important to talk with each other, and to know the needs and expectations of each other. This is difficult, because people with diabetes are 24/7 influenced by diabetes. For a person not knowing what diabetes is, it is difficult to grasp what it exactly does to a patient. This lack of empathy plays an important role. Partners do not know how the patient feels, they cannot put themselves in the same situation. They try to understand what it is like, but they do not really get it. It creates a sort of distance between the partners. This distance, and not exactly knowing what is going is difficult to deal with according to the participants.

Knowledge is also an issue considering the results of the literature study. In the interview information collection and sharing was also covered. Partners get mainly information through the patient. In the beginning of a relation documents are given or only verbal communication is used. Later on the partner mainly gets knowledge by being in close contact with the patient. They are able to see which instruments are used, how the patient behaves in case of hypos and hypers and how this influences the behavior. Other sources of information for partners are diabetes events, knowing other people with diabetes, having basic knowledge because of education. Some of the partners also look actively on the internet, there is a lot of information about diabetes online. However, this is mainly biological orientated only. In some cases the partner also joins hospital visits, to gather information, interpret information and to think along with the patient. Patients indicated that they appreciate the presence of their partner in diabetes related events, for the partner it is good to also see other diabetics and learn from their experiences too to get more involved.

It is important to see diabetes as a shared problem, to enhance the self-management of the patient. During the interviews it became clear that the couples in which the disease was seen as shared, the support was good and the partner indicated having enough knowledge to support the patient. In one case the partner of a patient indicated that he did not have enough knowledge about diabetes to support the patient and that he wanted to be involved more. When interviewing he stated that he always wanted to help the patient, but that she wanted to do everything on her own. She did not accept his help. He said she is too stubborn. This indicates that the problem is not seen as shared by both, resulting in not optimal support. Another reason could be that he is not supporting in the way the patient wants to receive support.

Patients themselves also seek for information. The health care professionals, mainly the diabetes nurse, is a valuable source for information at any time. Peers are also an important source, they share questions, tips and tricks with each other. Mainly about practical issues, that only users of certain equipment can answer and is not found on websites. Patients mainly using diabetes as an excuse and micro managing the partner. Worrying because the partner has heard stories about other people having diabetes that ended badly is unwanted. Too much interference does not help.

To summarize, how do relatives support the patient now, is by providing mainly practical support and to some extent emotional support. Partners also support the patient by being educated about diabetes. This knowledge is mainly gathered by living together with the patient and experiencing what it does. Other ways of supporting are joining the patient in hospital visits and diabetes events. It is also perceived as positive support when the partner adapts his/her life to diabetes as well to a certain extent. How can support be improved is the other part of the research question. Based on the interviews it can be concluded that emotional support can be improved by talking more about emotions and feelings. This is very personal and needs a personal approach and discussion, and is not described in booklets. This can also improve empathy. Partners do not know how it is to have diabetes and this causes frustration and a feeling of not getting close to the partner. It might help to join diabetes events to also see others with diabetes and to learn from their experiences. Another aspect to improve is to see the disease as a shared problem by both the partner and the patient. The patient should also accept that the partner wants to help.

Many insights were gathered during the interviews, not limited to only the support from relatives, but also the importance of peers and caregivers. However this study is focused on social support from relatives. So the critical node, related to this specific topic, based on the interviews is that there is a distance between the patient and the partner. The partner cannot come close to the patient, because it is difficult to exactly know what diabetes does to the patient. Diabetes is sometimes not seen as a shared problem by the patient, leading to the partner willing to help, but the patient not accepting it. Therefore it is even more difficult to grasp what is going on. The partner wants to help but feels excluded. This distance or not able to come close to the patient can lead to overconcerned behavior, in which they try to micromanage the patient. However, this is highly undesired by the patient.

## Design implications

Design implications gathered from this study are listed. These can be used for designing a tool in the next phase. Requirements and wishes are created from these design implications. Indications which requirement is linked to which implication is shown.

### Personal approach

People have different preferences and diabetes is perceived different by every patient. A personal approach for every patient is demanded. *(Requirement 2)*

### Adaptability

Since every patient is different, the design should be adaptable to wishes of the patient. The design should also be relevant for different levels of user engagement. *(Requirement 2)*

### Design for information over a longer period

Information is provided right after diagnosis, a folder, a booklet etc. in which general information is given. However, diabetes is not a static condition, it changes over time and evolves. A day with diabetes is never the same. Information for dealing with unexpected and specific circumstances is not provided. People look at this for themselves and can be supported in this. *(Requirement 6)*

### Ongoing support

Diabetes is a chronic condition, patient have to deal with it 24/7. It is therefore important to provide ongoing support. *(Requirement 6)*

### Enhance motivation

Support from relatives can motivate the patient to take better care of the self-management. It is important that this motivation is enhanced. Patient should always be acknowledged and positively encouraged for even small positive changes in their self-management. *(Requirement 5, 6, wish 8, 9, 10)*

### Let the partner show interest

It is important that the partner is involved and shows interest. So the tool should also attract interest from the partner and should be nice to use, also for them. *(Requirement 1, 3, 4, 9 wish 1, 4, 6, 12)*

### Support problem solving

Problem-solving plays an important role in the self-management of diabetes. It is desired that patients get support while looking for solutions if they cannot come up with one themselves. It is important to link interventions to the patient's life and its context. *(Requirement 1, 2, 4, 5, 6 wish 5, 6)*

### Adapt both to the disease

It is essential for the self-management of the patient that diabetes is seen as a shared problem. This can be by solving problems together, but also by adapting life to diabetes also for the partner. This helps the patient in some cases too. *(Wish 5)*

### Providing feedback

Providing feedback is essential for the patient. Sometimes the patient is not aware of its behavior due to the effects of diabetes. *(Wish 5)*

### Improve communicating about the emotional side of diabetes

People share mainly information about their equipment. Conversations about the emotional side of diabetes is most of the time avoided, because it is difficult to talk about. This should be stimulated. *(Requirement 8, wish 11)*

### Create empathy

Share feelings and emotions by means communication. This can enhance the feeling of empathy and recognition, which might help supporting the patient. *(Requirement 8, wish 11)*

### Support sharing experiences

People with diabetes benefit from tips, suggestions and tricks provided by other diabetics. Not everyone is actively looking for information this way, because the barrier is high. A design tool could support exchange of experiences between patients. *(Wish 8)*

### Life next to diabetes

People with diabetes have indicated that diabetes is not their life. It plays an important role, but they also want to focus on the fun things in life. In the design it should be kept in mind that those people already deal with diabetes 24/7 and that they prefer to keep their mind busy with other things. *(Wish 6, 7)*

# 1.4 CONCLUDING THE DISCOVER PHASE

The discover phase provided insights on a lot of aspects of how patients and partners deal with diabetes. This sections provides a summary and discussion of the findings from the discover phase.

The insights that were gathered in the discover phase provided justification for the problem indicated in the introduction of this report. There it was stated that social support is important but not always given in the right way. Relatives want to be more involved, but they do not know how to positively support the patient, because they lack knowledge and understanding on how the patient relates to the disease (Baig et al., 2015; White, Smith, & O'Dowd, 2007; Kovacs Burns et al., 2013).

Diabetes is a very personal disease, and patients should take responsibility of their own diabetes management. This mainly includes normalizing blood glucose levels. Several factors have an influence on these blood glucose levels. It is therefore important to have the right knowledge to control these values and to effectively manage diabetes. Support from relatives, especially the partner, is important. They can guide the patient, support them and enhance the motivation. However people often do not understand diabetes to an extent to be really able to support in patients' self-management. There is no general approach to inform relatives about diabetes. This has mainly to do with the fact that every patient is different and the diabetes is for everyone different as well.

The desired elements of social support from relatives to diabetes patients according to literature are: Involvement of partners in self-management of diabetes; active engagement of the partner; perceiving the disease as a shared problem; be knowledgeable to help the patient; play can support this active engagement.

However no clear indication to stimulate involvement, engagement and supporting is described in literature. Only one article state that play can have an positive influence. The type of play is not clearly defined. This way the problem will not be solved and partners do not have solutions or tools to become more involved or to come closer to the patient.

The interviews with diabetes patients and its partners indicated that in some cases the support is going very well, and in other cases the support from the partner could be improved. In literature it is stated that around 40-50% would like to be more involved (Kovacs Burns et al., 2013). In this current study the 40%  of the partner participants (2 out of 5)indicated, they wanted to be more involved. From all participants involved in the study insights were gathered on how good support and sufficient involvement is achieved. First of all, every diabetes patients is different and manages diabetes in its own way. They have their own mindset regarding diabetes, some are more negative/positive than other. This is of importance to take into account during the whole process.

All participants, who have a partner, indicated that the support from their partner is most valuable,  since this person is most of the time together with the patient and they have a lot of contact together and they know their personality characteristics and daily routines. An increased need of support is found for patients in moments of change in their life, for example a new job, getting pregnant, or extra complications.

It is important to gain knowledge. According to the interviews partners mainly gained knowledge by experience or via the patient itself. Other ways to share information are via Information booklets, or information on the internet, however this is mainly medical oriented, not personalized and not clustered. This way not all partners are informed as they wish, they receive information at the wrong moment or they receive only very general information. Information only means something in the context of the patient's life and the information in booklets without practical relevance is not understood or not directly applicable to the personal situation of the reader.

Since it is shown that partners play an essential role in supporting the patient, it is needed that there should be tools targeting the partner, and not only the patients. Since there is a need for the partner to gain knowledge about diabetes, it would be advisable that information is provided to the partner which is  practical and personal. This information can  be retrieved from experiences from other patients, instead of only medical facts that can be read online. They need to see what the impact of their actions is, why it is important and what they can do with this information to solve the problem. Now they sometimes do not how to solve problems, if they are confronted with them.

The best way to support the patient is to see the disease as a shared problem. Seeing diabetes as a shared problem is indicated by both literature and interview findings found to be a an important factor of support behavior (Helgeson et al. 2019).  However in practice it is difficult for the partner to really get what diabetes is to the patient. This can cause a feeling of being excluded. This can be improved by for example communicating about emotions and feelings using a personal approach. This can improve empathy and recognition. This is what happens in situations the partner and patient do support each other well.

A negative aspect of support can be managing the disease of the patient as a partner. This should be avoided, because it cause frustration for the patient. They have the disease, they know how to manage it. They do not want to get unwanted advice or comments on their blood glucose levels, because they can see them as well. They also know if that is good or bad. It is better to let them explain their choices than saying what they have to do or checking if they have done their tasks already.

# 1.5 CRITICAL NODE

The critical node is a term used to describe the critical element which is the reason for the stated problem. The critical node is based on the findings in the discover phase.

What seemed to be critical here is the way in which the partner cannot come close to the partner regarding diabetes. For the patient it is important the he/she is supported by the partner. This is also revealed during the literature study and the conducted interviews. In order to provide good support, it is important that the partner knows enough about diabetes and how this affects the partner and how he/she can help. From the interviews it becomes clear that the partner is willing to do so, however it is difficult to exactly get what is going on and how it feels having diabetes.

The patient is also aware of this and realizes that the partner is affected too by their diabetes, but it is difficult to express and explain what is going on in their body and mind in a way the partner understands it correctly, because the partner cannot relate to it and there is no recognition. In some cases the patient also do not want to share everything, because it is their own disease, not the partners'.

The partner can therefor feel excluded. He/she wants to help but is not sure how to help in an optimal way. This way a distance is created between patient and partner. The partner might compensate for this by worrying and showing overinvolvement overconcerned behavior.

The needs for the **patient** are: Getting support to improve the effectiveness of the self-management of the disease.
Able to explain what they feel and experience in a way that partners can relate to it, getting recognition and empathy

The needs for the **partner** are: Coming closer to the patient, their loved one, by understanding what they feel and experience. Not feeling excluded. Finding good ways to support the patient in a way they want to receive support and benefit from it. Gaining more knowledge about diabetes specific to their situation.

From this we conclude that the critical node touches upon the partner feeling excluded by not having diabetes and therefore not exactly knowing how the patient really feels. This feeling of being excluded can lead to overconcerned behavior or frustration, not knowing how to help.

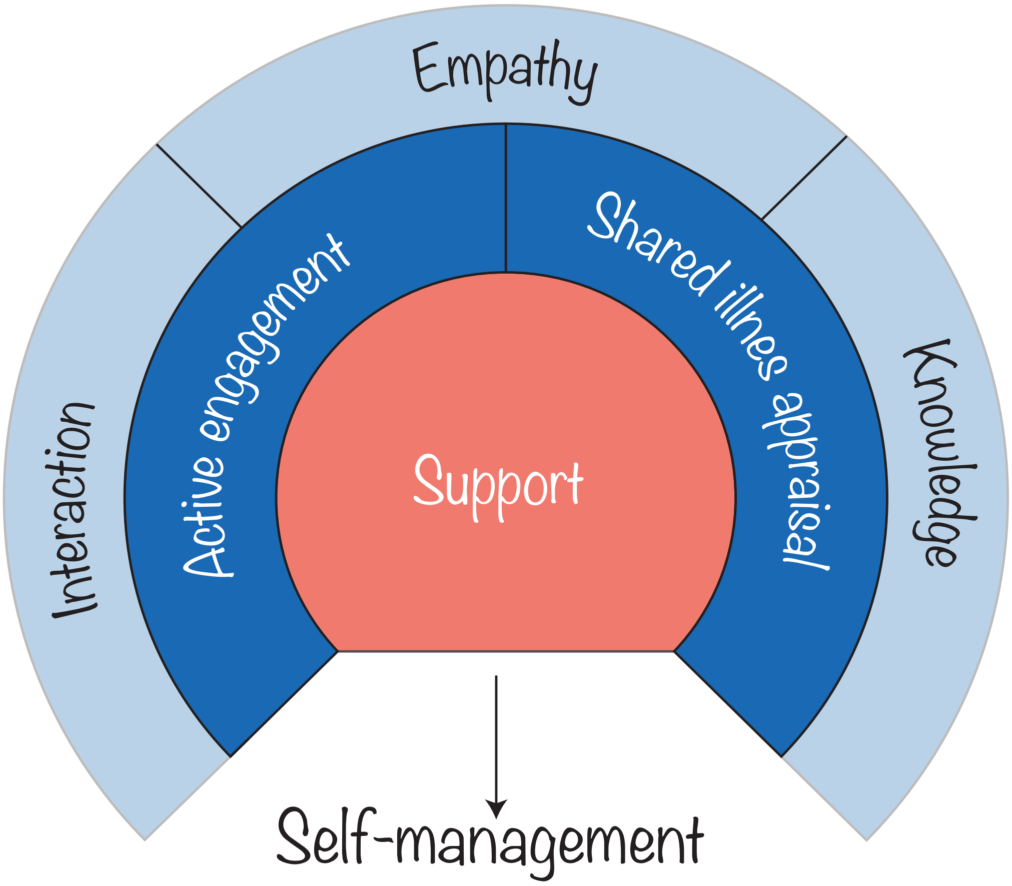
What is crucial in changing the current situation is that seeing diabetes as a shared problem is accepted by both parties. By being able to express how one feels and how one wants the other to behave, the aim of achieving continuous and effective support for the patient can be fulfilled.

# Elements to improve support

**Active engagement.** (In order to be able to provide good support, active engagement from the partner to the patient is necessary according to Helgeson et al. (2019). Active engagement means according to the literature playing games, to open up discussion (Van Vleet et al, 2019). According to patients that were interviewed active engagement means, helping with practical issues (filling reservoirs, counting carbohydrates etc.) and providing emotional support by listening, thinking along with problem solving.

**Shared illness appraisal** (Diabetes is a shared problem, it affects both people in a relationship and this should be accepted by both parties. By perceiving diabetes as a shared problem, positive effects of support and self-management are reported by Helgeson et al (2019).

**Support** helps people to sustain and improve their self-management of diabetes.

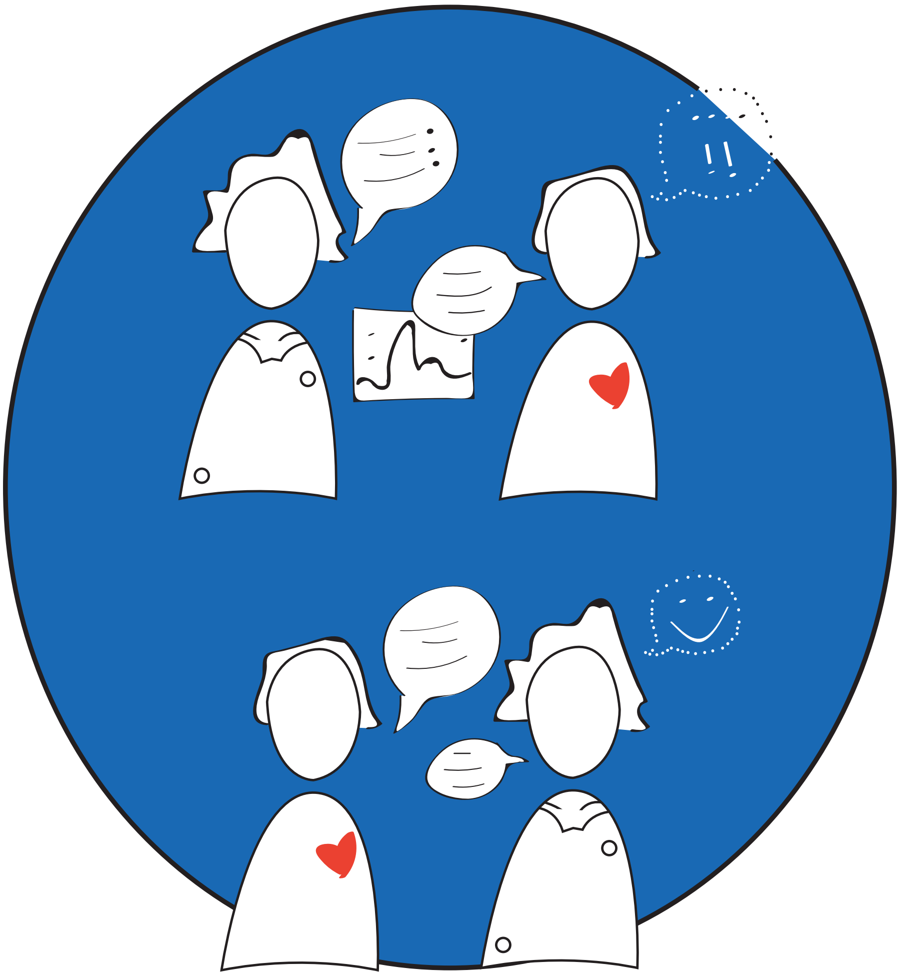


Sufficient **interaction** between patient and partner is important. The interaction should consists of accepting each other's help and providing help if needed.

They have create **empathy** for each other. This can be achieved by talking about emotions and feelings the both can relate to. By being able to understand what one feels and experiences, recognition can take place. The feeling of being excluded should be eliminated.

**Knowledge** should be gained about factual aspects of the disease, but more importantly is to understand what diabetes does to the patient, and what the person values and what not.

# Needs for patient and partner



The needs for the patient are: Getting support to improve the effectiveness of the self-management of the disease. Able to explain what they feel and experience in a way that partners can relate to it, getting recognition and empathy.

The needs for the partner are: Coming closer to the patient, their loved one, by understanding what they feel and experience. Not feeling excluded. Finding good ways to support the patient in a way they want to receive support and benefit from it. Gaining more knowledge about diabetes specific to their situation.

## PHASE 2

# DEF

# FINE

## Introduction

The main objective of this phase is to generate solutions for the problem as found in the discover phase.

## Methodology

This phase starts with defining the problem and the design vision. A list of requirements is created based on the design implications given in the discover phase. Thereafter ideas for possible solution are given and two are selected as concept directions.

# 2.1 DESIGN VISION

The findings of the discover phase including the critical node and the needs for both the patient and the partner are used to a design vision, as starting phase for the design phase of a tool.

The aim of this graduation project is to design a tool. Based on the critical node formulated in the discover phase, the tool should fulfill the needs of the patient and the partner.

The needs for the patient are: Getting support to improve the effectiveness of the self-management of the disease.
Able to explain what they feel and experience in a way that partners can relate to it, getting recognition and empathy

The needs for the partner are: Coming closer to the patient, their loved one, by understanding what they feel and experience. Not feeling excluded. Finding good ways to support the patient in a way they want to receive support and benefit from it. Gaining more knowledge about diabetes specific to their situation.

Main goal is to ensure that partners get closer to each other, both feeling not excluded. This way it is aimed that support will be given in an optimal way. This support is needed to improve the effectiveness of the self-care management.

## Design vision

In order to design the tool, a design vision is created. The tool will be designed with taking the partner in mind. When the partner has a tool to support the patient, the patient will indirectly benefit from it. So the main target group for the tool will be the partner.

Designing a tool that guides the process of finding a way for the partner to come closer to the patient by understanding what the patient feels and experience as regards diabetes. This will help the partner to create empathy and improve the way support is given. This improved support in daily life is helpful to stimulate the patient in the self-management of diabetes.

The design vision originated from the insight that patients need support from their surroundings, especially their partner. The partner is a very important person in the life of the patient to provide support. It is envisioned that in the beginning of a relationship the partner has more difficulties how to support the patient than later in a relationship. Currently there are no tools targeting the partner. Therefore the design vision is created stating that a tool will be designed for partners.

From the conducted studies in the discover phase, it is found that the critical node relates to the partner feeling excluded, because he/she does not know exactly what diabetes does to the patient and how he/she can relate to that. This feeling of being excluded can lead to overconcerned behavior or frustration, not leading to good support.

The tool will help to guide the process in which the partner gets closer to the partner, by understanding what diabetes exactly does to the patient and how the partner can support in this. Diabetes should be seen as a shared problem in which both the partner and patient can support each other.  It is envisioned that patients will be motivated to take better care of their self-management by getting support from their partner.

## List of requirements

The list of requirements is based on the discover phase and the design direction. In the discover phase the design implications are listed including which requirements are eveolved from there.

## Requirements

Knowledge

1. The design should help educate the user (partner or patient) to increase knowledge and gain insights about diabetes.
2. The design should be patient centered, in which the information is adjusted to the specific needs and wishes of the user and the user can adjust the design to personal preferences, so the conent is tailored to their own situation.
3. The information provided by the design should be up to date.
4. The design should stimulated patients and partners to share information with each other.

Support

5. The design should provide practical guidelines on how to support the patient with diabetes.
6. The design should provide suggestions for ongoing support for a long period of time, because diabetes is a disease that develops over time and new measures should be taken.
7. Should provide support in moments of change.

Empathy

8. The design should be able to explain emotions and feelings to improve empathy. Emotions are relatable to people without diabetes, only numbers not.

Context

9. The design should be used in the home-environment (not in a hospital setting), because self-management is mainly done outside the hospital. This does not mean that it is only used in home, but that it can also be used outside during travelling, at friends, at a café etc.
10. The design should support patients and its partners in the beginning of their relationship (1-5 years)
11. The design should be use by people with diabetes type 1and its partners between 18-30 years old.

## Wishes

1. The design should be as simple as possible, not overwhelming the user
2. The design should have included a playing element
3. The tool should not like a medical device. People with diabetes are confronted with their disease 24/7 and have medical equipment with them all the time. This tool should be focused on having a good conversation about their life, needs and wants etc.
4. The design should direct to both people in the relationship
5. The design should support shared illness appraisal
6. The design should be integrated as much as possible in the tasks the patient is already doing, so it would not take extra time or effort.
7. The design should make it possible to tailor content according to a patient's own wishes and situation.
8. The design should include experiences from others, to share experiences but also to identify with others and learn from them.
9. The design should stimulate providing feedback
10. The design should make the person with diabetes feel supported.
11. The design should facilitate communicating about the emotional side of diabetes.
12. The design should enable patients to contact or share information with others to their own preferences and frequency.

# 2.2 IDEATION

This section describes the idea generation for solutions for the problem statement.

Idea generation
To come up with ideas in this define phase, brain writing and brain drawing techniques were used including "How to-questions" (Delft Design guide). The outcomes from the interviews and literature study were used as input to generate ideas. They were stated as design implications in the previous chapters.

The ideation phase started by generating 5 how-to questions. Those questions are based on the needs of the partner.

- How to share and gather information (in a personal way)?

It is important for the partner to gain information about diabetes in order to get the basics of what is going on and to understand the symptoms. Not only information about diabetes should be shared and gathered, also information about the person itself, and its feelings and emotions. Providing information in a personal will probably lead to more interest and more willingness to gather it.

- How to motivate people to gather information and knowledge and what are the benefits?

It is important that the partner is motivated to be involved in the disease of the patient. This is the first aspect of providing support.

- How to create empathy?

How to create empathy is added as a How to question, because it is stated by several participants of this study that people without diabetes, also the partner, does not know what diabetes actually does to a patient. It is very difficult to explain to people who never experienced this. It would be valuable if more empathy can be created, to get the partner more involved.

- How to make needs and expectations negotiable?

Since partners can feel excluded, because they cannot feel hoe the patient is feeling, it is important to communicate about feelings, but also about what to expect from each other. This way the partner knows what the patients wants to get in terms of support.

- How to learn from others?

Since partners mainly get the information through the patient, because the partner is in close contact with the partner, it is important that partners learn from this. Also because information in booklets and internet is not targeted to the personal situation. Another finding finding indicates that patients value information and experiences from peers, because this information is practical and reliable. Another finding, that is related to this question is that partners have to provide feedback on how the patient is behaving, because sometimes the patient does not know this by themselves. How to provide this feedback should be learned. Learning from others is an essential part in this project. Communication is important, as well as being transparent, discussing several options and collaborating together.

In figure 13 ideas can be found as well as in appendix 5.

During the idea generation for finding suitable solutions, it became clear that aspects of different ideas could be combined into one concept.

Figure 13: Idea generation sketches

## Morphological chart

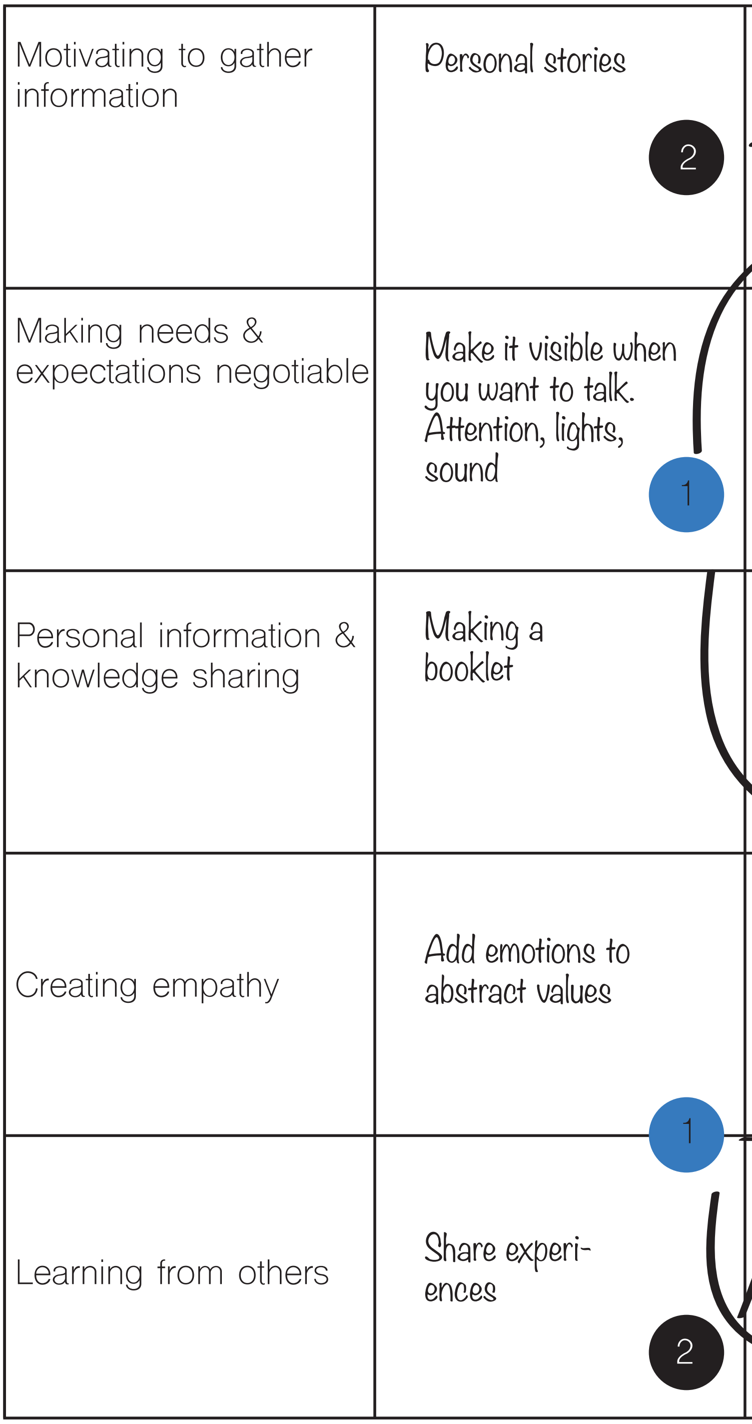
A morphological chart (figure 14) was created with promising ideas generated during brain writing and drawing, to select ideas that fit together (Roozenburg & Eekels, 1998). It was decided to create two different concept directions, with several aspects from the morphological chart.

The functions that the tool should fulfill are:

- **Motivating to gather information** (partners should be motivated to gather information about the patient and its diabetes to support them).
- **Making needs and expectations negotiable** (it is important for the partner that needs and expectations are expresses, so the partner knows how to act).
- **Personal information and knowledge sharing** (it is important for the partner that personal information is shared, not only general information about diabetes. Personal knowledge sharing will lead to feeling more closely related).
- **Creating empathy** (Empathy is needed to understand what is going on, and to feel what the other person experiences. This is now lacking, and the partner can therefore feel excluded and the partner not feeling supported).
- **Learning from others** (partners learn from each other, but also from other people in the same situation. Learning is essential in the process of developing).

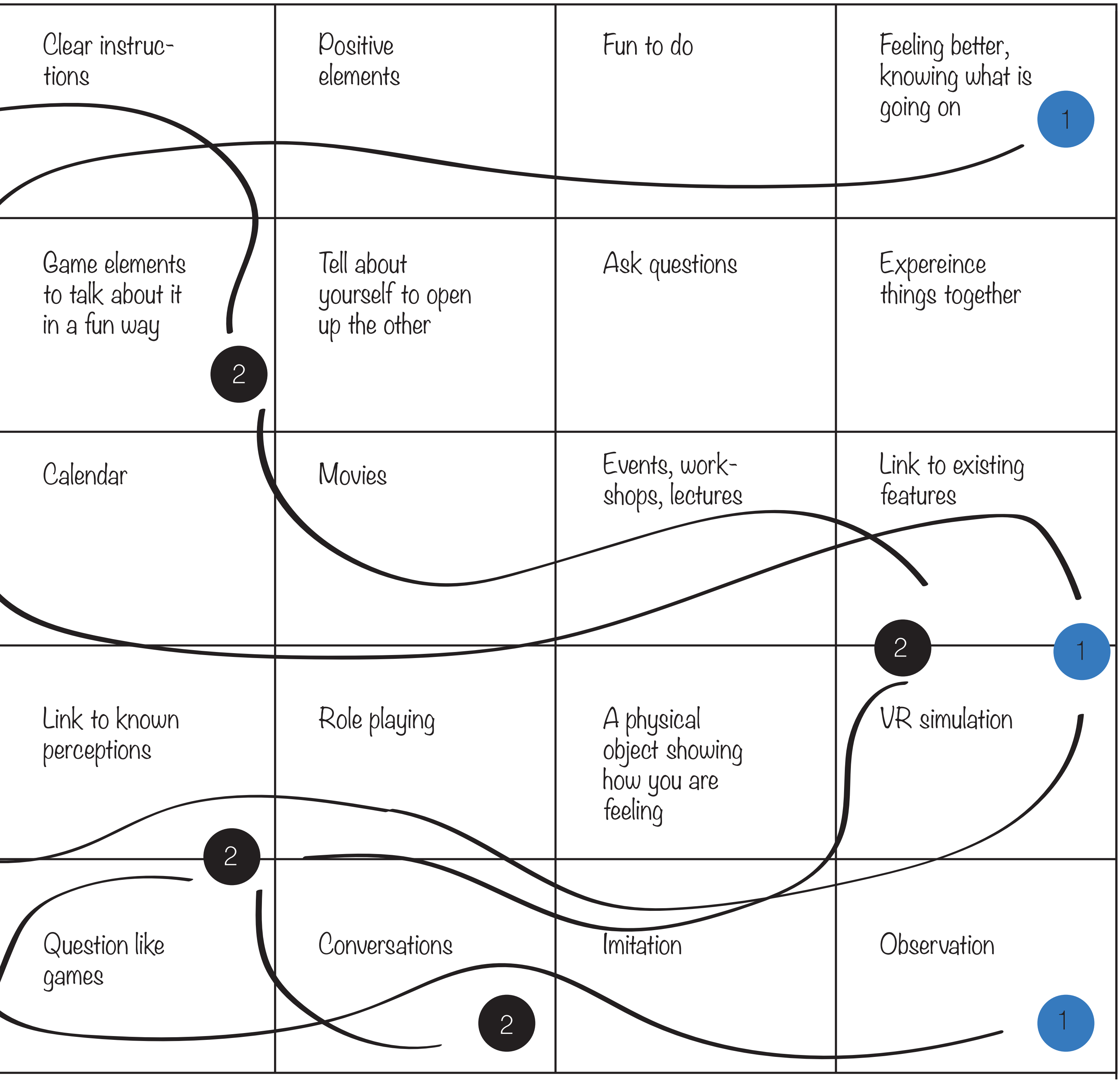
The concept directions are combining: Knowing what is going on, make it visible when to talk about needs and expectations, link to existing features that partners and patients already use to make information and knowledge sharing easier, add emotions to abstract values to create empathy, use observation to learn from others. This concept direction 1 is developed, visualized and explained in the next section.

The other concept is combining the aspects of personal stories to motivate people to gather information, to use game elements to make difficult topics negotiable, link to features that people already using to share and gain information, so there is not hurdle that needs to be overtaken, this is also linked to creating empathy by linking emotions and feelings to perceptions that others will recognize, to learn from others will be achieved by sharing experiences and conversations. This concept direction 2 is developed, visualized and explained in the next section.



| | |
|---|---|
| Motivating to gather information | Personal stories<br>2 |
| Making needs & expectations negotiable | Make it visible when you want to talk. Attention, lights, sound<br>1 |
| Personal information & knowledge sharing | Making a booklet |
| Creating empathy | Add emotions to abstract values<br>1 |
| Learning from others | Share experiences<br>2 |

Figure 14: Morphological chart



| | | | |
|---|---|---|---|
| Clear instructions | Positive elements | Fun to do | Feeling better, knowing what is going on |
| Game elements to talk about it in a fun way | Tell about yourself to open up the other | Ask questions | Expereince things together |
| Calendar | Movies | Events, workshops, lectures | Link to existing features |
| Link to known perceptions | Role playing | A physical object showing how you are feeling | VR simulation |
| Question like games | Conversations | Imitation | Observation |

# 2.3 CONCEPT DIRECTIONS

## Concept direction 1: Enrich data with feelings and emotions

The first concept direction is the application in which data is enriched with feelings and emotions. Diabetes patients gather a lot of data from his/herself, such as blood glucose level, intake of carbohydrates, amount of insulin, hba1c values. This concept direction is adding emotional value to these data.

Key features of the concept are:

- Link emotions to values
- Visualizing of emotions
- Share emotions with partner
- Get insight in your own emotions
- Link emotions to influencing factors
- Create moments of reflection

What
This concept direction will be an application in which data that is already gathered and saved by the patient can be enriched with emotions and feelings of the patient.

How?
Patients are able to choose an emotion while collecting data. This can be done manually and the emotion will be linked to the data. If it is not going well, or someone wants to discuss what is going on, a warning will be activiated, such as a light on the table, a bracelet, or a notification on the phone.

Why?
The principle behind the concept direction is to gain insights in the patients emotions and feelings during the day. This can create more empathy and understanding for the partner. Nowadays it is for the partner difficult to interpret the data from the patient's diabetes devices, since it only provides a number and a graph. It is envisioned that adding emotions give more value and information to the data that is already out there. Since diabetes is a very personal condition, it is not possible to say: within the range of 4.0mmol/L -8.0mmol/L the patient feels good, although this could be concluded based on the data and the generic information gathered. This concept will help the partner to create empathy, understand the feelings linked to diabetes influences. For the patient itself it might also be valuable, since insight in emotions can be gathered and are related to diabetes influences pattern can be recognized and actions can be taken upon them.

Relation to critical needs
Adding an emotion to the values, provides an insight in the numbers in a way a person without diabetes, i.e. a partner, can understand what it means. Emotions are more relatable than numbers and graphs. This way the partner can feel more connected to the patient and can adjust the behavior on it.

For the patient it is an easy way to explain how they feel, by connecting emotions to values. It is a very personal solution. It might be possible that a relation between diabetes influences, such as a high blood glucose levels, and an emotion can be found.

A visualization of the concept is shown in figure 15.

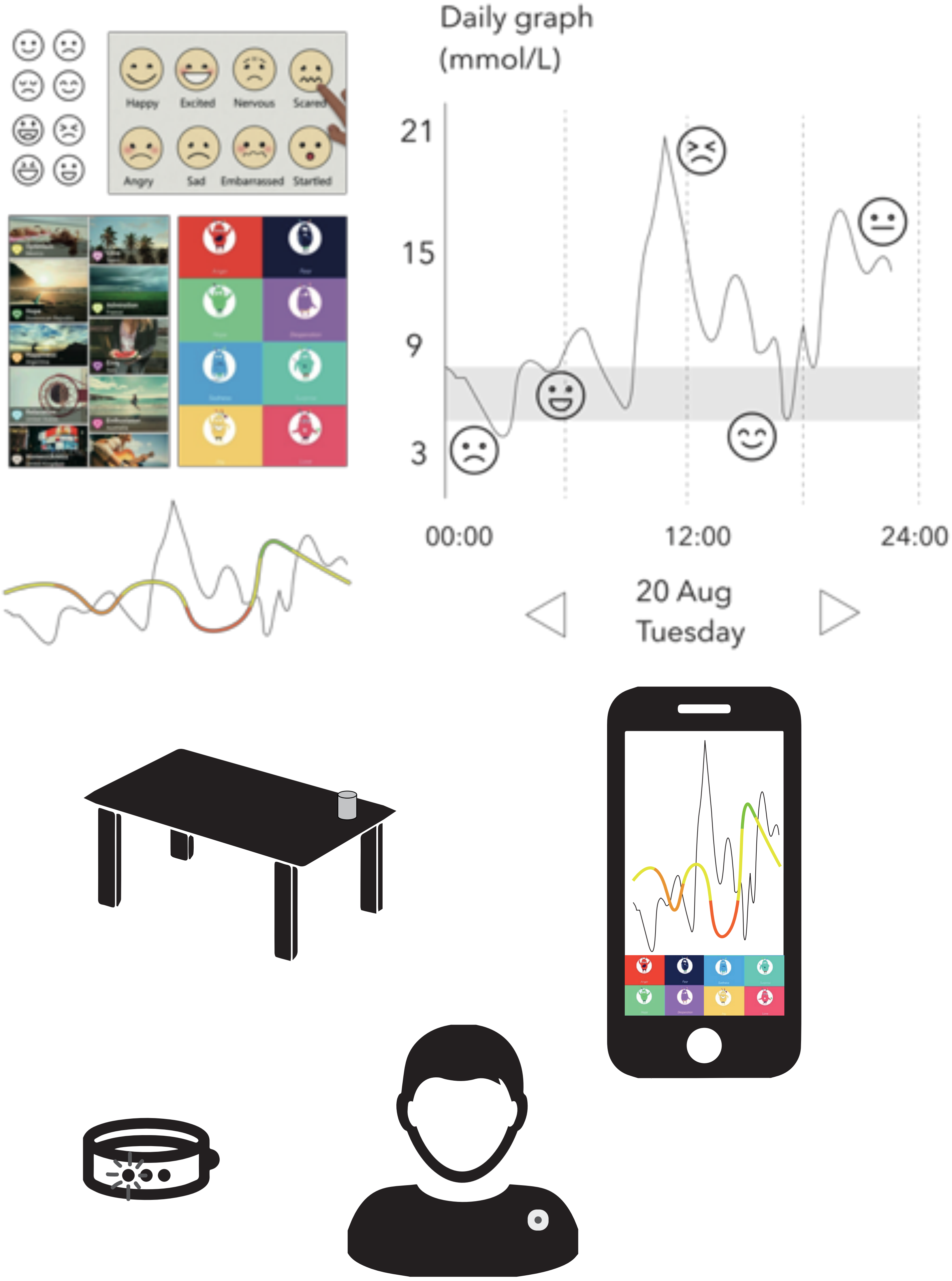


Figure 15: Visualization of Concept direction 1: Enrichment of data with emotions and feelings

## Concept direction 2: D1Alemma (dilemma’s and cases)

The second concept direction is a tool in which dilemmas and cases are used to learn more about diabetes and especially learn more about each other’s needs and wants regarding diabetes management. It is a way to start conversations about diabetes.

Key features of the concept are:

- Learn based on scenarios
- Playful activity
- Share experiences
- Use as conversation starter
- Learn about each other’s needs and wants
- Learn what partner already knows
- Learn where there is a discrepancy
- Reflection moment
- Tips in context
- Insights from peers

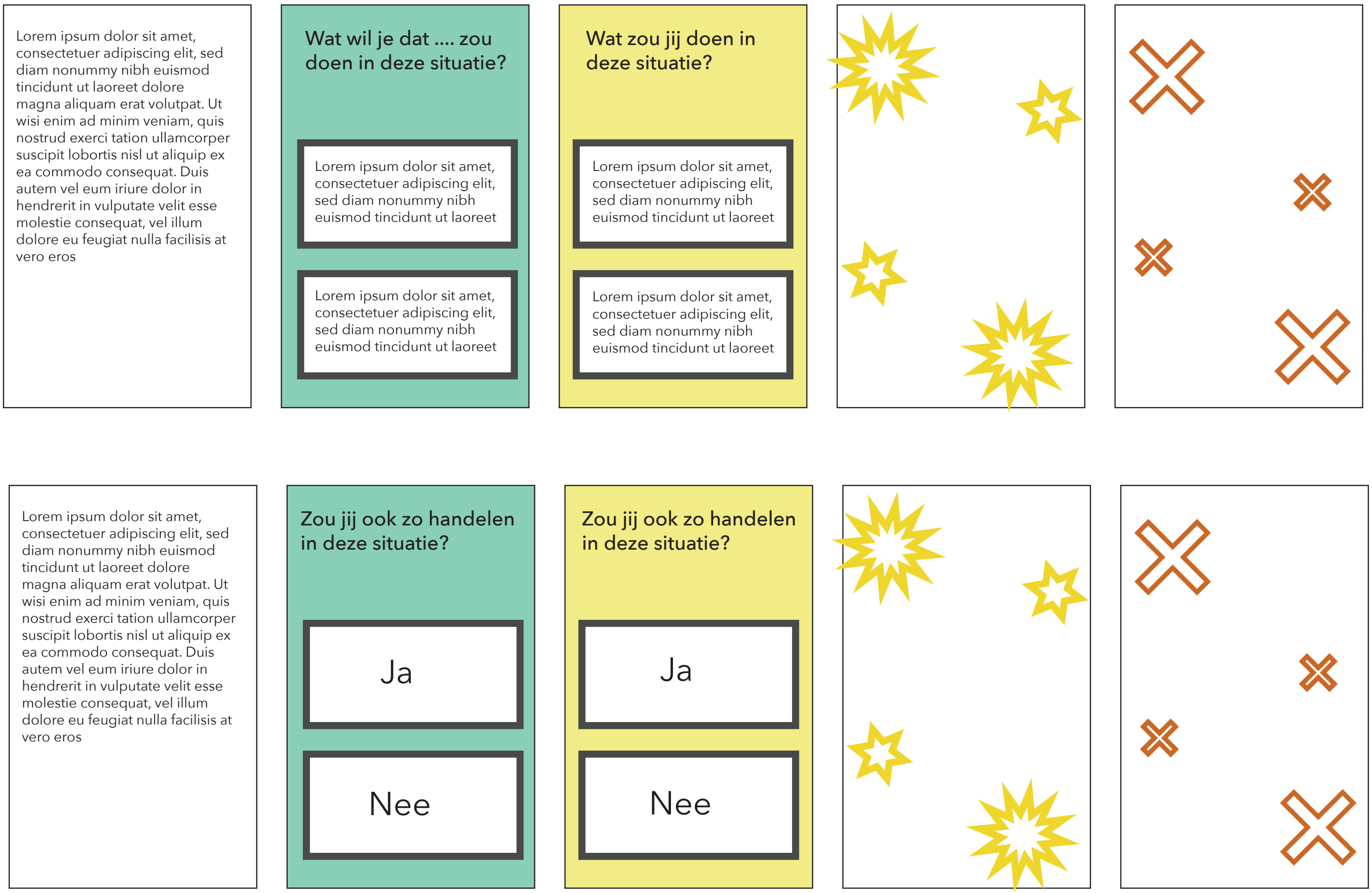
What?
This concept direction is a playful activity in which patients and partners learn about diabetes and about each other’s preferences and needs by answering questions.

How?
Patient and partner will answer questions. Topics to be addresses can vary from; dilemma’s, situation questions, challenges, knowledge questions, need and wants questions. This activity can be played for example using an app or cards. In case of an app two people can play the app in their own time. Questions will be asked and you can play as long as you want. When both patient and partner have answered the question the result will be shown on how each respondent on questions and dilemmas. In case of a card game you need to be together to play.

Why?
The principle behind this concept is to use questions and dilemmas to get to know how one deals in different situations, how one feels about certain topics, and how one expect others to react. It highlights what partner and patients do in certain situations in a relationship. It is then possible to identify if there is agreement or disagreement about certain statements. This can be used as conversation starters. This way the partner and the patient learn about the disease in a playful way. The situations and dilemmas function also as experience sharing for patients. Since the questions are based on situations from experiences of other patients. They learn how other people deal in situations and how they solve problems. They can relate to the feeling that they are not alone. For partners is it also highly educational, they learn not only about diabetes, but also how to act in situations.

Relation to critical needs
This concept direction can be used as a conversation starter about diabetes. Situations which are related to daily life issues are presented. By answering questions how you would act in a situation, preferred behavior and actions become clear. By thinking about situations and later on discuss about these topics, a feeling of being connected can be created. You can connect when and where you want. Answering questions and having conversations about the questions will reveal diabetes specific issues and how this personally relates to the people answering the questions. For the partner more insights can be gathered and clear directions on how to support will become clear.

A visualization of the concept is shown in figure 16.


Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat. Ut wisi enim ad minim veniam, quis nostrud exerci tation ullamcorper suscipit lobortis nisl ut aliquip ex ea commodo consequat. Duis autem vel eum iriure dolor in hendrerit in vulputate velit esse molestie consequat, vel illum dolore eu feugiat nulla facilisis at vero eros

Wat wil je dat .... zou doen in deze situatie?

Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet

Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet

Wat zou jij doen in deze situatie?

Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet

Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet

Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat. Ut wisi enim ad minim veniam, quis nostrud exerci tation ullamcorper suscipit lobortis nisl ut aliquip ex ea commodo consequat. Duis autem vel eum iriure dolor in hendrerit in vulputate velit esse molestie consequat, vel illum dolore eu feugiat nulla facilisis at vero eros

Zou jij ook zo handelen in deze situatie?

Zou jij ook zo handelen in deze situatie?

Figure 16: Visualization of Concept direction 2: DIAlemma

## PHASE 3

# DEVE

# ELOP

## Introduction

This section describes the development of the two concept directions that were generated in the define phase. The main objective of this section is to develop the concepts together with the target group. It aims to gain insights in values and wishes of diabetes type 1 patients and partners. The main goal is to get insights in how they perceive the concepts and how they see them or other diabetes patients using this in the ideal situation.

## Methodology

A co-design sessions with participants are held. This has led to iterations on the concepts. A Harris profile is used to select a concept to further develop the tool.

# 3.1 CO-DESIGN

## Research set up

Co-design sessions were held with eight participants, of which five were patients with diabetes type 1 and three were partners.

During this co-design session the two concept directions on how to involve the partner in the diabetes of the patient were presented. These ideas were developed by the researcher, based on the first 6 interviews of this study. The concepts were general ideas and were described without any details, to leave enough room for own interpretation and let the participants show how they see this idea can be helpful for them and which elements should be in there. After explanation of the concept, the participants received an A3 sheet with the main question: how would this idea function in your ideal situation? Additional questions are listed on the A3 sheet to stimulate creativity and to let the participants think about elements they want to see in a future tool. Sheets differ per concept and also differ for the patient and the partner, since other questions are listed to help the further if they are stuck. After drawing their ideal tool related to the two suggested concepts, a questionnaire is provided. Questions on this questionnaire reveal which idea would suit them best, what they see as valuable, if they would like to use it and if they think other people in a new relation would be helped with these ideas.

## Participants

A total of eight people participated in this study. Five were diabetes type 1 patients and three were partners of a diabetic. People were gathered via diabetes trefpunt of the diabetes vereniging nederland. Selected patients were between 18 and 30 years, diagnosed with diabetes type 1 and living in the Netherlands. Informed consent was given by all participants, before they participated in the research activities (figure 17, 18, 19).

Given the privacy and the location of the participants, the sessions were done in private settings. Since diabetes is also a very personal disease and everyone deals with it its own way, was also a reason to do the interviews in separate sessions. The sessions took place at a location of the participant's preference, either at their home, at a public place in their hometown or at the Delft University of Technology. In case the partner of the diabetic was willing to join, he/she was involved as well. The sessions took about 45min-1hour and were recorded.

## Analysis of the results

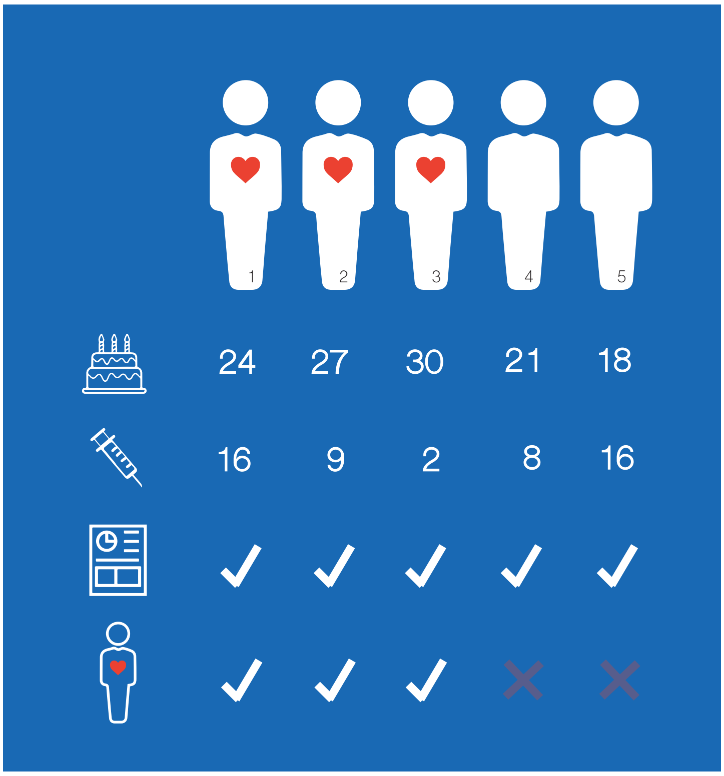
The development process of the concepts mainly consisted of sketching and writing. The complete sketches and writings made for the concepts are documented figure 20 and in appendix 6.
The spoken ideas and suggestions of the participants are recorded and transcribed verbatim. These results are summarized and listed per category.

## Research tools

Explanation of two ideas, visualized with simple figures
Assignment sheet A3 x 2 for person with diabetes
Assignment sheet A3 x 2 for partner
Questionnaire about the suggested ideas
Pens and pencils

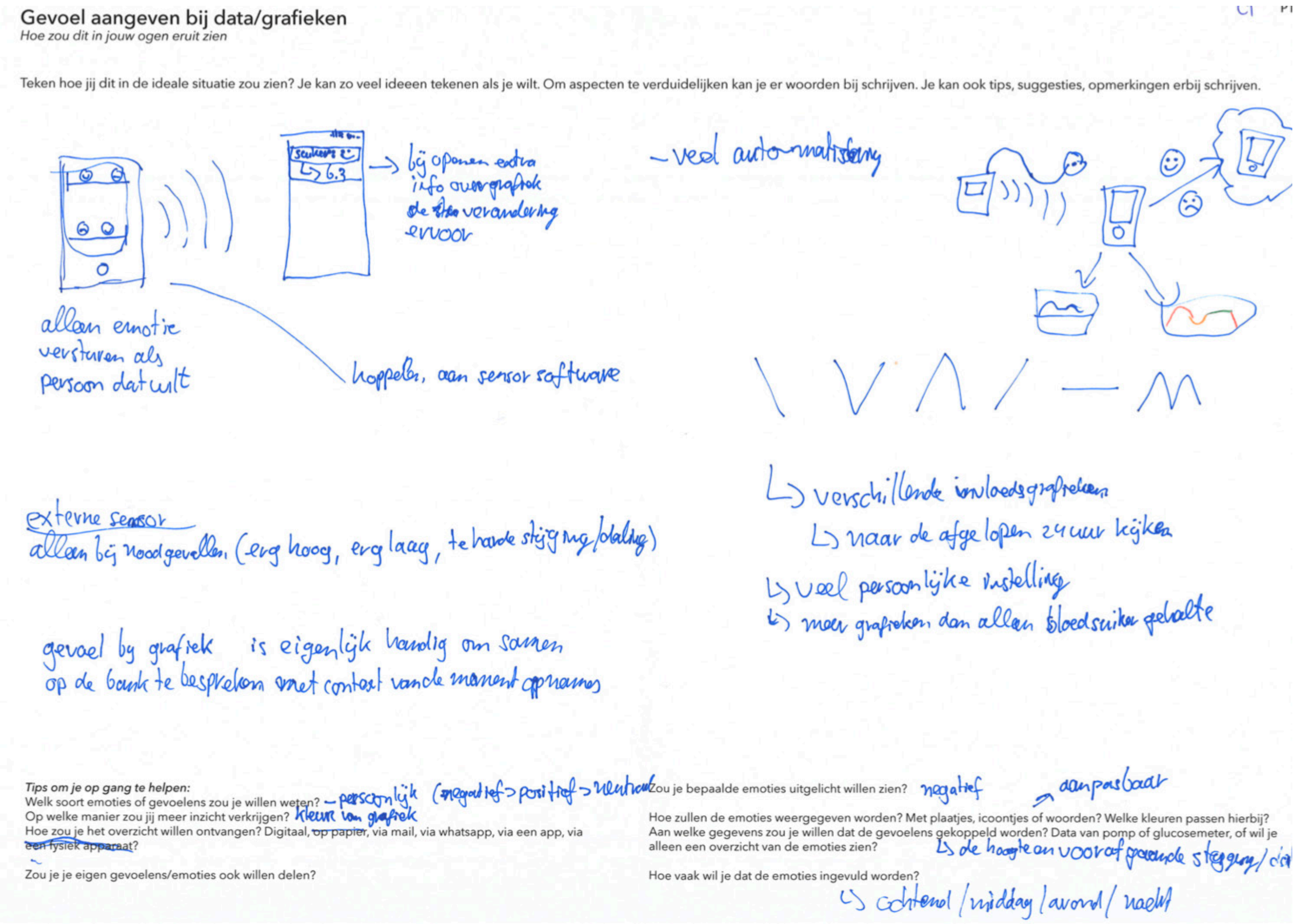
Figure 17: People participating in the co-design sessions.

Figure 18: Overview of residences of participants in this study.



|  | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
|  | ♥ | ♥ | ♥ |  |  |
|  | 24 | 27 | 30 | 21 | 18 |
|  | 16 | 9 | 2 | 8 | 16 |
|  | ✓ | ✓ | ✓ | ✓ | ✓ |
|  | ✓ | ✓ | ✓ | ✗ | ✗ |

**Figure 19: Overview of participants in this study.** First row indicated participant number, heart means that the participant is in a relationship. Second row indicates the age of the participant. Third row indicates the age on which the participant was diagnosed with diabetes type 1. Fourth row indicates if the participant participated in the co-design session.The last row indicated if the partner of the participant participated in the research.



## Gevoel aangeven bij data/grafieken

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

→ bij openen extra info over grafiek de [illegible] verandering ervoor

– veel automatisering

allen emotie versturen als persoon dat wilt

koppelen, aan sensor software

↳ verschillende invloedsgrafieken
↳ naar de afgelopen 24 uur kijken
↳ veel persoonlijke instelling
↳ meer grafieken dan allen bloedsuiker gehalte

externe sensor
allen bij noodgevallen (erg hoog, erg laag, te harde stijging/daling)

gevoel bij grafiek is eigenlijk handig om samen op de bank te bespreken met context van de moment opnames

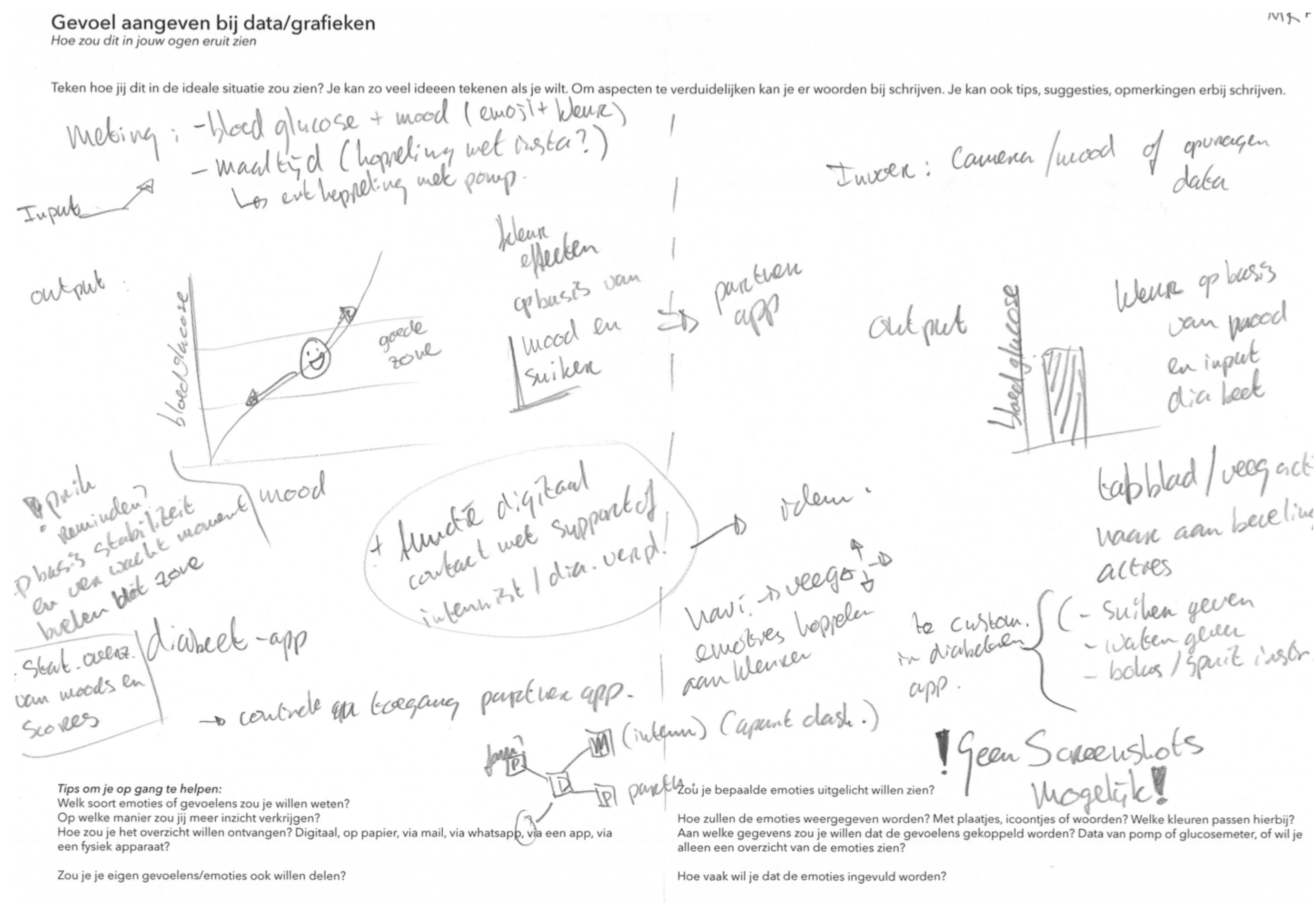
*Tips om je op gang te helpen:*
Welk soort emoties of gevoelens zou je willen weten? – persoonlijk (negatief > positief > neutraal
Op welke manier zou jij meer inzicht verkrijgen? kleur van grafiek
Hoe zou je het overzicht willen ontvangen? Digitaal, ~~op papier~~, via mail, via whatsapp, via een app, via ~~een fysiek apparaat~~?

Zou je je eigen gevoelens/emoties ook willen delen?

Zou je bepaalde emoties uitgelicht willen zien? negatief ↗ aanpasbaar

Hoe zullen de emoties weergegeven worden? Met plaatjes, icoontjes of woorden? Welke kleuren passen hierbij?
Aan welke gegevens zou je willen dat de gevoelens gekoppeld worden? Data van pomp of glucosemeter, of wil je alleen een overzicht van de emoties zien?
↳ de hoogte en voorafgaande stijging/da

Hoe vaak wil je dat de emoties ingevuld worden?
↳ ochtend / middag / avond / nacht



## Gevoel aangeven bij data/grafieken

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

Meting: - bloed glucose + mood (emoji + kleur)
- maaltijd (koppeling met insta?)
↳ evt koppeling met pomp.

Input

output:

kleur effecten op basis van mood en suiker

⇒ partner app

• punt
• reminder?
op basis stabiliteit en een vast moment buiten de zone

stat. overz. van moods en scores

diabeet-app

→ controle en toegang partner app.

+ functie digitaal contact met support of internist / dia. verp!

→ [illegible]:

navi. → veeg
emoties koppelen aan kleuren

(intern) (apart dash.)

partn.

Invoer: Camera / mood of opvragen data

output

kleur op basis van mood en input diabeet

tabblad / veeg acti
naar aanbeveling acties

te custom. in diabeten app.

(- suiker geven
- water geven
- bolus / spuit instr.

! Geen Screenshots mogelijk!

*Tips om je op gang te helpen:*
Welk soort emoties of gevoelens zou je willen weten?
Op welke manier zou jij meer inzicht verkrijgen?
Hoe zou je het overzicht willen ontvangen? Digitaal, op papier, via mail, via whatsapp, via een app, via een fysiek apparaat?

Zou je je eigen gevoelens/emoties ook willen delen?

Zou je bepaalde emoties uitgelicht willen zien?

Hoe zullen de emoties weergegeven worden? Met plaatjes, icoontjes of woorden? Welke kleuren passen hierbij?
Aan welke gegevens zou je willen dat de gevoelens gekoppeld worden? Data van pomp of glucosemeter, of wil je alleen een overzicht van de emoties zien?

Hoe vaak wil je dat de emoties ingevuld worden?

Figure 20: Selection of filled sheets by participants of the co-design session.

# Concept direction 1: enrich data with emotions

| | | |
|---|---|---|
| **Category:** | **Valuable aspects/reason for existence** | |
| Codes: | Combination of value with emotion is important | 1, 1b, 5 |
| | Provide insights; for example, in good values do not mean I am feeling good, or the other way around. | 1,1b, 2, 3, 4, 5 |
| | People care too much about values and not about my feelings, so it is important to share them as well | 5 |
| | More involvement and understanding | 1, 4 |
| | Easy to share and clear | 5 |
| | Directly knowing how someone feels and act on it | 3b |
| **Category:** | **How to indicate emotions** | |
| Codes: | Provide only if you feel good or bad | 2,4 |
| | Emoticons/ smileys | 1, 5, 3b |
| | Make the emoticons large | 2 |
| | Colors | 2 |
| | Automatic recognition of emotions | 2b |
| | Option for extra comments to indicate how you feel. | 1, 2b, 4 |
| | Partner should also indicate emotions | 2 |
| | Able to look back at the emotions of the day/week/month | 1 |
| **Category:** | **With who to share what and when** | |
| Codes: | Diabetic has own choice who to share it with | 1b, 1, 2, 2b, 4, 5 |
| | Would share it with my partner | 1, 5 |
| | Link with location, do not share when partner is far away | 2 |
| | An overview of the whole day including the graph to also link it to strong increase or decrease of value | 1, 1b, 3b |
| | Also including date with average levels, to put the values in comparison with other days | 1b |
| | In the beginning of a relationship if it is a real relation | 1, 1b, 3 |
| **Category:** | **Link with software** | |
| Codes: | Link to free style libre up | 1 |
| | Partner app | 2b |
| | App to connect from a distance | 1 |
| | Link to graph of blood glucose level | 5 |
| **Category:** | **Not sharing data** | |
| Codes: | It won't help me, because I am already very open about it. | 2 |
| | I do not want to share data with my partner, I do not want comments, I want to keep emotions for myself. | 3 |
| **Category:** | **Doctors** | |
| Code: | This would also be good to use for doctors. | 1 |

## Input on concept direction 1

This concept was presented first. Patients reacted that they clearly understand the idea behind the concept. They reacted positively to the idea and indicated that this is actually a problem. They say that it is good to link values with an emotion, because values do not say that much. An example: Nowadays, my partner has the freestyle libre up app, when he sees a high or low value, he texts me asking if I am doing okay. Sometimes when a value is good, he says: Oh it is good, but then I have to say; No I am feeling really bad. The other way around is also possible. Another participants stated: It would help to add an emotion, because people ask you about it if they see the values, but they do not take into account your emotions. People react only on values, and that is what I can see as well, it frustrates me. They do not take into account emotions. This idea will lead to more involvement and understanding of how I feel and what diabetes does to me. It is an easy way to share it in a clear way.

Extra suggestions and extra ideas for this concept are summarized.

## How to indicate emotions.

The way to indicate emotions differ between use of colors, use of emoticons/smileys to only indicating if you are doing well or not with pluses and minuses or even automatic recognition of the emotions. A good suggestions was to make this adaptable to the preferences of the user. An option to provide extra comments on your emotion or feelings should be added. This would bring the extra finesse to the concept. Other comments were related to the size of the emoticons, these should be large, so in case you have a hypo you are still able to select the right one. An overview of the emotions over the day/week/month should be visualized as well. This can be used to recognize patterns.

With who to share what and when
Sharing this data with other people is a sensitive topic. What is mentioned by almost all participants is that the patient should have the choice what to share and when to share the data and emotions. If they will share the data and emotions, it would be in the first place the partner.
The partner should then be able to see an overview of the whole day, including average levels of the patient to compare the data with and to recognize patterns. By seeing the whole graph of a day the emotion can be linked to the values, and it might become clear that emotions are linked to a strong increase or decrease of blood glucose values.

The moment when to use this would be in the beginning of a relationship, because then you talk a lot about it and this concept would help to start or keep talking. Especially in the beginning it is important to share feelings, than the partner knows what it is and what to do. Be careful at the beginning of a relation that falling in love has also influence on emotions and feelings.

## Link with software

It should definitely be an app, and preferably kinked to existing software. People with an FSL scan and use the FSL app a lot during the day. Adding an emotion would not be of a hustle for them. The FSL app has already a partner app. However this one is limited, since it only sends a value to the partner after scanning. Adding an emotion would help, as well as sharing the whole graph of the day to inform the patient. One of the participants is already using the partner app of the FSL, so this would be ideal for them. The hurdle of sharing information is already taken.

## Not sharing data

If people do not share data yet, it is more difficult to implement this in their life. They do not want to share their data in general. They do not want comments or they do not want to update their partner every time. Surprisingly, the two participants with diabetes stating that they would not like to share the data, their partners indicated that they prefer this concept.

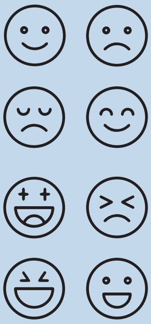
## Doctors

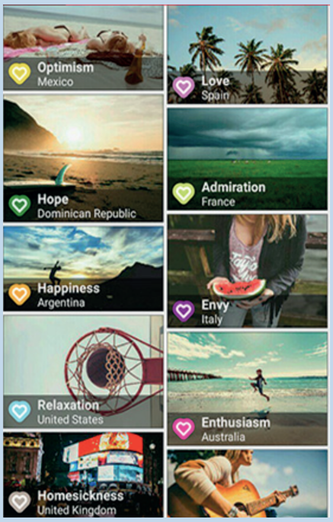
This concept would also be valuable when sharing data with your doctor. Doctors mainly look at values, but they do not look at my feelings or emotions. If average values are good, they are satisfied, even if I am feeling terrible.

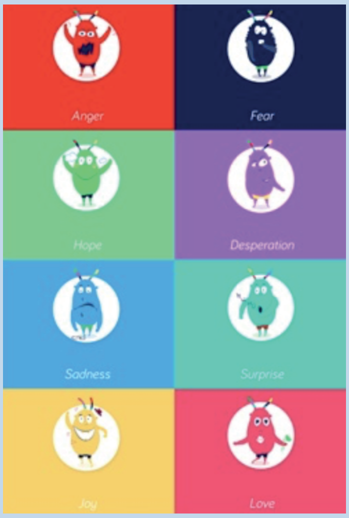
A visualization of the recommendations given is shown in figure 21 and 22.

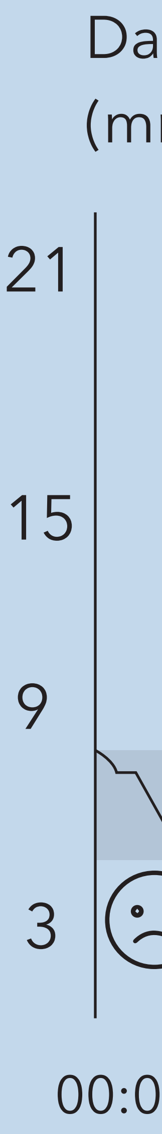
Show the grap

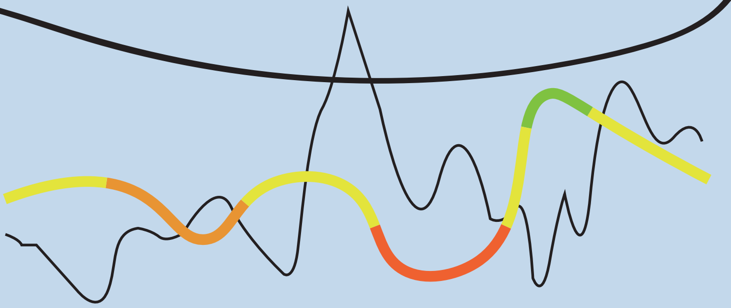
Adjust the visual design to preferences of the user. Make it large.









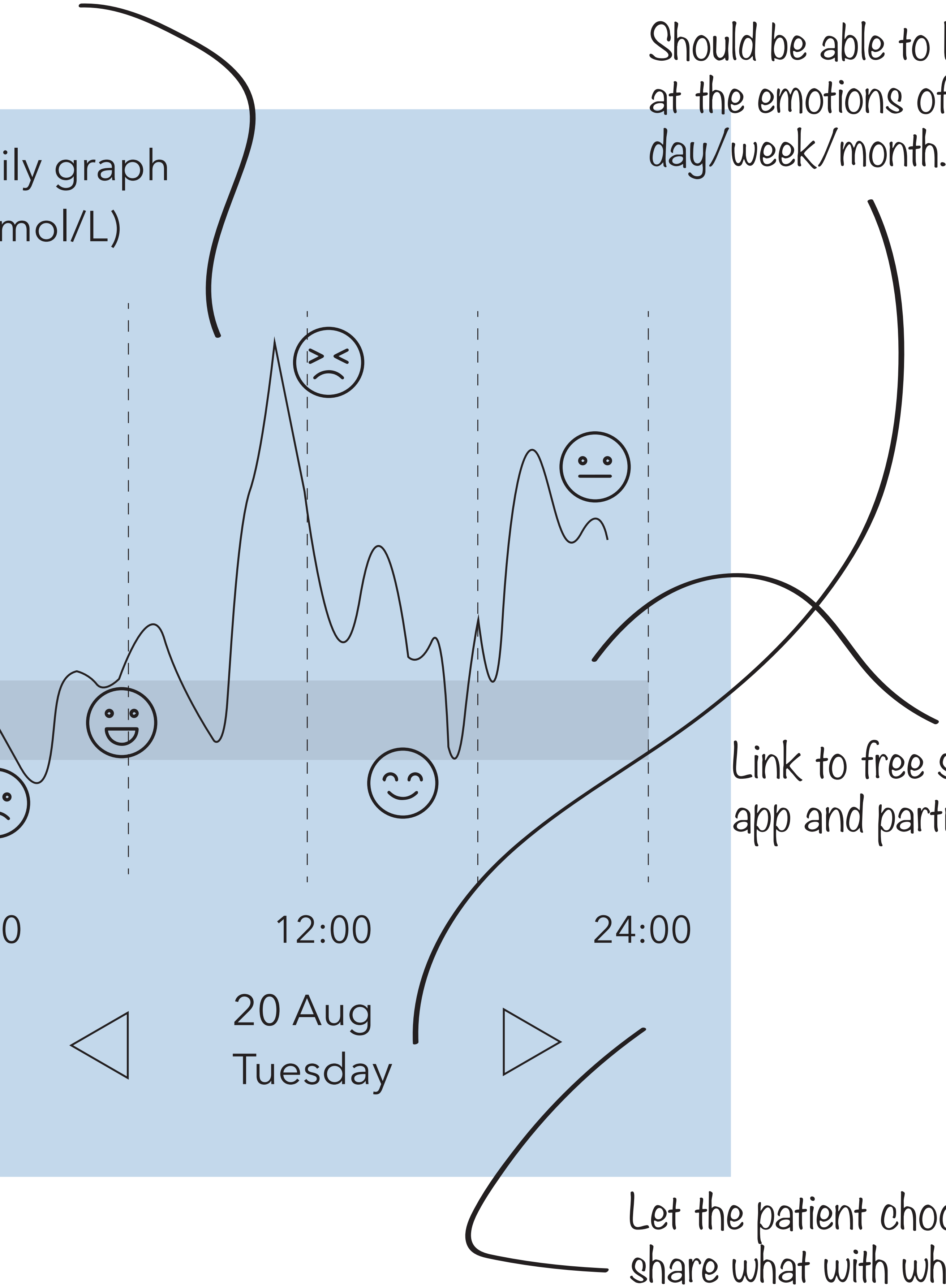


Create a section in which comments can be placed.

Keep it as simple as

ph to the partner.

Should be able to look back at the emotions of the day/week/month.

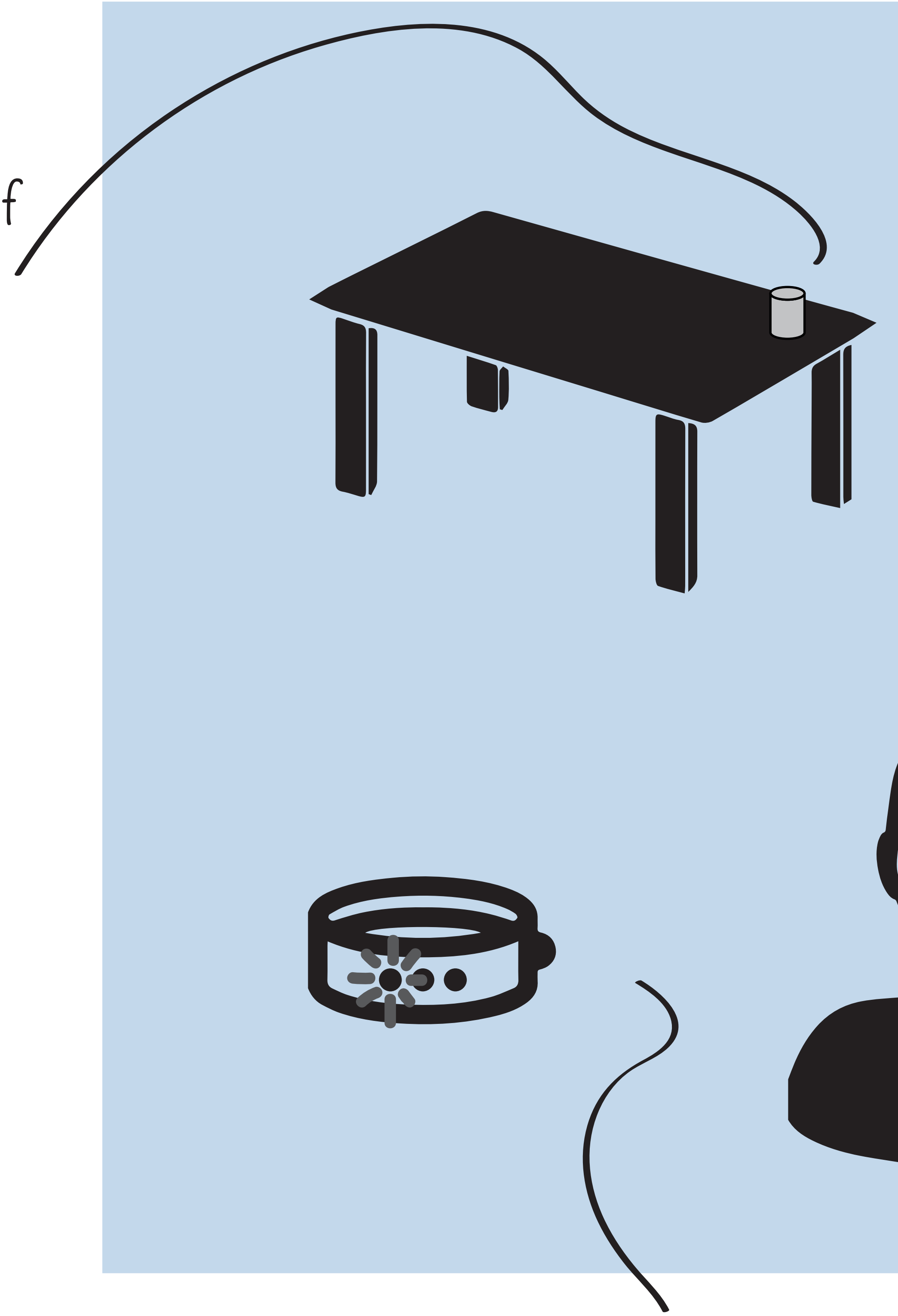


Link to free style libre app and partner app.

Let the patient choose to share what with whom.

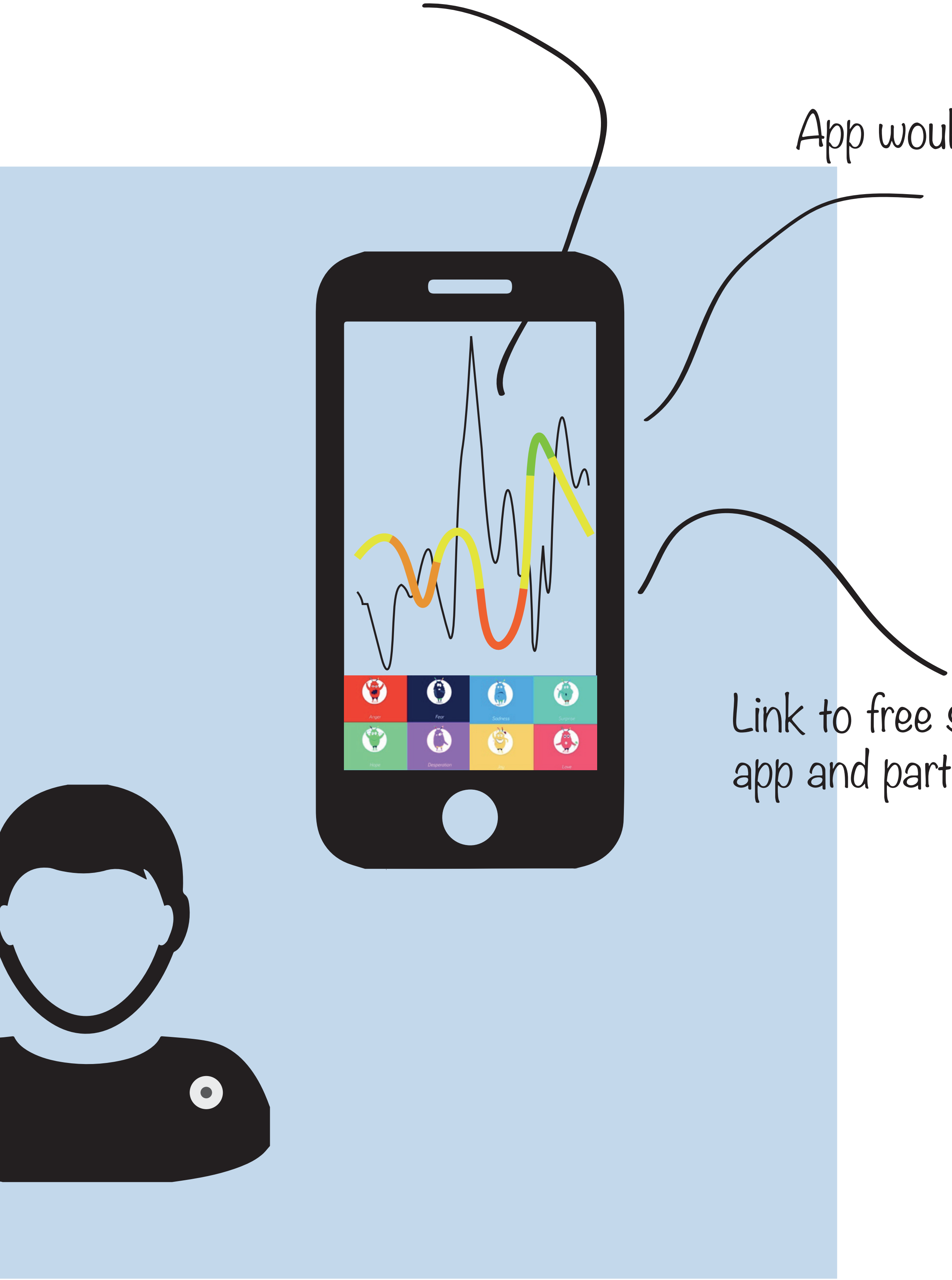
s possible.

Figure 21: Summarized recommendations from participants in the study for concept direction 1



Only in case of emergency

Too flashy



Show the graph to the partner.

App would be ideal

Link to free style libre app and partner app.

Figure 22: Summarized recommendations from participants in the study for concept direction 1

# Concept direction 2: DIAlemma

| Category: | **Valuable aspects/reason for existence** | |
|---|---|---|
| Codes: | Accessible, not intrusive | 4 |
| | Everyone can learn from it, people with and without diabetes | 4 |
| | Educational | 1,1b |
| | Personal | 1 |
| | Makes it easier to talk about diabetes in a specific way as a conversation starter and discussion | 1, 2, 3, 3b, 4 |
| | Challenging | 2 |
| | Playful way to learn and share experiences | 3 |
| | Able to play together or alone | 5 |

| Category: | **Content** | 1b |
|---|---|---|
| Codes: | Definition, knowledge | 1b, 3, 5 |
| | Dilemma's | 1b, 3 |
| | Preferences | 1b, 5 |
| | Own input | 5 |
| | Insights, realistic situations | 1, 4 |
| | Add a chat function for optional chats | |

| Category: | **Other people to play with (except from partner)** | |
|---|---|---|
| Codes: | Friends or at school | 1b, 4, 5 |
| | Friends to go on holiday with | 1, 1b, 3 |
| | Connect with other diabetics to share experiences | 3, 4 |

| Category: | **When to play** | |
|---|---|---|
| Codes: | Beginning of a relationship | 1b |
| | To start a discussion | 1b |
| | Entertainment | 1b, 5 |
| | Together or alone, both possible, but should be connected with each other | 2b, 5 |

| Category: | **Playing elements** | |
|---|---|---|
| Codes: | Create levels for different kinds of questions and different target groups | 1, 2<br>1b, 2b |
| | Keep a score | 1b, 5 |
| | Physical cards also fun | |

| Category: | **Other comments** | |
|---|---|---|
| Codes: | Change lay-out | 2 |
| | Do not connect with blood glucose level device for privacy issues | 2 |

## Input on concept direction 2

This concept direction was received with a lot of enthusiasm. I would definitely play it myself, would be fun (4). Oh that sounds funny, good idea, nice, interactive (1b). Oh funny, that is really cool. I think people would do this easily. I would like it. I would not play a game for 1,5 hours, or something that is too serious from the diabetesfonds, but this seems very easy! (5). This seems cool to do, I think that people will talk more because of this (3). I would try it for fun, it would be nice to do a conversation based on this (2). It is more than just this, it connects, there is a deeper layer. It is like a mirror in which you can look together, without the mirror shining in your eyes. It deepens the relationship (2). The main valuable aspects of this concept mentioned by the participants are that it is accessible, not intrusive, educational, playful and challenging. Everyone can learn from it, people with and without diabetes. It is a good way to start a conversation or a discussion. It makes it easier to talk about diabetes this way.

Additional suggestions, ideas are listed below.

## Content

According to the participants the content should consist of knowledge questions with definitions and dilemmas.  Dilemmas would be good to know preferences, to get insights and to answer questions about realistic situations. Being able to add own input for questions is also mentioned as valuable. Then they can make specific topics negotiable in an easy way. A suggested extra function is the addition of a chat function. So in case you are not together while playing and you want to discuss something directly it is possible to use the chat.

Other people to play with (except from partner)

This idea is not limited to playing it with your partner, participants stated they would also like to play it with friends before going on holiday, or with friends at school, or to play it with other people with diabetes to share experiences.

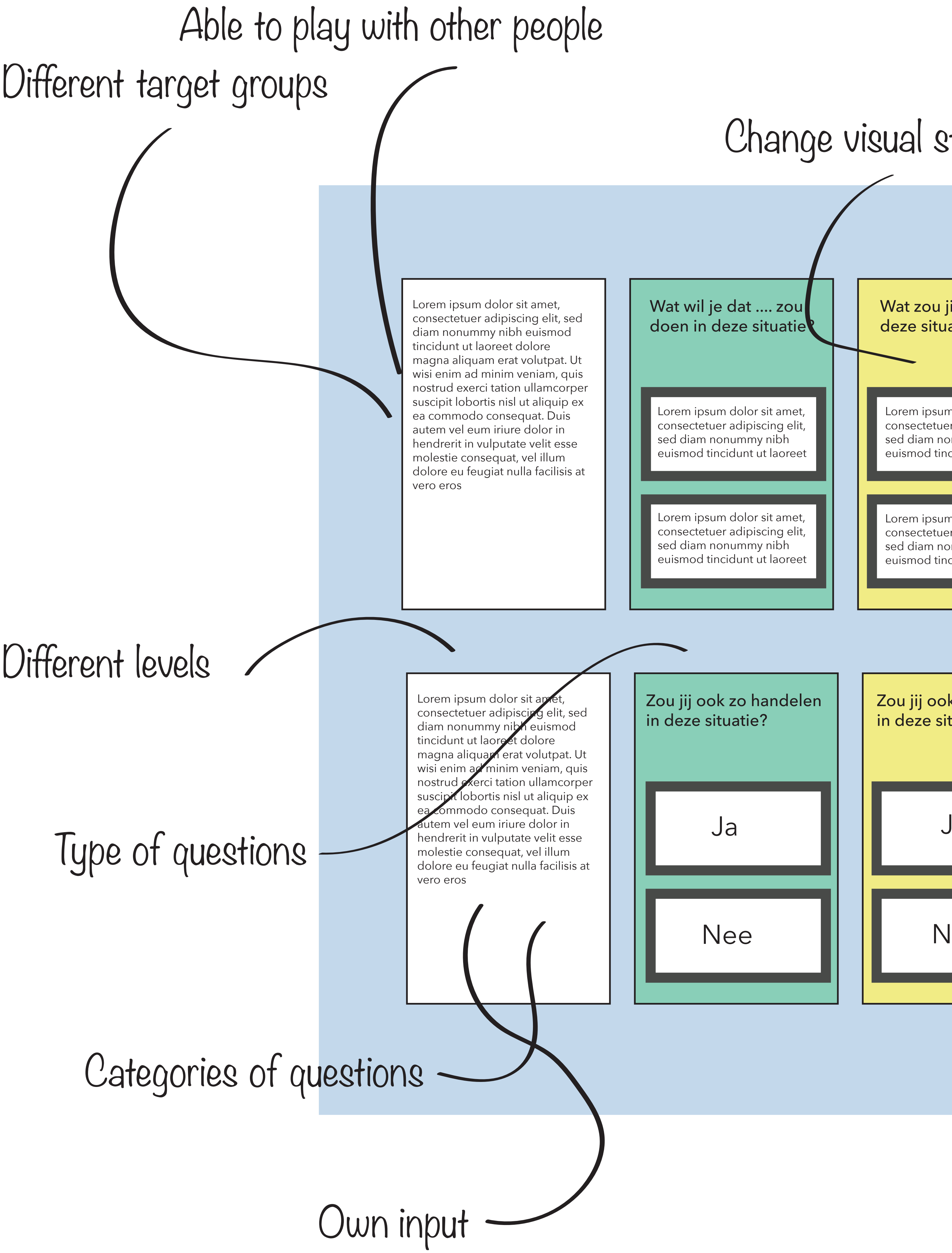
## When to play

When played with a partner, the best moment would be at the beginning of a relationship. It is a good way to start a conversation or discussion about diabetes, also with friends. It is a good for entertainment as well.

## Playing elements

By having different types of questions it would be good to create different levels for the type of questions. Since people would like to play it with partner, or fiends the type of questions would also change, so this should also be adjustable. Some participants indicated that they would also like to keep a score. It could also be played with physical cards, but then you should be together while playing, however it will stimulate a discussion.

A visualization of the recommendations given is shown in figure 23.



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Wat wil je dat .... zou doen in deze situatie?

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Wat zou ji
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Zou jij ook zo handelen in deze situatie?

Ja

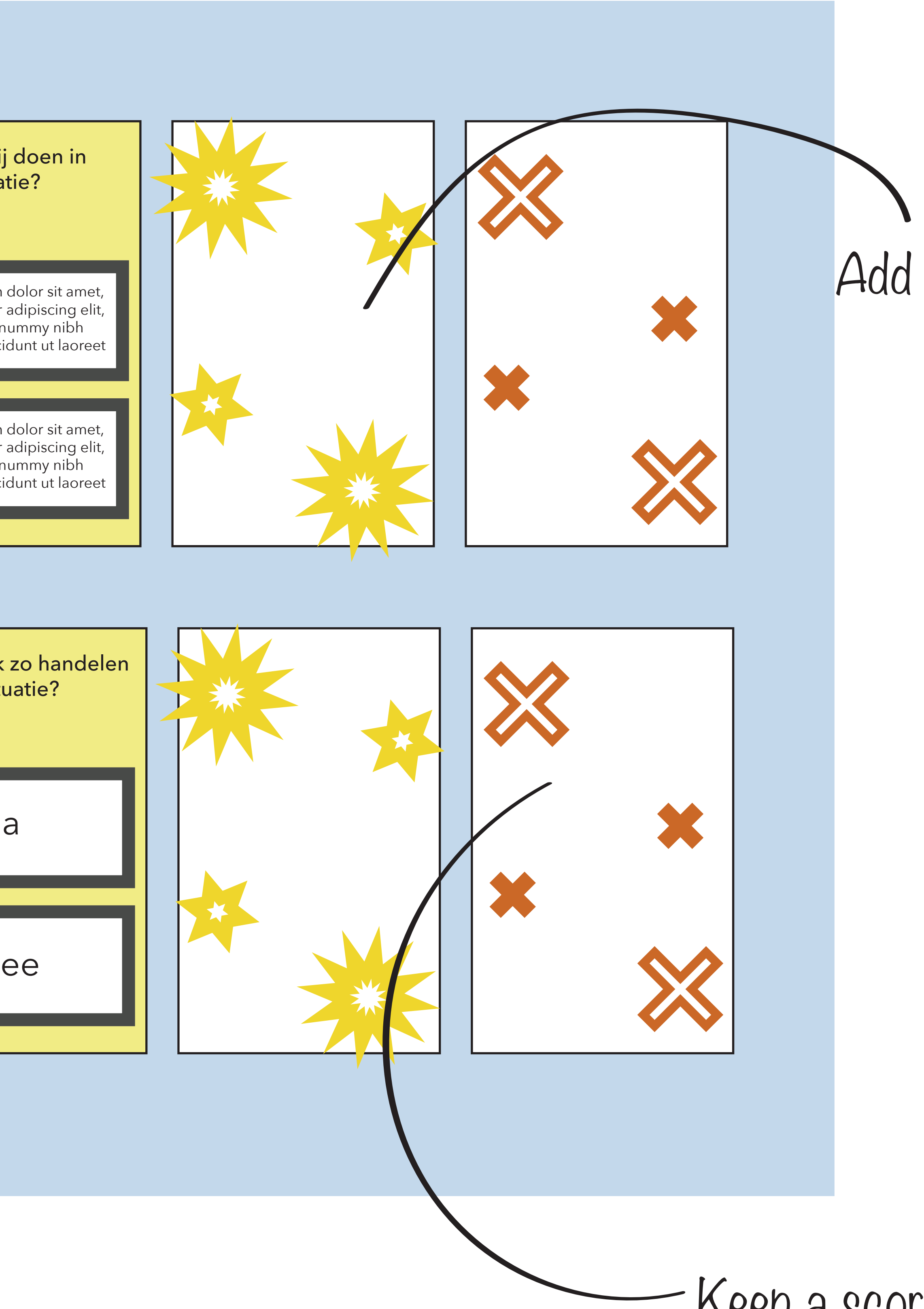
Nee

Zou jij ook
in deze sit

J

N

# tyle



Add a chat function

Keep a score

Figure 23: Summarized recommendations from participants in the study for concept direction 2

# 3.2 CONCEPT CHOICE

This section covers concept choice to select which concept direction will be further developed. The main objective is to determine which of the two concepts is the best solution for the identified problem in the discover phase.

## Selection criteria

In order to select a concept direction, selection criteria were defined. These criteria were based on the wishes from the list of requirements. Next to this selection method, the preference of the participants is taken into account.

## Selection

The concept direction were rated using a Harris profile in which they got a score between 1 and 4 according to the method of cardinal weighted criteria (Roozenburg & Eekels, 1998). In this system the concepts are rated relative to each other. The scheme with the rating is visible in figure 25. The scores of the rating are add up. Concept direction 2 DIAlemma received the best rating.

The patient that participated in the study have indicated that they preferences on a questionnaire. Figure 24 shows the outcomes. They prefer concept direction 2 DIAlemma (4 out of 5). The partners preferred the data enrichment with data (2 out of 3). On the question if the participants need one of these concepts 3 out of 5 indicated yes, 1 maybe and 1 no. Main reason for answering yes was that it makes it easier to talk about diabetes. “I think it is important to make diabetes more negotiable and that it should be easier to obtain knowledge about it.” “Good reason to talk about it with others.” “It makes it easier to talk about diabetes and it will probably also let you think about how you feel at different blood glucose levels.”

The person who answered maybe indicated that she did not need it, but would like to use it. The person answering no indicated that things are going fine now.

2 out of 3 partners indicated that they would need one of the concepts. They stated that it is nice and handy and that they like to play games. The person who does not need it, says that she would be too involved otherwise.

On the question if such a concept direction would be useful for patients in a relationship with someone who have insufficient knowledge about diabetes, the participants respondent 7 times with yes and once with maybe. On the question which concept direction would be most valuable and useful, participants choose DIAlemma 6 times and enrichment of data with emotions also 6 times (people were allowed to choose both options). (Appendix 7 for filled questionnaires)

From the Harris profile method rating (figure 25), the DIAlemma concept was rated higher, however the difference between the enrichment of values with emotions was not that big. They scored different on several aspects, such as the design should be integrated in the tasks the patient is already doing. The preference of diabetes patients is clear, they prefer DIAlemma.

To continue it is chosen to further develop DIAlemma for this project, since it fits mostly with the problem definition and design vision. It is the best solution for the problem and has more content to inform and educate the target group. This way partners will have more options to get more insights in living with diabetes, felling less excluded and being able to better support the patient.  Reactions during the co-design session were all very positive.

The main reason why the first concept is not chosen, is because the patients do not want to share their data with their partner every time. They do not want them to see those values, because they do not want the partner to comment on it, or do not want the partner to ask questions about it. If patients do not want to share the data, the partner will not benefit from it.. It would only be beneficial for patients who already shared their values with their partner, which is a limited group. For this group adding emotions is a useful addition to what they use now. The libre link up application, which is an app for relatives, linked to the sensor of the patient is already able to send values of the sensor directly to the partner. This is an ideal starting point for the first concept direction. The free style libre link application and the free style libre link up (partner version) can be further developed with adding concept direction 1. A version of this can be found in appendix 8. However in this project we will continue further developing concept direction 2 DIAlemma.

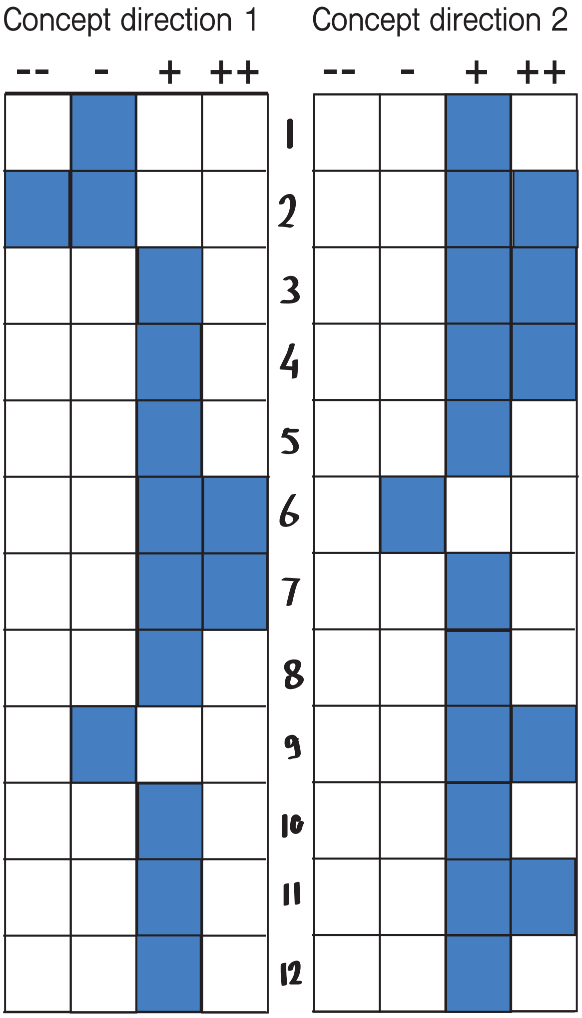
| | Patients | Partners |
|---|---|---|
| *Preference of one of the concepts* | | |
| Concept direction 1: | 4 | 1 |
| Concept direction 2: | 1 | 2 |
| | | |
| *Need of interventions* | | |
| Yes | 3 | 2 |
| Maybe | 1 | |
| No | 1 | 1 |

*Would patients in a relationship with someone who does not know something about diabetes benefit from these concepts?*
Yes: 7
Maybe: 1

*Which idea would be best for people with diabetes in a relationship with someone who does not know something about diabetes*
Concept direction 1: 6
Concept direction 2: 6

Figure 24: Preferences and needs of participants

1. The design should be as simple as possible, not overwhelming the user
2. The design should have included a playing element
3. The tool should not like a medical device.
4. The design should direct to both people in the relationship
5. The design should support shared illness appraisal
6. The design should be integrated as much as possible in the tasks the patient is already doing.
7. The design should make it possible to tailor content according to a patient's own wishes and situation.
8. The design should include experiences from others, to share experiences but also to identify with others and learn from them.
9. The design should stimulate providing feedback
10. The design should make the person with diabetes feel supported.
11. The design should facilitate communicating about the emotional side of diabetes.
12. The design should enable patients to contact or share information with others to their own preferences and frequency



| | Concept direction 1 | | | | Concept direction 2 | | | |
|---|---|---|---|---|---|---|---|---|
| | -- | - | + | ++ | -- | - | + | ++ |
| 1 | | ■ | | | | | ■ | |
| 2 | ■ | ■ | | | | | ■ | ■ |
| 3 | | | ■ | | | | ■ | ■ |
| 4 | | | ■ | | | | ■ | ■ |
| 5 | | | ■ | | | | ■ | |
| 6 | | | ■ | ■ | | ■ | | |
| 7 | | | ■ | ■ | | | ■ | |
| 8 | | | ■ | | | | ■ | |
| 9 | | ■ | | | | | ■ | ■ |
| 10 | | | ■ | | | | ■ | |
| 11 | | | ■ | | | | ■ | ■ |
| 12 | | | ■ | | | | ■ | |

Figure 25: Harris profile

# 3.3 ITERATION ON DIALEMMA TOOL

In this phase iterations on the concept directions are done based on the recommendations from the participants in the co-design session. A clear description of the tool is given, including its key features, context of use and user scenario.

### Key features of the concept are:

- Use as conversation starter
- Playful activity
- Learn based on scenarios
- Share experiences
- Tips in context
- Learn about each other's needs and wants
- Learn what partner already knows
- Learn where there is a discrepancy
- Reflection moment
- Insights from peers

### What?

DIAlemma is a tool in which dilemmas and cases about situations are used to learn more about diabetes and especially learn more about each other's needs and wants regarding diabetes management. This is done using a playful application on a phone. The activity should be played together with the patient and the partner (or another relative).

An added feature of the app are knowledge questions. These are targeted to the partners to increase their knowledge about diabetes. This can be done individually.

### How?

Both the partner and the patient have to install the application on their phone. There is a version for the patient (DIAlemma) and a version for the partner (DIAlemma link). For the situation questions the patient and relative are linked. A situation is described and questions of how you will react in the situation, or how you want others to react in the situation are asked. The other person answers the same questions. This can be done at different times, so you do not have to be together or play at the same time. Answering the questions can learn what to expect from each other and what others desires. After playing an overiew is created which shows on which aspects both players agree with each other and on which aspects there is no agreement. It is envisioned that answering questions will start a conversation, either via a chat or face-to-face.

### Why and relation to needs

The principle behind this concept is to use questions and dilemmas to identify what the patients wants the partner to do in certain situations and what a partner will do in a situation. It is then possible to identify if there is agreement or disagreement about certain statements. This will be done in a playful way, because the study of Van Vleet et al. (2019) has indicated that doing play activities with the partner can stimulate more open communication about related issues they deal with. The outcomes of the game can be used as conversation starters.

This is needed since partners can feel excluded from their partner regarding diabetes. This tool makes it possible to start conversations about diabetes in an easy way, leading to more open communication. This will be beneficial for the partner in a way that more is shared about what they patients feels and experiences regarding diabetes, and that this can lead to more understanding. Questions related to how support would like to be provided and received will be raised too, giving direct guidelines on how to support the patient. Situations that might happen in the future could have been discussed already playing DIAlemma, leading to partner and patient knowing what to do. An additional function of the app is that the described situations can also help patients to recognize situations and see how other people deal with it. Next to that they will be reminded that they are not the only one suffering from diabetes.

## Visual design

The visual design of the application should look like a fun game to play, and should not look medical or too professional. The app should be intuitive to use; a clean and simple interface in which the navigation is clear. These characteristics were used to make the design of the application designs. Bright colors were chosen, as they have the feeling of positivity and play. Playful fonts were chosen which match with the playful interaction that wants to be achieved. Color combinations are used to separate between different categories.

## Context of use

The context in which this design will be used, is at any location where the patient or partner wants to open the application and play. Conversations or discussions about the topics can be done by chatting or by means of face to face communication when they players are together. Linking players in the app can be done by the patient. A code can be send to the one who the patient would like to play with. That person can enter the code and then they are connected and can play the situation questions. It is also possible to connect with friends, in that case less categories and questions are available.

## Different users

This design is available for everyone with diabetes type 1 and has a smartphone. The design targets multiple personalities and uses, since diabetes is a highly personal condition. The design is adaptable, since people can choose from different categories and also own input can be created in the application.

What the partner and patient can achieve by using this design are:

- Learn about needs, preferences, expectations, habits.
- Reflect on choices made, the situation the relation, and expectations of each other.
- Adapt behavior to wishes, and expectations of each other.
- Learn from others and how other diabetics act in several situations.

Questions and situations are used as conversation starters, which makes it more easy to start a conversation or to start talking about a topic that would have not been addressed otherwise. This makes it more easy to share experiences, knowledge and feelings. This will lead to more communication about specific situation to which both can relate. Specific guidelines on how to support will also become clear, by answering the questions and potential conversations.

More intensive use of the design, will lead to better possible support, because more information and experiences are shared and more insights can be gained.

## Link to literature

The elements that need to be addressed according to the literature (discover phase) to support the patient from a partner perspective are: Involvement of partners in self-management of diabetes; active engagement of the partner; perceiving the disease as a shared problem; be knowledgeable to help the patient; play can support this active engagement.

In this tool, those elements are addressed. By using the DIAlemma app, the partner is actively engaged by the diabetes, by in the first place acknowledging that diabetes plays a role in their life too, and therefor starts playing DIAlemma. Involvement in self-management can be achieved by following the advice given to each other.

That play can support this active engagement, is taken into account. DIAlemma is a playful tool to start talking about diabetes.

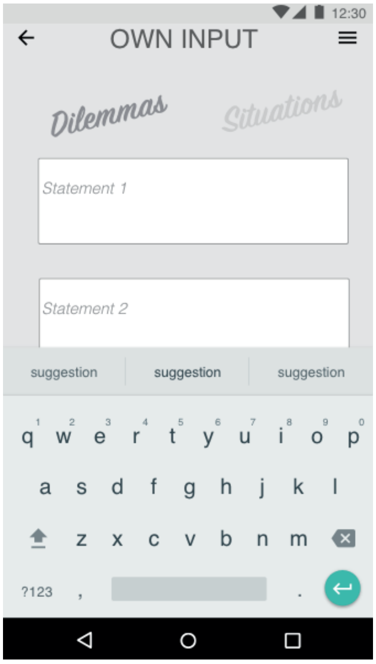
Perceiving the disease as a shared problem is highlighted, since the DIAlemma app is targeting both the partner and the patient. By already targeting both groups, it makes clear that diabetes affects both people. Questions are addressed to help the partner as well as the patient.

# Patient version

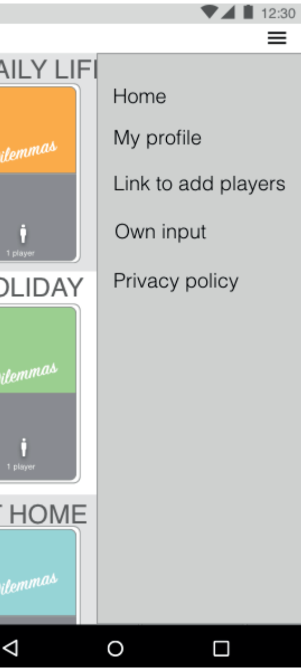
Log in patient

Categories for questions
Situations (2 players)

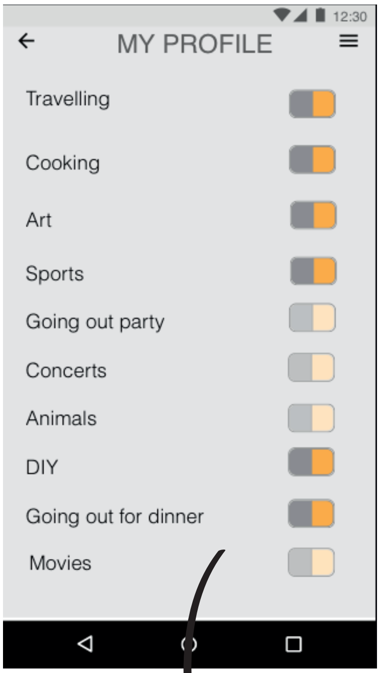
Categories can be chosen, to answer questions of topics you like in that moment.



Own input can be generated in the app. If one wants to know how someone will behave in a situation, the person can use that situation as question in the app. This makes it even more personal en fun to play.



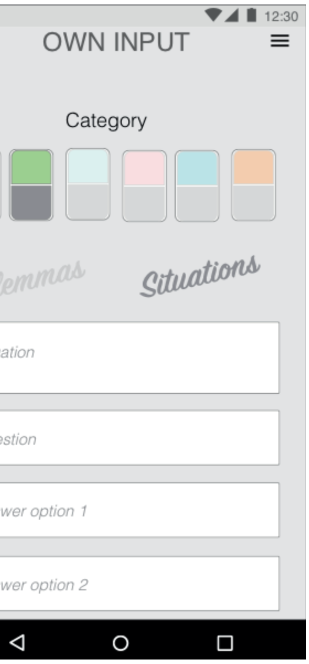
| | |
|---|---|
| Age | 23 |
| Gender | Male |
| Country | Netherlands |
| Insulin pump | ● |
| Sensor | ○ |
| In a relationship | ● |
| Children | ○ |
| Sports | ● |
| Job | ● |



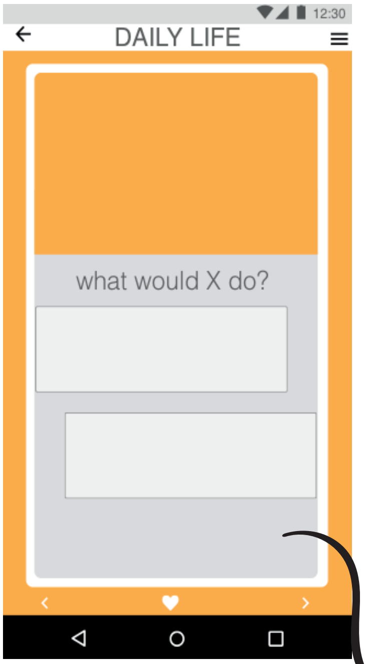
| | |
|---|---|
| Travelling | ● |
| Cooking | ● |
| Art | ● |
| Sports | ● |
| Going out party | ○ |
| Concerts | ○ |
| Animals | ○ |
| DIY | ● |
| Going out for dinner | ● |
| Movies | ○ |

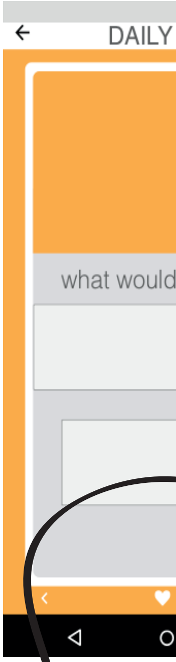
In order to get relevant questions, a profile can be made. Questions will be adjusted. So if you do not have children, all questions about children will be skipped. This makes the app more patient-specific.

Preferences for subjects can be chosen. If you never go out for dinner, those questions will not be relevant and will not be visible.



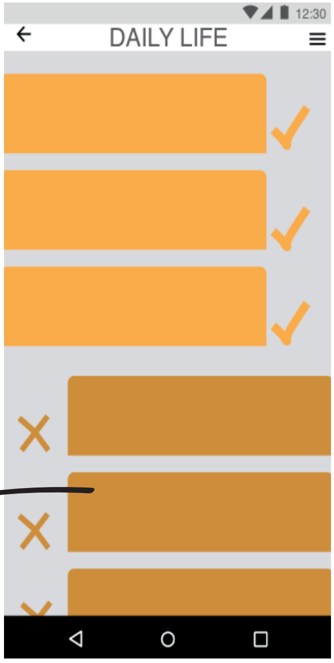
To be able to play DIAlemma with a partner (or other relative) you need to be linked. This can be done in this screen. An activation code will be generated which can be shared.

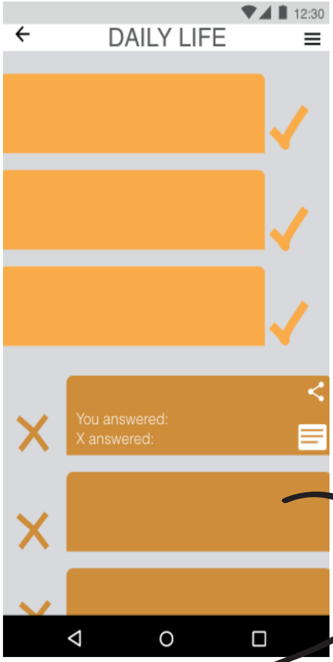


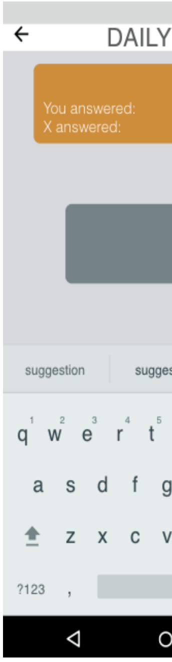


These screens are part of the situation questions for the category daily life. You are able to choose with whom you want to be linked to answer questions.

A situation is described
like what would you do,
X do, or what would yo
will be asked. You click
of your choice.

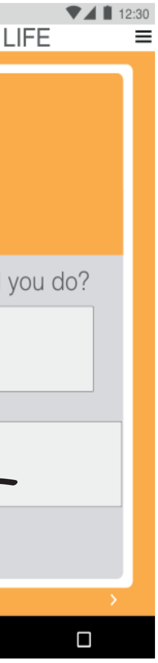


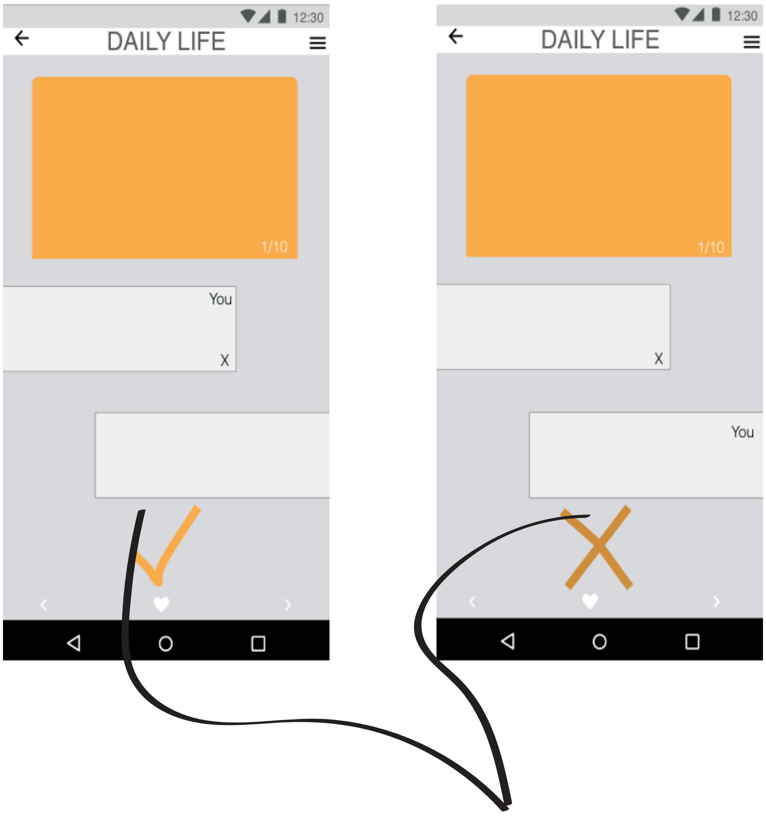




An overview of answered questions can be generated. Questions are sorted on mutual responses and different responses.

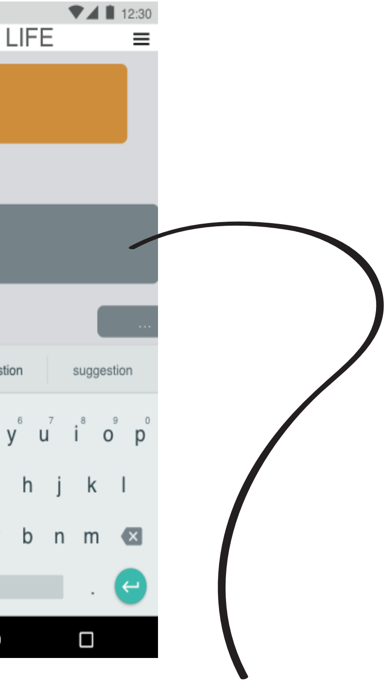
If you click on a question, the a
It is possible to share this quest
facebook etc, so you can chat
app which can be used. This is
together and want to discuss.





, and questions
or what would
u like X to do
on the option

After answering the question (and the person to who you are linked has answered as well) you get to see what the other responded. This way you can see if you agree or disagree with each other, or it the other person expects you to do something else.

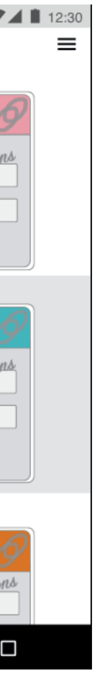


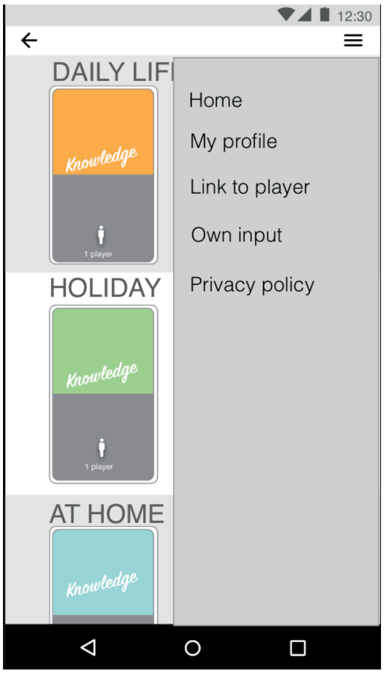
nswers of both of you will be visible.
tion with answer via whatsapp, mail,
about it. There is also a chat in the
only needed in case you are not

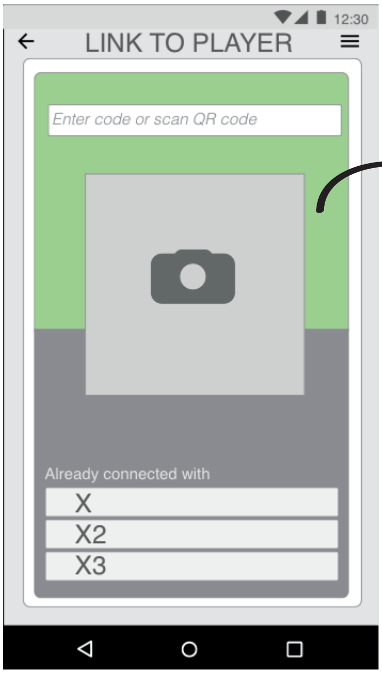
# Partner version

The partner can also participate in the knowledge questions. This way knowledge about diabetes will be increase, which might help understanding the patient better and help adhere to treatment plans.

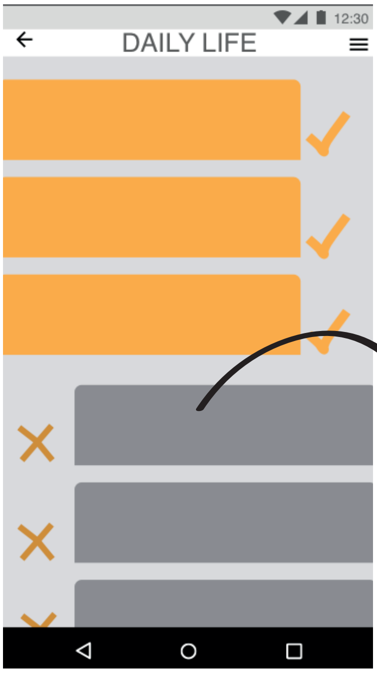
To start playing, you select with whom you want to play.





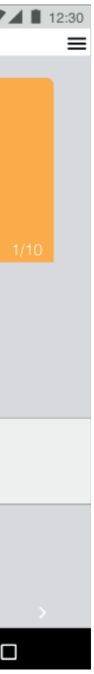


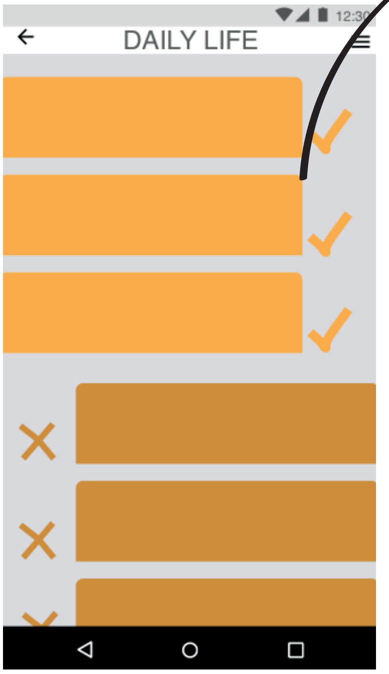
To be able to play DIAlemma with a partner (or other relative) you need to be linked. If you get a code to link to a diabetes patient, you can scan the code or enter the code.

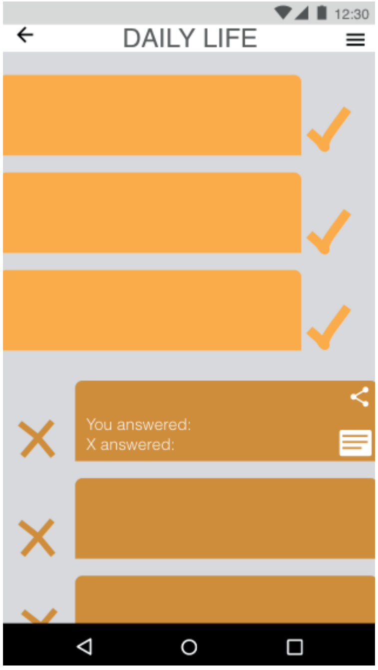


An overview of answered questions can be generated. Questions are sorted by right or wrong answered. You are always able to look back at the questions you have answered.

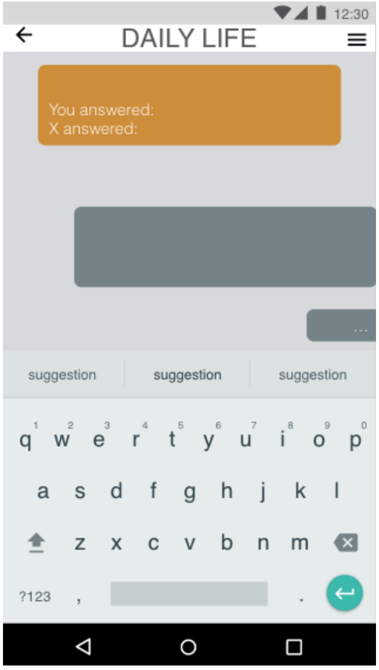
Also the partner will get an overview of the answered questions. This will be the same screens as the patient version.







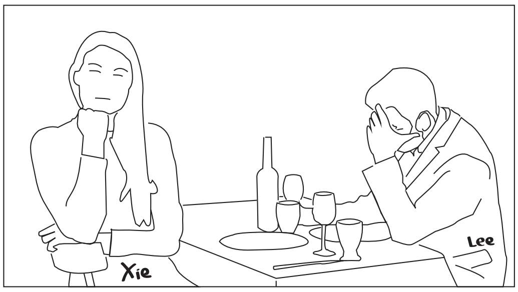
You answered:
X answered:



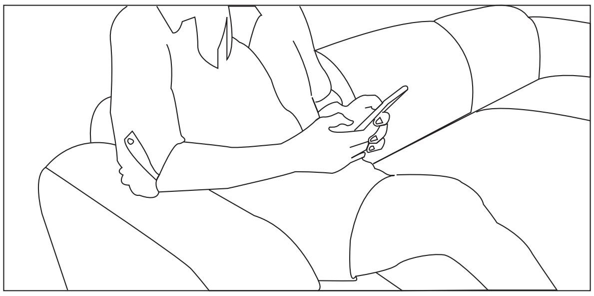
You answered:
X answered:

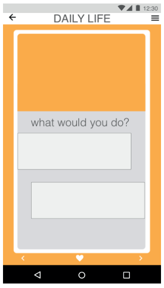
# User scenario

Xie and Lee started dating 2 years ago and are living together for 7 months now. Xie has diabetes type I since he was 14 years old. He manages his diabetes quite well, however he is always influenced by the disease affecting his daily activities. For X2, Xie is the first person she met with diabetes type I, for her everything is new, and she wants to help Xie with everything she can, but she finds it difficult to find the right way to support Xie.

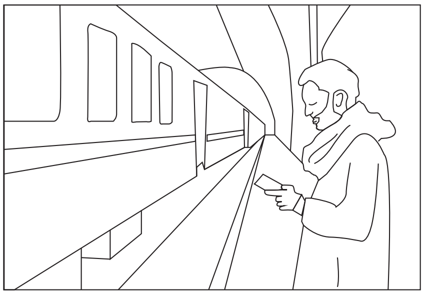


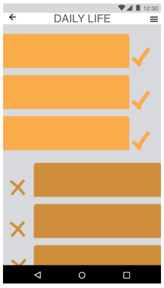
Lee sees that Lee did not measure his blood glucose level before dinner. That is strange, he always does that. She says: Did you measure your blood glucose level? Lee answers yes. Xie asks: Was it high or low? Lee answers: low. More and more questions were asked. This led to a frustrated Lee, because he becomes tired of all the questions, while Xie is worried because she does not know why he becomes so frustrated and angry. What did she do wrong?



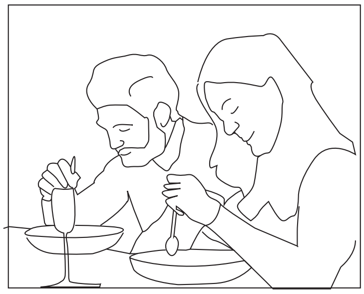


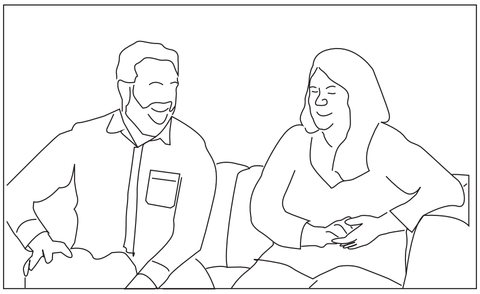
The next day, she discovered the DIAlemma app. This is something for her. She opens the app and start discovering the knowledge questions. Then she found the situation questions. She opens it, and it looks interesting. She connects with Lee and starts answering questions, what would she do in several situations. It gives her insights in what diabetes can cause and how she can react in those situations. She is curious what Lee would answer on the questions and what he expects from her.

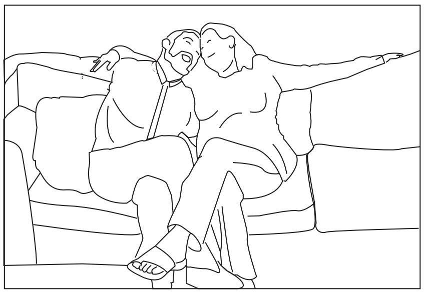




Lee is done with work and goes back home by train. He checks his phone and receives a notification from Xie about the DIAlemma app. He opens the app and sees that Xie has invited him to answer questions for the Daily Life category. He likes that Xie is involved and interested in diabetes. In the train he sits down, and answers the question. It is interesting to see what Xie will do in situations, and if they relate to what I expect. When Lee is home, he will ask her about the answers she gave and tells her what he thinks about it and shares his experiences and thoughts.







During dinner, in a relaxed atmosphere, Lee and Xie are talking about the questions they got in the DIAlemma app. They answered differently on several questions. Lee explains why he chose different options. For Lee it is good to hear those reasons, it helps her to know what she can do, and it also feels she is more connected to Lee, since he is more open about what he feels and experiences. They continue discussing on the couch, and the evening ends much better than the day before.

## Example questions

In the app several categories can be chosen. For every category some examples are given here. Questions are based on conducted interviews in this study and facebook posts in the group: Diabetes type 1 (nederland en belgie). In the questions X1 and X2 is mentioned; X1 refers to patient, X2 refers to partner.

### AT HOME

*1. Het is midden in de nacht, X2 wordt wakker. Zoals X2 altijd doet, wordt je sensor gescand. Je hebt een hypo en X2 maakt je wakker.*

*Wat wil je dat er gebeurd?*
*Wat denk je dat X1 wilt dat er gebeurd?*

*X1 pakt een dextro of iets anders te eten of drinken naast het bed.*
*X1 loopt zelf naar de koelkast om iets te eten of drinken.*
*Ik ga X1 iets te eten of drinken brengen.*
*Niets.*

*2. X2 heeft voor het avondeten gezorgd. Voor het avondeten bolus je bij. Omdat jij vandaag niet zelf hebt gekookt, is het lastiger om te bepalen hoeveel koolhydraten er in de maaltijd zitten.*

*Hoe kom je hier het liefste achter?*
*Wat denk je dat X1 fijn zou vinden in deze situatie?*

*Dat ik de koolhydraten in de maaltijd uitreken*
*Dat ik de verpakkingen van de maaltijd bewaar, zodat X1 het zelf kan uitrekenen*
*X1 berekent het aantal koolhydraten zelf op basis van ervaring en kennis*
*X1 maakt gebruik van een app om het aantal koolhydraten te bepalen*
*Anders*

*3. Het is nacht, je wordt wakker om 5uur. Om 6 uur staat de wekker en moet je eruit. Je meet je bloedsuikerspiegel. Je ziet dat je richting een hypo gaat, maar een echte hypo heb je nog niet.*

*Wat doe je in deze situatie?*
*Wat zal X1 doen in deze situatie?*

*Onderbreekt liever de pomp en loopt zo het risico hoog te te komen*
*Neemt wat sap met het risico niet meer in slaap te vallen*

*4. Inmiddels weet je dat voor de maaltijd X1 bolust. Je merkt dat X1 dit vanavond niet doet. Ook weet je dat X1 het vervelend vindt als jij je met de diabetes bemoeit.*

*Wat doe je?*
*Wat wil je dat X2 doet?*

*Niets*
*Vragen of ik mijn bloedsuiker moet meten*
*Vragen of ik alles heb gedaan wat zou moeten*
*Hinten naar bloedglucoseniveau via iets anders, zodat ik er misschien aan ga denken*
*Anders*

*5. Je zit samen op de bank en je checkt je bloedsuikerniveau. X2 is nieuwsgierig en vraagt of er meegekeken mag worden. Je hebt een hypo en eigenlijk wil je dit liever niet laten zien, maar je stemt toch toe.*

*Hoe zou je willen dat X2 op jouw waardes reageert?*
*Hoe denk je dat X1 zou willen dat je reageert op de waardes?*
*Hoe zou jij reageren?*

*Meelevend, oh wat vervelend*
*Niets, ik zie het zelf ook wel*
*Negatief, mij aansporen om mij te motiveren het beter te doen*
*Positief, ook de positieve kanten benaderen*

*Extra vragen over waardes:*
*Deel je je waardes wel eens met X2? Zou dit extra inzicht kunnen geven?*
*Zou je willen dat X1 de waardes met jou deelt?*
*Zou dit je extra inzicht kunnen geven?*
*Zou je afspraken willen maken over hoe vaak waardes gedeeld kunnen worden?*
*Zou je vaker mee willen naar evenementen over diabetes?*
*Zou je meer openheid willen in diabetes, omdat X1 nu alles voor zich houdt?*

## HOLIDAY

*1. Jullie gaan op vakantie. Jullie reizen per vliegtuig. Je moet rekening houden met je diabetes en daarom moet je extra spullen meenemen, zoals voldoende insuline.*

*Hoe neem je die insuline mee?*
*Hoe neemt X1 de insuline mee?*

*In de handbagage*
*In de ruimbagage*

*2. Jullie zijn op vakantie en gaan hiken. Jullie zijn al 30 minuten aan het lopen totdat je merkt dat je je diabetes maatregelen niet hebt genomen, je hebt geen extra eten of energiepakketten bij je.*

*Wat doe je?*
*Wat gaat X1 doen?*

*Verlaagt de basalen met 90% tijdens de wandeling en hoopt dat bloedglucoseniveau niet daalt*
*Loopt 30 minuten terug naar de auto en pakt daar eten en energiepakketten voor onderweg.*

## LOVE

*1. Na een gezellige avond belanden jullie samen in bed. X1 heeft diabetes en daarom is er altijd een pomp gekoppeld aan X1.*

*Wil X1 de pomp afkoppelen tijdens de seks?*
*Zou X2 willen dat je de pomp afkoppelt?*
*Wil X1 de pomp afkoppelen?*
*Wil jij dat X1 de pomp afkoppelt?*

*Ja*
*Nee*

## GOING OUT

*1. Je bent op een verjaardag, het gaat even niet goed en je spuit extra insuline bij. Er komen opmerking "je hebt echt zware diabetes", "je zal het wel heel erg hebben". Alsof er ook een lichte versie bestaat van diabetes.*

*Wat doe jij in deze situatie?*
*Wat zou X1 in deze situatie doen?*

*Ik adem in, adem uit, en leg het maar weer eens uit.*
*Ik laat ze in hun waan en knik.*
*Anders*

*Zou je willen dat X2 zich in deze discussie mengt?*
*Zou jij je in deze discussie mengen?*

*Ja, het zou fijn zijn als X2 het even kort uitlegt.*
*Nee, X2 hoeft zich hier niet mee te bemoeien.*
*Nee, anderen hoeven geen uitleg.*

*2. Je bent bij een concert, je valt flauw en X2 is bij je. Er moet snel gespoten worden in je been. De opties zijn door de broek heen spuiten of de broek naar beneden trekken en op de blote huid spuiten.*

*Wat zou X2 volgens jou moeten doen?*
*Wat zou jij doen?*

*Door de broek heen spuiten*
*Broek naar beneden doen en dan spuiten*
*Hulp van iemand anders vragen*
*Anders*

*3. Jullie zijn op een feest, het is happy hour en voor een biertje betaal je slechts 1euro.*

*Wat doe je in deze situatie?*
*Wat zou X1 doen in deze situatie?*

*Bolust en eet iets voordat het bloedglucoseniveau daalt*
*Bolust niet en laat bloedglucoseniveau omhoog gaan, en zorgt later wel dat het weer naar beneden gaat.*

*4. Je voelt je slecht. Bent wakker geworden met een hypo. Dit gaat heel je dag beinvloeden. Jullie zouden naar de verjaardag van een vriend van X2 gaan. Je ziet het niet zitten om te gaan.*

*Hoe ga je dit vertellen?*
*Hoe zou je willen dat X1 dit vertelt?*

*Laat waardes zien en legt dit uit*
*Zeggen dat hij/zij niet mee kan door de diabetes*
*Zegt dat hij/zij niet mee kan*
*Gaat toch mee*
*Anders*

## DAILY LIFE

*1. . Diabetes kan op lange termijn ernstige complicaties opleveren. Het kan voorkomen dat de nierfunctie zodanig is verslechterd dat het noodzakelijk is om een donornier te implanteren.*

*Als het mogelijk zou zijn om de nier van X2 te transplanteren, zou jij dat dan willen?*
*Zou X2 zijn nier afstaan, wanneer dit mogelijk zou zijn?*
*Zou jij je nier afstaan aan X1, mocht dit mogelijk zijn?*
*Denk je dat X1 zou willen dat jij je nier zou schenken?*

*Ja*
*Nee*

*2. Na een lange dag werken kom je thuis. Je zegt gedag tegen X2 en gaat vervolgens naar de wc. Je voelt dat je een hypo hebt.*

*Roep je X2?*
*Wil je dat X2 je komt helpen?*
*Wil je dat X1 jou roept om je te waarschuwen en zo nodig te helpen?*

*Ja*
*Nee*

*3. Je bent net verhuisd en je nieuwe buurvrouw is te weten gekomen dat je diabetes hebt. Ze zegt: ja, maar dat van jou valt wel mee hé? Jij bent niet dik. Ik ken iemand die superdik is. Dan heb je erge diabetes hoor.*

*Wat doe je?*
*Wat zou je willen dat X2 doet?*

*Zeggen dat we dat gesprek maar een andere keer gaan voeren.*
*Vertellen wat diabetes is en de verschillen tussen type 1 en type 2.*
*Instemmend knikken.*
*Niets.*

*4. Je continue glucose monitoring sensor moet om de 14 dagen vervangen worden.*

*Hoe wil je het liefst dat dit gebeurd?*
*Wat doe je in deze situatie?*

*Ik doe dit zelf*
*Ik vind het fijn als X2 mij helpt daar waar nodig*
*Ik wil dat X2 de sensor plaatst*
*Anders*

*5. Je krijgt een hypo, er zijn twee opties mogelijk.*

*Welke kies je?*
*Wat zou X1 doen in deze situatie?*

*een gesmolten chocoladereep eten die onderin je tas ligt*
*sprite drinken die al lang open in de koelkast staat*

*6. Het is tijd voor lunch. Je zit hoog.*

*Wat doe je?*
*Wat kiest X1?*

*Slaat de lunch over, om te zorgen dat de hoge bloedsuiker de kans krijgt om omlaag te gaan, maar daardoor is X1 wel hongerig en knorrig en verpest X1 de routine voor de rest van de dag*
*Hanteert het normale schema met het gevaar dat de hoge bloedsuikerspiegel nog hoger wordt.*

*7. Wat kies je liever?*
*Wat kiest X1?*

*Een dagelijks gemiddelde van 140 waarbij je waardes de gehele dag hetzelfde blijven, geen pieken en geen dieptepunten*
*Een dagelijks gemiddelde van 110, maar daarbij moet je 1 of 2 dieptepunten corrigeren en ook 1 of 2 eenheden nemen om hoogtepunten te corrigeren.*

*8. Je weet dat diabetes een ziekte is die je goed in de gaten moet houden. Je kan bloedglucosewaarden constant bijhouden en bekijken. Vaak merk je dat X1 dit doet, ook heb je gemerkt dat X1 vaak stemmingswisselingen heeft. De reden die hiervoor wordt gegeven is diabetes. Soms zegt X1 ook wel eens dat hij/zij hoog of laag zit. Soms merk je al dat X1 chagrijnig is. Je vraagt dan of X1 niet het bloedsuikerniveau moet bekijken en daar actie op moet ondernemen. X1 vind dit vaak vervelend als jij dit vraagt. Hoe kan je dit ook oplossen?*

*Open antwoord*

*9. Af en toe merk je dat je met problemen zit, die je niet zelf kan oplossen. Je wilt dat X2 meedenkt met het oplossen van problemen, eerder deed je dat vaak met je moeder. Maar nu je met X2 woont is het fijn dat je het daarmee kan bespreken.*

*Hoe pak je dit aan?*
*Hoe zou je willen dat X1 dit aanpakt?*

*Laat dit terloops ter sprake komen*
*Zorgt voor het juiste moment*
*X1 bereid mij hierop voor*
*Anders*

*10. Je hebt een fijne dag samen. Maar dan zit je zit hoog en merk je dat je chagrijnig bent.*

*Hoe laat je je X2 weten dat dit door de diabetes komt?*
*Hoe zou jij willen dat X1 dit aan jou laat weten*

*Ik laat X2 mijn waardes zien*
*Ik vertel X2 dat het komt door de diabetes*
*Ik vertel niets*
*X2 merkt het vanzelf*
*Anders*

PHASE 4

# DEL

# IVER

## Introduction

In the define phase the DIAlemma tool is designed. This is a tool targeting partners of diabetes patients to provide support to the patient to make the self-management of diabetes more effective. The design is made by making use of brainstorm and brain writing techniques as well as co-design session with diabetes patients and their partners.

This last phase, called the deliver phase is evaluating the tool and providing answers on the research questions, limitations of this study are written down in the discussion section and in the last chapter recommendations for further development of the tool are listed.

## Methodology

The tool is evaluated with list of requirements, that was generated in the define phase of this report. The tool is evaluated against every requirement in order to see if the requirement is met or not. When a requirement is not met, reasons for this will be explained or recommendations are given to obtain this requirement in the future.

Because of the limited time assigned to this project (15ECTS) no final user test is conducted to test the tool with the target group. Therefore no clear statements about the usefulness, understandability, effectiveness or use in context can be made, leading to a lack of insights in the performance of the design in practice over a longer period of time. Additional testing and analyzing the tool should verify the influence and effects of the final designs on the received support from the partner.

# 4.1 EVALUATION ON REQUIREMENTS

The DIAlemma tool will be evaluated with the list of requirements, that was generated in the define phase of this chapter. An explanation whether a requirement is met or not will be given.

In the list of requirements a division is made between requirements and wishes. The requirements are musts in order to let the tool function optimally, the wishes are not must-haves, but would be ideal to incorporate in the tool. The requirements are qualitative criteria and the wishes are quantitative criteria. The qualitative ones or norms or product-specifications. (Roozenburg & Eekels 1998).

## Requirements

Knowledge

1. The design should help educate the user (partner or patient) to increase knowledge and gain insights about diabetes.

This requirement is met, assuming that users will play the game as it supposed to be used. This is the goal of the tool. Answering questions and discussions with partner and patient will probably lead to increased knowledge and insights. Although this design tool is theoretically formed and is a solution for the problem, there is a major limitation, which is that it only facilitates. It is directly dependent on the user, if they do not want or do not use the tool, nothing will be improved and not knowledge or insights are gained. However this is not tested with the target group.

2. The design should be patient centered, in which the information is adjusted to the specific needs and wishes of the user and the user can adjust the design to personal preferences, so the content is tailored to their own situation.

This requirements is met, since users of the app can change settings to their own preferences and own input can be given to create own content.

3. The information provided by the design should be up to date.

This requirement is not tested, but if the development of the app will take place, it should be kept up to date by and administrator by adding new questions and link it to new developments taking place in the industry for example. If users of the app create own content, then they can make sure themselves that the content is up to date.

4. The design should stimulated patients and partners to share information with each other.

This requirement is not tested, but the tool stimulates thinking about situations and stimulates to discuss disagreements with each other. Also for this, the tool only facilitates, and the outcomes are highly dependent on the users willingness to use the tool.

Support

5. The design should provide practical guidelines on how to support the patient with diabetes.

This requirement is not met. No clear guidelines will be given by the application. This is because every person is different and requires a different approach. However, it is stimulated to start a conversation. It is assumed that from this conversation practical guidelines will arise, in order to know how to support, behave or act is specific situations. It can be that the situation itself provides guidelines in how to behave, since a situation is given, if both parties agree on this, you also know how to react etc.

6. The design should provide suggestions for ongoing support for a long period of time, because diabetes is a disease that develops over time and new

measures should be taken.

This requirement is not met, since to studies are conducted on the long-term. It is advised to create enough content, renew the content, surprising questions, for example unlocking categories, to keep the user attracted to the tool. When the tool is working and addresses the needs of the user, it is probable that the users will keep on using it or do not need it anymore.

7. Should provide support in moments of change.

This requirement is not met, since the tool does not allow to keep track of your life, so it does not know when the moment of change are happening.

Empathy

8. The design should be able to explain emotions and feelings to improve empathy. Emotions are relatable to people without diabetes, only numbers not.

This requirement is not tested, but is believed to be met when users actively use the application.

Context

9. The design should be used in the home-environment (not in a hospital setting), because self-management is mainly done outside the hospital. This does not mean that it is only used in home, but that it can also be used outside during travelling, at friends, at a café etc.

This requirement is met, because the application can be opened when and wherever you are. Since diabetes patients and partners are most of the time of their lives not in the hospital, they will use it in other settings. No documents, registration, approval from hospitals is needed to use the tool.

10. The design should support patients and its partners in the beginning of their relationship (1-5 years).

This requirement is not tested, but it is highly probable that people in the beginning of their relation have the needs that are addressed by this tool. The tool is shown to participants who were in a relations between 1-5 years, and they reacted positively, assuming that they are the right target group for this tool. People who are together for a longer period of time, might not need this solution, since they found ways around the problem to deal with it. However, this might not always be the case, and therefore people in longer relationships can benefit from it too.

11. The design should be use by people with diabetes type 1and its partners between 18-30 years old.

This requirements is tested to invite people from this age-group to join co-design sessions. By having these people thinking along about the design, it can be assumed that the tool is targeting this age-group.

## Wishes

1. The design should be as simple as possible, not overwhelming the user

This wish is not tested, but the reactions of the participants in the co-design session were all positive, not indicating that this would overwhelm them or that it is too much. The application looks like a playing game, which also takes out the serious side of having diabetes. It is more too enlighten than to overwhelm.

2. The design should have included a playing element

This wish is met, the tool consists of playing elements. Those are based on truth or dare, and would you rather (dilemma) games.

3. The tool should not like a medical device. People with diabetes are confronted with their disease 24/7 and have medical equipment with them all the time.
This tool should be focused on having a good conversation about their life, needs and wants etc.

This wish is not tested, but the design is created taking this wish into account, leading to a playful appearance of the application. During the co-design session, people spoke already about a game, so this playful element is addressed well.

4. The design should direct to both people in the relationship

This wish is met, because using the tool you need two people, the patient and the partner. Two applications are made, one specifically for the partner, and one specifically for the patient. The two accounts can be linked.

5. The design should support shared illness appraisal

This wish is not tested. However if people are playing this game, they will realise that they are both affected by diabetes and that they can take their responsibility in several ways to help each other.

6. The design should be integrated as much as possible in the tasks the patient is already doing, so it would not take extra time or effort.

This wish is not tested, but it is related to conversations they have about diabetes. If people do not have conversations about diabetes (which is probably never the case) this would require extra time and effort and then this wish would not be met.

7. The design should make it possible to tailor content according to a patient's own wishes and situation.

This wish is met, since users of DIAlemma can enter personal preferences and there is a function of creating own content.

8. The design should include experiences from others, to share experiences but also to identify with others and learn from them.

This requirement is met, since the situations and dilemmas are based on experiences from other people with diabetes. At least that is the goal. However it is not possible to trace the person who experienced the situation.

9. The design should stimulate providing feedback

This wish is not tested. However the tool is stimulating a conversation. In the conversations feedback can be provided.

10. The design should make the patient with diabetes feel supported.

This wish is not tested. Further tests in which the tool will be used should reveal if the patient with diabetes feels supported.

11. The design should facilitate communicating about the emotional side of diabetes.

This wish is not tested. The aim of the tool is that a conversation will be started, in which also the emotions and feelings of patients and partners are revealed. Literature (Van Vleet, 2019) have indicated that playing games, creates more openness in communication.

12. The design should enable patients to contact or share information with others to their own preferences and frequency.

This wish is met, because the tool is an application which can be opened at any time. So users can play it when and where they want. However it is dependent on the other person answering question too to see an overview of the answers given form both people.

## Conclusion

Not all requirements and wishes are met. The reason for this is that the tool is not tested in this study. The tool is not tested with the target group, and for some requirements long-term testing is needed to be assessed. People should be researched before having the tool, and after having the tool. Differences in knowledge and support behavior should be analyzed. Or different groups should be observed, people without the tool (control group) and people with the tool from the same age-group and years in a relationship.
More recommendations will be given in section 4.5.

# 4.2 CONCLUSION

This section answers on the main research question will be given as well as answers on the sub research questions. It also functions as a summary of the findings in this graduation project.

## Problem

The problem that was addressed is that partners of people with diabetes do not know how to support the patient, while the patients need this support in order to improve their self-management of diabetes. This is associated with the feeling of being excluded from a partner perspective, since this person does not know what it is to have diabetes, and is not able to grasp what is really going on regarding the diabetes of the patient. The goal of this project was to design a tool to help partners of diabetes patients to come closer to the patient, by conversations about diabetes, to gain more insights in how the patients feels and how to support. In the deliver phase the design of the tool DIAlemma is shown.

To come up with a tool, several studies were conducted; a literature study, context mapping and interviews, co-designing, and designing. The first two studies were conducted to gain enough knowledge to start designing a tool which benefits the user and actually solves a problem. The research questions answered using these methods were: How can relatives of patients with diabetes type 1 support the patient to indirectly improve their self-care management? Which elements of social support are desired from relatives for people with diabetes type 1 according to the literature? and How do relatives support the person with diabetes now? How can support be improved according to the patient and the relative?

## Sub research question

The discover phase of this report started with a systematic literature study to find out which elements for support are desired for patients with diabetes and partners. From this literature study it became clear that a lot of studies are conducted for children and their parents, or for adults with diabetes type 2. Since diabetes type 1 is often diagnosed in childhood, and diabetes type 2 in adulthood, this makes sense. However, while diagnosed in childhood does not mean that you do not have diabetes as an adult. This research is targeting adults with diabetes type 1 and their partners. It became clear that social support is important, and that partners play an essential role in this, since they are closely related to the lives of the patient.

At first a systematic literature study is conducted in which elements of social support between partner and patient are identified. According to the studied literature the elements of social support that are desired for the partner are: Involvement of partners in self-care of diabetes; active engagement of the partner, in which play activities can play a role to support open communication; seeing the disease as a shared problem, since both the patient and the partner are affected by the disease and this should be acknowledged; be knowledgeable to help the patient, because this helps to support the patient to for example adhere to the treatment plan.

After the literature study, context mapping is used, in which participants filled out a booklet followed by an interview. These findings were used to answer the sub research questions: How do relatives support the person with diabetes now? How can support be improved according to the patient and the relative?

Support is mainly given by providing practical support and to some extent emotional support. Partners also support the patient by being educated about diabetes. This knowledge is mainly gathered by living together with the patient and experiencing what it does. Other ways of supporting are joining the patient in hospital visits and diabetes events. It is also perceived as positive support when the partner adapts his/her life to diabetes to a certain extent.

Support can be improved by talking more about emotions and feelings. This is not described in booklets, it is very personal and needs a personal approach and discussion. This can also improve empathy, since this is lacking. Partners do not know how it is to have diabetes and this causes frustration. This relates to the study of Joensen et al. (2016) in which participants indicated that they lacked a real dialogue about diabetes with relatives. It is difficult to have these kind of conversations.

It might help to join diabetes events to also see others with diabetes and to learn from their experiences. Another aspect to improve is to see the disease as a shared problem by both the partner and the patient. The patient should also accept that the partner wants to help. This shared illness appraisal is linked to seeing diabetes as our problem, instead of my problem or your problem. Dyadic coping strategies, such as joint problem solving, joint information seeking, relaxing together, might stimulated shared illness appraisal. Most important is that the partner is involved. (Helgeson et al., 2019). When partners and patients perceive that diabetes is shared, it may be easier to ask for and provide support and it is expected that the partner feels involved, which makes it more comfortable giving support (Helgeson et al., 2019).

Negative supportive behavior consists of worrying, not knowing what the disease is, using diabetes as an excuse and micro managing the partner. Worrying because the partner has heard stories about other people having diabetes that ended badly is unwanted. Too much interference does not help.

The critical node that is identified is that the partner cannot identify with the patient, regarding diabetes. This can lead to a feeling of being excluded. This is in agreement with the study of Morris et al. (2006) in which partners explained that they have negative feelings, because of a lack of involvement in the management of the patients, which led to increased frustrations and feeling on helplessness. Which links to critical node “the feeling of being excluded” in this report.

The need for the partner is to come closer to the patients, by understanding what they feel and experience in regards to diabetes. This way the partner gains more knowledge about diabetes itself, how this affects the partner, and how they can support. For the patient it is known that they benefit from support of their partner to improve the effectiveness of their self-management. So it is important that this support is provided and received in the right way.

In order to help the partner in achieving this a tool is designed. This tool is also used to answer the main research question: How can relatives of patients with diabetes type 1 support the patient to indirectly improve their self-care management?

## Design tool

The insights from the studies performed in the discover phase were used to create a tool. It forms a solution to get the partner closer to the patient, by understanding how diabetes. affects them, how they feel and how they want to receive support. Providing and receiving support in a suitable way is especially in the beginning of a relationship. In this phase a lot is still unknown and therefore a lot will be shared between the patient and the partner. If people are already longer in a relationship, partners become more involved in diabetes with time, and therefor will see the illness as a shared issue (Helgeson et al., 2019). This is why the tool will be targeted to young couples.

The problem arose from a systematic literature study. The principles of the design are based on user research, co-design with users, leading to two promising concept direction for tools.

The first concept direction is a tool which enriched the data of the blood glucose sensor with emotions and feelings. Adding emotions will make the data more comprehensible and more relatable for partners. The other design tool is DIAlemma, a digital application in which dilemmas and questions can be answered by both the patient and the partner to gain insights in how diabetes affects them, to reveal needs, expectations and wishes.

This application stimulates conversations and discussions about diabetes. This is needed since partners can feel excluded from their partner regarding diabetes.

User research and co-design demonstrated that both concept directions are useful and valuable solution areas in their opinion. It will increase the understanding of diabetes in their surroundings. Users have acknowledged that the identified problem is existing and that they value the design directions. It is a great addition to what is already out there. However, participants of the study had a preference for concept direction 2, because this is an accessible playful tool, in which a lot can be shared with each other. Also from the Harris profile, a weighting criteria method, concept 2 came out best. Concept direction 1 enrichment of data with emotions is only beneficial for a limited group, because not all patients wants to share their data. If patients do not want to share the data, the partner will not benefit from it.

## Main research question

So in this study the research question: How So in this study the research question: How can relatives of diabetes type 1 patients support the patient to improve their self-care management? can answered by stating that it is important in the first place that the relative (partner) should be able to come closer to the patient, by knowing and understanding what diabetes is to them and how it affects them. The DIAlemma tool can help in this. DIAlemma is a play activity. Play is thought to be a bonding factor between patient and partner. It can lead to being more comfortable opening up after playing (Van Vleet et al., 2019). When patient and partner openly communicate and are trying to solve problems together this results in active engagement, leading to higher relationship satisfaction (Trief et al., 2017)

DIAlemma uses real situations in which both the patient and the partner answer question about the situation, how they will act and how they expect the other to react. People can choose from different categories to answer questions. The questions are related to situations that can happen during the day, not necessarily medical knowledge. This medical knowledge can be read in booklets or online, and people know the basics of that. Participants of a study conducted by Joensen et al (2016) indicates that they want a real dialogue about diabetes with relatives in which they prefer to have opportunities to reflect on their lives by linking it to experiences including more general and more specific topics. In which the general topics would include worry and concern having diabetes, and the more specific topics would include travel, sports, food. The DIAlemma tool aims to involve these types of categories.

The DIAlemma tool stimulates to start a conversation.  This way a shared problem appraisal is stimulated, which eliminates the feeling of being excluded by the partner. Joint problem solving and joint information seeking, relaxing together, might stimulated shared illness appraisal(Helgeson et al., 2019). With the DIAlemma tool this is achieved by playing a game together in which both the partner and the patient are informing each other and possibly also solve problems. When both people in the relationship perceive that diabetes is shared, it may be easier support each other, because they feel more comfortable and it is expected that the partner wants to help (Helgeson et al., 2019).

The tool is accessible, practical guidelines of support are provided, if questions are answered by both. It is therefore easy to get to know what to expect and be confronted with problems before they will happen in real life. The conversations afterwards are easy to start, because topics are already addressed. Deeper insights might be gathered from those conversation on how to provide support in the best way. Eventually, better provided support will help the patient in their self-management.

In conclusion, the DIAlemma tool has potential to be used as social support mechanism to indirectly improve the self-management of diabetes. However, this cannot be proved within the context of this project and needs to be further researched.

# 4.3 DISCUSSION OF THE METHODS

In this project several research methods are used; an empirical study and design based research. The discover phase started with an empirical study, which was a systematic literature review. This was done to get an overview of the important elements of support in the perspective of a relative and a patient. This was important for the next steps, in which design based research was conducted, to in the end make a support tool.

## Phase 1: Discover phase

The systematic literature review was used to gain more knowledge of the topic, to identify the relevance of the project, to identify the elements of social support provided by the relative described in literature and to form a basis for interview questions and design implications for the tool.

During the selection of the articles, the first step was to select articles based on title read. This was done for all 4376 articles, which is a method that can easily lead to mistake, leaving out relevant articles. Better would be to first select the articles on other criteria, like citations, so the amount of articles for title reading are less.

The interviews were part of the context mapping research method. First participants get a booklet in which they do small assignment, to get familiar with the topic and to let them thin about questions beforehand. A few days/weeks after filling the booklet interviews took place, which used the input from the assignments in the booklet. I received many positive reactions about the design of this research. They liked to participate and to fill the booklet. Most of the participants had indicated that they expected a boring questionnaire. People did not indicate that they did not understand a question. However, one remark indicated by multiple participants was that the timeline started with waking up and ended by going to sleep. Diabetes is a disease that is 24/7 influencing your life, also during the nights. So the nights should have been visible on the timeline too.

The selection criteria to participate in this study were not strict, leading to also participants joining without a partner. For further research it is important to set clear inclusion criteria for the participants. Participants included in this study might not be fully representative for all people with diabetes type 1. The participants have responded to invitations send out by email, facebook, forum themselves, meaning that they might be more open towards sharing experiences, are conscious about their life with diabetes, and interested in new ways to improve their life or other reasons. People that have an attitude of not looking actively looking for support or new innovations, might not be present in these diabetes communities or would not sign up to volunteer in a study.

Due to time limitations of this study, no more participants could be included. To increase the reliability of the study, a larger amount of participants should be included. Out of twelve participants with diabetes nine were female, which does not represent the 55/45 male female ratio in the Netherlands (FaMe-net 2011-2015). From five participant the partner was involved in this research too. This number could also be increased to gain more reliability and credibility. Three out of twelve participants did not have a partner at the moment of interviewing. Having a participant group with participants in the same stage of life with similar conditions would improve the results.

Interview times differed between 45 minutes and 2 hours. This had to do with the type of person who was interviewed. Some people had a lot to say and gave a lot of examples, while others were less talkative. Interviews in which people were interviewed by skype or phone lasted shorter than the interviews that were conducted face to face. For the reliability of the research it would be better to conduct the interviews all in the same way, either skype, phone call or face to face, in which face to face is preferred.

## Phase 2: Define

In the define phase the list of requirements was created. This was done based on creating a difference between requirements and wishes according to Roozenburg and Eekels (1998). The requirements and wishes were formed from the findings of the literature study and the interview sessions. First the finding were translated into design implication and in this section into design requirements.

A brain writing sessions with How to questions was done. I did this on my own. Inviting professionals to think about ideas as well would have made it probably more valuable and would have resulted in richer and more diverse ideas.

## Phase 3: Develop

In this phase the tool is developed. This is done in close collaboration with the user, i.e. diabetes patients and its partners. Co-design sessions were held, in which participants were stimulated to think about design solutions based on two presented concept directions. Guidance was given by explaining what they had to do and what was expected from them. In the beginning people were a bit hesitant, but when they started drawing or writing they kept going. Results were discussed between me and the users, but also between the patient and the partner, already leading to interesting discussions. Participation of the user resulted in clear recommendations for further development of the tool. Since in this session, two concept directions were provided, the participants were already steered in a direction. More open or smaller assignments, earlier in the design phase could have helped coming to another design tool.

Also here the selection criteria for people to participate in this study were not strict, leading to diabetes patients joining without a partner. Although in this study three patients with diabetes and their partners contributed, as well as two patients with diabetes without a partner.

## Phase 4: Deliver

The evaluation of the tool is done by analyzing the features of the tool with the list of requirements. This could have been strengthened by testing the design with the target group, since only testing it on the requirements is theoretical, while it is most interesting to see hoe this tool would work in practice. It would be advisable to test this tool over a longer period of time to see if this tool lead to improved support.

# 4.4 DISCUSSION OF THE RESULTS

The results of the different phases are discussed here.

## Phase 1: Discover

The systematic literature review was conducted and as a result elements of support that are desired from the partner towards the patient are listed. Findings from the articles were analyzed by creating categories. This was done by the researcher itself, which resulted in only one person interpreting the results. To improve the reliability and the credibility of these results, more researchers should have been involved to check on the interpretation and creating categories. Other limitations of the systematic literature study are that a small number articles are included in this literature review. This might suggest that this topic is not researched in full detail. Qualitative and quantitative studies were included in this review. In the articles not all participants were the same target group. In some studies only the patient participated, in other studies both the patient and the partner participated. The studies were conducted in several countries; Denmark, United Kingdom, United States of America. Differences in culture between the countries might limit the results, however it are all western countries.

The questions in the sensitizing booklet and in the interview protocol steered the direction of the outcomes of the study. The questions were based on a literature study and the scope that was created. On the one hand it is positive to have questioned narrowed down to the scope of the project. On the other hand, information about other relevant aspects of having diabetes could have been overlooked or not been investigated. Since this project was limited to a graduation project for a set amount of hours, it was good to scope the project and the interviews.

The analysis of the interviews was done by one person. Interpretations of only one person is therefore used. By increasing reliability and credibility of the results, more researchers should be included in the analysis of the results. The results are reported in a way that reasoning behind coding, and categorizing is clear. This makes the analysis section transparent and by that more credible and trustworthy. The interpretations of the interviews were not checked with the participants afterwards. The participants do not all have a scientific background, and are educated on different levels. The quotes were taken out of context, and participants could therefor argue the comments they made. Since the interviews were all recorded and transcribed verbatim, the researcher took the quotes out of context to make a good interpretation.

## Phase 2: Define

The design phase listed the design requirements for the tool. Those requirements were later used to evaluate the tool. Not all requirements could be tested within this project. A selection of which requirements were able to test within this project could have been made, to evaluate the end results in a more structured way.

The ideas generated in this session were combined using a morphological chart. This resulted in two concept directions. Clearer indications on why these elements of the morphological chart were selected could have been made, to clearly identify on which elements the concept directions were based on.

## Phase 3: Develop

In this phase the tool is developed with help of the user. This was done by organizing co-design sessions. The recommendations and preferences of the users were taken into account while selecting the best concept to further develop. This selection was also based on the wishes of the list of requirements, since this are the criteria on which the design directions can differ.

Since the users in this co-design session developed ideas based on the two concept directions, they were steered into this direction. The results are therefore also limited to recommendations on these two concept directions.

From the concept selection, DIAlemma resulted to be the best solution. Iterations on this concept direction were done, based on the recommendations, feedback and suggestions of the co-design session. Leading to a design, which is created with the target group, which is a valuable aspect of this design.

## Phase 4: Deliver

The main goal of this phase is to evaluate the tool. In this project this is done with the list of requirements. Not all requirements were met, mainly because not requirements could be tested within this project, due to the scope and time limitations.

The design is developed with the user, is theoretically formed and is a solution for the problem, is that it only facilitates. It is directly dependent on the user, if they do not want or do not use the tool, nothing will be improved. Patients or partners cannot be forced to use this tool. The consequence of not using it, would be that support is not given in an optimal way, leading to not optimized self-management.

Also the final design of the tool is not tested with the target group in practice. Therefore no clear statements about the usefulness, understandability, effectiveness or use in context can be made, leading to a lack of insights in the performance of the design in practice over a longer period of time. Additional testing and analyzing the tool should verify the influence and effects of the final designs on the received support from the partner.

# 4.5 RECOMMENDATIONS

Recommendations for further research and further developments of the tool are listed.

As already stated before, several requirements could not be met, because not enough tests were conducted to validate the usage of the tool. It is important that the tool will be tested with the target group. In order to develop the tool further it is important that more content will be created.

Thereafter it is important to know if they understand the user interface, if they understand the questions, if they can find all features and if they would like to use this application. Later on it is important to do a long term study with patients and partners to see the value of this tool in relation with providing and receiving support. For this test participants should be researched before using the tool and after using the tool for some time. Differences in support can then be identified. Another option to test if the tool is useful is to create two groups of people with similar characteristics, like age an years in a relationship. One group is not using the tool (control group) and the other group is able to use the tool. Differences between the groups will reveal the effects of the tool. Later on, another study should reveal if the type of support given by the partners using this tool is beneficial for the self-management of diabetes of the patient.

It would also be recommended to involve more stakeholders in the design of the tool, for example health care professionals. They have contact with multiple patients and have experience with diabetes which can be useful for developing the application further. This can be done by making use of living labs.

If the tool will be put on the market, a complete wireframe should be made including the app structure, data flows. Then a business case and cost estimations should be made. A clear plan for market release have to be made, including the cost-effectiveness of the tool.

Recommendations for further development of the tool are given. The main addition is the creation of more content for dilemmas and situations and testing of the tool with more users.

# 4.6 PRACTICAL IMPLICATIONS

## Science communciation

The value of this graduation report for the department of science communication is that it contributes to the "Integrated care program for type 1 diabetes mellitus patients with insulin pump" (INCAP) project of which the science communication department is a partner. INCAP can use the findings of this graduation project in the development of their own project.

Since this project is focused on the social aspect of having diabetes and includes the relative of the patient, which is different from the initial focus of the INCAP project, the insights can be used to create an even more integrated care program for patients with diabetes type 1. This would even give more strength to their project and final products.

In this project a considerable amount of people participated in several studies. The participation of these people helped in designing the tool, but also provided many insights on living with diabetes, having a partner while having diabetes, contact with their healthcare professionals etc. All the interviews were transcribed verbatim, and can be used for further studies. For example Ferdoos Esrail can use the interview transcripts and the findings of this report for his PhD project about communities of practice in which also INCAP is involved.

This study also actively involved patients in the process of research and design. This co-creation is essential in creating new designs or services. EIT Health is also promoting this kind of research. They state that citizens are always considered in their activities, by involving them in innovations and ensuring human-centered research (EIThealth, 2018).

## Academic research

This study contributes to the literature on social support in diabetes. A new approach to connect the partner more to the patient has been developed. For this a practical tool is created, which adds to the theoretical based descriptions found in literature. Not only knowledge or active involvement, but gaining deeper insights in why a person is feeling that way. The critical node in this project is feeling excluded. This is addressed within this project. DIAlemma has potential to be used in practice to help partners of diabetes patients giving the best support in an easy and fun way. The tool is adaptable to own preferences, linking to different patient types and personalized care which becomes more and more important. Extra studies can be done to research this topic further, by testing this tool, or using it.

Results of this study are leading towards a tool that facilitates better support from the partner to the patient. This can result in better self-management leading to improved health outcomes. Better health outcomes, will lead to fewer hospital visits, leading to lower healthcare costs. Since health care costs are rising, all efforts to limit this increase are valuable. Findings and results of this project can probably also be used for other types of diseases. However, this study is only focus on diabetes only.

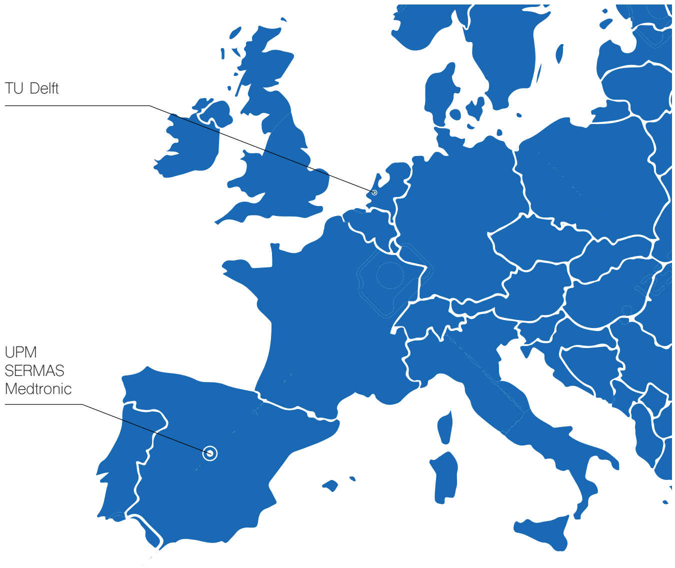


Figure 30: INCAP partners

# 5. REFERENCES

Baig, A. A., Benitez, A., Quinn, M. T., & Burnet, D. L. (2015). Family interventions to improve diabetes outcomes for adults. Annals of the New York Academy of Sciences, 1353(1), 89–112. https://doi.org/10.1111/nyas.12844

Barlow, J., Wright, C., Sheasby, J., Turner, A., Hainsworth, J. (2001) Self-Management approaches for People with Chronic Conditions: a Review. Patient Education and Counseling, 48, 177-187.

Bodenheimer, T., Lorig, K., Holman, H., Grumbach, K. (2002) Patient Self-management of Chronic Disease in Primary Care. American Medical Association, 288(19).

Delft Design Guide, 2013, Yvo Zijlstra Roos van der Schoor, Uitgever: BIS Publishers BV, Co-auteur: Jaap Daalhuizen Yvo Zijlstra Roos van der Schoor Annemiek van Boeijen
Engels Druk: 1 9789063693275

FaMe-net (2011-2015) https://www.volksgezondheidenzorg.info/onderwerp/diabetes-mellitus/cijfers-context/huidige-situatie#node-aandeel-diabetes-type-1-totaal-naar-leeftijd-en-geslacht

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. Nurse Education Today, 24(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Helgeson, Vicki, S. (2017). Young Adults With Type 1 Diabetes: Romantic Relationships and Implications for Well-Being. Spectrum Diabetes Journals, 30(2), 108–116. https://doi.org/10.2337/ds16-0020

Helgeson, V. S., Mascatelli, K., Reynolds, K. A., Becker, D., Escobar, O., & Siminerio, L. (2015). Friendship and Romantic Relationships Among Emerging Adults With and Without Type 1 Diabetes. Journal of Pediatric Psychology, 40(3), 359–372. https://doi.org/10.1093/jpepsy/jsu069

Helgeson, Vicki S, Berg, C. A., Kelly, C. S., Van Vleet, M., Zajdel, M., Lee Tracy, E., & Litchman, M. L. (2019). Patient and partner illness appraisals and health among adults with type 1 diabetes. Behavioral Medicine, (42), 480–492. https://doi.org/10.1007/s10865-018-0001-1

Joensen, L. E., Filges, T., & Willaing, I. (2016). Patient perspectives on peer support for adults with type 1 diabetes: a need for diabetes-specific social capital. Patient Preference and Adherence, Volume 10, 1443–1451. https://doi.org/10.2147/PPA.S111696

Jørgensen, H. V, Pedersen-Bjergaard, U., Rasmussen, A. K., & Borch-Johnsen, K. (2003). The impact of severe hypoglycemia and impaired awareness of hypoglycemia on relatives of patients with type 1 diabetes. Diabetes Care, 26(4), 1106–1109. https://doi.org/10.2337/diacare.26.4.1106

Kovacs Burns, K., Nicolucci, A., Holt, R. I. G., Willaing, I., Hermanns, N., Kalra, S., ... Peyrot, M. (2013). Diabetes Attitudes, Wishes and Needs second study (DAWN2TM): Cross-national benchmarking indicators for family members living with people with diabetes. Diabetic Medicine, 30(7), 778–788. https://doi.org/10.1111/dme.12239

Lorig, K., Holman, H. (2003) Self-Management Education: History, Definition, Outcomes and Mechanisms. Annals of Behavioral Medicine, 26(1), 1-7.

Morris, M., Parker, L., Booker, S., & Johnson, A. (2006). Partners' experiences of living with someone with type 1 diabetes. Journal of Diabetes Nursing, 10(5), 194–198. Retrieved from https://www.diabetesonthenet.com/uploads/resources/dotn/_master/272/files/pdf/jdn10-5-194-8.pdf

Polonsky, W. H., Fisher, L., Hessler, D., & Johnson, N. (2016). Emotional Distress in the Partners of Type 1 Diabetes Adults: Worries About Hypoglycemia and Other Key Concerns. Diabetes Technology & Therapeutics, 18(5), 292–297. https://doi.org/10.1089/dia.2015.0451

Rintala, T. M., Paavilainen, E., & Åstedt-Kurki, P. (2013). Everyday life of a family with diabetes as described by adults with type 1 diabetes. European Diabetes Nursing, 10(3), 86–90. https://doi.org/10.1002/edn.234
Tracy, E. L., Berg, C. A., Baucom, K. J. W., Turner, S. L., Kelly, C. S., Vleet, M. Van, ... Helgeson, V. S. (2018). Daily sleep quality and daily stressors in couples coping with type 1 diabetes. https://doi.org/http://doi.org/10.1037/hea0000690

Roozenburg, N. Eekels, J., (1998) Productontwerpen, structuur en methoden.
Second edition. Publisher Lemma, The Hague, The Netherlands.

Sanders, E., & Stappers, P. J. (2013). Convivial toolbox. Generative research for the front end of design.

Trief, P. M., Jiang, Y., Beck, R., Huckfeldt, P. J., Knight, T., Miller, K. M., & Weinstock, R. S. (2017). Adults with type 1 diabetes: Partner relationships and outcomes. Journal of Health Psychology, 22(4), 446–456. https://doi.org/10.1177/1359105315605654

Van Vleet, M., Helgeson, V. S., & Berg, C. A. (2019). The importance of having fun: Daily play among adults with type 1 diabetes. Journal of Social and Personal Relationships, 1–16. https://doi.org/10.1177/0265407519832115

White, P., Smith, S. M., & O'Dowd, T. (2007). Living with type 2 diabetes: A family perspective. Diabetic Medicine, 24(7), 796–801. https://doi.org/10.1111/j.1464-5491.2007.02171.x

WHO (2016) Global Report on Diabetes World Health Organisation, France

Williams, L. B., Laffel, L. M. B., & Hood, K. K. (2009). Diabetes-specific family conflict and psychological distress in paediatric Type 1 diabetes. Diabetic Medicine, 26(9), 908–914. https://doi.org/10.1111/j.1464-5491.2009.02794.x

# APPE

# ENDIX

# 1. CODING STEPS LITERATURE STUDY

| **Study** | **Aim** | **Type of research** | **Group** | **Results** |
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| Jorgensen et al. 2003 | The aim of this study was to compare patients' and relatives' assessments of rates of severe hypoglycemia and state of awareness and to explore the influence on involvement and concern of relatives. | Cross-sectional paired questionnaire survey | n=284 cohabitants (3% not partner) Mean 18 years cohabitants<br>Denmark<br>Age: 44 | Cohabitants recall more episodes of severe hypoglycemia than PWD. Rate ofSH and state of hypoglycemic awareness influence the degree of cohabitant involvement in PWD's disease. Only 35% of partners rated PWD's hypoglycemia awareness as normal. |
| Morris | Experiences of partners living with someone with type 1 diabetes | Qualitative, interpretive phenomenology analysis (interviews) Cross-sectional<br>Semi-structured interviews | N = 15 **spouses**; age range 37–71; marriage duration range 4–50 years<br>7 male, 8 female<br>UK | Partners expressed concerns of PWD for the future, emotional impact (anxiety, isolation, frustration), perceived lack of control, need for diabetes specific knowledge and support. |
| Polonsky | Investigate prevalence and sources of diabetes distress in partners of people with diabetes and examine associations of diabetes distress with demographic/contextual factors | Cross sectional Qualitative interviews | N=11 for interviews<br>N= 317 **partners**, mean age 43.4; 90.5% white; mean length of relationship 13.6 years<br>USA | All subscales of diabetes distress survey significantly correlated with depression, general life stress, and diabetes-related relationship satisfaction. Hypoglycemia distress was reported by 64.4% of partners. Low levels of diabetes support reported by partners. |
| Trief | to examine associations between relationship status, relationship factors, and outcomes in adults with type 1 diabetes. | Survey measuring relationship satisfaction and perceived partner support style. | n=1660<br>63% female<br>Age 40<br>Race: white 95% | Higher relationship satisfaction, and having an engaged, not over-protective, partner was associated with better glycemic control and self-care. Helping partners support patients, avoiding over-protection, may |

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| | | | | enhance relationship and diabetes-related patient outcomes for adults with type 1 diabetes. |
| Helgeson 2015 | To examine whether friendship and romantic relationships of emerging adults with type 1 diabetes differed from this of a comparison group, and to determine whether these relationships were associated with psychological and diabetes health outcomes. | Online questionnaires | High school seniors with diabetes (n=122)<br>Without diabetes (n=118)<br><br>Half female<br><br>Race 93% white<br>Age: 18 | Those with diabetes reported less friend support but similar friend conflict compared with controls. Aspects of romantic relationships and friend relationships were associated with health outcomes, but there were more effects involving romantic relationships. On some indices, romantic support was more beneficial for controls and romantic conflict was more troublesome for those with diabetes. |
| Helgeson 2019 | how patient appraisal of the diabetes as shared versus individual was associated with collaborative, supportive and unsupportive behavior and whether patient shared illness appraisal was most beneficial for health when it occurred in the context of supportive behavior. | Online survey to be completed before in-lab visit.<br><br>In lab visit: online questionnaire, brief interview | n=199 couples (398 individuals)<br>Married 92%<br>Age 47<br>White 90%<br>Non hispanic (94%)<br>52% female<br><br>USA | partners were more likely than patients to hold shared illness appraisals. Patients' shared appraisals were associated with more collaborative and instrumental support, more emotional support, less protective buffering, and more overprotective behavior. When patients and partners were consistent in their shared appraisals, support was highest. |
| Helgeson 2017 | to examine whether young adults with type 1 diabetes involve romantic partners in their illness, and, if so, how their involvement is related to relationship quality and psychological well-being | Phone interviews | n=68<br>Age 26<br>Involved in a romantic relationship<br><br>Female 59%<br>Race: White 94%, asian 3%, african american 1% white african amaerican 1%<br><br>Married 21%, living | The most common partner supportive behaviors were emotional and instrumental support. The most common partner unsupportive behavior was worry about diabetes. Correlational results showed that communal coping was |

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| | | | together 27% dating 53% | related to greater partner emotional and instru- mental support, but also to greater partner overprotective and controlling behaviors. Partner overinvolvement in diabetes management had a mixed relation to outcomes, whereas partner underinvolvement was uniformly related to poor outcomes. |
| Joensen 2016 | To explore the function of peer support from the perspective of adults with type 1 diabetes in | Workshops, group and individual interviews | Denmark<br>n=20 | Adults with type 1 diabetes found peer support highly relevant to reduce a burden- some feeling of diabetes-specific loneliness. Peer support showed potential to create diabetes- specific social capital not only by creating reciprocal social support between peers but also, more importantly, by creating space for genuine trust and a feeling of communality. Participants perceived peer support as particularly relevant in relation to big changes in life, for example, in family life, at work, or through treat- ment events such as getting an insulin pump |
| Tracy 2018 | To examine the influence of daily sleep quality in patients with type 1 diabetes (T1D) on that of their spouses and to investigate the influence of couples' sleep quality on patients' diabetes-specific stressors and couples' | 14 day diary for sleep quality and presence of general stressors | n=199 couples. (398 individuals)patients with type 1 diabetes and their spouses<br>Age: 47<br>USA | Greater patients' daily sleep quality was related to their spouses' greater sleep quality. Increases in the patients' own daily- and average sleep quality were uniquely associated with fewer next day diabetes-specific stressors. Better own |

|  |  |  |  |  |
|---|---|---|---|---|
|  | general stressors the following day. |  |  | daily- and average sleep quality were associated with fewer general stressors for both partners. Spouses' increased daily sleep quality was associated with fewer general stressors of patients. |
| Van Vleet 2019 | We hypothesized that daily play with one's romantic partner would be linked to better mood, greater diabetes disclosure, greater support receipt, greater perceived coping effectiveness with one's most important daily stressors, and better self-care regarding type 1 diabetes. We examined these hypotheses i | Daily diary measures for 14 days | n=199 adults with type 1 diabetes USA<br>Age 47<br>52% female<br>Race 90% white<br>Hispanic 6% | Daily play was linked to better mood, greater diabetes disclosure to one's partner, greater support received from one's partner, and greater perceived coping effectiveness with the day's most important dia- betes and general stressors. Mediation analyses further indicated that positive mood explained links from daily play to perceived coping effectiveness, and diabetes disclosure explained links from daily play to support. These findings indicate that having fun with one's partner may have important psychological and relationship benefits for individuals with chronic illness. |

Included articles were read completely. Afterwards the text was analyzed using codes to create overarching themes. This was done according to the Bryman coding. First the text of the 12 articles was read as a whole, notes were added and major themes were observed these were highlighted in the text using yellow. In the next step text relevant to answer the research question was highlighted and accompanied by notes and labels for codes. This was done by coping all the highlighted text and to highlight the sentences again by using different colors for groups. In the step after the text was systematically marked with colors, the text was indexed. This was done by hand. Codes were reviewed and grouped (appendix 1) The groups created are:.

- Missing elements in support (red)
- Diabetes distress in patients and partners (green)
- Emotional support and active engagement (yellow)
- Appraisal and collaboration (blue)

In the first 2 pictures you see how the text from the articles was highlighted. The other pages show the text with highlighted colors, refering to themes.

**Figure 1** Analytic approach.

Analyses were performed by the first and last authors, both of whom were present during all workshops. To ensure transparency and validity, the subthemes were presented to workshop participants; their comments and perspectives were incorporated into the analysis. Researchers involved in the workshops also commented on the subthemes.

# Results

## Diabetes-specific loneliness

Among participants, a widespread feeling existed that diabetes was pervasive throughout all aspects of life, and it was thus relevant to discuss diabetes with peers in relation to all aspects of life with type 1 diabetes. In general, participants' descriptions of the function of peer support were connected to a feeling of loneliness related to their diabetes. Participants pointed out their experiences of dissatisfaction with social relations with regard to diabetes that included, 1) being on one's own, 2) lack of connectedness and communality, and 3) lack of feeling understood (Table 3).

### Being on one's own

Participants expressed that they felt "on their own" not only in relation to specific situations, such as travel planning, but also in general in daily life with diabetes, for example, "having no one to talk to" (male, age 35 years) and "having to make your own experiments on how to live well with diabetes" (male, age 46 years). Participants described how questions, feelings, and uncertainties arise in daily life with diabetes; they felt they had to handle most things by themselves. A woman diagnosed in adulthood expressed the feeling of being on her own:

> No matter how good and well-meaning a health care professional is, it is in your everyday life that you face these problems, or challenges I would rather call them, and it is actually here that you need someone to talk to about your day and other things. So, I have to deal with all my thoughts and feelings on my own. Of course I can share these things with my friends and family, but they can … they can only listen, not engage in a dialogue. [Female, age 48 years]

Another woman from the Central Region of Denmark stated:

> I don't have anyone in my everyday life … I have a thing with counting carbohydrates – it would be amazing to come into contact with someone and ask them about how do you do it? and does it have any benefits for you? … and so on. [Age 56 years]

Feeling on one's own also included the feeling of not having enough time with health care professionals.

**Table 3** Main themes based on empirical findings

| Main themes | Empirical subthemes |
|---|---|
| Diabetes-specific loneliness | |
| Being on one's own | Having no one to talk to about diabetes<br>Experimenting individually about how to live well with diabetes in daily life<br>Lacking time with health professionals |
| Lack of connectedness and communality | Feeling different<br>Feeling less worthy/burdensome<br>Feeling shoved out of community |
| Lack of feeling understood | No real dialogue about diabetes<br>No understanding of how difficult it is to live with diabetes |
| Diabetes-specific social capital | |
| Experience sharing | Sharing real-life experiences<br>No professional knowledge |
| Cohesion and collectiveness | Experiencing type 1 diabetes as normal<br>Feeling mutual understanding<br>Being able to mirror oneself in others |
| Trust and confidence | Feeling safe<br>Trusting others<br>Having confidentiality |
| Reciprocity and social participation | Mutual trust and support<br>Necessary similarities and/or benefits of being different<br>Wanting to help and create possibilities for others with type 1 diabetes |

### Lack of connectedness and communality

Participants described feeling "excluded from society", "different than the rest", and "worth less than others". One woman expressed the feeling of "being second-rate" and "being shoved out of the community" in relation to employment: "When there's an economic crisis like we have now, with lots of people unemployed, then having diabetes is a disadvantage, it becomes a kind of sorting mechanism" (age 60 years). She did not inform employers about her diabetes when applying for a new job. In a similar vein, other participants described feeling uncomfortable with others knowing about their diabetes. One woman expressed feeling that society requires people with type 1 diabetes to deal with diabetes in such a way that they do not become a burden. A related comment from another participant described feeling that health care professionals judged her as a number:

> … when you consult the professional you have 15 minutes and it … you are just a social security number … and the lower your average blood sugar level is the better. It's even fine if your blood sugar is a little low at times. That will lower the average [of the clinic's overall population] slightly. It doesn't matter that you are shaking a bit, it's good for your Hba1c! [Female, age 35 years]

Other participants expressed feeling less worthy. A 35-year-old man stated: "I don't think there are any girls who should content themselves with me. I feel like I am a sickness and a burden to people".

### Lack of feeling understood

Participants spoke frequently of experiences of lack of understanding from friends, family, health professionals, and society. A participant expressed the lack of understanding by society very explicitly:

> If there was more recognition in our society, that there is also a lot going on in your head when you get the disease, it would be easier to talk about. I mean, the majority of people seem to be of the opinion that as long as you get your injections you'll be fine … but it's not quite like that. [Male, age 35 years]

Several participants felt that "friends and family can only listen" to their experiences of living with diabetes but cannot "really understand". Participants lacked what they called "a real dialogue about diabetes" with family, friends, and colleagues. Participants also stated that they found it difficult or impossible to have a real dialogue about daily life with diabetes and to feel understood by health care professionals, even though the latter had relevant and important clinical knowledge. However, participants also stated that health care professionals often grasped problems during consultations.

## Diabetes-specific social capital

Participants' views of relevant peer support could be interpreted as a need for diabetes-specific social capital. The need for diabetes-specific social capital included perceptions of the importance of peer support and its ability to create experience sharing, cohesion and collectiveness, trust and confidence, and reciprocity and social participation related to life with type 1 diabetes (Table 3).

### Experience sharing

Participants were very clear in distinguishing between experiences and knowledge when they talked about their need for peer support. As an example, one participant stated:

> We don't like the word "expert" [in relation to peer support]. We talk about experience. We are not experts – we are experienced. One's expertise from living with diabetes cannot necessarily be applied to another person with type 1 diabetes. We live different lives. You cannot do that. [Male, age 57 years]

Participants did not want advice from peers based on general or "medical knowledge" of type 1 diabetes; they preferred to have the opportunity to reflect on their own lives in the light of other's experiences. A 39-year-old woman pointed out that real-life experiences of others can be "the missing link" between knowledge obtained from physicians and how it can be used in their own lives.

Participant preferences for experience sharing included general and more specific topics. More general topics included worries and concerns about living with diabetes and those related to family and work. More specific topics included food, hypoglycemia, travel, sports/exercise, relationship with the doctor/nurse, use of social services, insulin pumps, etc. Participants emphasized that peer support is particularly relevant in relation to big "changes in life", for example, in family or work situations or events such as getting an insulin pump.

### Cohesion and collectiveness

Participants frequently expressed that peer support can create a "safe place" arising from just being among others with type 1 diabetes. A 46-year-old man expressed this feeling in a group discussion: "Just the fact that she [another participant]

Helgeson et al. ( 2015 )
The social environment of youth with and without chronic illness, including type 1 diabetes, is not solely composed of parents and in fact increasingly includes peers. Those with diabetes had less friend support than controls, but there were not group differences in conflicts with friends. Females with diabetes reported less romantic support than control females. Males are not distinct from their peers. It may be more difficult to disclose and discuss diabetes with a romantic partner than a friend, as the relationship is one in which you expect to have a higher level of investment.
General support from a romantic partner may not translate into support that is helpful in regard to diabetes. In fact, having a close rela-tionship with a romantic partner may place additional bur-dens on the individual with diabetes. Taking care of diabetes also might interfere with the more intimate and sexual aspects of romantic relationships.

Helgeson et al ( 2019)

Illnesses such as type 1 diabetes involve daily stressors (e.g., highs and lows in blood glucose, forgetting to check blood glucose) that frequently affect not only the person with diabetes but close relationship partners (Berg. A shared illness appraisal is an individual's perception that the illness is ''our prob-lem'' rather than ''my problem'' or ''your problem.'' Positive outcomes result when dyadic coping involves support or collaboration (Berg et al., 2008b), and negative outcomes result when dyadic coping involves control strategies such as protective buffering (Hagedoorn
Similarly, Bodenmann (1997) outlined a number of positive dyadic coping strategies, one of which—common dyadic coping—largely reflects collaboration (i.e., joint problem-solving, joint information-seeking), but also includes other positive ways of relating to one another (e.g., relaxing together). Patient common dyadic coping has been linked to diet and exercise adherence among persons with type 2 diabetes (Johnson et al., 2013) and to fewer depressive symptoms 5 months later among women with breast cancer (Rottman et al., 2015). The common dyadic coping scale is the subscale that shows the strongest links to good health outcomes (Falconier et al., 2015).
Patient shared illness appraisal should be connected to greater supportive (both emotional and instrumental) and collaborative behaviors involving the partner. When patients perceive that the illness is shared, it may be easier for them to ask for support from partners because they recognize their partners play an active role in diabetes management (Helgeson et al., 2018).
Patients may also be more receptive to support offered by partners because such support is perceived as teamwork or ''working together'' toward a common goal rather than assistance provided to the patient which could be perceived as threatening (Bolger & Amarel, 2007). Similarly, when partners perceive the patient's illness as shared, it may be easier for them to provide support and collaborate with the patient in managing the illness. Partners with a shared illness appraisal expect to be involved in diabetes management, which may make them feel more comfortable providing support and not feel as if they are overstepping any bounds in doing so.

Consistent with Helgeson et al. (2016) who found greater communal coping in couples with longer relationships, we found that patients reported more shared illness appraisals when they had been in longer relationships. With time, partners may become more involved in diabetes and patients may come to view the illness as a shared issue. Thus, intervention efforts that might aim to enhance a

shared illness appraisal in patients and partners might find older couples and couples in longer relationships to be more amenable to such an intervention; however, because younger couples are likely to score lower on this dimension, they may have the most potential to benefit from such an intervention. When individuals have shared illness appraisals, they may interpret their partner's support attempts in the most positive light. In other words, shared illness appraisals may provide the lens through which patients come to view their partners' behavior as more collaborative and supportive. In addition, engaging in collaboration and receiving support from one's partner may lead one to develop a more shared illness appraisal.
A contribution of the present study was in examining both instrumental and emotional support and revealed the important role that emotional support may play in understanding positive health outcomes.

Helgeson et al. ( 2017)

Much of the research in the area of diabetes focuses on either children with type 1 diabetes or adults with type 2 diabe- tes. Although type 1 diabetes is often diagnosed in childhood, 80–85% of those living with type 1 diabetes are adults (1).
shows the strongest relationships to psychological and physical health and is most desired from family, friends, and health care professionals.

Thus, this research focuses, through two specific goals, on how young adults with type 1 diabetes involve their partners in the management of their illness and how their partners respond to diabetes. When asked how partners help with diabetes, the primary response was emotional support, which largely took the form of listening to problems and providing encouragement. In terms of unsupportive interactions, the primary issue identified was that partners were worried or distressed about diabetes. This worry then became a source of concern for the person with diabetes. Two other prominent responses were that part- ners sometimes made it difficult to eat healthy (e.g., buying unhealthy food [16%]) and a lack of emotional support (e.g., failing to understand or being insensitive [13%]). Participants who reported that their partners were not involved enough reported receiving less emotional support from partners and greater partner avoidance compared to participants who were satisfied with their partner's level of involvement. Participants who said their part- ners were involved just the right amount reported lower levels of psy- chological distress than participants whose partners were too involved or not involved enough. Emotional support and in- strumental support were related to higher relationship quality. Avoidance was related to lower relationship quality. Controlling and overprotective behaviors were not related to relation- ship quality. Emotional support was related to less psychological distress. Instrumental support was unrelated to psychological distress. Avoidance and controlling behaviors were both related to more psychological distress. Overprotective behavior was unre- lated to psychological distress. Interestingly, respondents were more likely to perceive the problem as shared than the responsibility as shared. This finding suggests that young adults with diabetes recog-nize that diabetes and its associated difficulties affect both people in the relationship, but they perceive that it is their own responsibility to deal with those problems. People with diabetes seem to be acutely aware that their illness is a source of dis- tress for their partners, which may impair partners' ability to provide support, as well as the willingness of people with diabetes to request support. . When couples approach the illness communally, they benefit from the support provided by partners, but also have to endure partners being overinvolved in the illness. . Emotional support revealed the most robust positive relationships. People who reported receiving more emotional support from their partners reported higher-quality relationships and lower levels of psychological distress. By contrast, instrumental support—concrete assistance—was related to relationship quality but not to the psychological distress index. Individuals also may vary in their desire for instrumental support from partners, whereas desires for emotional support are more likely to be uniform. Receipt of instrumental support could undermine feelings of competence and threaten inde- pendence. We examined two categories of unsupportive interactions: overinvolvement and underinvolvement. A small group of participants reported that their partners were too involved in their diabetes. This group received greater support from partners and had higher relationship quality, but also reported greater controlling and overprotective behaviors on the part of their partners. By contrast, partner underinvolvement in diabetes was clearly linked to poor outcomes. A sizeable minority of individuals reported that they would prefer their partners to be more involved in their diabetes than they actually are. Partner avoidance was more strongly related to psychological distress among females than males, and partner controlling behavior was more strongly related to lower relationship quality for males than females. This study showed that the majority of participating young adults with type 1 diabetes do not view diabetes as a shared problem, but that their partners are involved in diabetes in some way. These findings suggest that future research and clinical care should be aimed at increasing partners' involvement in type 1 diabetes, with the caveat that patient preferences should be taken into consideration. Health care professionals should involve partners in diabetes discussions to facilitate patient-partner communica- tion. The key is to involve partners in the management of diabetes without increasing partner burden because partner distress is a primary concern of patients. To the extent that partners are more knowledgeable about the disease, they can be more helpful to patients, and patients may be less worried about partner distress.

Joensen et al. ( 2016)

Constructs of social capital and loneliness as an interpretive framework is used in this study. Participants pointed out their experiences of dissatisfaction with social relations with regard to diabetes that included, 1) being on one's own, 2) lack of connectedness and communality, and 3) lack of feeling understood (Table 3). Participants expressed that they felt "on their own" not only in relation to specific situations, such as travel planning, but also in general in daily life with diabetes, for example, "having no one to talk to" (male, age 35 years) and "having to make your own experiments on how to live well with diabetes" (male, age 46 years). Participants described how questions, feelings, and uncertainties arise in daily life with diabetes; they felt they had to handle most things by themselves. Participants described feeling "excluded from society", "different than the rest", and "worth less than others". One woman expressed the feeling of "being second-rate" and "being shoved out of the community" in relation to employment. Several participants felt that "friends and family can only listen" to their experiences of living with diabetes but cannot "really understand".

Participants lacked what they called “a real dialogue about diabetes” with family, friends, and colleagues. Participants also stated that they found it difficult or impossible to have a real dialogue about daily life with diabetes. Participants did not want advice from peers based on general or “medical knowledge” of type 1 diabetes; they preferred to have the opportunity to reflect on their own lives in the light of other’s experiences. Participant preferences for experience sharing included general and more specific topics. More general topics included worries and concerns about living with diabetes and those related to family and work. More specific topics included food, hypoglycemia, travel, sports/exercise, relationship with the doctor/nurse, use of social services, insulin pumps, etc. Participants emphasized that peer support is particularly relevant in relation to big “changes in life”, for example, in family or work situations or events such as getting an insulin pump.

Jorgensen et al (2003)
The patients reported a significantly lower rate of severe hypoglycemia compared with cohabitants. Cohabitants’ involvement Among the cohabitants, 45% reported a high degree of involvement, 33% re- ported some involvement, and 22% reported a small degree or no involvement. Among relatives of patients with normal hypoglycemic awareness, 28% reported no involvement and 39% a high degree of involvement compared with relatives of patients with hypoglycemic unawareness (7% reported no involvement and 70% a high degree of involvement). Forty-four percent of the cohabitants reported disturbed sleep due to fear of their partner getting an episode of severe hypoglycemia during nighttime.In conclusion, our study supports the view that the psychosocial impact of hy- poglycemia on family members should receive more attention. Cohabitants of patients with type 1 diabetes who are prone to severe hypoglycemia inevitably get involved in their partners’ disease and should be offered support and education to cope with episodes of severe hypoglycemia.

Morris et al (2006)
A consolidated list of master themes derived from the transcripts included: ‘emotional issues’, ‘lifestyle changes’, ‘control’, ‘thoughts about the future’ and ‘knowledge’. Partners explained that negative feelings concerning control are due to a lack of involvement in the management regimen, which was associated with increased feelings of helplessness and frustration when things go wrong and they cannot help. 2. Partners, like people with type 1 diabetes, require a greater understanding of the condition to enable them to integrate diabetes into their lives and achieve a sense of control in its management. The impact perhaps results from a knowledge
deficit and a need for a greater understanding of diabetes and its management by them both. they explained that these negative feelings are due to a lack of involvement in the management regimen, which was associated with increased feelings of helplessness and frustration when things go wrong and the partner cannot help. However, knowledge acquisition is limited and often obtained second-hand through chance conversations. Yet healthcare professionals assume that partners have the knowledge. the next stage of the research will be to respond to these guidelines and the needs of partners – taking into account the findings from the parallel project – by developing, implementing and evaluating a programme of education and support for them.

Polonsky et al. (2016)

found that T1D partners reported levels of hypoglycemic fear that were, on average, greater than those of their PWD.

Partners of patients with type 2 diabetes experience levels of psychological distress as high or even higher than patients, especially if the partner is female.5 Low levels of concordance suggest that partners can be distressed even if PWDs are not. In sum, there is growing evidence that partners of T1Ds display significant DD, which can affect not only their own quality of life, but also their relationship and partners' diabetes management.

In the current report we address these omissions by addressing the following questions: how common is DD among T1D partners, what are the specific sources of T1D partner distress, and how is T1D partner distress associated with key PWD and T1D partner demographic and contextual factors. These findings suggest that DD in T1D partners is relatively

common, occurring in over 30% of T1D partners. Four major sources ofDDwere identified: hypoglycemia distress (concerns about the threat and danger of severe hypoglycemia in their PWD); emotional distress (the sense of being overwhelmed by the demands of T1D); management distress (concerns and ag- gravations that their PWD is not managing T1D as needed); and role distress (uncertainty regarding how to be involved in their PWD's disease management). However, DD level varied across the four domains. Hypoglycemia distress was the most common source (64.4% of T1D partners), whereas the least prevalent source was management distress (28.4%). The findings add to recent qualitative reports highlighting

the unrecognized plight of many T1D partners4,8 and their needs for education and support. DD found that the majority of the T1D family members they interviewed indicated a lack of understanding and support from friends, family, and healthcare professionals.

Tracy et al. 2018

The results support that sleep quality is a dyadic phenomenon among couples and suggest that better sleep quality may buffer diabetes specific and general stress in couples coping with T1D. These results indicated that patients' and spouses' daily sleep quality were interrelated. such that on days when patients reported having better sleep quality than their average, they reported fewer diabetes-specific stressors on the next day. However, our findings indicate that there is overlap in patient and spouse sleep quality, suggesting that patients' sleep quality reflects, in part, spouses' sleep quality as well. In addition, this study found that daily general stressors of patients with T1D are affected not only by their own daily sleep quality, but also by their spouses' sleep quality. This study found that better average sleep quality was associated with both fewer diabetes-specific and general stressors, and having more diabetes-specific and general stressors on average was associated with poorer sleep quality (between-person effects).

Trief et al. 2017

Interdependence Theory notes that partners in relationships have significant effects on each other (Kelley and Thibaut, 1978), and that it is important to understand these effects if we are to develop interventions that promote collaborative coping and mutual support, and thus help patients and partners alike. . In patients with diabetes, some have warned of potential negative effects of partner involvement, when the spouse becomes the "diabetes police". Focusing on positive aspects of support, better marital quality has been shown to relate to better adherence (Trief). Thus, it is clear that family/partner support is a complex construct, with evidence that family support can result in negative (i.e. conflict) and positive interactions, and that the relationships may help, or hinder, patients in their efforts at self-management. We believe that these studies show that the effect of partners on patients needs to be better understood, and this is especially true for adults with T1D who receive scant research attention. ) named two ways a partner may give support: "active engagement" (AE), when partners openly communicate and solve problems together, and "pro- tective buffering" (PB), when one partner avoids discussion and hides his or her concerns to protect the other. Studies with medical patients found that greater AE relates to greater Relationship Satisfaction. higher AE and lower PB were associated with greater RS. Similarly, PB has a negative association with RS, although results are inconsistent.

Greater AE and less protectiveness related to better RS. and partners, found that greater AE was associated with higher RS (both patients and partners. . They concluded that Over Protection can be "disabling" and decrease self-efficacy, which can in turn increase distress. we cannot determine whether greater perceived AE and less PB and OP cause patients to be more satisfied in their relationships, or whether low satisfaction causes partners to withdraw support. Similarly, while positive support may enhance self-care, and thus better glycemic control, perhaps poorer glycemic control leads partners to withdraw or to be more protective.

Van Vleet et al. (2019
The current work aims to build on this theoretical foundation by testing links from play activities shared with a relationship partner to emotional, relationship, and self-care outcomes among a sample of adults with type 1 diabetes—a group of people who must perform a number of difficult daily tasks as part of their self-care regimen. We expect that play will help reduce the emotional and cognitive toll of daily diabetes management and bond patients to partners, which may increase partners' impact on patients' well-being and self-care. Thus, play will have emotional, relationship, and, ultimately, diabetes management benefits for adults with type 1 diabetes. play is thought to serve a bonding function between partners (Betcher, 1981; Johnson, 2003; Van Vleet & Feeney, 2015b), and so partners may feel more comfortable opening up to each other after participating in a shared play activity. Play may help individuals with type 1 diabetes better regulate their emotions when obstacles to self-care occur by equipping individuals with resources that are necessary for effective diabetes management. Unconscious thought theory (e.g., Dijksterhuis & Nordgren, 2006) suggests that unconscious thought is more adaptive for making complex decisions, while conscious thought is more effective when making simple decisions. For instance, individuals faced with complex decisions per- formed better if they engaged in a distractor activity (presumably because this task offered an opportunity for unconscious thought) than if they spent the same amount of time consciously thinking about the information relevant to their decision. Given that self-care decisions often involve complex information, play may provide an opportunity for patients to unconsciously process such information and arrive at optimal self-care decisions. As such, we expect that play will lead to greater diabetes

disclosure to the partner, which will in turn elicit greater diabetes support from the partner and lead to better self- care.

On days that individuals participated in a play activity with their partners, they reported better mood, they told their partner more about their diabetes issues, they felt their partner was more supportive, and they felt they handled their most pressing diabetes and non-diabetes stressors better than on days they did not play. As a whole, these results suggest that daily play is associated with a positive emotional and relational climate and with feeling one is more effective in handling diabetes stressors but not necessarily better self-care. Although play predicted improved perceived problem-solving (i.e., handling one's stressors effectively) and more open diabetes communication between partners—which we viewed as important elements of diabetes management—this did not translate into better self-care. We suspect that play activities shared together may help relieve stress, strengthen problem-solving abilities, and improve relationship quality for both partners. Findings from this and future work may be used as the basis of interventions in which couples are encouraged to make time for play, with the goal of improving well- being and bringing the partners closer together. From this solid relational base, couples may be better equipped to successfully work as a team in diabetes management.

# 2. INTERVIEW QUESTIONS

Instructies

Algemene instructies
Goedemorgen/middag. Mijn naam is ____. Bedankt dat u tijd heeft om dit gesprek te voeren. Ik ben een Science Communication (wetenschapscommunicatie) student van de TU Delft en dit interview is onderdeel van mijn afstudeerproject. Ik doe onderzoek naar mensen met diabetes type 1. Dit omdat er een samenwerking is tussen de universiteit van madrid en de technische in delft. Zij maken samen met medtronic een nieuwe insulinepomp en willen daarbij een nieuwe app creëren. Ik vond dit een interessant onderwerp, en wilde mij graag focussen op het sociale aspect van diabetes. Daarvoor heb ik een literatuurstudie gedaan, waaruit is gebleken dat sociale ondersteuning erg belangrijk is en dat dit ook kan helpen in het self-care management. Ook kwam er uit de literatuur dat in sommige gevallen ondersteuning van de sociale omgeving niet optimaal is. Er is een bijvoorbeeld een gebrek aan begrip of mensen zijn te betrokken of te weinig betrokken bij de diabetes van iemand in hun nabijheid.

Ik wil in mijn project focussen op mensen met diabetes en hun partner. Ik wil kijken hoe de communicatie tussen deze partijen verloopt. In welke gevallen gaat dit goed en in welke gevallen minder. En zou dit verbeterd kunnen worden of kan ik met een ontwerp de communicatie bevorderen in de gevallen dat het minder goed gaat.

In dit interview zal ik dus vooral vragen gaan stellen over sociale ondersteuning.

In het interview zijn geen goede of foute, gewenste of ongewenste antwoorden. Ik wil dat je je comfortabel voelt bij het beantwoorden van de vragen, als je een vraag niet wilt beantwoorden is dat altijd mogelijk.  Antwoordt zoals je er echt over denkt en over voelt. Het interview beoordeelt niet uw kwaliteiten en prestaties. Ik ben enkel geïnteresseerd in je mening, ervaringen.
Opname instructies
Als het OK is, neem ik ons gesprek op [ALS OK: ZET OPNAMEAPPARATUUR AAN]. Het doel hiervan is dat ik beschik over alle details van ons gesprek maar tegelijkertijd in staat ben een aandachtig gesprek met u te hebben. Alle opmerkingen zullen vertrouwelijk blijven. In de verslaglegging kan het zijn dat sommige opmerkingen van geïnterviewden worden gebruikt, maar we zullen nooit naar individuen verwijzen.
Toestemming instructies
In het deelnemen aan dit onderzoek geeft u expliciet toestemming voor de zojuist genoemde voorwaarden. U geeft hiermee tevens aan dat uw participatie volledig vrijwillig is . Het is op ieder moment mogelijk uw toestemming in te trekken.

Diagnose en invloed van diabetes op leven
Kan je jezelf kort introduceren
Hoe oud was je toen je bent gediagnosticeerd met diabetes?
Hoe gebeurde dat?
Hoe beïnvloedt diabetes je leven nu?
En hoe was dat vroeger, is dat veranderd in door de jaren heen?
Welke hulpmiddelen gebruik je voor je diabetes? Bijvoorbeeld een pomp of een app?
Wat is het verschil in diabetes wanneer je thuis bent of wanneer je op stap bent?
Wat gaat er buitenshuis wel eens mis? En wat binnenshuis?
Is het moeilijker om rekening te houden met diabetes als je thuis bent of buitenshuis?
Welke aspecten van diabetes zie je als positief en welke als negatief en waarom?

Sociaal netwerk
Wie zijn belangrijke personen in je leven en waarom?
Je hebt aangegeven dat je een partner hebt, hoelang duurt deze relatie al?
Hoe was dat vroeger met relaties aangaan? Denk je dat het hebben van diabetes daar een rol in heeft gespeeld?
Hoe is je partner betrokken bij jouw diabetes?
Hoe communiceren jullie hierover? Wist hij hier al veel van af? Hoe heeft hij informatie tot zich gekregen?
Vind je het fijn om het hierover te hebben met je partner?
Is de betrokkenheid van je partner over de tijd veranderd? Zou je willen dat hij meer of minder betrokken zou zijn?
Vind je dat je partner jou goed begrijpt, wat betreft diabetes?

Welke momenten in de afgelopen maand waren het moeilijkst voor je om met diabetes om te gaan? Wat gebeurde er, wie waren erbij, hoe is het afgelopen, had het voorkomen kunnen worden?
Wat was de meest stressvolle diabetes gerelateerde gebeurtenis die je hebt meegemaakt? Wat gebeurde er toen, wie waren erbij, hoe is het opgelost, had dit voorkomen kunnen worden.
Praat je hier nog wel eens over? Weet je partner hiervan af?
Lopen jullie wel eens tegen problemen aan? Hoe lossen jullie die dan op?
Heb je het gevoel dat betere ondersteuning leidt tot betere management van diabetes?

Contact met andere diabeten
Heb je contact met andere mensen die diabetes hebben?
Hoe verloopt dat contact en wat voor soort informatie wisselen jullie uit?
Hoe zijn deze gesprekken over diabetes anders dan de gesprekken over diabetes die je met je partner voert?

Contact met artsen en verpleegkundigen
Hoe verloopt het contact in het ziekenhuis met artsen?
Hoe is het nu bij de internist?
Hoe vaak ga je naar het ziekenhuis?
Met welk gevoel ga je daarheen?
Met wie praat je het vaakst over diabetes? Waarom diegene?

# 3. CODING STEPS INTERVIEWS

Theme: Lack of recognition

Category Misconceptions
Subcategory: Confusion with type 2

Meaning unit: 2  Ja het beïnvloed toch wel 24 7 je leven.Ook al merken vaak de mensen om jou heen dat niet.Heel veel mensen zijn bekend met diabetes type 2 en vragen dan Oh heb je teveel suiker gegeten dan?Mensen zijn vaak te weinig geïnstrueerd dat daar ook een verschil tussen zit.Dat is gewoon soms vervelend.
Condensed meaning unit: Misconceptions they think it is type2 and ask if you have eaten too much sugar
Code: They think you have type 2 and you have eaten too much sugar

Meaning unit: 7 Ik heb nu een leeftijd dat mensen denken dat het diabetes type 2 is. Vaak krijg ik leefstijladviezen, terwijl ik toch niet helemaal overgewicht heb.
Condensed meaning unit: Misconception, people think it is type 2, unwanted advice.
Code: They think you have type 2 and you have eaten too much sugar

Meaning unit: 6 Sommigen vragen wel van goh hoe kom je eraan heb je altijd zo slecht gegeten of slecht voor jezelf gezorgd. Daar kan ik makkelijker mee om gaan omdat ik niet echt het idee geef dat ik zwaarlijvig ben.
Condensed meaning unit: Misconception type 2
Code: They think you have type 2 and you have eaten too much sugar

Meaning unit: 12 Andere mensen die, bv dat is het meeste struikelpunt, is dat mensen niet het verschil weten tussen type 1 en 2. Dat is heel vervelend. Dat is ook wel een paar keer misgegaan in zo’n biologieles. Dat alles op 1 hoop worden gegooid, dan wordt je echt zo vies aangekeken. Dus dan ga ik wel een beetje in de verdediging.
Condensed meaning unit: Misconception type 2, have to defend myself.
Code: I have to defend myself

Meaning unit: 10 Ja soms lichte irritatie die constant vragen ja maar het is toch alleen bij mensen die veel snoepen, dik zijn etc.
Condensed meaning unit: Irritation, only people who eat candy and are fat.
Code: Slight irritation

Meaning unit: 10 Toen de rest van onze vriendengroep in die tijd die was verbaasd en doe dachten allemaal maar je eten toch niet veel en je bent niet dik, dus die dachten allemaal dat het type 2.
Condensed meaning unit: You did not eat too much, you are not fat
Code: They think you have type 2 and you have eaten too much sugar

Subcategory: Misconceptions drugs

Meaning unit: 6 In den haag in een middagpauze in een koffiehuis iets had gekocht om te eten, en ik moest bij bolussen, ik zat op een bankje, er kwam een keurig echtpaar voorbij en ik hoorde ze net tegen elkaar zeggen: zo die junks die zijn tegenwoordig wel mooi gekleed.
Condensed meaning unit: Misconception drugs, people think im using heroin
Code: People think I use heroin

Meaning unit: 3 1x op een terras ging ik spuiten en vroeg iemand oh doe je heroïne, en toen dacht ik ga echt in the out of the open doen.
Condensed meaning unit: Misconception drugs on a terrace.
Code: People think I use heroin

Subcategory: people don’t know what it is

Meaning unit: 11 Ja heel vaak. Vooral over dit dingetje natuurlijk (wijst naar sensor op arm). En ik heb er ook afdrukken van en iedereen van: oh wat heb jij gedaan. En met spuiten meer de oogjes. Mensen zeggen er niet echt

iets over maar kijken van oh wat is zij aan het doen. Sommigen weten het en anderen denken er de gekste dingen over. Ik kan wel tegen de opmerkingen maar ik kan het goed uitleggen en vertellen. Maar opmerkingen zijn er zeker.
Condensed meaning unit: Mensen weten niet wat het is, stellen vragen of kijken alleen maar raar
Code: People ask weird questions

Meaning unit: 3 Je ziet wel eens blikken van mensen, maar ze vragen niet snel. Vaak krijg ik blikken naar mn sensor. Laatst bij de fietsenmaker keek iemand echt zo naar mn arm en zei ze je hebt iets op mn arm. No shit.
Condensed meaning unit: Mensen kijken vaak naar sensor
Code: People stare at me

Meaning unit: 7 Het is heel fijn dat mensen adviezen geven, dat is lief en goed gevoeld, maar het hoeft niet zo.
Condensed meaning unit: Ongewenste adviezen
Code: People give unwanted advice

Meaning unit: 7 Ten eerste dat diabetes zo veel complicaties kan opleveren is bij veel mensen onbekend. In nijmegen een hoogleraar als behandelaar en ik behoor daar ook helaas tot de ja uitzonderingsgevallen. Mijn complicaties zijn best veel. Vele mensen kennen dit niet zo. Ik heb door de jaren heen wel proberen uit te leggen, maar is voor veel mensen ingewikkeld, dat doe ik ook niet meer zo.
Condensed meaning unit: Onbekendheid van de ziekte
Code: Complications of the disease are unknown

Meaning unit: 6 Zeker in het begin vd diabetes heb je ook mentaal minder tot bepaalde dingen in staat bent, ingewikkelde berekeningen maken, oplossingen voor problemen bedenken, analytisch bezig zijn. Ik denk dat ik zeker carrièrekansen gemist heb. Men ziet mij niet als volwaardig aan of dat ik gewantrouwd werd, kunne we dat jou toevertrouwe, kan je dat wel aan. Misplaatste bezorgdheid. Daar kon ik in een bepaalde fase boos om worden, hoe vaak moet ik me bewijzen. Daar krijg je ook de kans niet voor. Vooringenomenheid, je bent chronisch ziek dus je kan het niet, of we hebben nog een diabeet die daar rondloopt en als we die zien dan neeee, doe maar wat rustiger aan. Heel frustrerend, je wordt over 1 kam geschoren, dat doet wel eens pijn.
Condensed meaning unit: Mensen weten niet wat het is. Scheren iedereen over een kam. Vooringenomenheid. Weten niet hoe ermee om te gaan.
Code:  Don’t know how to handle it.

Meaning unit: 6 Maar het is heel confronterend en heel kwetsend om te ervaren dat je door de maatschappij in groot verband wordt gezien als incompleet terwijl er niks aan je te zien is.
Condensed meaning unit: Door de maatschappij gezien worden als incompleet
Code: To be seen by society as incomplete

Meaning unit: 7 Daarnaast loop ik er heel erg tegen aan dat elke poli een eilandje is. Als ik met mijn probleem bij de ene poli ben, ja diabetes komt overal voor, dan moet ik de informatie van de een naar de ander sjouwen. Ik moet overal mijn brede verhaal doen. Ik had mijn middenvoetsbeentje gebroken, weet wel ik voel niks dus ik kan geen gips. Ik moet daar uitleggen waarom ik geen gips kan, ik moet er heel erg voor knokken en dan bereik ik wat ik wil. Uit zichzelf kennen ze heel globaal wat diabetes is, maar verder niet. Alles wat niet bij de hoofdbehandelaar is, moet ik allemaal zelf doen. Dat vraagt soms heel veel. Zeker als je dan, ik ben op zich redelijk mondig en kan m’n verhaal doen, als er iets met mn lijf mis is dan vraagt dat ook energie. Soms heb ik de puf er dan niet voor, maar het moet wel anders gaat het niet goed. Daar lopen veel mensen met diabetes tegenaan.
Condensed meaning unit: Zelfs onwetendheid bij artsen kan leiden tot frustratie.
Code: Even ignorance by doctors (other disciplines)

Meaning unit: 7 Als ik strijd lever had was het met jonge artsen, erg standaard zo heb ik het geleerd en zo ga ik het doen. Ja hangt er ook van af wie de arts is. Die hebben toch een stukje, bredere ervaring, vaker meegemaakt dat iets niet volgens het boekje loopt.

Condensed meaning unit: Strijd met artsen over behandeling
Code: Even ignorance by doctors (other disciplines)

Meaning unit: 9 Ja lage bloedsuiker en mijn meter was leeg. Ik kon niet precies zien hoe laag ik zat en kon er niet op reageren. Ik had niet geprikt, want ik zat bij een docent die het eigenlijk niet zo leuk vond dat ik ziek ben. En die zei ook zo van nee, het is nog maar 20 minuten, blijf maar zitten. De eerste keer dacht ik ik hou het nog wel vol. Bij 5 minuten dacht ik ik ga toch wel, en toen ben ik toch gevallen.En ik had toen ook mijn pomp en die ging af omdat mijn reservoir te laat was. Ik zei: mijn pomp is leeg, ik moet m even vullen. Kost hooguit 10 minuten. Mag ik dat even doen. Nee dat mag niet. Dat ding blijft natuurlijk piepen, want het is best belangrijk dat ik insuline binnenkrijg. Op een gegeven moment piepte die steeds harder. Toen pakte ze dat ding af en trok ze eraan en toen trok ze de canule eruit. Dus ja toen op haar bureau gelegd. Toen heb ik m'n spullen gepakt, opgestaan, mijn pomp van het bureau gepakt, en naar huis gefietst.
Condensed meaning unit: Teachers do not know what diabetes is and act in a completely wrong manner.
Code: Ignorance by teachers

Category: Lack of empathy

Meaning unit: 2 Vaak begrijpt hij mij wel en vaak niet. Hij zegt het maakt hem niet uit en zegt doe maar rustig.
Condensed meaning unit: Snapt niet goed hoe ik mij voel
Code: Dont know how I feel

Meaning unit: 2 Ja als ik er dingen over Vertel dan begrijpt hij het niet zo goed in die zin dat hij zich er niet in kan verplaatsen. Daarom snapt hij het niet. Daarnaast kan ik heel veel mensen die suiker hebben en hij kent er geen één. met hen kan ik wel over zaken praten en Zij snappen het direct. X zegt wel ja en doe maar rustig omdat hij zich daar niet in kan verplaatsen.
Condensed meaning unit: Partner snapt het niet omdat hij zich niet in de situatie kan verplaatsen.
Code: Cannot put themselves in the situation

Meaning unit: 2 Ja maar het basis stukje van diabetes dat snapt hij. Hoe diabetes ontstaat en wat de verschillen zijn tussen verschillende mensen met diabetes dat is voor hem een groot vraagstuk.
Condensed meaning unit: Partner weet de basis maar verder niet
Code: Does know the basics, but not the details. Try to understand it, but don't really get it.

Meaning unit: 2b Ik heb er eigenlijk nooit niks van af geweten totdat ik X heb leren kennen. toen pas is het balletje een beetje gaan rollen. Ik vind het best wel moeilijk om te begrijpen allemaal omdat ik er zelf niet in thuis ben.
Condensed meaning unit: Inlevingsvermogen mist
Code: Cannot put themselves in the situation

Meaning unit: 12 Ik denk dat ze het altijd wel willen begrijpen en dat ze het wel snappen en begripvol zijn van moet je gewoon doen. Maar ik denk niet dat ze het echt snappen, maar dat kan natuurlijk ook niet echt, maar dat stoort me niet. Het is alleen maar fijn dat ze het niet snappen in principe.
Condensed meaning unit: Vrienden snappen het niet
Code: Does know the basics, but not the details. Try to understand it, but don't really get it.

Theme: Motivation

Category: Motivations
Subcategory: Positive influences

Meaning unit: 2 Omdat ik hypo's steeds minder voel aankomen. Ik ben geregeld van de trap gevallen. Het wordt eigenlijk een beetje gevaarlijk en om mijn wens door te zetten.
Condensed meaning unit: Kinderwens om diabetes beter te managen
Code: Wish to have children

Meaning unit: 6 Dingen die niet met diabetes te maken hebben. Plezier in het werk hebben, of resultaat in je werk ziet. Dat je weet dat het goed omgaan van je medische toestand een bijdrage daartoe levert. Het is voor mij persoonlijk moeizaam om uit een goede diabetes huishouding zoveel energie te ontlenen om het nog een stapje beter te doen
Condensed meaning unit: Motivatie haal je uit de dingen die niet met diabetes te maken hebben
Code: Other things than diabetes itself. Have fun at work, know that handling your medical condition contributes to this.

Meaning unit: 10 Omdat ik toen ik in het ziekenhuis kwam wel echt een doel had, ik wil mijn zwarte band nog halen. 1 week voordat ik in het ziekenhuis kwam had ik het examen net niet gehaald. Ik wil iets, en ik heb wel echt een doel in mijn leven wat ik wil bereiken.
Condensed meaning unit: Motivatie om doel in het leven van voor de diabetes te behalen
Code: Reach goals in life that were set before diabetes diagnosis

Meaning unit: 5 Maar wat ook speelt is dat bij mijn laatste controle bij de internist was mij hba1c iets hoger. Een gemiddeld waarde van hoe je de afgelopen 3 maanden heb gezeten. Dat was wat opgelopen, dus nu wil ik het extra goed doen om het wat lager te krijgen.
Condensed meaning unit: Waardes verbeteren omdat waarde is gestegen
Code: Improve values

Meaning unit: 11 Maar ik weet wel dat de band die ik heb met mijn ouders me heel erg heeft geholpen. Ook voor hun wel goed wilde doen
Condensed meaning unit: Het goed willen doen voor anderen die je helpen
Code: Want to do well for others who help

Meaning unit: 3 Eigenlijk is het omslagpunt geweest dat ik met Ryan een relatie kreeg, en dat hij mij is gaan helpen een beetje. En het idee dat ik er niet meer alleen voor stond. Dat hielp mij heel erg om er weer mee aan de slag te gaan. Inmiddels gaat het eigenlijk wel oke. Toen dacht ik als hij, terwijl hij geen diabetes heeft en het eigenlijk niet hoeft te doen, dit wel alsnog voor me wilt doen, dan moet ik ook mijn aandeel brengen. En nu merk ik ook hoe fijn het is om wat stabieler te zijn, dus dat zorgt er ook voor dat ik gemotiveerd ben om ermee door te gaan.
Condensed meaning unit: Het idee dat je het samen doet en er niet alleen voor staat. Goede waardes zorgen er ook voor dat ik me beter voel.
Code: Want to do well for others who help

Subcategory: Negatieve motivaties/frustratie

Meaning unit: 6 Een dag later kreeg ik te horen: nee we nemen je niet aan want je bent diabeet en dat staat op de rode lijst. Geen discussie over mogelijk. Als er nu 1 organisatie is die rekening zou moeten houden met medische aandoeningen van mensen, daar sta je als rode kruis, dan zouden jullie het moeten zijn. Maar er was geen discussie over mogelijk.
Ja, dat soort ervaringen geeft je toch een terugslag op de wijze hoe je met diabetes omgaat. Dan denk ik ik had mn bek moeten houden. Of ik had dit niet moeten vertellen.
Condensed meaning unit: Frustratie, onbegrip, niet motiverend. Buitenaf geen kennis
Code: Frustration

Meaning unit: 6 Maar ik vind het anticiperen en voorbereidingen treffen en organiseren van werk minder lastig dan omgaan met tegenslag als je te horen krijgt we nemen je niet aan, omdat dat je zelfbeeld ondermijnt. Die andere dingen kan je zelf regelen. Maar iemand die de kwalificatie ongeschikt op je plakt, geeft een hele andere vorm van teleurstelling.
Condensed meaning unit: Teleurstelling door mensen van buitenaf

Code: People from outside have no knowledge, a lot of misunderstanding and disappointment.

Meaning unit6 Het heeft zeker invloed op de diabetes zeker om raakvlakken met de neerslachtigheid die kan hebben de wijze waarop je therapietrouw blijft. Ik kan me heel goed voorstellen dat diabete zeggen het kan me gestolen worden, het maakt me niet uit wat mijn waardes zijn. heb ik ook wel eens gehad, zeker in de eerste fase.
Condensed meaning unit: Gevolgen van diabetes. Niet meer gemotiveerd zijn door frustratie
Code: Frustration

Meaning unit: 6 Onderbelicht element van de ziekte, emotie. 2 stappen vooruit en weer eentje terug. Je maakt wel wat teleurstelling mee.
Condensed meaning unit: Teleurstelling door terugvallen
Code: Disappointment

Meaning unit: 6 Ja ik weet hoe het was om geen diabetes te hebben. Emotionele kant nog belangrijker omdat je geconfronteerd wordt met het gemis. Dat gecombineerd met een aantal expliciete afwijzingen omdat je diabetes hebt, dus we kiezen niet voor jou maar voor iemand anders.
Condensed meaning unit: Weten hoe het is zonder diabetes
Code: Knowing what it is like without diabetes

Meaning unit: 3 Na drie maanden aan de bel getrokken, met ik voel me echt doodziek, dit gaat niet zo. Toen bleek dat ik nog geen insuline echt nodig had. Vanaf toen is het niet meer goed gegaan, vooral mentaal ging het heel slecht. Omdat ik dacht dat ik dacht dat de artsen hier meer vanaf moeten weten, en ik heb geen idee wat ik moet doen en zij maken best wel een belangrijke fout. Vertrouwen verloren in de ondersteuning die ik had.
Condensed meaning unit: Vertrouwen verloren in artsen
Code: Loss of confidence in doctors

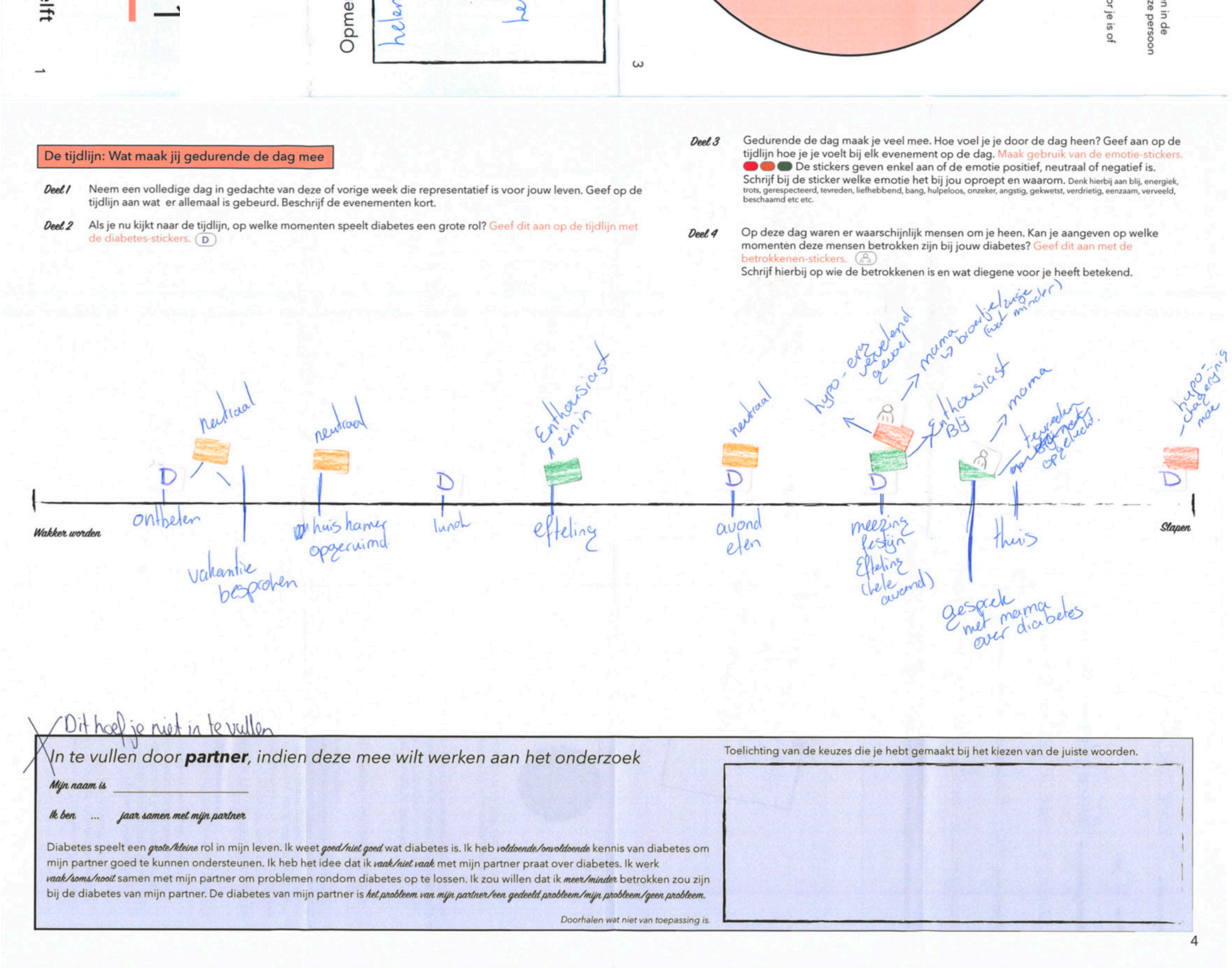
Meaning unit: 6Suikerhuishouding is toch heel subtiel in het bepalen van je stemming. En hoe je op dit moment in je vel voelt zitten.
Condensed meaning unit: suikerhuishouding bepaalt stemming
Code: Influence of blood glucose determines mood

Meaning unit: 12 als ik me niet lekker voelde zei ik dat gewoon. Niet hele diepgaande dingen ofzo. Als ik wel slechte bloedsuikers heb, voel ik me ook slecht. Dan komt alles gewoon in 1x, niet alleen bloedsuiker, maar dan praat ik ook wel vaak met internetvrienden. Maar gaat niet direct over bloedsuikers, maar komt wel door de bloedsuikers.
Condensed meaning unit: Emoties slechte bloedsuikerwaardes, slecht voelen
Code: Influence of blood glucose determines mood

Meaning unit: 10 Als het heel erg hoog is dan ga ik wel iets geïrriteerder weg.
Condensed meaning unit: Emoties, hoog is geirriteerd
Code: Influence of blood glucose determines mood

Meaning unit: 1 En verder praten erover vaak, als ik hoog zit dan ben ik best vaak chagrijnig, beetje aangebrand
Condensed meaning unit: Emoties, hoog zitten chagrijnig
Code: Influence of blood glucose determines mood

# 4. FILLED BOOKLETS



De tijdlijn: Wat maak jij gedurende de dag mee

**Deel 1** Neem een volledige dag in gedachte van deze of vorige week die representatief is voor jouw leven. Geef op de tijdlijn aan wat er allemaal is gebeurd. Beschrijf de evenementen kort.

**Deel 2** Als je nu kijkt naar de tijdlijn, op welke momenten speelt diabetes een grote rol? Geef dit aan op de tijdlijn met de diabetes-stickers. (D)

**Deel 3** Gedurende de dag maak je veel mee. Hoe voel je je door de dag heen? Geef aan op de tijdlijn hoe je je voelt bij elk evenement op de dag. Maak gebruik van de emotie-stickers. 🟥🟧🟩 De stickers geven enkel aan of de emotie positief, neutraal of negatief is. Schrijf bij de sticker welke emotie het bij jou oproept en waarom. Denk hierbij aan blij, energiek, trots, gerespecteerd, tevreden, liefhebbend, bang, hulpeloos, onzeker, angstig, gekwetst, verdrietig, eenzaam, verveeld, beschaamd etc etc.

**Deel 4** Op deze dag waren er waarschijnlijk mensen om je heen. Kan je aangeven op welke momenten deze mensen betrokken zijn bij jouw diabetes? Geef dit aan met de betrokkenen-stickers. 
Schrijf hierbij op wie de betrokkenen is en wat diegene voor je heeft betekend.

~~Dit hoef je niet in te vullen~~

~~In te vullen door **partner**, indien deze mee wilt werken aan het onderzoek~~

*Mijn naam is* ______

*Ik ben ... jaar samen met mijn partner*

Diabetes speelt een *grote/kleine* rol in mijn leven. Ik weet *goed/niet goed* wat diabetes is. Ik heb *voldoende/onvoldoende* kennis van diabetes om mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik *vaak/niet vaak* met mijn partner praat over diabetes. Ik werk *vaak/soms/nooit* samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik *meer/minder* betrokken zou zijn bij de diabetes van mijn partner. De diabetes van mijn partner is *het probleem van mijn partner/een gedeeld probleem/mijn probleem/geen probleem.*

*Doorhalen wat niet van toepassing is.*

Toelichting van de keuzes die je hebt gemaakt bij het kiezen van de juiste woorden.

4

Onderzoek

Diabetes type

rkingen, suggesties, vragen

naal
goed
gedaan
zo!

t was erg duidelijk, en het
opende mijn ogen
een beetje.

5

## Het onderzoek

Bedankt voor je aanmelding en medewerking! Zoals je inmiddels weet doe ik onderzoek naar diabetes type 1 voor mijn afstudeerproject van science communication aan de Technische Universiteit in Delft.

Uit literatuuronderzoek dat ik heb gedaan, is gebleken dat sociale ondersteuning erg belangrijk is voor mensen met diabetes type 1, maar dat de ondersteuning nog niet altijd optimaal is. Ik wil onderzoeken wanneer dit wel goed gaat en wanneer niet en ga op zoek wat hier verbeterd kan worden. Hier zal ik een ontwerp voor gaan maken.

Het onderzoek bestaat uit twee onderdelen: dit boekje en een interview. Het boekje is een voorbereiding op het interview.

In dit boekje maak je opdrachten waarbij je soms stickers op kan plakken. Dit is onderdeel van een methode die het makkelijker maakt om ervaringen te verwoorden en inzichtelijk te maken. Probeer je creativiteit de vrije loop te laten! Voel je vrij om te tekenen als je dat fijn vindt. Een voorbeeld van een ingevuld boekje heb ik naar je gemaild.

De opdrachten gaan over jou. Er zijn dus geen verkeerde antwoorden mogelijk. Ik ben benieuwd naar jouw ervaringen.

De resultaten zullen anoniem verwerkt worden in het verslag dat ik zal schrijven.

Voordat je de opdrachten maakt is het belangrijk dat je het "informed consent" invult. Deze is per mail naar je verzonden. Zo weet je, en ga je ermee akkoord, dat je vrijwillig meedoet en vragen over kunt slaan als je deze niet wilt beantwoorden. Ook kan je op elk moment stoppen zonder daarvoor een reden te geven.

Wanneer je klaar bent met de opdrachten wil ik je vragen het boekje zo snel mogelijk terug te sturen in de daarvoor meegestuurde envelop.

*Xandra*

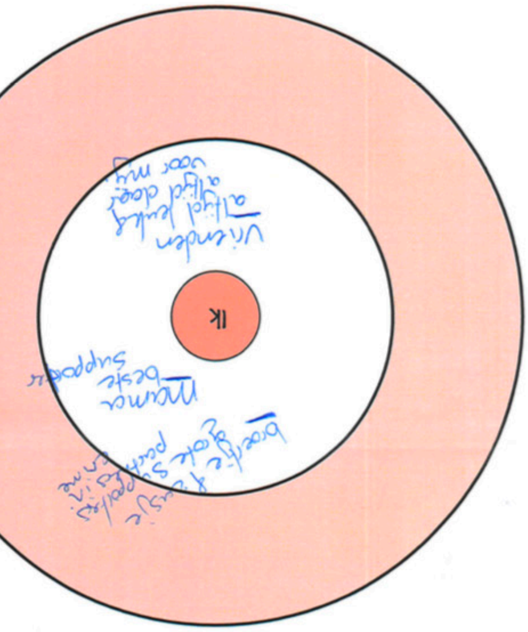
Voor vragen neem contact op via
x.l.vanmegen@student.tudelft.nl
0647075147

2

## De cirkel: Wie zijn belangrijk voor jou

Welke personen zijn belangrijk in jouw leven? Schrijf deze persone
cirkel. Hoe dichterbij je de persoon bij "ik" zet, hoe belangrijker de
voor jou is.

Schrijf bij elk persoon kort op waarom deze persoon belangrijk voo
hoe deze persoon jou helpt.



*Mijn naam is* -

*Ik ben* 21 *jaar*

*Ik word gelukkig van* tekenen, lezen, leren,

outings met vrienden & familie

*Ik ben trots op* het behalen van mijn ♡

in 1 jaar, ondanks alle tegenslagen

*Ik communiceer het liefst via* telefoon of face to face

***Mijn levensmotto***

always be yourself
there are plenty
of others already

## De tijdlijn: Wat maak jij gedurende de dag mee

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**Deel 4** Op deze dag waren er waarschijnlijk mensen om je heen. Kan je aangeven op welke momenten deze mensen betrokken zijn bij jouw diabetes? Geef dit aan met de betrokkenen-stickers. Schrijf hierbij op wie de betrokkenen is en wat diegene voor je heeft betekend.

we werden wakker in een hotel in Duitsland ind ontbeit
je wordt vaak wakker met een lage bloedsuiker dus moet zo snel mogelijk eten

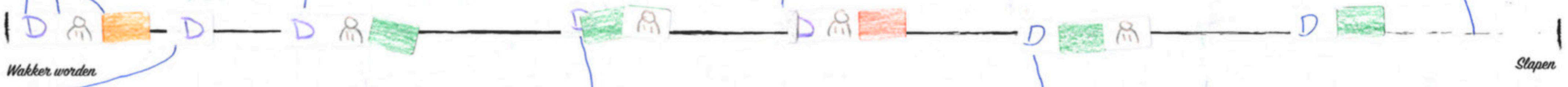
mijn vriend zorgde ervoor dat ik alvast wat te eten had in de tijd dat we wachten op het ontbijt

je voelt een hypo aankomen en krijgt haast

bij aankomst check je nogmaals je waarde je bent bewust van dat je de hele tijd in beweging bent. De mensen waarmee ik was lette ook op hoe ik ben en voel

door de warmte en het vele lopen kreeg ik een hypo
mijn vriend zorgde dat ik wat te eten en drinken had om mijn suiker weer omhoog te krijgen

altijd meten voor het slapen, 8 voor de nacht, eventueel wat eten en je nacht insuline spuiten



we gingen naar movie park met de auto, elke keer voor het rijden moet je weten of je niet te laag komt te zitten

het is lunchtijd ook hier check je je waardes en spuit je insuline voor je lunch

we verlieten het park voor dinner, ook dan weer meten en spuiten voor je maaltijd

### *In te vullen door **partner**, indien deze mee wilt werken aan het onderzoek*

**Mijn naam is** ____________________

**Ik ben** ... **jaar samen met mijn partner**

Diabetes speelt een ***grote/kleine*** rol in mijn leven. Ik weet ***goed/niet goed*** wat diabetes is. Ik heb ***voldoende/onvoldoende*** kennis van diabetes om mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik ***vaak/niet vaak*** met mijn partner praat over diabetes. Ik werk ***vaak/soms/nooit*** samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik ***meer/minder*** betrokken zou zijn bij de diabetes van mijn partner. De diabetes van mijn partner is ***het probleem van mijn partner/een gedeeld probleem/mijn probleem/geen probleem.***

*Doorhalen wat niet van toepassing is.*

Toelichting van de keuzes die je hebt gemaakt bij het kiezen van de juiste woorden.

*Mijn naam is* ______

*Ik ben* 22 *jaar*

*Ik word gelukkig van* Met vrienden en familie zyn en van reizen

*Ik ben trots op* Hoe positief ik in het leven blyf staan

*Ik communiceer het liefst via* face 2 face of watsapp

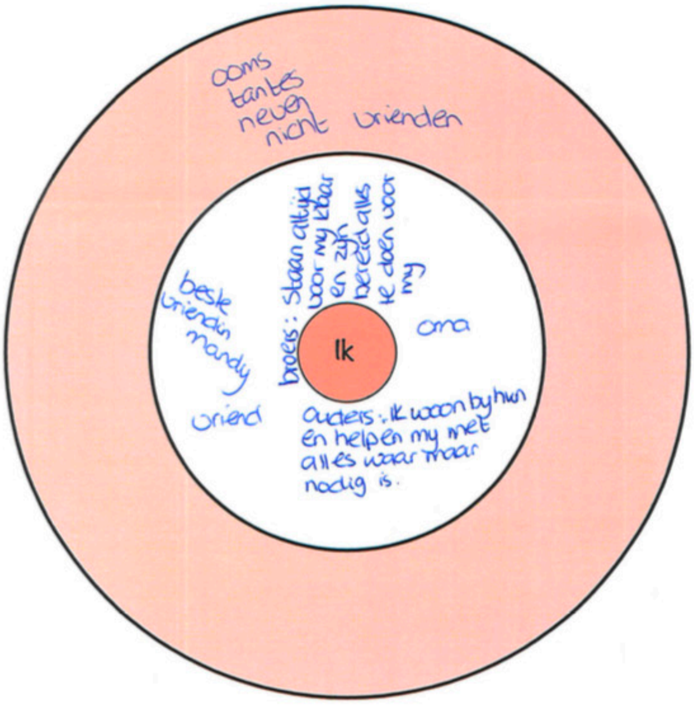
**Mijn levensmotto**

als je het half ken moet je het heel doen.

## De cirkel: Wie zijn belangrijk voor jou

Welke personen zijn belangrijk in jouw leven? Schrijf deze personen in de cirkel. Hoe dichterbij je de persoon bij "ik" zet, hoe belangrijker deze persoon voor jou is.

Schrijf bij elk persoon kort op waarom deze persoon belangrijk voor je is of hoe deze persoon jou helpt.



broers: Staan altijd voor my klaar en zyn bereid alles te doen voor my

ouders: Ik woon by hun en helpen my met alles waar maar nodig is.

oma

beste vriendin mandy

vriend

ooms tantes neven nicht

vrienden

# Onderzoek

# Diabetes type 1

TU Delft

## Het onderzoek

Bedankt voor je aanmelding en medewerking! Zoals je inmiddels weet doe ik onderzoek naar diabetes type 1 voor mijn afstudeerproject van science communication aan de Technische Universiteit in Delft.

Uit literatuuronderzoek dat ik heb gedaan, is gebleken dat sociale ondersteuning erg belangrijk is voor mensen met diabetes type 1, maar dat de ondersteuning nog niet altijd optimaal is. Ik wil onderzoeken wanneer dit wel goed gaat en wanneer niet en ga op zoek wat hier verbeterd kan worden. Hier zal ik een ontwerp voor gaan maken.

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De opdrachten gaan over jou. Er zijn dus geen verkeerde antwoorden mogelijk. Ik ben benieuwd naar jouw ervaringen.

De resultaten zullen anoniem verwerkt worden in het verslag dat ik zal schrijven.

Voordat je de opdrachten maakt is het belangrijk dat je het "informed consent" invult. Deze is per mail naar je verzonden. Zo weet je, en ga je ermee akkoord, dat je vrijwillig meedoet en vragen over kunt slaan als je deze niet wilt beantwoorden. Ook kan je op elk moment stoppen zonder daarvoor een reden te geven.

Wanneer je klaar bent met de opdrachten wil ik je vragen het boekje zo snel mogelijk terug te sturen in de daarvoor meegestuurde envelop.

*Xandra*

Voor vragen neem contact op via
x.l.vanmegen@student.tudelft.nl
0647075147

## Opmerkingen, suggesties, vragen

## De tijdlijn: Wat maak jij gedurende de dag mee

**Deel 1** Neem een volledige dag in gedachte van deze of vorige week die representatief is voor jouw leven. Geef op de tijdlijn aan wat er allemaal is gebeurd. Beschrijf de evenementen kort.

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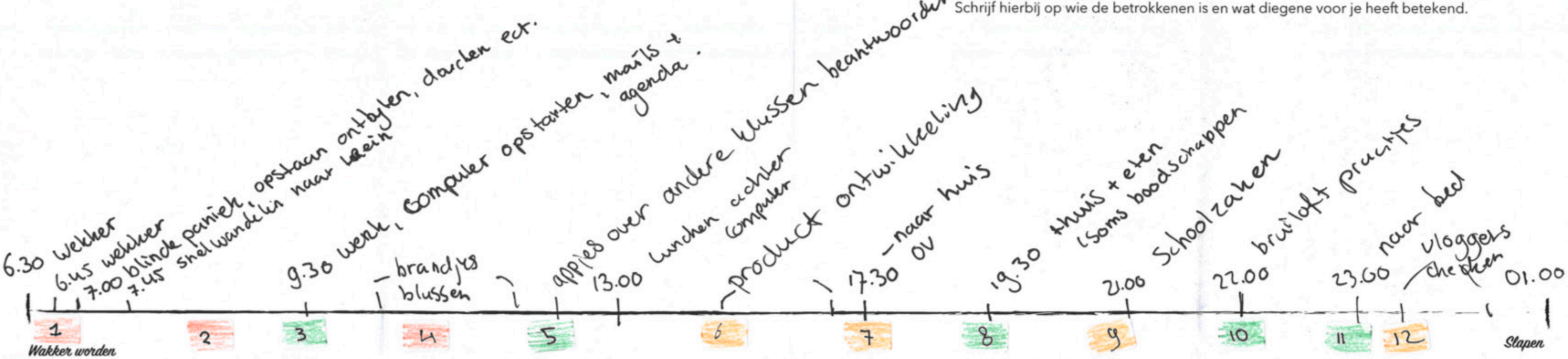
**Deel 4** Op deze dag waren er waarschijnlijk mensen om je heen. Kan je aangeven op welke momenten deze mensen betrokken zijn bij jouw diabetes? Geef dit aan met de betrokkenen-stickers. (👤) Schrijf hierbij op wie de betrokkenen is en wat diegene voor je heeft betekend.



D ~~6:15 wakker worden~~
~~7.15 naar werk~~
~~17.30 terug van werk~~

↗

Dirk wilde ook wat extra's invullen

1. Opstaan = irritatie
2. vermoeid
3. vrolijk
4. irritatie
5. verrast
6. werkend, emotieloos
7. ↗ tevreden & geliefd
8. ↳ [illegible]
9. Soms irritatie, soms geinteresseerd
10. Hyped!
11. vermoeid
12. leegstarende, laatste energie verspillend

D 👤 collega, gewoon interesse

D

D

D 👤 meestal prikken met Dirk het erover hebben en handelen

*In te vullen door* ***partner****, indien deze mee wilt werken aan het onderzoek*

*Mijn naam is* [redacted]

*Ik ben* 4,5 *jaar samen met mijn partner*

Diabetes speelt een *~~grote~~/kleine* rol in mijn leven. Ik weet *goed/~~niet goed~~* wat diabetes is. Ik heb *voldoende/~~onvoldoende~~* kennis van diabetes om mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik *~~vaak~~/niet vaak* met mijn partner praat over diabetes. Ik werk *vaak/~~weinig~~/~~nooit~~* samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik *meer/minder* betrokken zou zijn bij de diabetes van mijn partner. De diabetes van mijn partner is *~~het probleem van mijn partner~~/~~een gedeeld probleem~~/~~mijn probleem~~/geen probleem.*

*Doorhalen wat niet van toepassing is.*

Toelichting van de keuzes die je hebt gemaakt bij het kiezen van de juiste woorden.

we kennen D geen grote rol toe. het is er gewoon. In het begin veel over gepraat, maar laatst is daar minder noodzaak voor. Zeker bij hypo's help ik veel, maar verder is er geen probleem.

# Onderzoek

# Diabetes type 1

TUDelft

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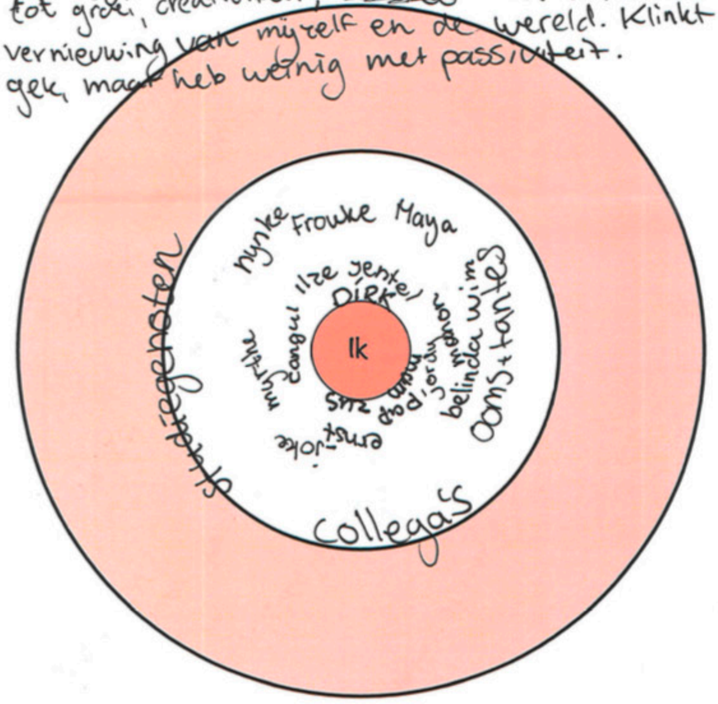
Schrijf bij elk persoon kort op waarom deze persoon belangrijk voor je is of hoe deze persoon jou helpt.

Ik verzamel alleen maar mensen om mijn heen die stimuleren en inspireren tot groei, creativiteit, reflectie en vernieuwing van mijzelf en de wereld. Klinkt gek, maar heb weinig met passiviteit.



*Mijn naam is* ___

*Ik ben* 27 *jaar*

*Ik word gelukkig van* Dirk, eten, fijne gesprekken, theater, kunst, een goed gestylde kamer

*Ik ben trots op* Mijn bedrijf, relatie, hoe een aantal vriendinnen bezig zijn om zichzelf te vinden.

*Ik communiceer het liefst via* echte gesprekken, telefoon, kaartjes, whatsapp, mail (in de huidige volgorde)

**Mijn levensmotto**

Ik heb het nog nooit gedaan, dus ik wil het tenminste proberen

## Opmerkingen, suggesties, vragen

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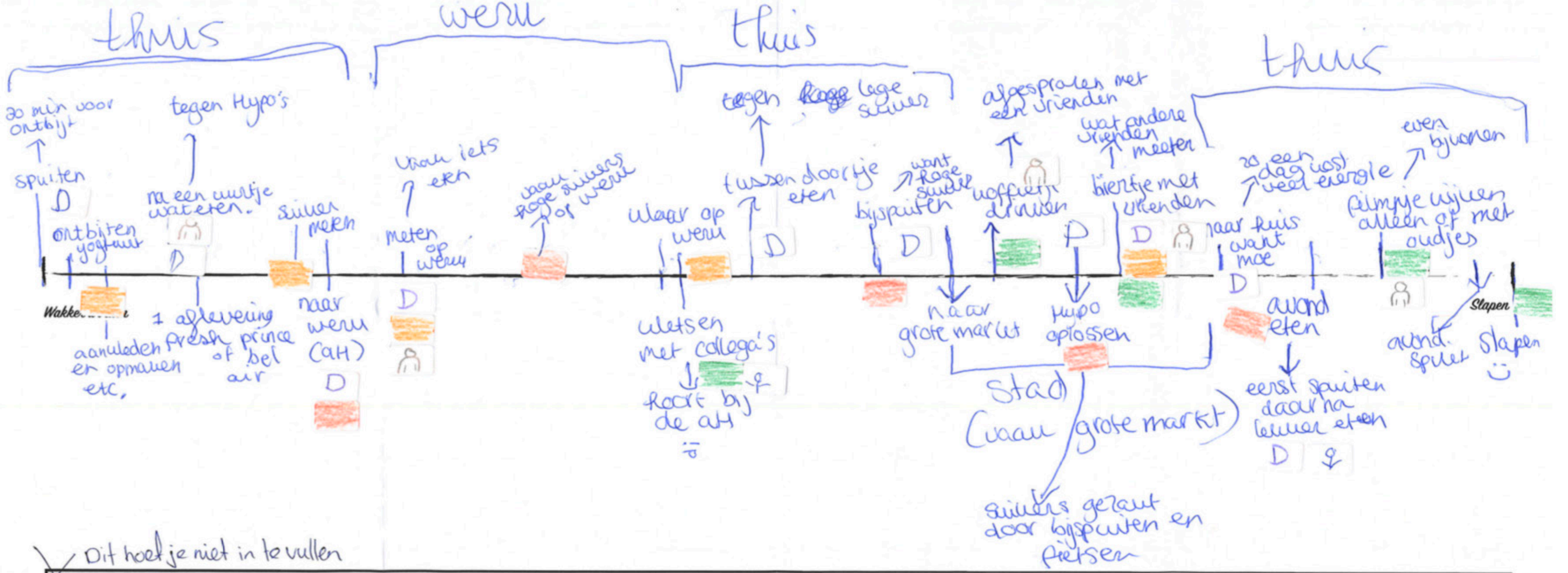

Dit hoef je niet in te vullen

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*Mijn naam is* ____________________

*Ik ben* ... *jaar samen met mijn partner*

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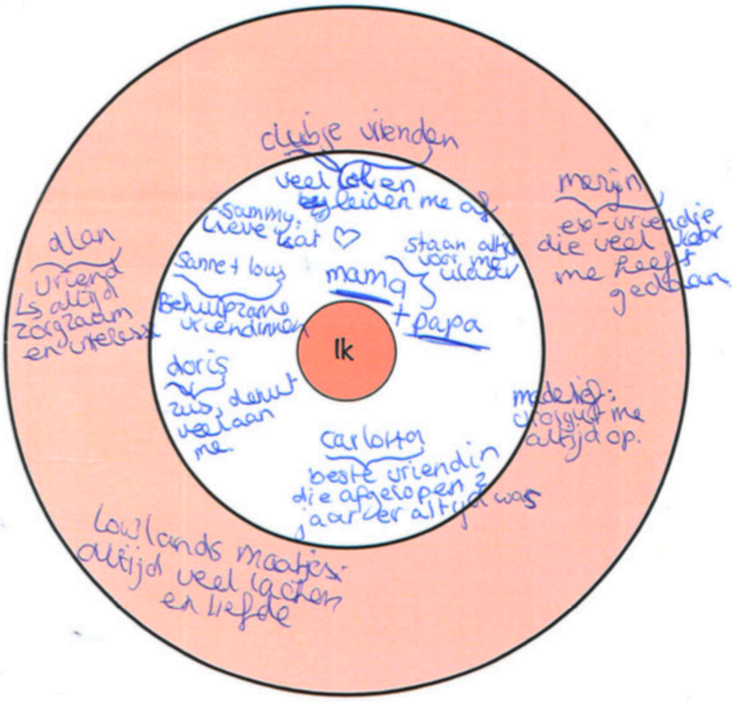

mama + papa: staan altijd voor me klaar

sammy: lieve kat ♡

clubje vrienden: veel lol en leiden me af

Sanne + louy: Behulpzame vriendinnen

doris: zus, denkt veel aan me.

carlotta: beste vriendin die afgelopen 2 jaar er altijd was

alan: vriend is altijd zorgzaam en vrolijk

merijn: ex-vriendje die veel voor me heeft gedaan

medelief: vrolijkt me altijd op.

Lowlands maatjes: altijd veel lachen en liefde

*Mijn naam is* –

*Ik ben* 18 *jaar*

*Ik word gelukkig van* muziek, festivals en lekker eten.

*Ik ben trots op* mijn openheid tegenover mijn diabetes en het doorkomen van moeilijke periodes.

*Ik communiceer het liefst via* persoonlijke gesprekken! Whatsapp is ook prima!

**Mijn levensmotto**

Geniet en heb lief ♡

Opmerkingen, suggesties, vragen

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| | | | | |
|---|---|---|---|---|
| $6^{00}$ | | **Wakker worden** | | 👤 Eva stond eerder op dan ik en heeft even bij mij gemeten |
| $6^{30}$ | 🟥 moe, totaal geen zin om op te staan | opstaan/douchen | | |
| $7^{00}$ | 🟧 wat onzeker denkend aan komende werkdag iets wakkerder | fietsen naar werk | D | |
| $7^{30}$ | wat onzeker, wil goede indruk maken op werk gerespecteerd, na goede slokdarmecho gemaakt te hebben op OK<br>🟧 aan het werk, weinig bijzonderheden wel lange OK in de ochtend. pas om $15^{00}$ kunnen lunchen | werk | D | |
| $17^{30}$ | blij en voldaan/tevreden bijkomen met collega's van zware werkweek 🟩 | vrijdagmiddagborreltje op werk | D | 👤 Gesproken met collega met zwangerschapsdiabetes over impact van diabetes en voeding |
| $18^{30}$ | blij en liefhebbend, samen zijn met Eva 🟩 | met Eva gegeten in de stad en op terras gezeten | D | 👤 Eva denkt mee over hoe om te gaan met de waardes |
| $21^{30}$ | tevreden 🟩 | uitrusten thuis | | |
| $23^{00}$ | tevreden 🟩 | **Slapen** | | |

### *In te vullen door* **partner***, indien deze mee wilt werken aan het onderzoek*

***Mijn naam is*** [redacted]

***Ik ben*** 3,5 ***jaar samen met mijn partner***

Diabetes speelt een *grote*/~~*kleine*~~ rol in mijn leven. Ik weet *goed*/~~*niet goed*~~ wat diabetes is. Ik heb *voldoende*/~~*onvoldoende*~~ kennis van diabetes om mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik *vaak*/~~*niet vaak*~~ met mijn partner praat over diabetes. Ik werk *vaak*/~~*soms*~~/~~*nooit*~~ samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik *meer/minder* betrokken zou zijn bij de diabetes van mijn partner. De diabetes van mijn partner is ~~*het probleem van mijn partner*~~/*een gedeeld probleem*/~~*mijn probleem*~~/~~*geen probleem*~~.

*Doorhalen wat niet van toepassing is.*

Toelichting van de keuzes die je hebt gemaakt bij het kiezen van de juiste woorden.

Diabetes speelt een grote Rol maar is niet overheersend aanwezig binnen ons Relatie.
Ik werk in de zorgen heb er dus voldoende kennis van.
De complicaties die kunnen optreden ken ik hier door ook. Wat ik soms wat zorgelijk vind.
Mijn betrokkenheid vind ik precies goed zo. Als mike twijfelt over bepaalde waardes denk ik met hem mee.
als ik eten kook hou ik er rekening mee door niet teveel koolhydraten erin te verwerken en de etiketten te bewaren. Verder vind ik dat mike er goed mee omgaat en zijn verantwoordelijkheid neemt.
Ik zie het als een onderdeel wat bij ons leven hoort.

# Onderzoek

# Diabetes type 1

TUDelft

---

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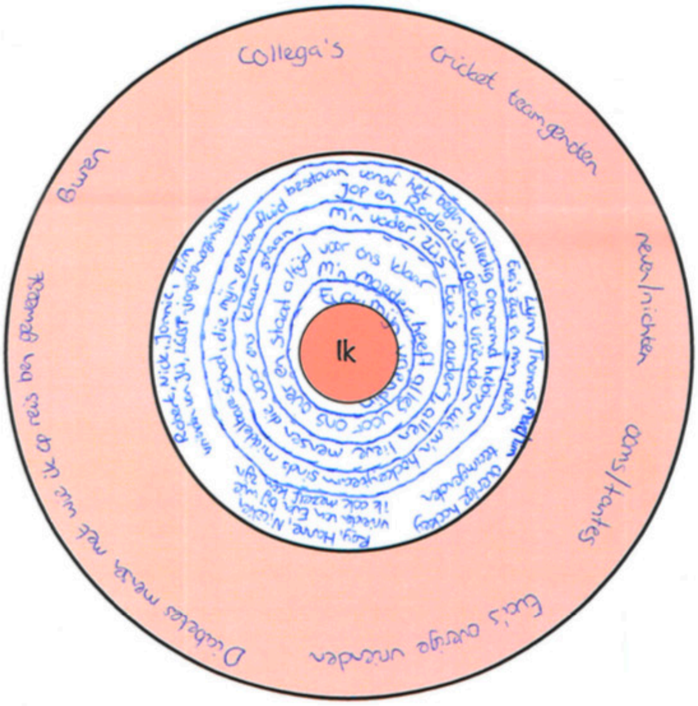

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*Mijn naam is* [illegible]

*Ik ben* 30 *jaar*

*Ik word gelukkig van* Eva, vrienden/familie, sport (met name cricket, kijken en zelf spelen), uiting geven aan mijn non-binaire gevoelens

*Ik ben trots op* Mijn en Eva's werk, onze families, en toch ook wel hoe ik omga met diabetes

*Ik communiceer het liefst via* face-to-face, anders Whatsapp en als dat niet kan e-mail.

**Mijn levensmotto**

Geniet van het leven want het is zo voorbij!

---

## Opmerkingen, suggesties, vragen

Het zijn leuke opdrachtjes. maar ik was er wel iets meer dan 10 minuten per opdracht aan kwijt!

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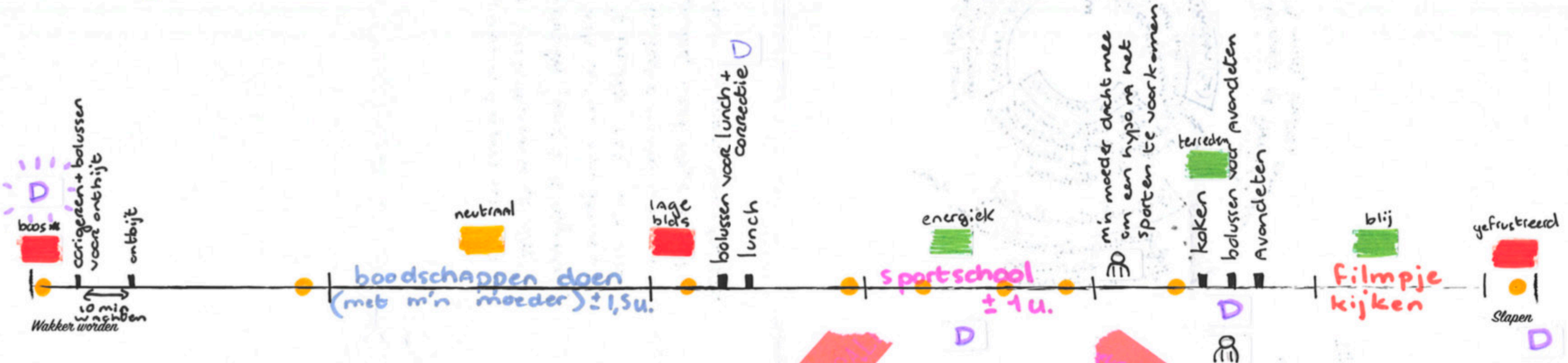
● = cgm scannen (freestyle libre)

vrijdag 9 augustus



hoef je niet in te vullen

In te vullen door **partner**, indien deze mee wilt werken aan het onderzo

gemaakt bij het kiezen van de juiste woorden.

*Mijn naam is* ______________

*Ik ben* … *jaar samen met mijn partner*

Diabetes speelt een *grote/kleine* rol in mijn leven. Ik weet *goed/niet goed* wat diabetes is. Ik heb *voldoende/onvoldoende* kennis mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik *vaak/niet vaak* met mijn partner praat over diabetes. *vaak/soms/nooit* samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik *meer/minder* bij de diabetes van mijn partner. De diabetes van mijn partner is *het probleem van mijn partner/een gedeeld probleem/mijn prob*

Doorhalen wat

# Onderzoek

# Diabetes type 1

## Het onderzoek

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Wanneer je klaar bent met de opdrachten wil ik je vragen het boekje zo snel mogelijk terug te sturen in de daarvoor meegestuurde envelop.

Als het goed is kom ik zaterdag 10aug langs. Je hoeft het dan ook niet terug te sturen

*Xandra*

Voor vragen neem contact op via
x.l.vanmegen@student.tudelft.nl
0647075147

## De cirkel: Wie zijn belangrijk voor jou

Welke personen zijn belangrijk in jouw leven? Schrijf deze personen in de cirkel. Hoe dichterbij je de persoon bij "ik" zet, hoe belangrijker deze persoon voor jou is.

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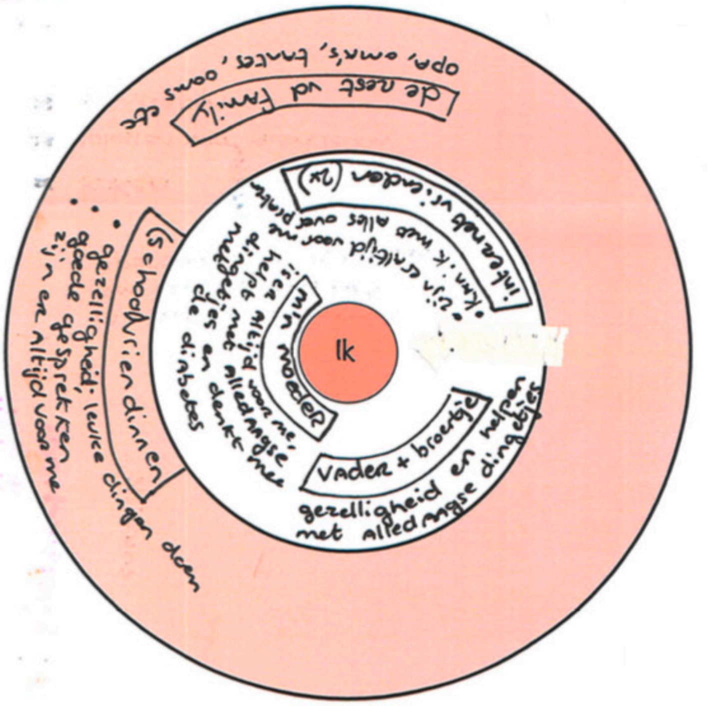

*Mijn naam is* ____

*Ik ben* 18 *jaar*

*Ik word gelukkig van* gezelligheid, Brad (m'n kat), fluffy dingen, lichte ruimtes, woonwinkels etc.

*Ik ben trots op* het feit dat ik al twee rijbewijzen en een gymnasium diploma gehaald heb

*Ik communiceer het liefst via* whatsapp, instagram of snapchat

*Mijn levensmotto*

MET VOLLE ANGST VOORUIT

## Opmerkingen, suggesties, vragen

De tijdlijn loopt van het moment dat je wakker wordt tot het moment dat je gaat slapen, maar ~~[illegible]~~ (over het algemeen) gebeurd er in het leven van iemand met diabetes 's nachts ook heel veel. In mijn geval in ieder geval wel en dan is m'n moeder heel erg betrokken met mijn waardes controleren etc. etc.

## De tijdlijn: Wat maak jij gedurende de dag mee

**Deel 1** Neem een volledige dag in gedachte van deze of vorige week die representatief is voor jouw leven. Geef op de tijdlijn aan wat er allemaal is gebeurd. Beschrijf de evenementen kort.

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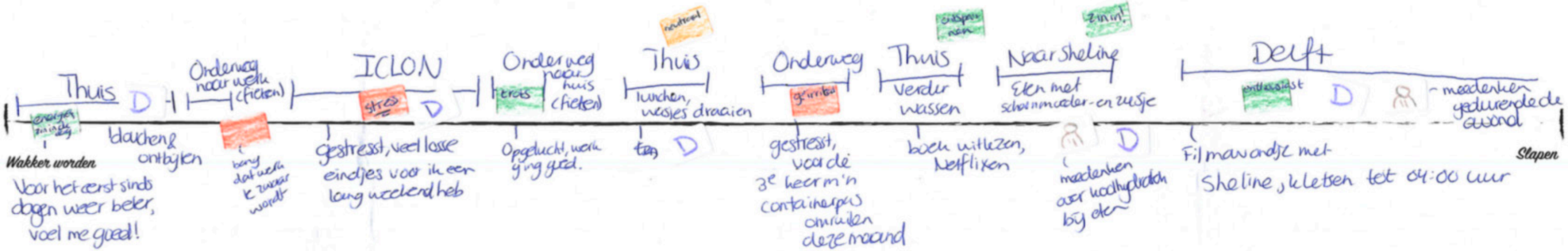

**Wakker worden**

Thuis D

energiek zin in de dag

douchen & ontbijten

Voor het eerst sinds dagen weer beter, voel me goed!

Onderweg naar werk (fietsen)

bang dat werk te zwaar wordt

ICLON

stress

D

gestresst, veel losse eindjes voor ik een lang weekend heb

Onderweg naar huis (fietsen)

trots

Opgelucht, werk ging goed.

Thuis

neutraal

lunchen, wasjes draaien

~~tea~~ D

Onderweg

geïrriteerd

gestresst, voor de 3e keer m'n containerpas omruilen deze maand

Thuis

ontspannen

verder wassen

boek uitlezen, Netflixen

Naar Sheline

Zin in!

Eten met schoonmoeder en zusje

👤 D

meedenken over koolhydraten bij eten

Delft

enthousiast

D 👤 meedenken gedurende de avond

Filmavondje met Sheline, kletsen tot 04:00 uur

**Slapen**

### In te vullen door **partner**, indien deze mee wilt werken aan het onderzoek

***Mijn naam is*** [redacted]

***Ik ben*** 2 ***jaar samen met mijn partner***

Diabetes speelt een ~~grote~~/[✓ kleine] rol in mijn leven. Ik weet [✓ goed]/~~niet goed~~ wat diabetes is. Ik heb [✓ voldoende]/~~onvoldoende~~ kennis van diabetes om mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik [✓ vaak]/~~niet vaak~~ met mijn partner praat over diabetes. Ik werk [✓ vaak]/~~soms/nooit~~ samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik [✓ meer]/~~minder~~ betrokken zou zijn bij de diabetes van mijn partner. De diabetes van mijn partner is ~~het probleem van mijn partner~~/een gedeeld probleem/mijn probleem/geen probleem.

*Doorhalen wat niet van toepassing is.*

Toelichting van de keuzes die je hebt gemaakt bij het kiezen van de juiste woorden.

bij de laatste zin heb ik alleen 'het probleem van mijn partner' doorgehaald omdat ik het zie als iets waar wij samen aan werken (een gedeeld probleem), ik er mij vaak mee bezig houdt (mijn probleem) en omdat als we er samen aan werken het geen probleem kan zijn!

# Onderzoek

# Diabetes type 1

Elisa

## Het onderzoek

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Voor vragen neem contact op via
x.l.vanmegen@student.tudelft.nl
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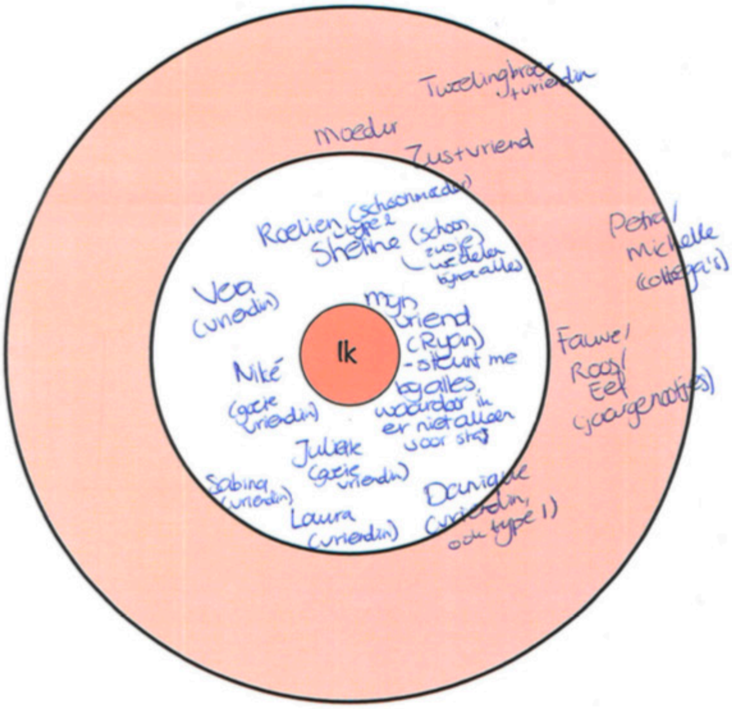

myn vriend (Ryan) - steunt me bij alles, waardoor ik er niet alleen voor sta

Vera (vriendin)

Niké (goede vriendin)

Juliek (goede vriendin)

Roelien (schoonmoeder) type 2

Shelline (schoonzusje) (we delen bijna alles)

Sabina (vriendin)

Laura (vriendin)

Danique (vriendin, ook type 1)

Moeder

Zus+vriend

Tweelingbroer +vriendin

Petra/ Michelle (collega's)

Fauwe/ Roos/ Eef (jaargenootjes)

*Mijn naam is* :

*Ik ben* 24 *jaar*

*Ik word gelukkig van* productieve dagen, vrienden, m'n vriend, familie, een goed boek

*Ik ben trots op* m'n hba1c onder de 60, mijn vriend die me bij alles ondersteunt én z'n eigen leven rockt!

*Ik communiceer het liefst via* whatsapp, bellen, e-mail

**Mijn levensmotto**

Nieuwe dag, nieuwe kansen!
I am greater than my highs and lows.
( I > ^ V )

## Opmerkingen, suggesties, vragen

## De tijdlijn: Wat maak jij gedurende de dag mee

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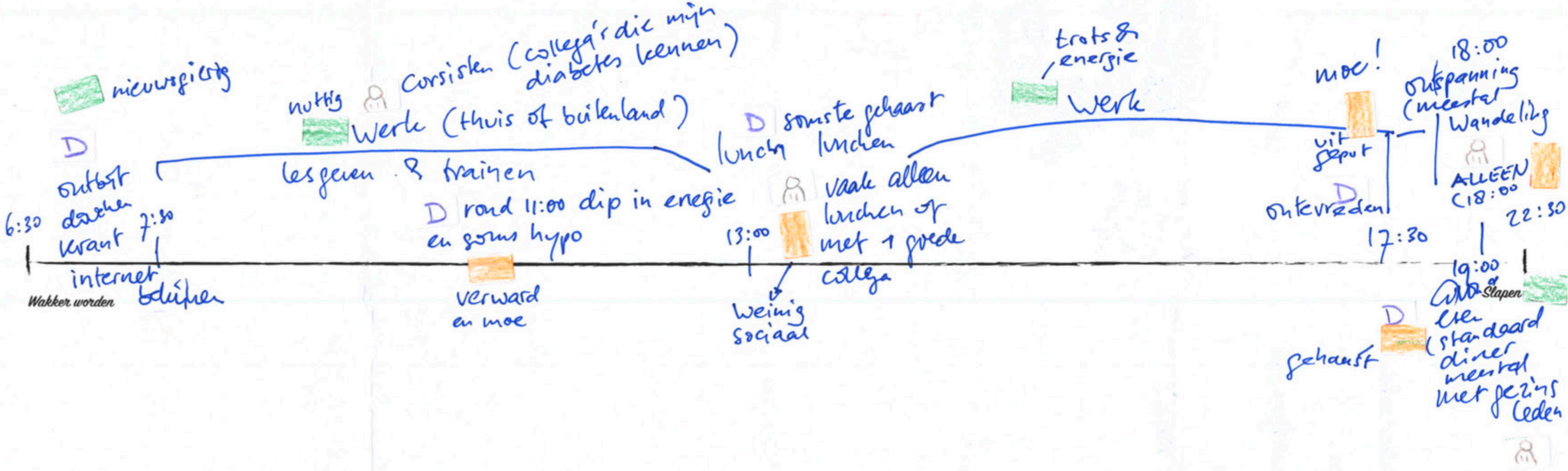

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*Mijn naam is* ______________________

*Ik ben* ... *jaar samen met mijn partner*

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# Onderzoek

# Diabetes type 1

TU Delft

## Het onderzoek

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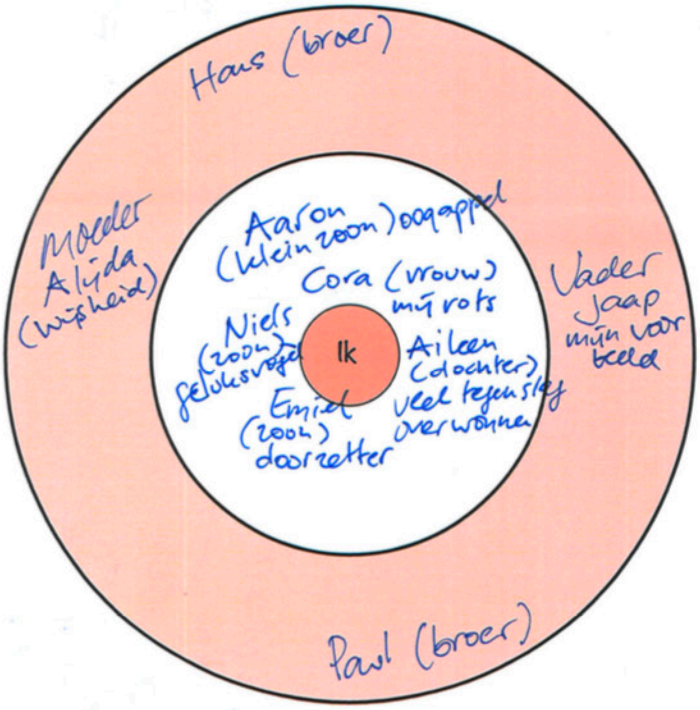

*Mijn naam is*

*Ik ben* 55 *jaar*

*Ik word gelukkig van* blije mensen, lekker eten verre reizen en motor rijden

*Ik ben trots op* mijn kinderen en echtgenote voor wat zij bereikt hebben

*Ik communiceer het liefst via* whatsapp en email

*Mijn levensmotto*

Check and check again!

Opmerkingen, suggesties, vragen

## De tijdlijn: Wat maak jij gedurende de dag mee

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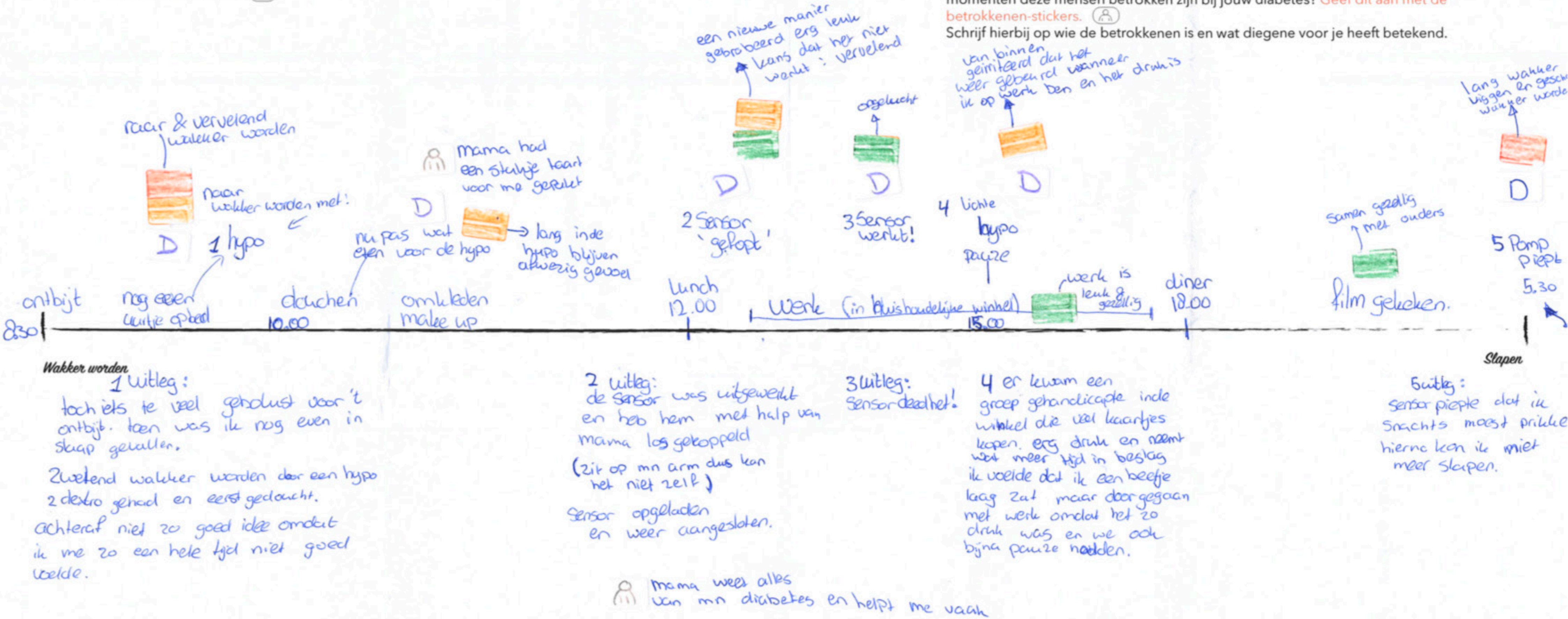

raar & vervelend wakker worden

naar wakker worden met:

nu pas wat eten voor de hypo

lang inde hypo blijven afwezig gevoel

mama had een stukje taart voor me gepakt

een nieuwe manier geprobeerd erg leuk

kans dat het niet werkt : vervelend

opgelucht

van binnen geimiteerd dat het weer gebeurd wanneer ik op werk ben en het druk is

werk is leuk & gezellig

samen gezellig met ouders

lang wakker liggen en gesch wakker worde

1 uitleg:
toch iets te veel gebolust voor 't ontbijt. toen was ik nog even in slaap gevallen.
Zwetend wakker worden door een hypo 2 dextro gehad en eerst gedoucht.
achteraf niet zo goed idee omdat ik me zo een hele tijd niet goed voelde.

2 uitleg:
de sensor was uitgewerkt en heb hem met hulp van mama los gekoppeld
(zit op mn arm dus kan het niet zelf)
sensor opgeladen en weer aangesloten.

mama weet alles van mn diabetes en helpt me vaak

3 uitleg:
Sensor deed het!

4 er kwam een groep gehandicapte inde winkel die veel kaartjes kopen. erg druk en neemt wat meer tijd in beslag ik voelde dat ik een beetje laag zat maar doorgegaan met werk omdat het zo druk was en we ook bijna pauze hadden.

5 uitleg:
sensor piepte dat ik snachts moest prikke
hierna kan ik niet meer slapen.

### *In te vullen door **partner**, indien deze mee wilt werken aan het onderzoek*

**Mijn naam is** ______________________

**Ik ben** … **jaar samen met mijn partner**

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TU Delft

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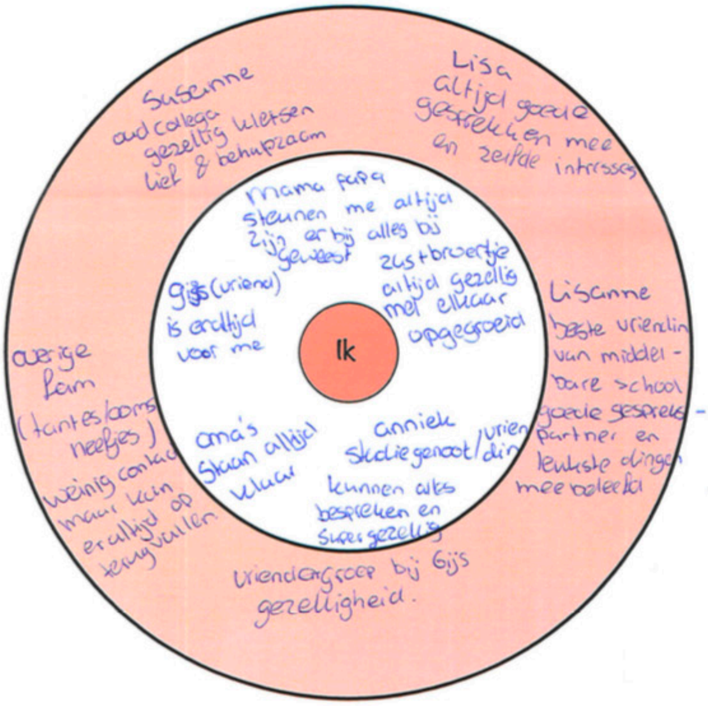


*Mijn naam is* ______

*Ik ben* 20 *jaar*

*Ik word gelukkig van* leuke gezellige momenten met vrienden & familie.

*Ik ben trots op* Mijn schoolloopbaan / prestaties en mijn doorzettingsvermogen.

*Ik communiceer het liefst via* persoonlijk contact of via bellen / Whatsapp.

**Mijn levensmotto**

Fouten en missers horen erbij. blijf kalm en blijf nuchter. geniet van alles!

## Opmerkingen, suggesties, vragen

- De nacht is bij diabeten ook een cruciaal punt waar veel gebeurd.
- Omdat het vakantie is, is dit een hele andere dag voor mij dan de rest van het jaar, waarbij ik minder doe en minder mensen zie.

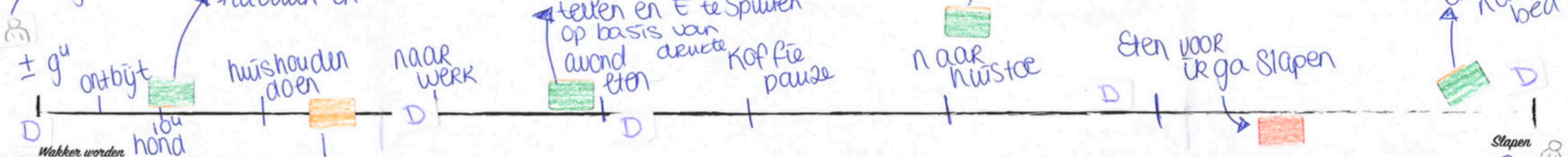
## De tijdlijn: Wat maak jij gedurende de dag mee

**Deel 1** Neem een volledige dag in gedachte van deze of vorige week die representatief is voor jouw leven. Geef op de tijdlijn aan wat er allemaal is gebeurd. Beschrijf de evenementen kort.

**Deel 2** Als je nu kijkt naar de tijdlijn, op welke momenten speelt diabetes een grote rol? Geef dit aan op de tijdlijn met de diabetes-stickers. (D)

**Deel 3** Gedurende de dag maak je veel mee. Hoe voel je je door de dag heen? Geef aan op de tijdlijn hoe je je voelt bij elk evenement op de dag. Maak gebruik van de emotie-stickers. 🟥🟧🟩 De stickers geven enkel aan of de emotie positief, neutraal of negatief is. Schrijf bij de sticker welke emotie het bij jou oproept en waarom. Denk hierbij aan blij, energiek, trots, gerespecteerd, tevreden, liefhebbend, bang, hulpeloos, onzeker, angstig, gekwetst, verdrietig, eenzaam, verveeld, beschaamd etc etc.

**Deel 4** Op deze dag waren er waarschijnlijk mensen om je heen. Kan je aangeven op welke momenten deze mensen betrokken zijn bij jouw diabetes? Geef dit aan met de betrokkenen-stickers.
Schrijf hierbij op wie de betrokkenen is en wat diegene voor je heeft betekend.



Scant Rogé wederom mijn glucose, haalt Snachts eten wanneer ik dit niet kan

Erg moe. Ik zit vaak in nachtelijke hypo's hierdoor sta niet uitgerust op.

± 9u ontbijt

10u hond wandelen

heerlijk samen de natuur in

huishouden doen

Scannen en eten. Moeilijk in te schatten hoe druk het op werk gaat worden.

naar werk

Even uitrusten moeilijk om KH te tellen en E te spuiten op basis van drukte

avond eten

Koffie pauze

Ik werk onregelmatig. Bij een vroege dienst eet ik om 5:30, ga ik werken van 7-15³⁰. Bij thuiskomst kook ik. Gaan Rogé en ik met Ollie de hond wandelen. Ook dan scant Rogé mij vaak 's avonds zit ik vaak in hypo na alle drukte

naar huis toe

altijd fijn 😃

Eten voor ik ga slapen

Ik moet hoog gaan slapen om nachtelijke hypo's te voorkomen

Dood moe, lekker naar bed

Rogé - Scant mij in de nacht de bloedglucose

*In te vullen door* **partner***, indien deze mee wilt werken aan het onderzoek*

*Mijn naam is* [redacted]

*Ik ben* 29 *jaar samen met mijn partner*

Diabetes speelt een ~~grote~~/kleine rol in mijn leven. Ik weet ~~goed~~/niet goed wat diabetes is. Ik heb ~~voldoende~~/onvoldoende kennis van diabetes om mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik ~~vaak~~/niet vaak met mijn partner praat over diabetes. Ik werk ~~vaak~~/soms/~~nooit~~ samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik meer/~~minder~~ betrokken zou zijn bij de diabetes van mijn partner. De diabetes van mijn partner is ~~het probleem van mijn partner~~/een gedeeld probleem/~~mijn probleem/geen probleem~~.

*Doorhalen wat niet van toepassing is.*

Toelichting van de keuzes die je hebt gemaakt bij het kiezen van de juiste woorden.

TUDelft

# Onderzoek

# Diabetes type 1

## Het onderzoek

Bedankt voor je aanmelding en medewerking! Zoals je inmiddels weet doe ik onderzoek naar diabetes type 1 voor mijn afstudeerproject van science communication aan de Technische Universiteit in Delft.

Uit literatuuronderzoek dat ik heb gedaan, is gebleken dat sociale ondersteuning erg belangrijk is voor mensen met diabetes type 1, maar dat de ondersteuning nog niet altijd optimaal is. Ik wil onderzoeken wanneer dit wel goed gaat en wanneer niet en ga op zoek wat hier verbeterd kan worden. Hier zal ik een ontwerp voor gaan maken.

Het onderzoek bestaat uit twee onderdelen: dit boekje en een interview. Het boekje is een voorbereiding op het interview.

In dit boekje maak je opdrachten waarbij je soms stickers op kan plakken. Dit is onderdeel van een methode die het makkelijker maakt om ervaringen te verwoorden en inzichtelijk te maken. Probeer je creativiteit de vrije loop te laten! Voel je vrij om te tekenen als je dat fijn vindt. Een voorbeeld van een ingevuld boekje heb ik naar je gemaild.

De opdrachten gaan over jou. Er zijn dus geen verkeerde antwoorden mogelijk. Ik ben benieuwd naar jouw ervaringen.

De resultaten zullen anoniem verwerkt worden in het verslag dat ik zal schrijven.

Voordat je de opdrachten maakt is het belangrijk dat je het "informed consent" invult. Deze is per mail naar je verzonden. Zo weet je, en ga je ermee akkoord, dat je vrijwillig meedoet en vragen over kunt slaan als je deze niet wilt beantwoorden. Ook kan je op elk moment stoppen zonder daarvoor een reden te geven.

Wanneer je klaar bent met de opdrachten wil ik je vragen het boekje zo snel mogelijk terug te sturen in de daarvoor meegestuurde envelop.

*Xandra*

Voor vragen neem contact op via
x.l.vanmegen@student.tudelft.nl
0647075147

## De cirkel: Wie zijn belangrijk voor jou

Welke personen zijn belangrijk in jouw leven? Schrijf deze personen in de cirkel. Hoe dichterbij je de persoon bij "ik" zet, hoe belangrijker deze persoon voor jou is.

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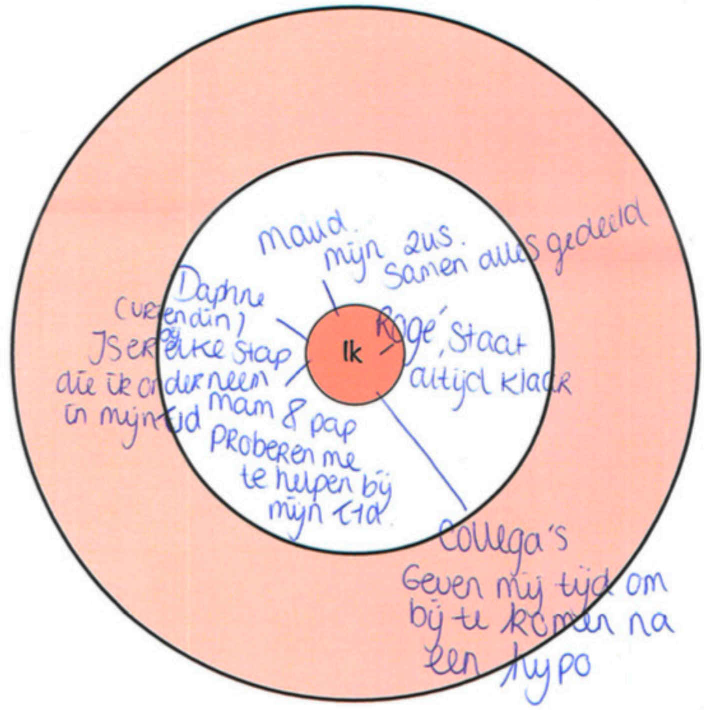

*Mijn naam is*

*Ik ben* 21 *jaar*

*Ik word gelukkig van* Leuke dingen te doen met vriend en vriendinnen. En tijd door te brengen met mijn huisdieren.

*Ik ben trots op* mijn beroep en hier in afgestudeerd te zijn (verpleegkundige)

*Ik communiceer het liefst via* de telefoon, niet altijd. Is fijn om dingen te delen die je moeilijk vind om te zeggen.

**Mijn levensmotto**

"meer dan één nummer."

Opmerkingen, suggesties, vragen

Een hele leuke en creative manier om mee te mogen doen

## De tijdlijn: Wat maak jij gedurende de dag mee

**Deel 1** Neem een volledige dag in gedachte van deze of vorige week die representatief is voor jouw leven. Geef op de tijdlijn aan wat er allemaal is gebeurd. Beschrijf de evenementen kort.

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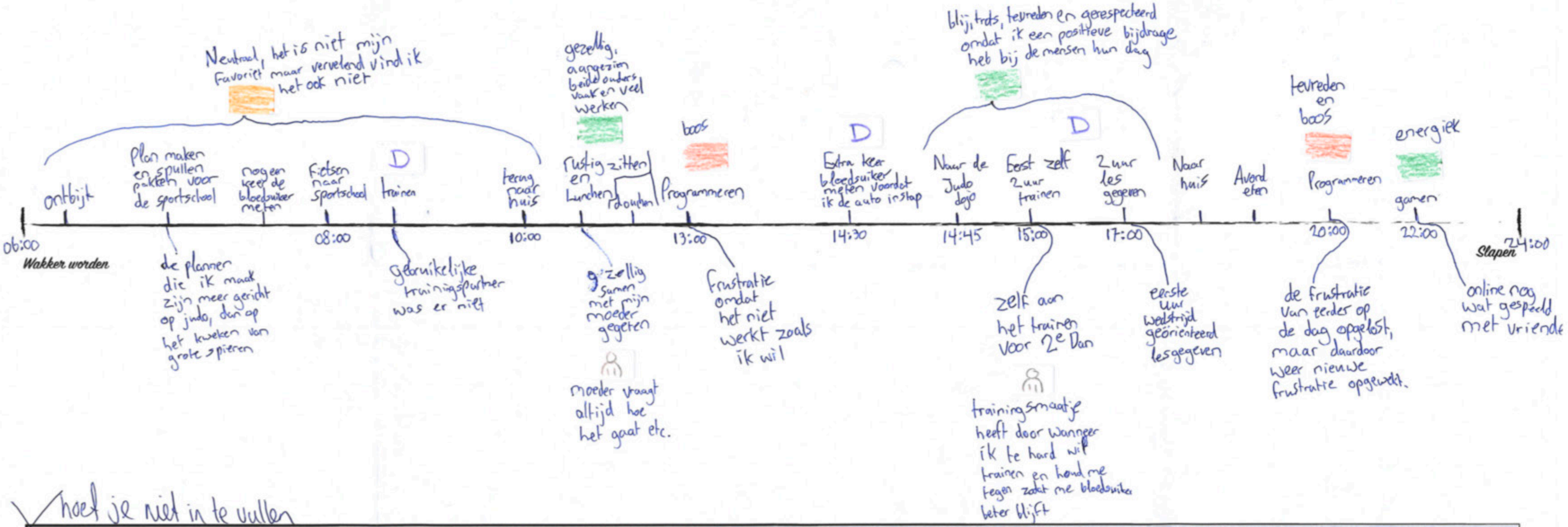
Schrijf hierbij op wie de betrokkenen is en wat diegene voor je heeft betekend.



06:00 **Wakker worden**

ontbijt

Plan maken en spullen pakken voor de sportschool

de planner die ik maak zijn meer gericht op judo, dan op het kweken van grote spieren

nog een keer de bloedsuiker meten

08:00 Fietsen naar sportschool

D

trainen

Gebruikelijke trainingspartner was er niet

10:00 terug naar huis

🟧 Neutraal, het is niet mijn Favoriet maar vervelend vind ik het ook niet

rustig zitten en Lunchen

🟩 gezellig, aangezien beide ouders vaak en veel werken

gezellig samen met mijn moeder gegeten

👤 moeder vraagt altijd hoe het gaat etc.

douchen

13:00 Programmeren

🟥 boos

frustratie omdat het niet werkt zoals ik wil

D

14:30 Extra keer bloedsuiker meten voordat ik de auto instap

14:45 Naar de Judo dojo

D

15:00 Eerst zelf 2 uur trainen

zelf aan het trainen voor 2e Dan

👤 trainingsmaatje heeft door wanneer ik te hard wil trainen en houd me tegen zodat me bloedsuiker beter blijft

17:00 2 uur les gegeven

eerste uur wedstrijd geöriënteerd lesgegeven

🟩 blij, trots, tevreden en gerespecteerd omdat ik een positieve bijdrage heb bij de mensen hun dag

Naar huis

Avond eten

20:00 Programmeren

🟥 tevreden en boos

de frustratie van eerder op de dag opgelost, maar daardoor weer nieuwe frustratie opgewekt.

22:00 gamen

🟩 energiek

online nog wat gespeeld met vriende

**Slapen** 24:00

hoef je niet in te vullen

*In te vullen door **partner**, indien deze mee wilt werken aan het onderzoek*

***Mijn naam is*** ____________________

***Ik ben*** … ***jaar samen met mijn partner***

Diabetes speelt een *grote/kleine* rol in mijn leven. Ik weet *goed/niet goed* wat diabetes is. Ik heb *voldoende/onvoldoende* kennis van diabetes om mijn partner goed te kunnen ondersteunen. Ik heb het idee dat ik *vaak/niet vaak* met mijn partner praat over diabetes. Ik werk *vaak/soms/nooit* samen met mijn partner om problemen rondom diabetes op te lossen. Ik zou willen dat ik *meer/minder* betrokken zou zijn bij de diabetes van mijn partner. De diabetes van mijn partner is *het probleem van mijn partner/een gedeeld probleem/mijn probleem/geen probleem.*

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**TU**Delft

# Onderzoek

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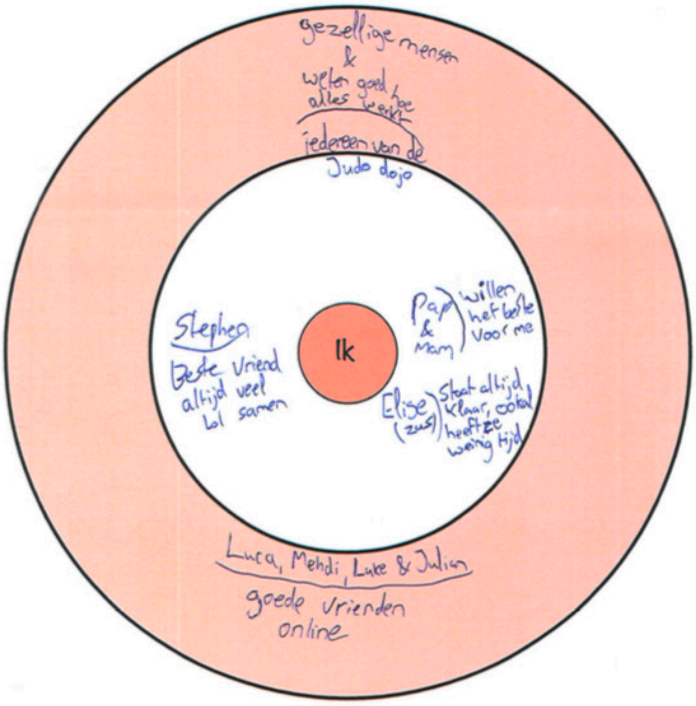


Stephen
Beste Vriend altijd veel lol samen

Pap & Mam
willen het beste voor me

Elise (zus)
Staat altijd klaar, ook al heeft ze weinig tijd

gezellige mensen & weten goed hoe alles werkt
iedereen van de Judo dojo

Luca, Mehdi, Luke & Julian
goede vrienden online

*Mijn naam is* ____________

*Ik ben* 19 *jaar*

*Ik word gelukkig van* Het zien dat de mensen om mij heen gelukkig zijn. En van judo.

*Ik ben trots op* Mijn zus en ouders

*Ik communiceer het liefst via* Gesprekken & via judo (vrij abstract)

**Mijn levensmotto**

It is not important to be better than someone else, but to be better than yesterday.

Opmerkingen, suggesties, vragen

# 5. IDEA GENERATION

## Hoe Kun Je informatie delen op een leuke manier?

## Hoe Kun Je informatie verkrijgen op een leuke manier?

Leren

Interactieve lezingen

Naar bijeenkomsten gaan

Information on demand

Adaptive

Filmpjes

Actief dingen doen

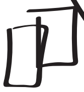
## Hoe Kun Je ingewikkelde informatie begrijpelijk maken?

Spel spelen

Visualisatie

Voorbeelden geven

Praktijk



Myth cards

Makkelijk deelbaar

Visualisatie

Bekijken mensen sneller dan lezen

Linken aan belevingswereld van ontvanger

Begrijpbaar voor meerdere mensen dan taal

Challenges

Entertainment

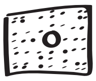
Stapsgewijs opbouwen, overzicht

Card game

Meer informatie in korte tijd

Begrijpbaar van jong tot oud

Board game



Betere inbeelding

Vragen stellen

Taalgebruik, terminologie

Persoonlijk maken

Tinder like, match or no match

Calendar with informations

Fotos, tekeningen, grafieken, schema's, video's

Kwartet

Verrassing

Dextro papiertje vraag

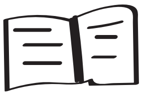
## Hoe Kun Je informatie persoonlijk maken?

Een dag visualiseren

Tijdlijn invullen, weekenden, werkdag, uitje

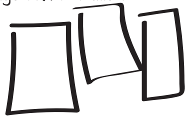
Flipbook

Bekende mensen als rolmodel



Interactive book

Kaartenspel waarbij je zelf dingen kan invullen



Workshop

Stripverhaal

Dagboek voor een ander

Verhaal

## Hoe Kun Je mensen motiveren informatie tot zich te nemen?

Experience

Complimenten geven

Laten zien waarom het goed is

Specifiek maken

Doelen stellen en halen

Eye opener

Duidelijke instructies

Tips, positive

## Welke voordelen heeft het als mensen het beter begrijpen

Goede beslissingen maken

Snappen waarom dingen gebeuren

Zelf actie kunnen ondernemen

Snappen hoe het werkt

Beter voelen. Weten waarom en wat je kan doen

Sneller zelf anticiperen

Minder angstig zijn, omdat ze weten hoe het moet of hoort te zijn. Wanneer dit niet zo is, actie ondernemen.

Uitleggen aan omgeving

Risico's inzien van eigen handelen

Beter weten wat er gebeurd als het niet goed gaat

## Hoe Kun Je in een relatie behoeften, verwachtingen bespreekbaar maken?

Relatietherapeut

Spelen

Vertrouwenspersoon

Band opbouwen

Schrijven

Anoniem

Relativeren

Laten zien waar behoefte aan is

Niet dingen aannemen, aanvullen of aanvallen

Gevoelens onder woorden brengen

Vertrouwen

Praten

Vragen stellen

Dilemmas

Persoonlijke behoeften

Vertel over jezelf, dat kan de ander opener maken

Inleven in de ander

Kennis opdoen

Stel vragen

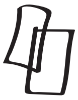
+

Positieve punten

Persoonlijk maken

Elkaar geruststellen

Myth cards



Feedback

Punten voor verbetering

Inleven in de ander

Samen afspraken maken

Op elkaar inspelen, aanvullen

Verdiepen in elkaar

Elkaar een spiegel voorhouden

Situation cards, what would you do

Karaktertrekken

Complimenten geven

Patronen herkennen en keuzes maken

Er de tijd voor nemen

Op zoek gaan naar dingen die je weerhouden

## Hoe Kun Je aangeven dat je het ergens over wilt hebben of dat iets niet goed gaat?

Persoonlijk maken

Een apparaat wat oplicht wanneer je wilt praten

Sleutelhanger als reminder

Hoe voel jij je, hoe voelt de ander zich, waardoor komt dat, hoe kunnen jullie elkaar helpen

Licht op wanneer er iets gebeurd

## Hoe Kun Je inlevingsvermogen verbeteren?

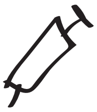
Iets fysieks dat uitbeeld hoe men zich voelt

Linken aan belevingswereld van de ander

Geluid opnemen

Gevoelens aangeven en erover praten

Herkenning



Dingen uitleggen op een niveau dat de ander het ook snapt

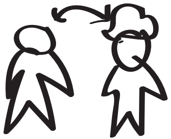
Opschrijven

Ook bloedsuiker prikken en iets inspuiten

Naar verhalen luisteren

Opdrachten uitvoeren

Rollenspel spelen
Patient <-> Partner



Relevant en praktisch maken

Ervaren hoe ben ik tijdens een hypo

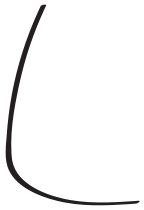
Touwtjes in handen bij patient

Iemand schaduwen

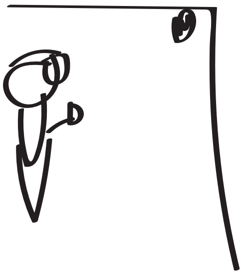
Draai een dag mee

Simulator met virutal reality

Pop-ups gedurende de dag



Naar bijeenkomsten gaan



buddy/ fictional character asking, how was your day

# Hoe Kun Je leren van anderen?

Praten

Feedback geven

Ervaringen delen

Samen problemen oplossen

Samen dingen doen

In bepaalde situaties terecht komen

Naar elkaar kijken

Lezen en schrijven

Vraagspelletjes spelen
Reden achter antwoord begrijpen

# 6. CO-DESIGN SESSION - IDEAS

## App met dilemma's, vragen, wat als ..., eigen input

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

Lijkt me een leuk iets om te doen met goede vrienden/familie die je niet elke dag ziet,
maar wel close mee bent.
Fysieke kaarten is "gezelliger", maar app kan ook.
Lijkt me ideaal om familie/vrienden en kennis van te laten nemen,
maar ook om met andere diabetes ervaringen uit te wisselen.

*Tips om je op gang te helpen:*

Wat voor soort vragen zou je willen beantwoorden? Kennis vragen over diabetes, dilemma's, hoe te handelen in verschillende situaties, behoeften en verwachtingen van jou en je partner?
Op welk moment zou je de app willen openen en spelen?
Welke inzichten zou je willen krijgen met het gebruik van deze app?
Zou je eigen input willen leveren? Antwoord krijgen op eigen vragen van de ander?

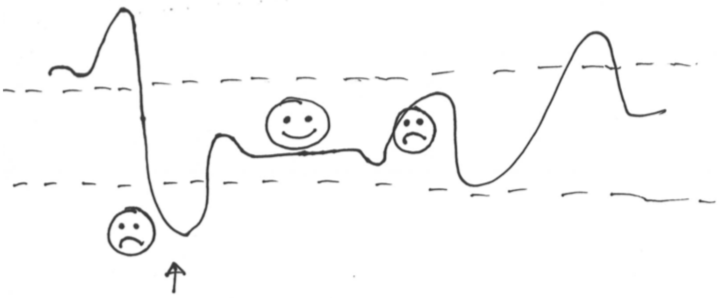
Zou je het in de vorm van een app willen spelen, of zou je liever fysieke kaarten hebben?

Zou je het individueel willen spelen of altijd in het samenzijn van de ander?

## Gevoel aangeven bij data/grafieken

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.



van deze hypo werd ik
wakker. Eva heeft er niks
van gemerkt. Wat gedronken
en weer gaan slapen.

Het liefst hou ik veel emoties voor mezelf.
Vooral omdat ik er continu mee bezig ben,
ook omdat het soms in gedrag niet merkbaar
is dat ik er mee bezig ben.
Aan de andere kant is het essentieel dat
naasten kunnen ingrijpen als het nodig is, dus
die moeten volledig op de hoogte zijn, kunnen
meten en kunnen ingrijpen

*Tips om je op gang te helpen:*
Aan welke gegevens zou je de emoties koppelen? Waardes van de pomp, glucosemeter, overzicht in een app etc? Teken bijvoorbeeld de grafiek van deze dag als startpunt op het papier.

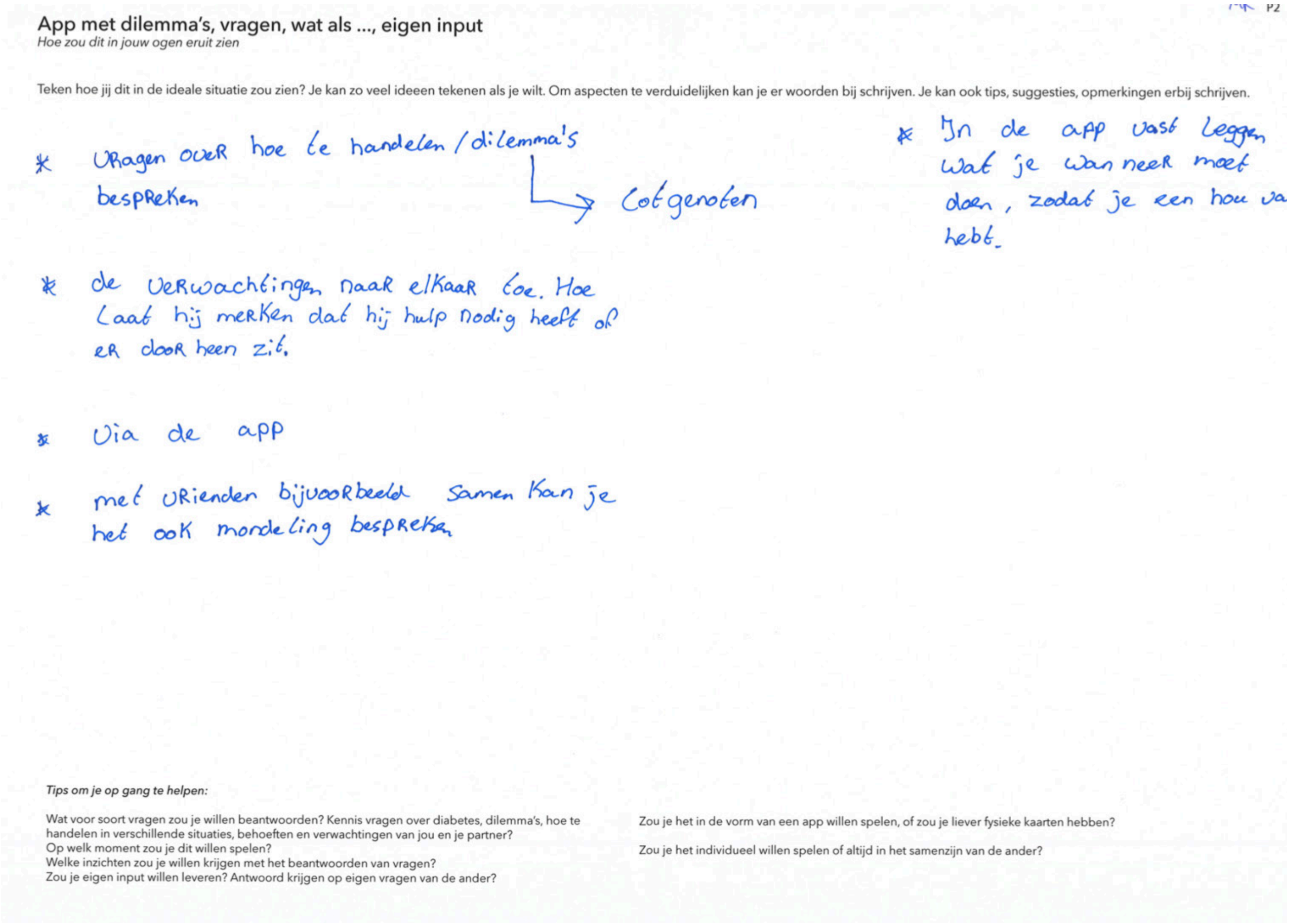
Uit welke emoties zou je willen kiezen? Zijn de emoties aan te geven met plaatjes, icoontjes, of woorden? Welke kleuren passen hierbij?

Hoe vaak op een dag zou je dit willen aangeven? Op welke momenten? Vast of variabel?

Hoe zou het eruit zien als je alles hebt ingevuld? Op een app, een fysiek apparaat, op papier?
Hoe zorgt dit ervoor dat je extra inzicht krijgt?

Zou je dit willen delen met je naasten? Hoe zou het overzicht eruit zien als jij de data doorstuurt? Wil je alles doorsturen, of wil je sommige emoties voor jezelf houden?

Wil je bepaalde emoties uitlichten?



MK P2

## App met dilemma's, vragen, wat als ..., eigen input

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

* Vragen over hoe te handelen / dilemma's bespreken → Lotgenoten

* de verwachtingen naar elkaar toe. Hoe laat hij merken dat hij hulp nodig heeft of er door heen zit.

* Via de app

* met vrienden bijvoorbeeld samen kan je het ook mondeling bespreken

* In de app vast leggen wat je wanneer moet doen, zodat je een hou va hebt.

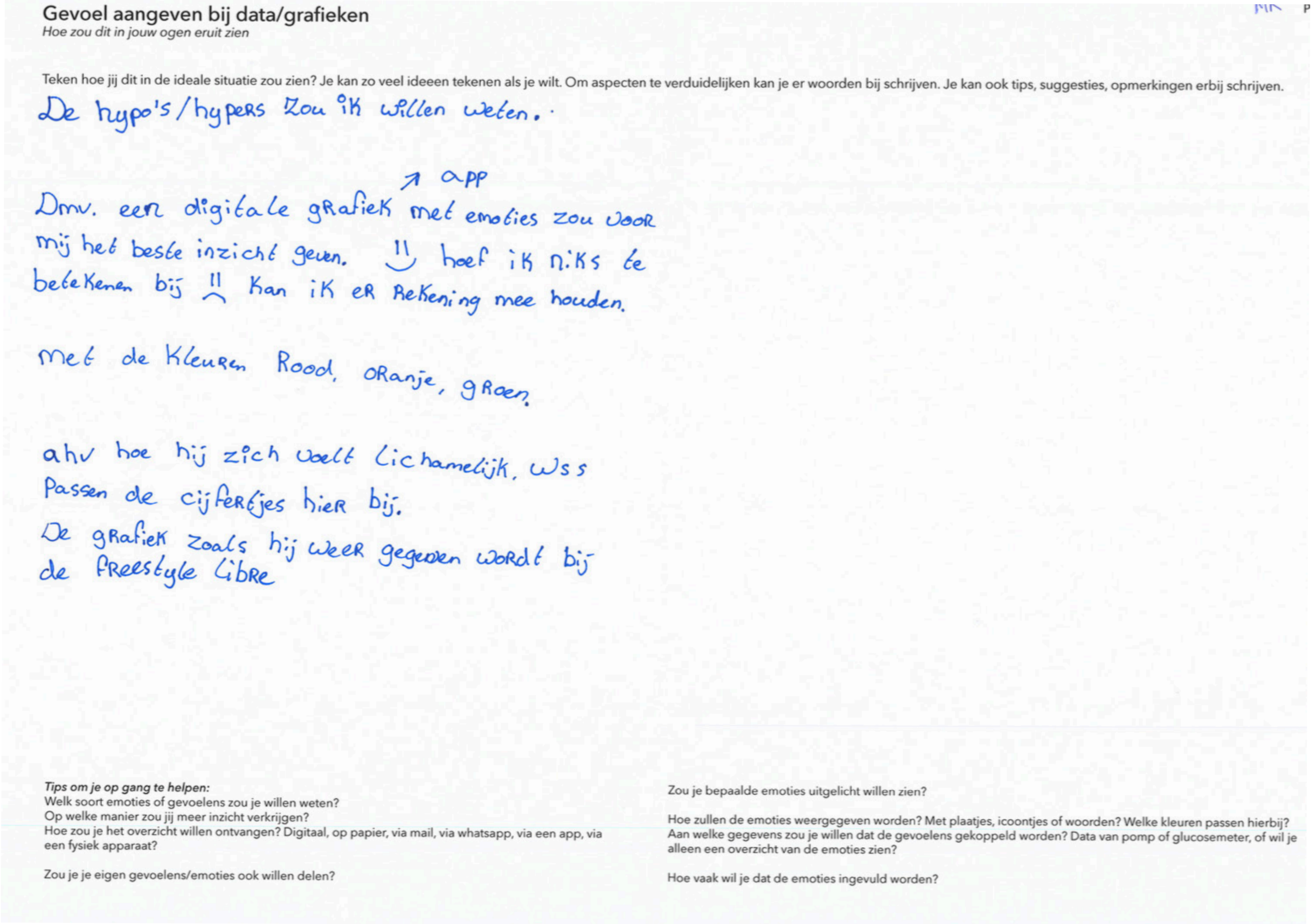
*Tips om je op gang te helpen:*

Wat voor soort vragen zou je willen beantwoorden? Kennis vragen over diabetes, dilemma's, hoe te handelen in verschillende situaties, behoeften en verwachtingen van jou en je partner?
Op welk moment zou je dit willen spelen?
Welke inzichten zou je willen krijgen met het beantwoorden van vragen?
Zou je eigen input willen leveren? Antwoord krijgen op eigen vragen van de ander?

Zou je het in de vorm van een app willen spelen, of zou je liever fysieke kaarten hebben?

Zou je het individueel willen spelen of altijd in het samenzijn van de ander?

---



MK P

## Gevoel aangeven bij data/grafieken

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

De hypo's/hypers zou ik willen weten.

↗ app

Dmv. een digitale grafiek met emoties zou voor mij het beste inzicht geven. ☺ hoef ik niks te betekenen bij ☹ kan ik er rekening mee houden.

met de kleuren rood, oranje, groen

ahv hoe hij zich voelt lichamelijk, wss passen de cijfertjes hier bij.
De grafiek zoals hij weer gegeven wordt bij de Freestyle Libre

*Tips om je op gang te helpen:*
Welk soort emoties of gevoelens zou je willen weten?
Op welke manier zou jij meer inzicht verkrijgen?
Hoe zou je het overzicht willen ontvangen? Digitaal, op papier, via mail, via whatsapp, via een app, via een fysiek apparaat?

Zou je je eigen gevoelens/emoties ook willen delen?

Zou je bepaalde emoties uitgelicht willen zien?

Hoe zullen de emoties weergegeven worden? Met plaatjes, icoontjes of woorden? Welke kleuren passen hierbij?
Aan welke gegevens zou je willen dat de gevoelens gekoppeld worden? Data van pomp of glucosemeter, of wil je alleen een overzicht van de emoties zien?

Hoe vaak wil je dat de emoties ingevuld worden?

## Gevoel aangeven bij data/grafieken
*Hoe zou dit in jouw ogen eruit zien*

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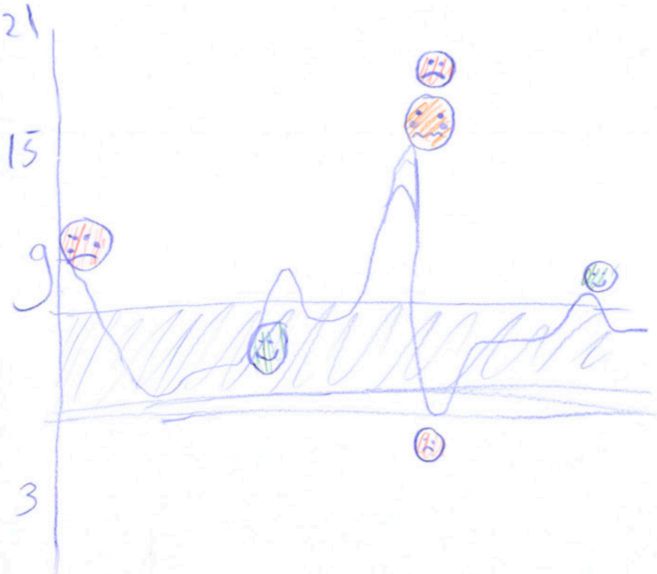


*Tips om je op gang te helpen:*
Aan welke gegevens zou je de emoties koppelen? Waardes van de pomp, glucosemeter, overzicht in een app etc? Teken bijvoorbeeld de grafiek van deze dag als startpunt op het papier.

Uit welke emoties zou je willen kiezen? Zijn de emoties aan te geven met plaatjes, icoontjes, of woorden? Welke kleuren passen hierbij?

Hoe vaak op een dag zou je dit willen aangeven? Op welke momenten? Vast of variabel?

Hoe zou het eruit zien als je alles hebt ingevuld? Op een app, een fysiek apparaat, op papier? Hoe zorgt dit ervoor dat je extra inzicht krijgt?

Zou je dit willen delen met je naasten? Hoe zou het overzicht eruit zien als jij de data doorstuurt? Wil je alles doorsturen, of wil je sommige emoties voor jezelf houden?

Wil je bepaalde emoties uitlichten?

## App met dilemma's, vragen, wat als ..., eigen input
*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

vragen: dilemma's, handelen

willekeurig → als een spelletje

→ handelen hoe?
→ gevarieerde situaties
→ wel leuk, anoniem + zelf
↳ meer best doen
→ app, ideale situatie
→ beide, samen een leuk gesprek
voeren, ook achteraf

*Tips om je op gang te helpen:*

Wat voor soort vragen zou je willen beantwoorden? Kennis vragen over diabetes, dilemma's, hoe te handelen in verschillende situaties, behoeften en verwachtingen van jou en je partner?
Op welk moment zou je de app willen openen en spelen?
Welke inzichten zou je willen krijgen met het gebruik van deze app?
Zou je eigen input willen leveren? Antwoord krijgen op eigen vragen van de ander?

Zou je het in de vorm van een app willen spelen, of zou je liever fysieke kaarten hebben?

Zou je het individueel willen spelen of altijd in het samenzijn van de ander?

MK PT

## Gevoel aangeven bij data/grafieken

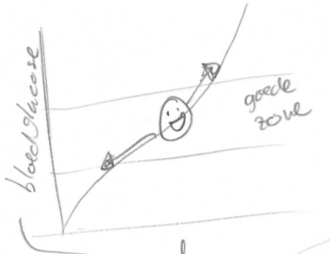
*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

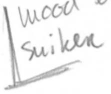
Meting : - blood glucose + mood (emoji + kleur)
- maaltijd (koppeling met insta?)
Los evt koppeling met pomp.

Input

output :



kleur effecten op basis van mood en suiker



⇒ partner app

push
· reminder?
op basis stabiliteit
en een vaste moment
buiten bl. zone

+ functie digitaal contact met support of internist / dia. verpl!

→ idem.

+ stat. overz. van moods en scores

diabeet-app

→ controle en toegang partner app.

Invoer : Camera / mood of opvragen data

output

kleur op basis van mood en input diabeet

tabblad / veeg acti
naar aanbeveling acties

navi. → vegen ↑ ↓ →
emoties koppelen aan kleuren

te custom. in diabeten app. { ( - suiker geven
- water geven
- bolus / spuit instr.

! Geen Screenshots Mogelijk!

*Tips om je op gang te helpen:*
Welk soort emoties of gevoelens zou je willen weten?
Op welke manier zou jij meer inzicht verkrijgen?
Hoe zou je het overzicht willen ontvangen? Digitaal, op papier, via mail, via whatsapp, via een app, via een fysiek apparaat?

Zou je je eigen gevoelens/emoties ook willen delen?

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---

## App met dilemma's, vragen, wat als ..., eigen input

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

Score → streak
bijhouden t.o.v. andere stellen in zelfde relatie fase

op mach minder 'pakjes penken'
meer zoals Trivia spellen
(30 sec, etc.)

optie vinkje 'aan/uit' in instellingen / voorkeuren

soort van vraag / dilemma van de dag.

*Tips om je op gang te helpen:*

Wat voor soort vragen zou je willen beantwoorden? Kennis vragen over diabetes, dilemma's, hoe te handelen in verschillende situaties, behoeften en verwachtingen van jou en je partner?
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## App met dilemma's, vragen, wat als ..., eigen input

*Hoe zou dit in jouw ogen eruit zien*

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Na goed/fout scherm een verwerkingsvraag. zodat je het erover kan hebben

Beetje zoals 30 seconds qua vormgeving, Deze vormgeving lijkt op 'Stoppen met Roken'.

Geen geluid.

Challenge bij antwoorden op het randje van lastig.

gegevens van spel scheiden vs bloedsuiker ding + transparantie. van gegevensgebruik

Met meer dan 2 personen speelbaar.

er bestaan al spellen mbt bespreken!

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Zou je het individueel willen spelen of altijd in het samenzijn van de ander?

---

MK D1

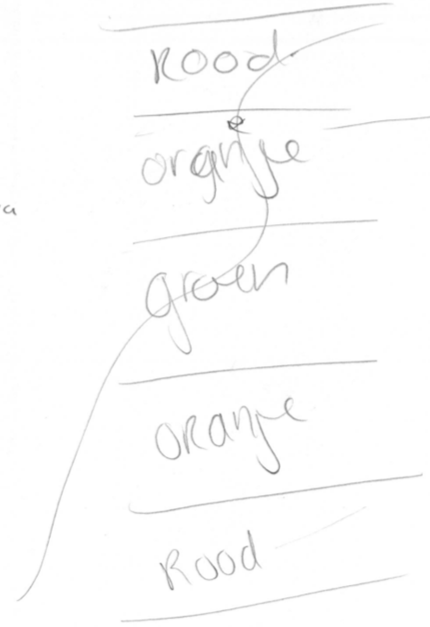
## Gevoel aangeven bij data/grafieken

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

Net zoals extra activiteit scrollen door de tijd.

Heldere vormgeving ivm slecht zicht Hypo's / Hypers.



Je partner is gestegen, Hoe gaat het?

vragen gebruiken als gespreksstarter + noodgrepen indien extremen.

⊙ locatie bepalen, zodat je niet altijd gealarmeerd wordt en jeugdheid behoudt. Werkt alleen in straal van 50m

*Tips om je op gang te helpen:*

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## App met dilemma's, vragen, wat als ..., eigen input

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

Ik zou verschillende levels gebruiken, waarbij je bij Level 1 bijv. vragen stelt zoals:

- Wat is een hypo / hyper?
- wat is diabetes?
- Wat is een ideaal suikergehalte?
- Wat doet kortwerkende insuline?
- Wat doet langwerkende insuline?
- Heeft een pomp kort- of langwerkende insuline?
- Wat kun je het beste doen bij een hypo/ hyper?

Bij Level 2 dan wellicht persoonlijkere vragen, zoals:

- Wat vind [naam diabetespers.] fijn om te doen bij een hypo/hyper?
- Vind [naam diabetespers.] dextro of Limonade prettiger om te nemen bij een hypo?

...

Dilemma's zijn ook leuk!

Inzichten: basiskennis allereerst en daarna vooral persoonlijke voorkeur en en ervaringen leren kennen/uitwisselen

Het is leuk als je er daarna misschien in de app over kan chatten (optioneel, niet verplicht)

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Zou je het in de vorm van een app willen spelen, of zou je liever fysieke kaarten hebben?

Zou je het individueel willen spelen of altijd in het samenzijn van de ander?
└ beide kan!

---

## App met dilemma's, vragen, wat als ..., eigen input

*Hoe zou dit in jouw ogen eruit zien*

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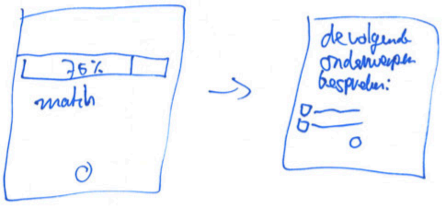
- breder trekken → diabetes als categorie?
- situaties / dilemma's kunnen [illegible]
- Soort diabetes vragen kunnen kiezen
- begin relatie, verveling
- discussie, voorkeuren weten van ander
  starten



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Zou je eigen input willen leveren? Antwoord krijgen op eigen vragen van de ander?

Zou je het in de vorm van een app willen spelen, of zou je liever fysieke kaarten hebben?
↑ ook leuk

Zou je het individueel willen spelen of altijd in het samenzijn van de ander?
↓ een quiz / kennis
↘ discussie / voorkeur ander

## Gevoel aangeven bij data/grafieken

*Hoe zou dit in jouw ogen eruit zien*

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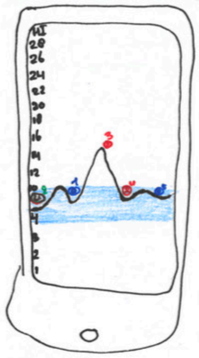
Ik zou de emoties koppelen aan waardes van de glucosemeter/sensor, liefst met kleurtjes, bijv. onder de 4 rood, tussen de 4 en de 10 ~~oranje~~ groen, tussen de 10 en de 15 oranje en boven de 15 rood.
Daarnaast is het misschien ook handig dat je bij een snelle stijging of daling aan kan geven dat je je niet goed voelt, of in elk geval de kleurtjes kan wijzigen, handmatig.
Naast kleurtjes zijn emoticons ook handig, waarbij ik voor blij/tevreden, moe/uitgeput en neutraal zou kiezen
Hierbij zijn vaste momenten denk ik niet handig omdat iedere dag anders is, dus een variabele optie zou ik kiezen.
Wellicht zou het idee van de Freestyle Libre LinkUp als uitgangspunt gebruikt kunnen worden, maar dat degene die gekoppeld is aan jouw app (de partner) dan niet alleen waarden in een kleurtje krijgt, maar ook de hele grafiek en dat je zelf de emotie-emoticons in de grafiek kan plaatsen. Een app is dus het handigste hiervoor denk ik.
Ik zou dit alleen met mijn partner willen delen, verder niemand. Emoties zoals blij en uitgeput zou ik uitlichten.



1 😐 neutraal
2 🙂 mooi suiker om de dag mee te beginnen
3 ☹ stijging → moe
4 ☹ harde daling → moe, ookal is suiker nu mooi
5 😐 neutraal, suiker is weer oke, maar wil wel slapen

Dan, in een ander scherm, een overzicht van de emoticons/suikergehaltes met evt. toelichting.

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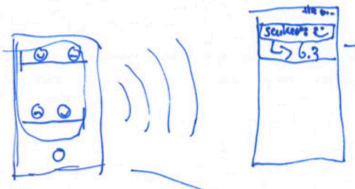
Wil je bepaalde emoties uitlichten?

---

## Gevoel aangeven bij data/grafieken

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.

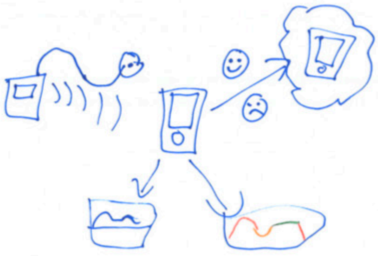


→ bij openen extra info over grafiek de ~~[illegible]~~ verandering ervoor

allen emotie versturen als persoon dat wilt

koppelen aan sensor software

- veel automatisering



↳ verschillende invloedsgrafieken
↳ naar de afgelopen 24 uur kijken
↳ veel persoonlijke instelling
↳ meer grafieken dan allen bloedsuiker gehalte

externe sensor
allen bij noodgevallen (erg hoog, erg laag, te harde stijging/daling)

gevoel bij grafiek is eigenlijk handig om samen op de bank te bespreken met context van de moment opnames

*Tips om je op gang te helpen:*
Welk soort emoties of gevoelens zou je willen weten? - persoonlijk (negatief > positief > neutraal
Op welke manier zou jij meer inzicht verkrijgen? kleur van grafiek
Hoe zou je het overzicht willen ontvangen? Digitaal, ~~op papier~~, via mail, via whatsapp, via een app, via ~~een fysiek apparaat~~?

Zou je je eigen gevoelens/emoties ook willen delen?

Zou je bepaalde emoties uitgelicht willen zien? negatief ↗ aanpasbaar

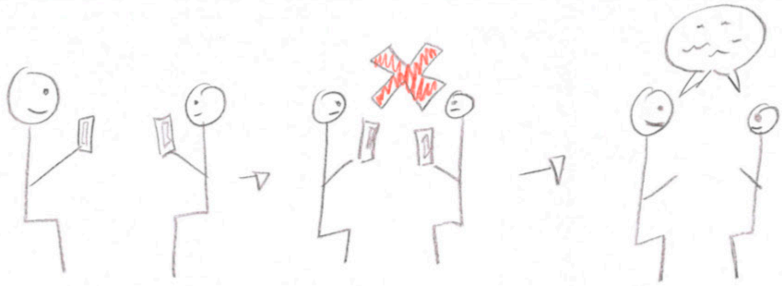
Hoe zullen de emoties weergegeven worden? Met plaatjes, icoontjes of woorden? Welke kleuren passen hierbij?
Aan welke gegevens zou je willen dat de gevoelens gekoppeld worden? Data van pomp of glucosemeter, of wil je alleen een overzicht van de emoties zien?
↳ de hoogte en voorafgaande stijging/daling

Hoe vaak wil je dat de emoties ingevuld worden?
↳ ochtend/middag/avond/nacht

## App met dilemma's, vragen, wat als ..., eigen input

*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.



Ik zou dit zeker spelen.
Ik zou de app zo maken dat er een chat functie is.
Zo hoef je iemand niet persoonlijk te kunnen of
in dezelfde ruimte te zijn om het te spelen.

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Wat voor soort vragen zou je willen beantwoorden? Kennis vragen over diabetes, dilemma's, hoe te handelen in verschillende situaties, behoeften en verwachtingen van jou en je partner?
Op welk moment zou je de app willen openen en spelen?
Welke inzichten zou je willen krijgen met het gebruik van deze app?
Zou je eigen input willen leveren? Antwoord krijgen op eigen vragen van de ander?

Zou je het in de vorm van een app willen spelen, of zou je liever fysieke kaarten hebben?

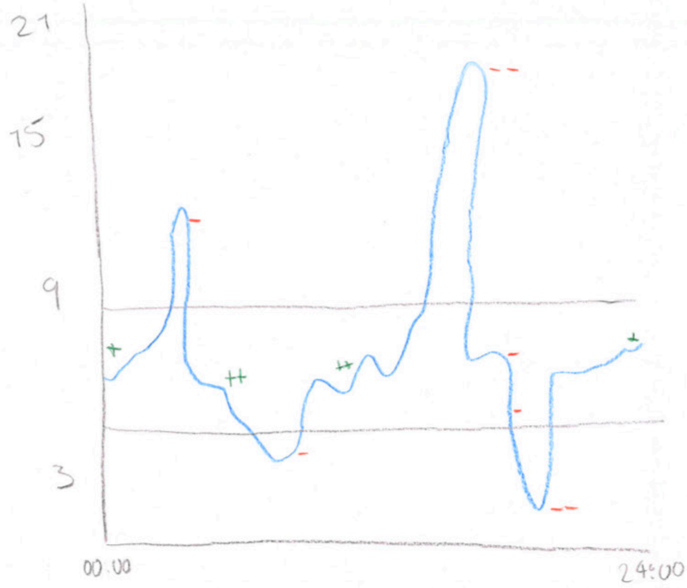
Zou je het individueel willen spelen of altijd in het samenzijn van de ander?

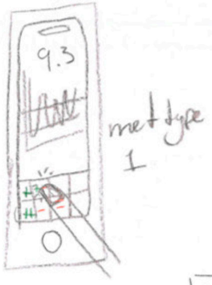
---

## Gevoel aangeven bij data/grafieken

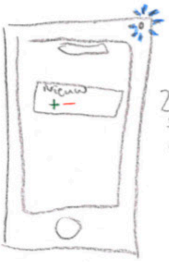
*Hoe zou dit in jouw ogen eruit zien*

Teken hoe jij dit in de ideale situatie zou zien? Je kan zo veel ideeen tekenen als je wilt. Om aspecten te verduidelijken kan je er woorden bij schrijven. Je kan ook tips, suggesties, opmerkingen erbij schrijven.





met type 1



zonder type 1

*Tips om je op gang te helpen:*
Aan welke gegevens zou je de emoties koppelen? Waardes van de pomp, glucosemeter, overzicht in een app etc? Teken bijvoorbeeld de grafiek van deze dag als startpunt op het papier.

Uit welke emoties zou je willen kiezen? Zijn de emoties aan te geven met plaatjes, icoontjes, of woorden? Welke kleuren passen hierbij?

Hoe vaak op een dag zou je dit willen aangeven? Op welke momenten? Vast of variabel?

Hoe zou het eruit zien als je alles hebt ingevuld? Op een app, een fysiek apparaat, op papier?
Hoe zorgt dit ervoor dat je extra inzicht krijgt?

Zou je dit willen delen met je naasten? Hoe zou het overzicht eruit zien als jij de data doorstuurt? Wil je alles doorsturen, of wil je sommige emoties voor jezelf houden?

Wil je bepaalde emoties uitlichten?

# 7. Co-design session- Questionna

1. Welke idee spreekt je het meest aan?

☑ Gevoel aangeven bij data/grafieken
☐ App met dilemma's en vragen

Waarom?

Je weet dan direct hoe iemand zich voelt en kan hulp aanbieden

2. Van het idee *"Gevoel aangeven bij data/grafieken"* zijn deze aspecten waardevol:

Ja, je kan dan handelen als diegene dat wil

3. Van het idee *"App met dilemma's en vragen"* zijn deze aspecten waardevol:

Ja je maakt het onderwerp bespreekbaar. Zowel met lotgenoten als je vrienden/ partner

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☐ Ja ☑ Nee

Waarom?

Dan ben ik er mogelijk teveel mee bezig. Hoe het nu gaat ben ik tevreden. mike geeft het aan als hij mij nodig heeft. Praten doen we er samen genoeg over

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

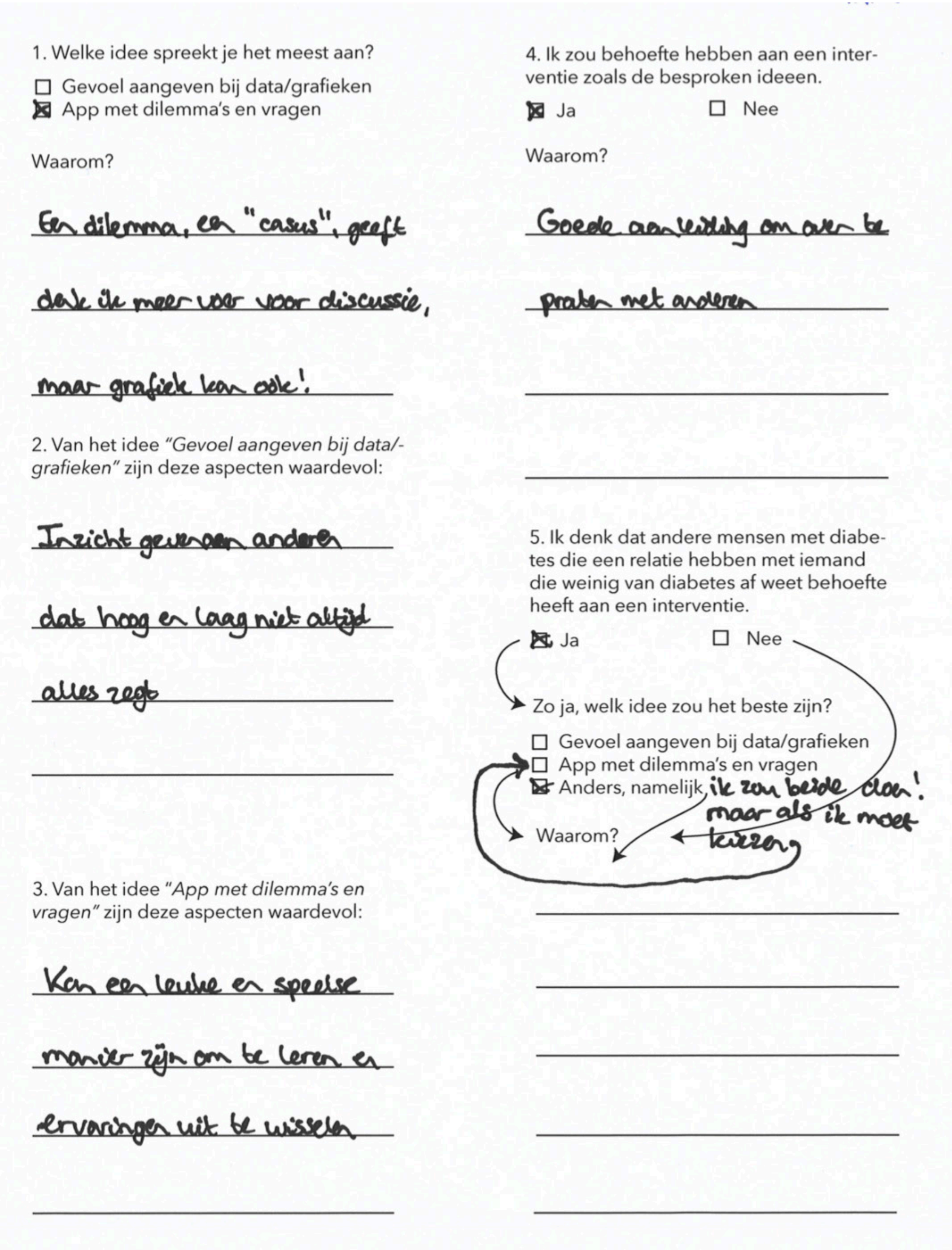
☑ Ja ☐ Nee

Zo ja, welk idee zou het beste zijn?

☐ Gevoel aangeven bij data/grafieken
☐ App met dilemma's en vragen
☑ Anders, namelijk

Waarom?

gevoel aangeven bij data/ grafieken, hierbij de interventies die je hierbij kan/moet uitvoeren



1. Welke idee spreekt je het meest aan?

☐ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen

Waarom?

Een dilemma, een "casus", geeft
dat ik meer voer voor discussie,
maar grafiek kan ook!

2. Van het idee *"Gevoel aangeven bij data/-grafieken"* zijn deze aspecten waardevol:

Inzicht geven aan anderen
dat hoog en laag niet altijd
alles zegt

3. Van het idee *"App met dilemma's en vragen"* zijn deze aspecten waardevol:

Kan een leuke en speelse
manier zijn om te leren en
ervaringen uit te wisselen

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☒ Ja ☐ Nee

Waarom?

Goede aanleiding om over te
praten met anderen

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

☒ Ja ☐ Nee

Zo ja, welk idee zou het beste zijn?

☐ Gevoel aangeven bij data/grafieken
☐ App met dilemma's en vragen
☒ Anders, namelijk, ik zou beide doen! maar als ik moet kiezen

Waarom?

1. Welke idee spreekt je het meest aan?

☒ Gevoel aangeven bij data/grafieken
☐ App met dilemma's en vragen

Waarom?

Dit idee heb ik het meest behoefte aan, belangrijk om te delen hoe ik me voel.

2. Van het idee *"Gevoel aangeven bij data/grafieken"* zijn deze aspecten waardevol:

- Duidelijke smileys bij de grafieken (overzichtelijk)
- Makkelijk om te delen

3. Van het idee *"App met dilemma's en vragen"* zijn deze aspecten waardevol:

- Leuke dilemma's etc, dat het niet saai wordt.
- Zowel individueel als samen mogelijk te spelen.

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☒ Ja ☐ Nee

Waarom?

Ik vind het belangrijk dat diabetes meer besproken wordt en dat het makkelijk wordt om er kennis over te krijgen.

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

☒ Ja ☐ Nee

Zo ja, welk idee zou het beste zijn?

☒ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen
☐ Anders, namelijk

Waarom?

Het gevoel aangeven is belangrijk qua communicatie en bij de app kan je makkelijk kennis geven en zo je partner bewust maken.

---

1. Welke idee spreekt je het meest aan?

☒ Gevoel aangeven bij data/grafieken
☐ App met dilemma's en vragen

Waarom?

Dat is voor het spel interessanter en bruikbaarder zijn

2. Van het idee *"Gevoel aangeven bij data/grafieken"* zijn deze aspecten waardevol:

delen van instructies/acties

3. Van het idee *"App met dilemma's en vragen"* zijn deze aspecten waardevol:

Trendgegevens voor begeleiding van diabeet ("X gebeurt vaak, bespreek dat", enz.)

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☒ Ja ☐ Nee

Waarom?

Ik hou van spelletjes

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

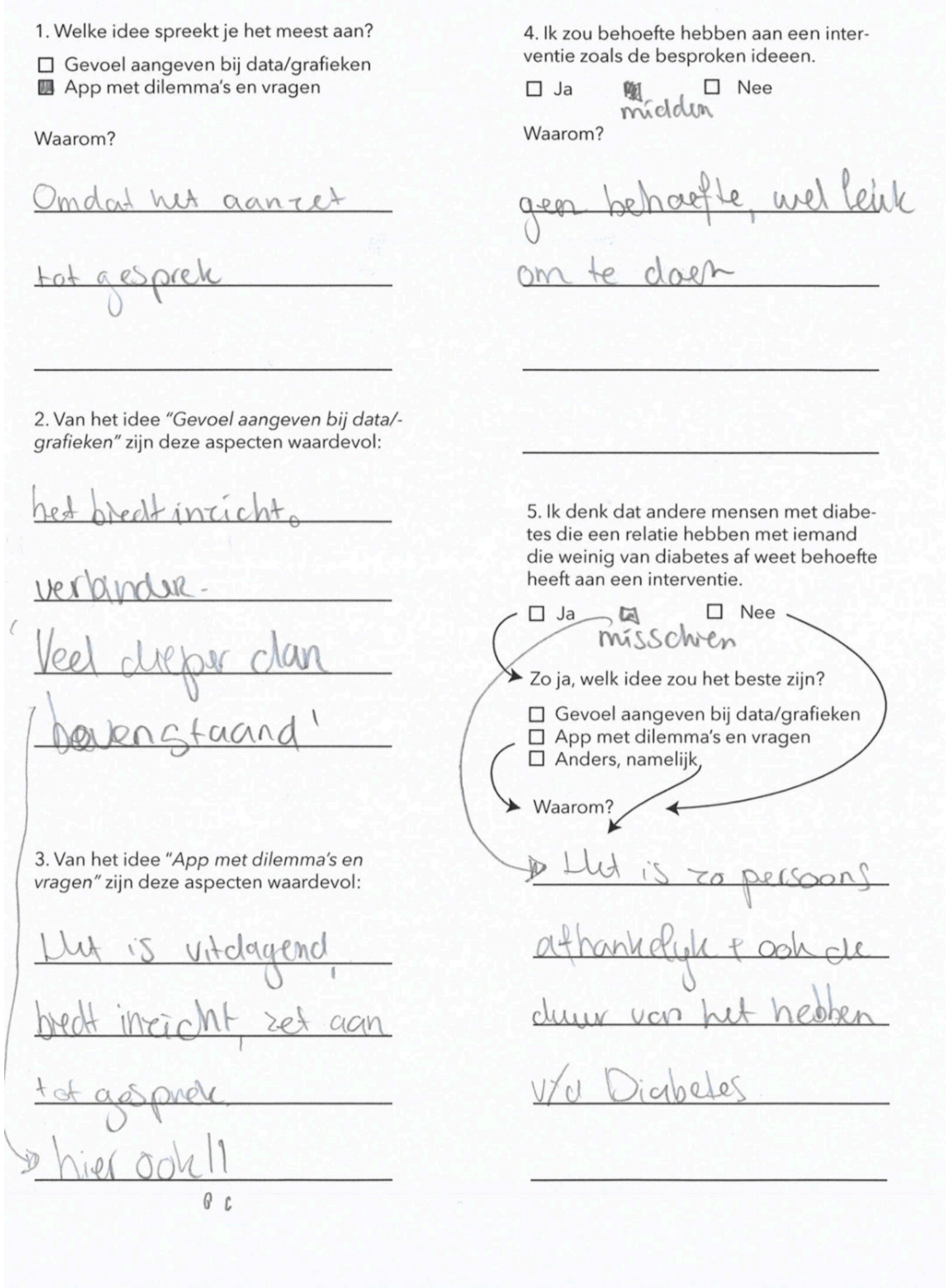
☒ Ja ☐ Nee

Zo ja, welk idee zou het beste zijn?

☒ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen
☐ Anders, namelijk

Waarom?

Ja, beiden, het ene bij hyper/hypo, de andere om gesprek op gang te helpen.



1. Welke idee spreekt je het meest aan?

☐ Gevoel aangeven bij data/grafieken
■ App met dilemma's en vragen

Waarom?

Omdat het aanzet
tot gesprek

2. Van het idee *"Gevoel aangeven bij data/-grafieken"* zijn deze aspecten waardevol:

het biedt inzicht,
verbinden.
'Veel dieper dan
bovenstaand'

3. Van het idee *"App met dilemma's en vragen"* zijn deze aspecten waardevol:

Het is uitdagend,
biedt inzicht, zet aan
tot gesprek
hier ook!!

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☐ Ja ■ midden ☐ Nee

Waarom?

geen behoefte, wel leuk
om te doen

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

☐ Ja ☒ misschien ☐ Nee

Zo ja, welk idee zou het beste zijn?

☐ Gevoel aangeven bij data/grafieken
☐ App met dilemma's en vragen
☐ Anders, namelijk

Waarom?

Het is zo persoons
afhankelijk + ook de
duur van het hebben
v/d Diabetes

1. Welke idee spreekt je het meest aan?

☐ Gevoel aangeven bij data/grafieken
■ App met dilemma's en vragen

Waarom?

meer kennis, meer beter

gevoel + waarde = belangrijk

2. Van het idee *"Gevoel aangeven bij data/-grafieken"* zijn deze aspecten waardevol:

het gevoel aan waardes
koppelen

3. Van het idee *"App met dilemma's en vragen"* zijn deze aspecten waardevol:

kennis en voorkomen
delen

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☒ Ja ☐ Nee

Waarom?

leuk en handig

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

☒ Ja ☐ Nee

Zo ja, welk idee zou het beste zijn?

☒ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen
☐ Anders, namelijk

Waarom?

Schept een band
begrijpt elkaar beter
leuk

1. Welke idee spreekt je het meest aan?

☐ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen

Waarom?

Het is wat minder opdringerig en toegankelijker voor iedereen.

2. Van het idee *"Gevoel aangeven bij data/-grafieken"* zijn deze aspecten waardevol:

inzicht geven in het leven van iemand met diabetes type 1 en wat meer begrip kunnen ontwikkelen.

3. Van het idee *"App met dilemma's en vragen"* zijn deze aspecten waardevol:

Iedereen kan hier van leren. Mensen met en zonder diabetes.

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☐ Ja ☒ Nee

Waarom?

Ik ben tevreden met hoe de dingen nu gaan.

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

☒ Ja ☐ Nee

Zo ja, welk idee zou het beste zijn?

☐ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen
☐ Anders, namelijk

Waarom?

Dit geeft mensen een kans om hele specifieke dingen te bespreken en om makkelijker duidelijk te maken wat de een van de ander verwacht.

---

. Welke idee spreekt je het meest aan?

☐ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen

/aarom?

pelelement maakt het
at luchtiger, maar nog
eeds leerzaam (en: het
estaat nog niet!)

. Van het idee *"Gevoel aangeven bij data/-*
*rafieken"* zijn deze aspecten waardevol:

aat zien dat iedereen
ich anders voelt bij de
aarden en getallen opzich
ijn gewoon niet voldoende.
moties hebben namelijk
k veel invloed op de
suikers.

. Van het idee *"App met dilemma's en*
*agen"* zijn deze aspecten waardevol:

euk!
eerzaam!
Ook goed toepasbaar op
et individu

4. Ik zou behoefte hebben aan een interventie zoals de besproken ideeen.

☒ Ja ☐ Nee

Waarom?

Het maakt het makkelijker om diabetes te bespreken en helpt misschien ook bij het nadenken hoe je je voelt bij je suikers.

5. Ik denk dat andere mensen met diabetes die een relatie hebben met iemand die weinig van diabetes af weet behoefte heeft aan een interventie.

☒ Ja ☐ Nee

Zo ja, welk idee zou het beste zijn?

☒ Gevoel aangeven bij data/grafieken
☒ App met dilemma's en vragen
☐ Anders, namelijk

Waarom?

Ik denk de app met dilemma's als allereerst en daarna het gevoel aangeven bij data/grafieken. Meer betrokkenheid/begrip!

# 8 CONCEPT: ENRICHMENT OF DATA WI

## Design overview

### Functions

The main function of this design is to clearly describe emotions and link them to blood glucose values. Patients keep already track of these data the entire day by mostly continuous blood glucose monitoring sensors. With this design the patient can keep an overview of the emotions and can recognize patterns or is able to see which influences play a role on their mood. If the patient decides to share this information with the partner, the partner is able to gain more knowledge of the values and can feel more connected to the patient, since an emotion is shown rather than only a number or graphs. The emotions are known to the partner, and therefore more empathy can be shown.

## Design features

Key features of the concept are:

- Link emotions to values
- Visualizing of emotions
- Share emotions with others
- Get insight in your own emotions
- Let others get insight in your emotions
- Link emotions to influencing factors
- Create moments of reflection
- Use as conversation starter
- Engagement of patient and partner in self-management

### What

This concept direction will be an application in which data already gathered and saved by the patient can be enriched with emotions and feelings of the patient.

### How?

Patients are able to choose an emotion while collecting data. After scanning the value of the blood glucose level is displayed on the screen, as is already achievable with the free style libre. Patients can adjust the settings, so they can also input emotions. When this is turned on, the patient can add an emoji or a plus or minus sign (their preference) right after scanning. If the partner has the link up application, data will be shared. In this new version, not only a single number will be shared, but the entire graph and the emotions.

### Why?

The principle behind this design is to gain insights in the patients emotions and feelings during the day. This can create more empathy and understanding. Nowadays it is for a relative, such as a partner difficult to interpret the data, since it only provides a number and a graph. It is envisioned that adding emotions give more value and information to the data that is already out there. Since diabetes is a very personal condition, it is not possible to say: within the range of 4.0mmol/L -8.0mmol/L the patient feels good, although this could be concluded based on the data and the generic information gathered. This concept will help the partner to create empathy, understand the feelings linked to diabetes influences. For the patient itself it might also be valuable, since insight in emotions can be gathered and are related to diabetes influences pattern can be recognized and actions can be taken upon them. It can be used as reflection moments, since it is also possible to look back at the emotions for several days. This design can engage the partner more, since the partner is better able to connect with the disease, since he/she can relate to the emotions shown.

### Visual design

The visual design of the application is based on the existing freestyle libre link application and the libre link up application. The style of these apps are used and the emotion section is added to this. From the co-design session it became clear that people should be able to choose how they want to insert the emotions. Three options are available which also change the visual style of the application.

### Context of use

The context in which this design will be

# TH EMOTIONS

used, is at any location where the patient is scanning the sensor to determine the blood glucose level. This can be done whenever and wherever the patient wants. If data sharing is turned on, the values will be directly send to the partner.

Different users
This design is limited to people using the free style libre. However the design targets multiple personalities and uses, since diabetes is a highly personal condition. The design is adaptable to the wishes of the user. The patient can choose which type of icons they want to use to indicate emotions. Next to that, there is an option to add additional comments.

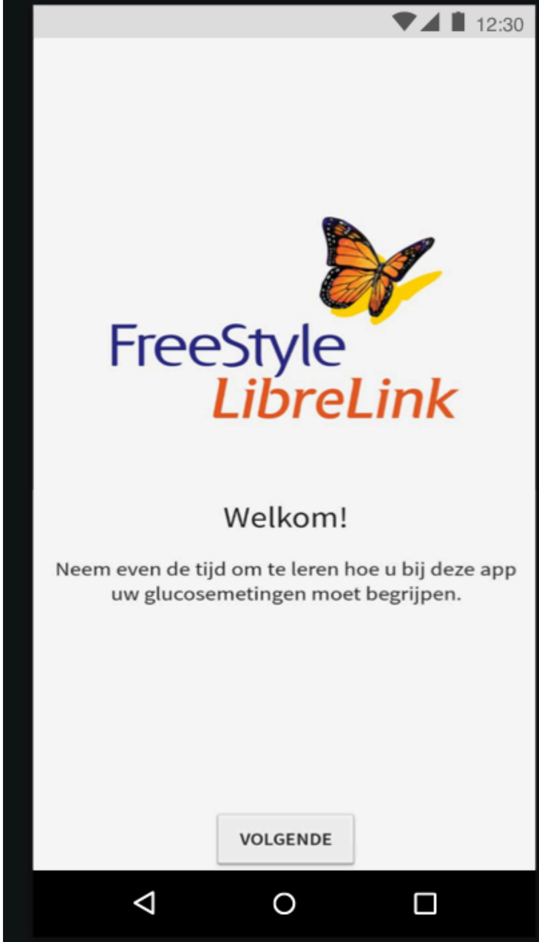
Use intentions
What the users can achieve by using this design are:
Learning: Learn about own emotions related to blood glucose values. (patient)
Learn about patients emotions as a partner and learn how these changes are linked to diabetes factors. (partner)
Reflect: Reflect on why emotions change and what the causes are. (patient and partner)

More intensive use of the design, will lead to better possible support, because more information is shared and more insights can be gained.

User scenario
Scanning
Adding emotion
Sharing
Looking back
Talk with each other about it.

Recommendations
Create a design for smartwatch applications. New blood glucose monitoring sensors can be linked to smartwatches.

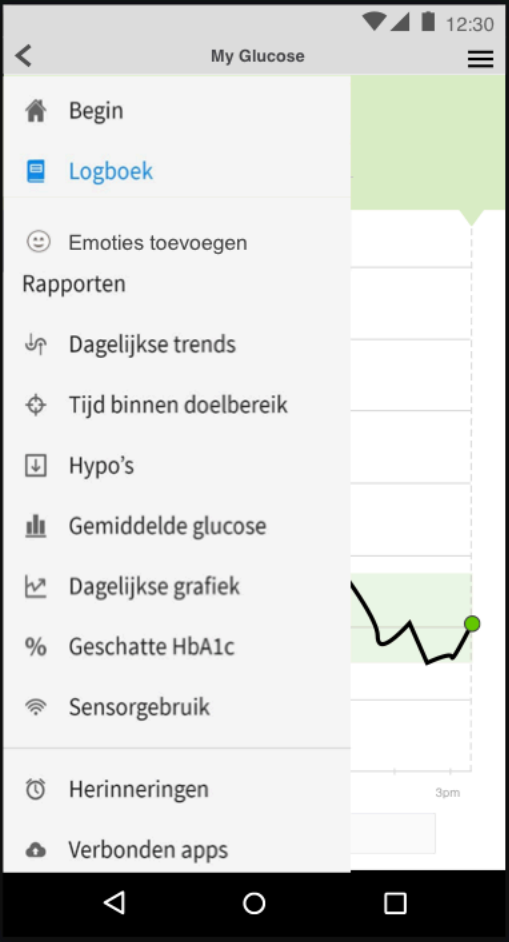
enrich data with emotions



Welkom!

Neem even de tijd om te leren hoe u bij deze app uw glucosemetingen moet begrijpen.

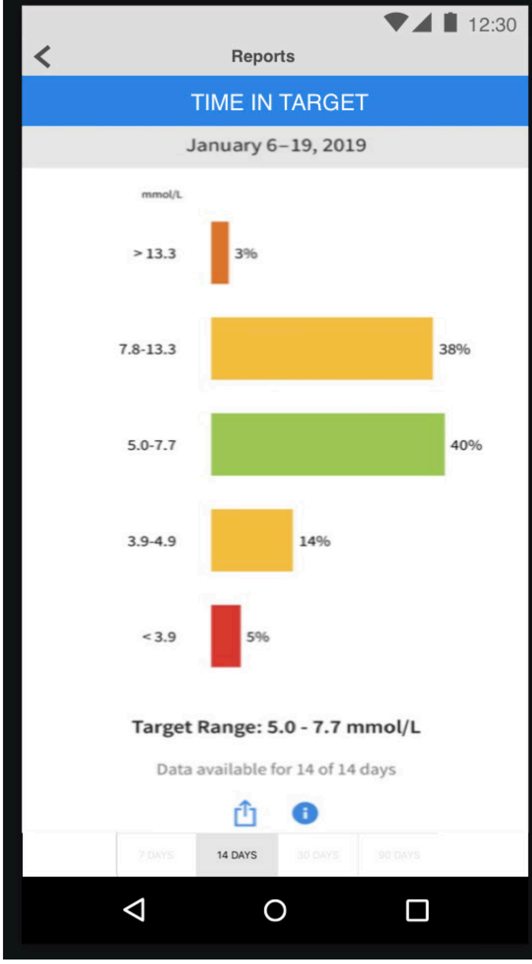
enrich data with emotions



enrich data with em

Add feeling to

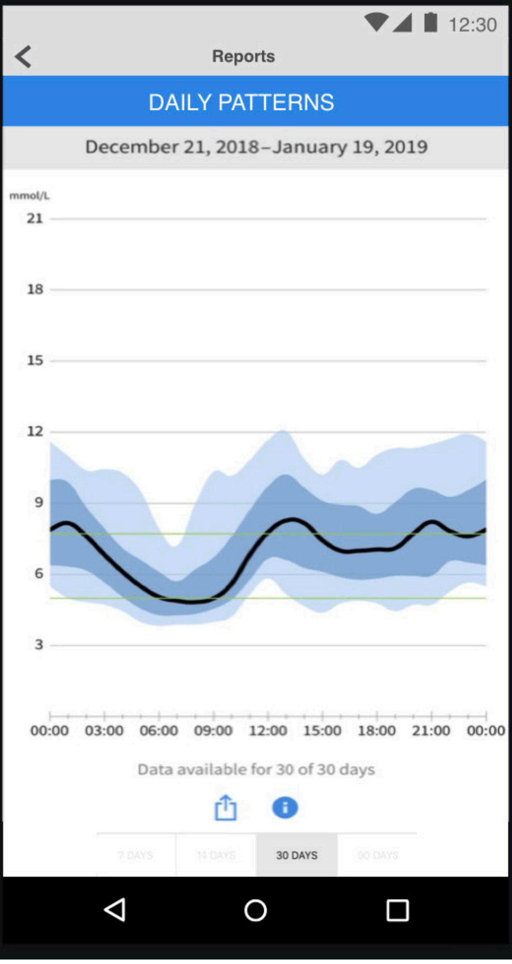
enrich data with emotions



Target Range: 5.0 - 7.7 mmol/L

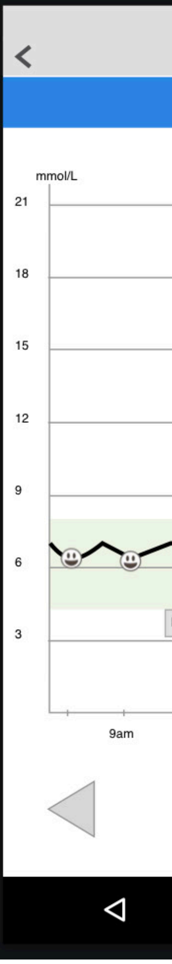
Data available for 14 of 14 days

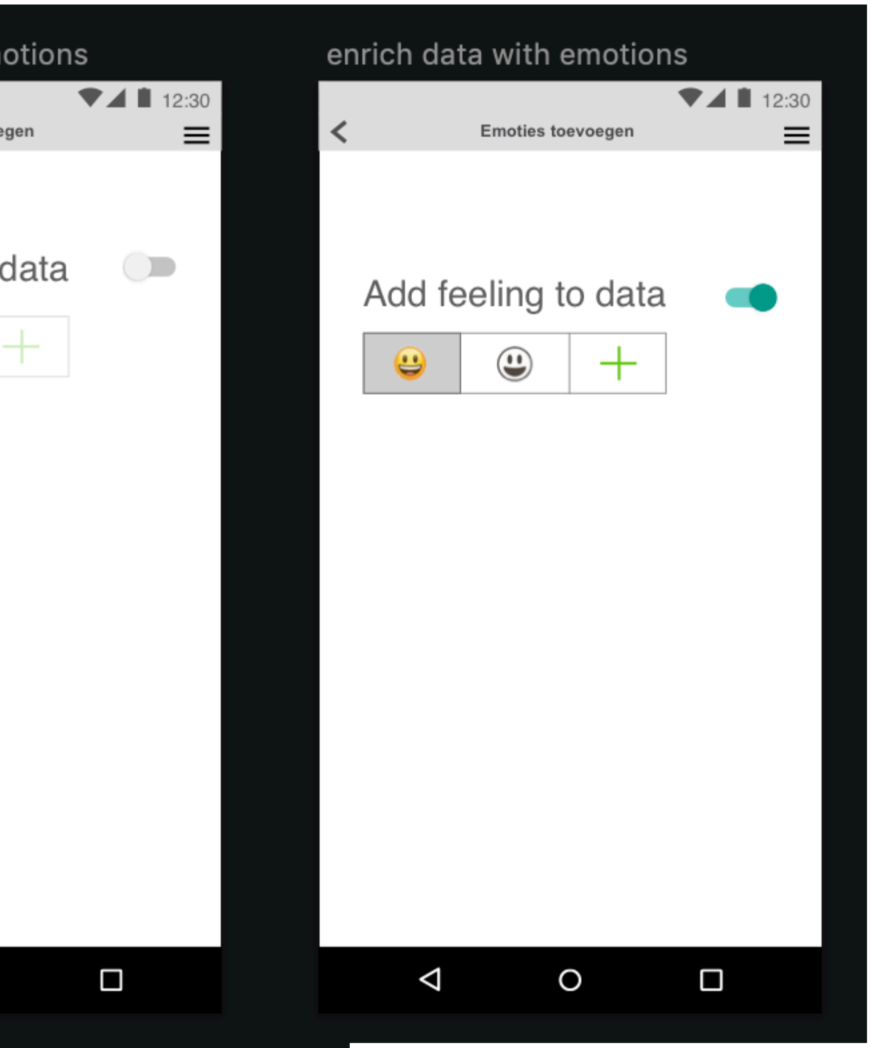
enrich data with emotions

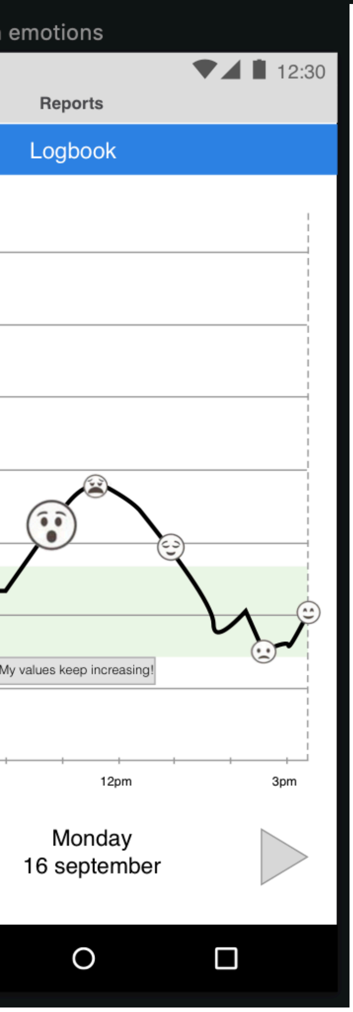


Data available for 30 of 30 days

enrich data with



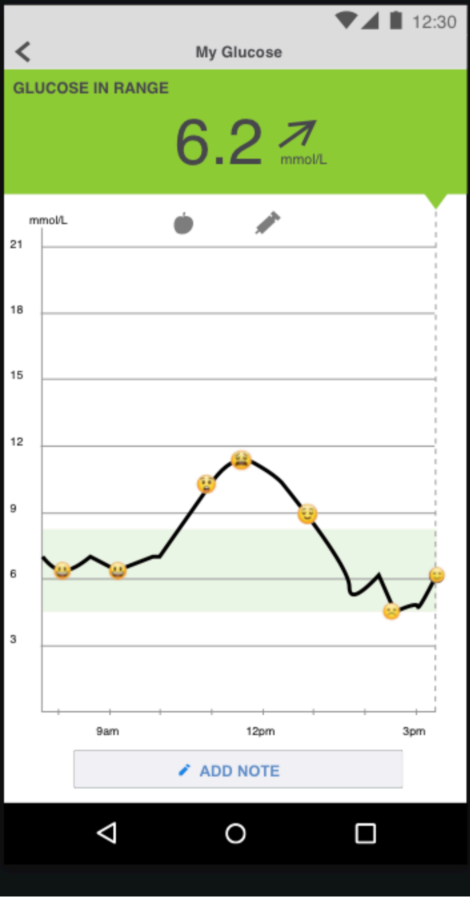

otions
12:30
egen
data
enrich data with emotions
12:30
Emoties toevoegen
Add feeling to data


emotions
12:30
Reports
Logbook
My values keep increasing!
12pm
3pm
Monday
16 september

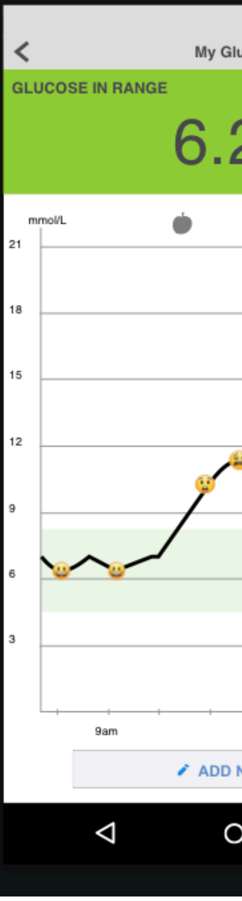
enrich data with emotions

enrich data with emotions

enrich data with emotions

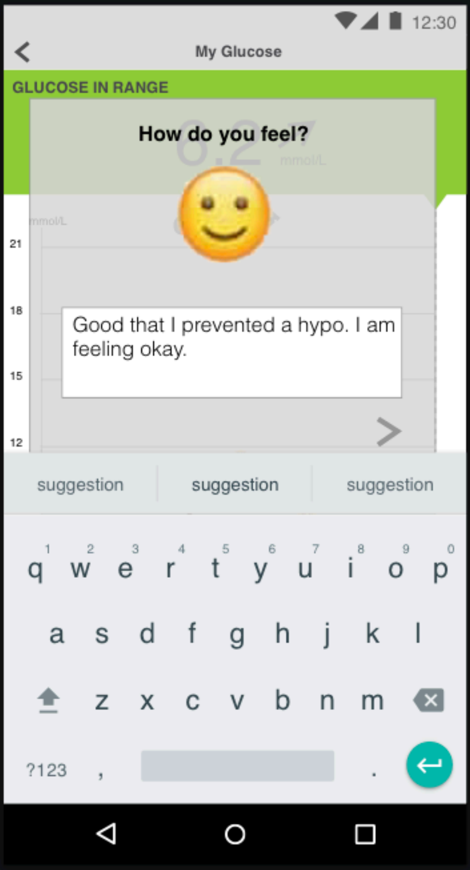


enrich data with



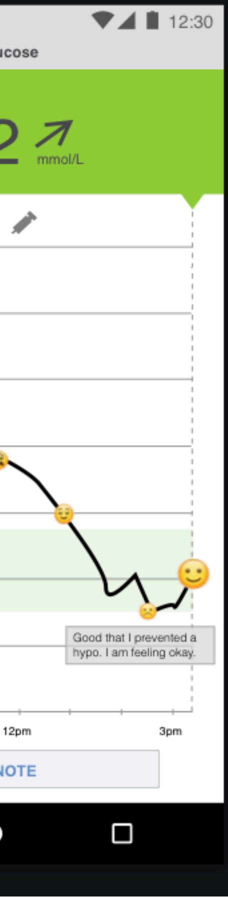
enrich data with emotions

enrich data with emotions



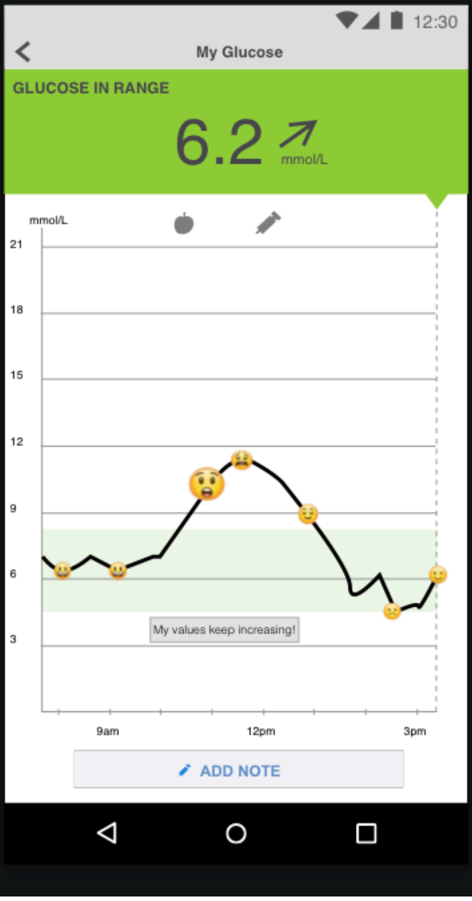
Good that I prevented a hypo. I am feeling okay.

emotions

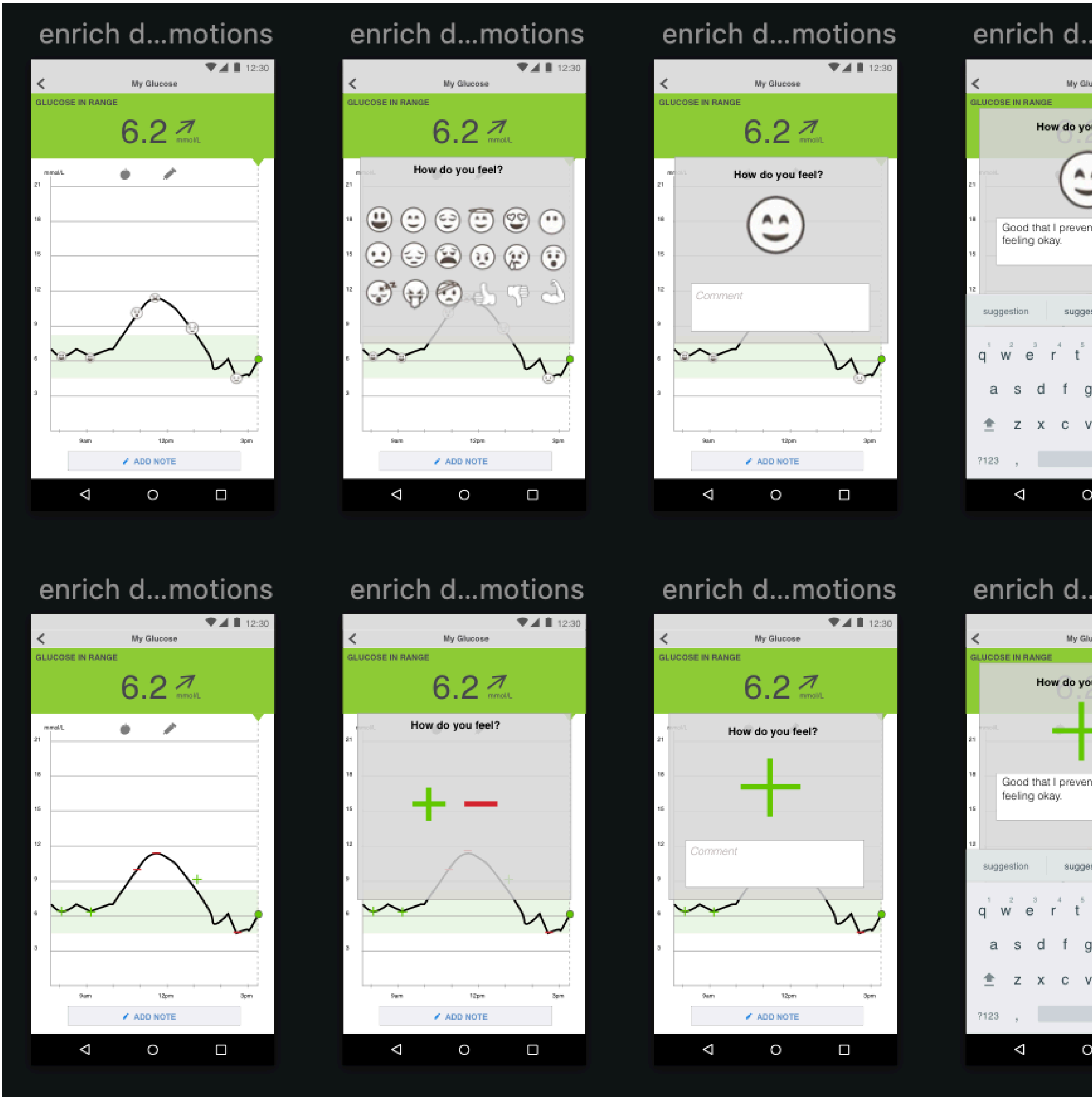


Good that I prevented a hypo. I am feeling okay.

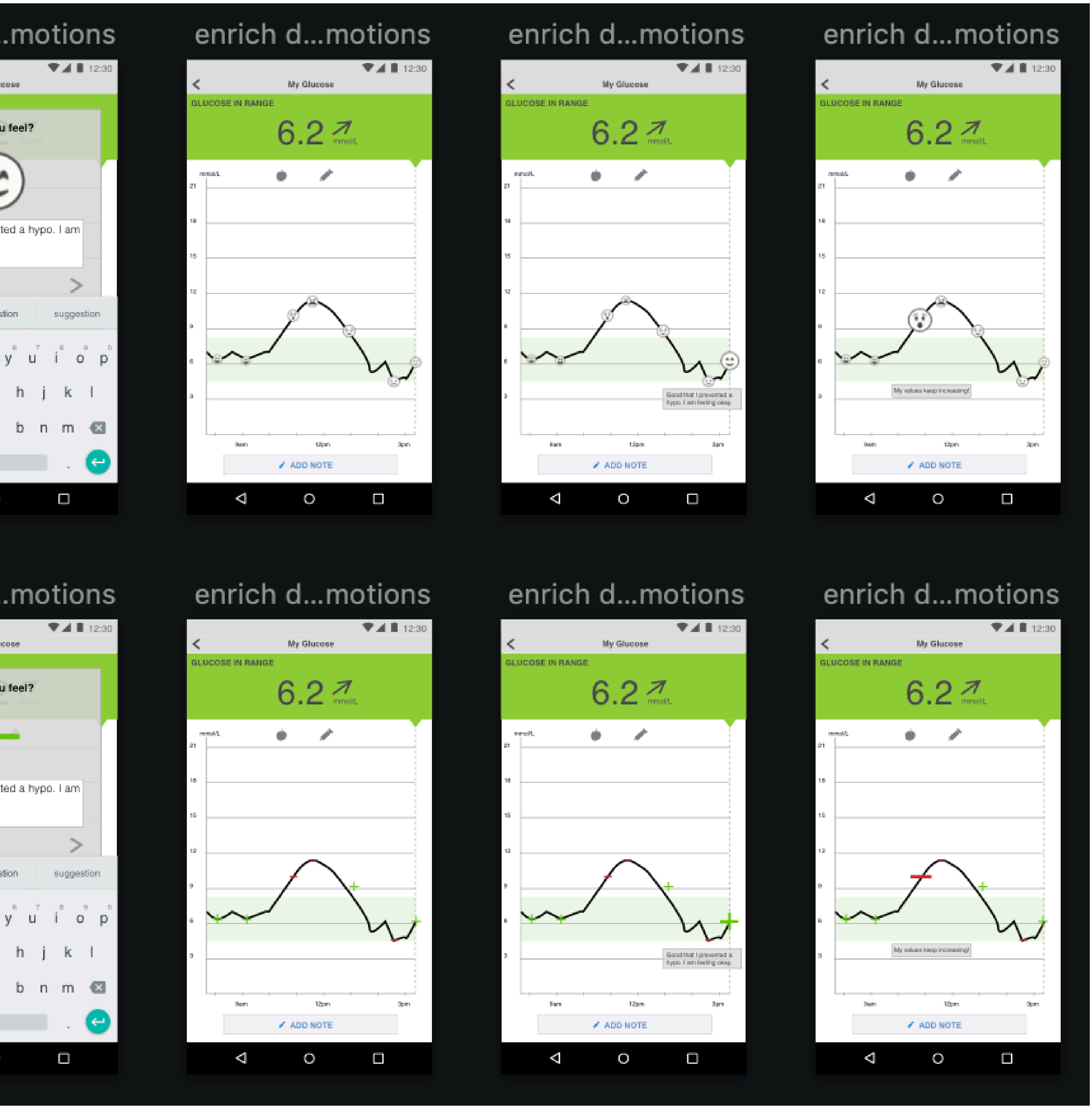
enrich data with emotions



My values keep increasing!



Good that I preven
feeling okay.



ted a hypo. I am

Good that I prevented a hypo. I am feeling okay.

My values keep increasing!

# PARTNER APP

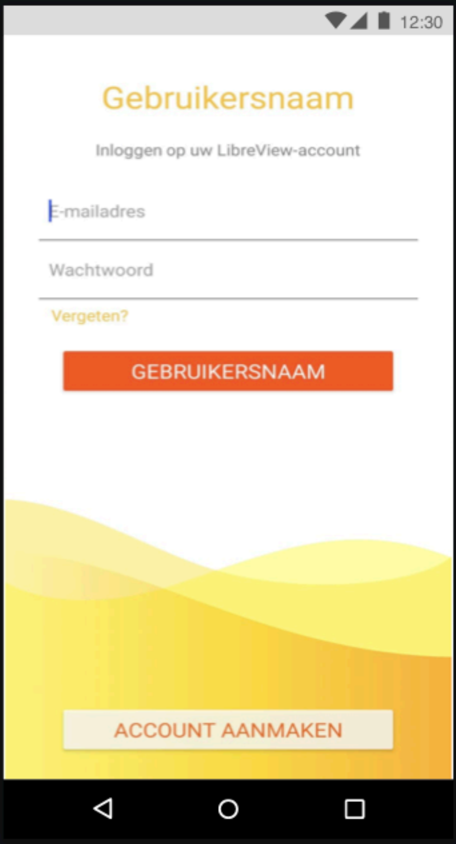
enrich data with emotions

12:30

LibreLinkUp

Glucosewaarden van familie en vrienden die de FreeStyle LibreLink gebruiken, direct op uw telefoon.

enrich data with emotions



12:30

Gebruikersnaam

Inloggen op uw LibreView-account

E-mailadres

Wachtwoord

Vergeten?

enrich data wit

LibreL

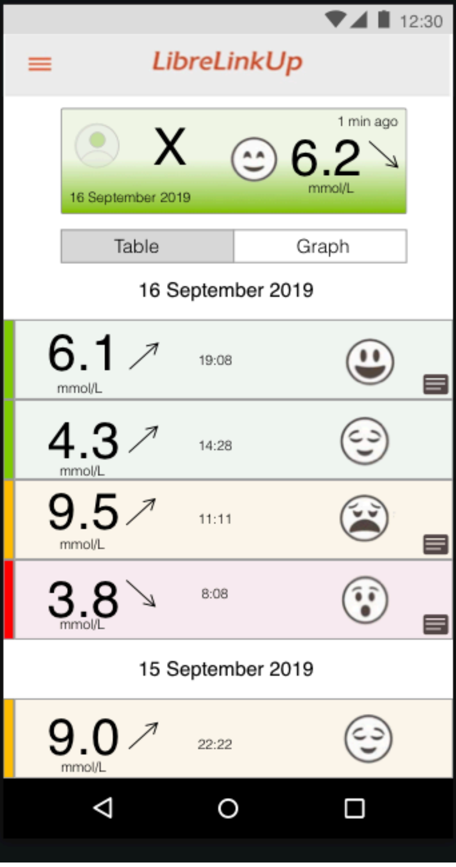
U bent nog niet ver
of vrienden. Iedere
LibreLink-app gebr
glucosewaarden m

St
De persoon die F
gebruikt gaat naar
app en n

St
U ziet een uitnodig
tele

St
Accepteer de u
beginnen de Fr
glucosewa

enrich data with emotions



12:30

LibreLinkUp

X 1 min ago 6.2 mmol/L
16 September 2019

16 September 2019

| | | |
|---|---|---|
| 6.1 ↗ mmol/L | 19:08 | |
| 4.3 ↗ mmol/L | 14:28 | |
| 9.5 ↗ mmol/L | 11:11 | |
| 3.8 ↘ mmol/L | 8:08 | |

15 September 2019

| | | |
|---|---|---|
| 9.0 ↗ mmol/L | 22:22 | |

enrich data with emotion

LibreLinkUp

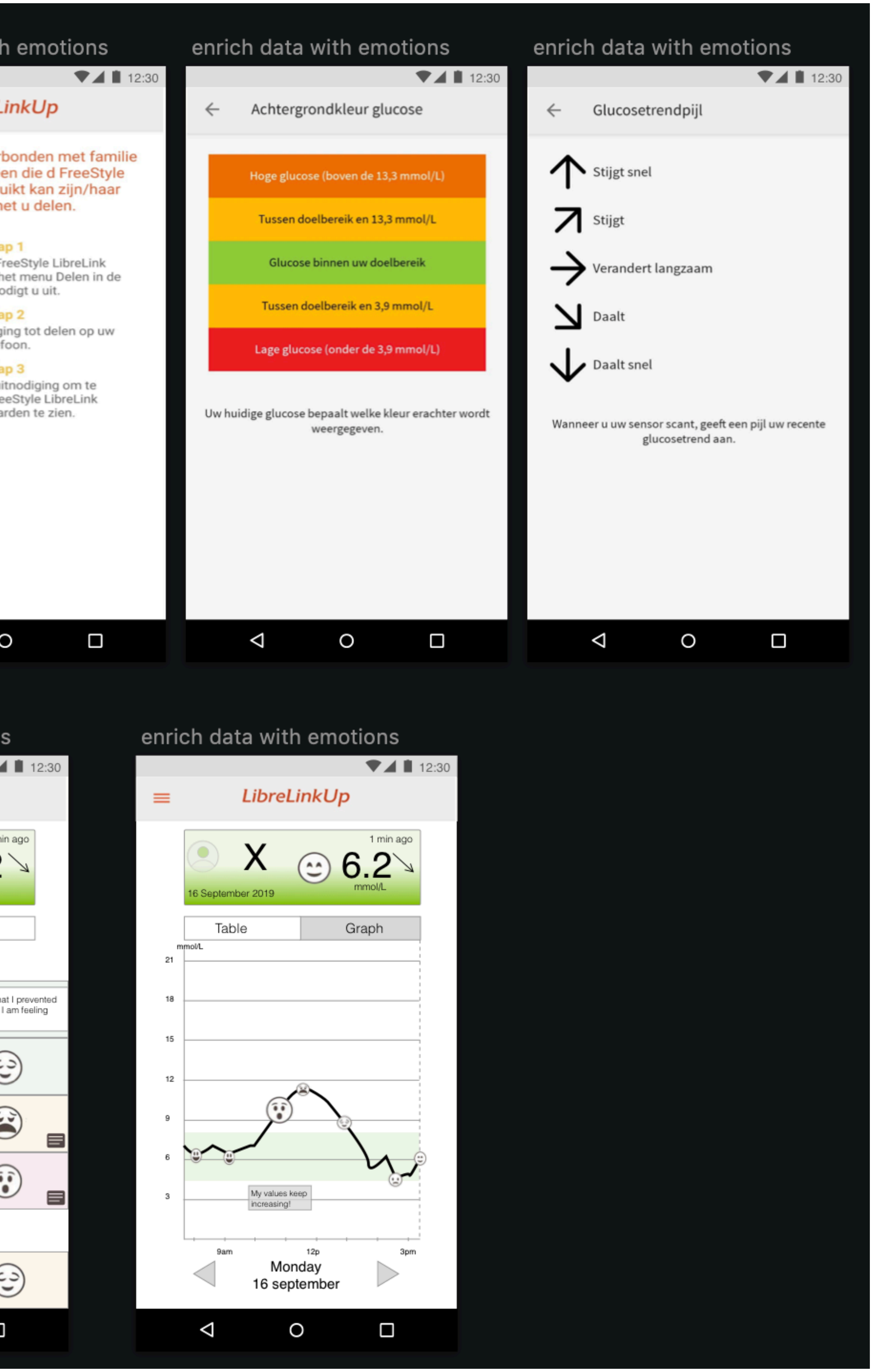
X 1 m 6.2 mmol/L
16 September 2019

16 September 2019

| | | |
|---|---|---|
| 6.1 ↗ mmol/L | 19:08 | Good th<br>a hypo.<br>okay. |
| 4.3 ↗ mmol/L | 14:28 | |
| 9.5 ↗ mmol/L | 11:11 | |
| 3.8 ↘ mmol/L | 8:08 | |

15 September 2019

| | | |
|---|---|---|
| 9.0 ↗ mmol/L | 22:22 | |



rbonden met familie
en die d FreeStyle
uikt kan zijn/haar
net u delen.

ap 1
FreeStyle LibreLink
het menu Delen in de
odigt u uit.

ap 2
ging tot delen op uw
foon.

ap 3
itnodiging om te
eeStyle LibreLink
arden te zien.

- 🟧 Hoge glucose (boven de 13,3 mmol/L)
- 🟨 Tussen doelbereik en 13,3 mmol/L
- 🟩 Glucose binnen uw doelbereik
- 🟨 Tussen doelbereik en 3,9 mmol/L
- 🟥 Lage glucose (onder de 3,9 mmol/L)

Uw huidige glucose bepaalt welke kleur erachter wordt weergegeven.

- ↑ Stijgt snel
- ↗ Stijgt
- → Verandert langzaam
- ↘ Daalt
- ↓ Daalt snel

Wanneer u uw sensor scant, geeft een pijl uw recente glucosetrend aan.

at I prevented
I am feeling

My values keep increasing!