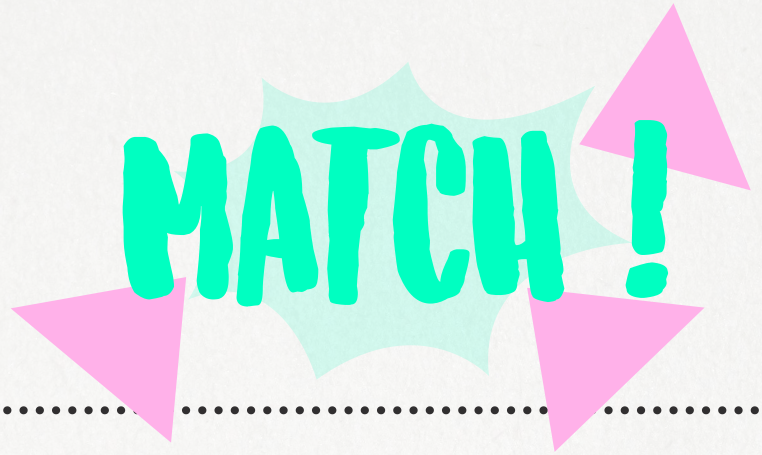

MATCH!

A DIABETES PATIENT PLATFORM TO FACILITATE NEW PEER FRIENDSHIPS

Master thesis by Julia Brinkmann

Disclaimer

This master thesis contains the final documentation of the graduation project titled "Match! - a diabetes patient platform to facilitate new peer friendships", executed in cooperation with the company "Roche Diabetes Care." This project completes the author's master program Design for Interaction at the faculty of Industrial Design Engineering in Delft.

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To Garda, my diabetes assistant, a wonderful person that gave me back the confidence and patience to handle my diabetes and showed empathy with the everyday struggles a MSc student faces, when graduating and diabetes come together.

To Wiert, who always listened without judging and encouraged me to stay positive and use my experience within this project.

To my parents, who would have probably never believed that I would voluntarily work on this topic when looking at the little girl that always had to go to the toilet to inject insulin. Especially thank you to my papa, for brainstorming with me via Whatsapp and using your own diabetes experience to help me.

To Angela for cooking delicious dinners for me whenever there was another deadline coming up.

PREFACE

“After hearing Dr. ir. Sleeswijk Visser, F., an assistant professor at the TU Delft, talking about her research project about the everyday life of diabetes patients in a lecture, I knew what my graduation topic would be. Being a type 1 diabetes patient since 24 years, this was the starting point of getting interested in my own disease again. After years of neglection, I realized that I could use my diabetes for something positive and patients can be the biggest motor behind health care innovations.

My new motivation to pick it up again was mainly triggered by building up a new informal and professional support network that showed empathy and cared. Therefore, my goal within this project is to develop a tool that will really help other diabetes patients to build up such a strong network themselves and find the right people to support them.

Therefore this project follows my wish of being a designer, who focuses all power and interest on issues that will not only make people’s life “nicer”, but to create new interactions that support personal development and emotional wellbeing.“

figure 1 me trying out a new meter at a diabetes reha clinic at the age of 8

ROCHE DIABETES CARE

The project was executed in a graduation internship within the department "Roche Diabetes Care", part of the company Roche, situated in Almere. The core strategy of the department is to provide patients with the tools for personalized diabetes management, ranging from blood sugar meters, insulin pumps and data analysis tools. One of their future strategy is to expand into services such as a diabetes community, a new direction that will be kicked-off with this project. The products are sold under the brand name Accu-Chek.

Company Mentor

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www.roche.nl
www.accu-chek.nl

DESIGN FOR INTERACTION

This master direction within the faculty Industrial Design engineering at the TU Delft, specializes in the analysis and implementation of human/product (service) interactions. To be able to design concepts that will truly benefit the user, a deep understanding of the physical, cultural and societal user context is essential.

University Supervisor Team

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MEDICAL TERMINOLOGY

This report contains terminology from the medical field, specialization diabetes mellitus. For some terms the corresponding Dutch terms are mentioned.

Bolus insulin

amount of insulin that is injected to cover expected rise in blood glucose level, often related to food intake or to correct higher blood sugar levels back into range. “To bolus” refers to the action of injecting this insulin into the body.

BGM - Blood Glucose Monitor

device that is used to measure the level of blood glucose within a patient’s body at that particular moment. The patient has to first lance the fingertip with the lancing device, then apply a drop of blood on the test strip and after a few seconds the level is known.

BSL - Blood Sugar Level

refers to the level of glucose in the bloodstream in mmol/L. Values in healthy people are between 4.0 and 6.0 mmol/L. Diabetes patient strive to stay between 4.4 and 10.0 mmol/L. This can vary per patient.

CGM - continuous glucose meter

a continuous glucose monitor determines blood glucose levels continuously over the day, with a specific time interval (e.g. ten minutes).

Diabulimia

Eating disorder especially known with diabetes patients. By decreasing, delaying, or completely omitting prescribed insulin doses, a person with diabetes can induce hyperglycemia and rapidly lose calories in the urine in the form of glucose

DVK - Diabetes Verpleeg Kundige

nurses that are specialized on diabetes. They function as an assistant for the doctor and can take over all tasks after consultation with the doctor.

DVN - Diabetes Vereniging Nederland

Dutch non-profit organization that supports people with diabetes in their battle for good health care and a comfortable life under the motto“living life to the max with diabetes.”

FPO - For Provit Organization

HBA1C - glycated hemoglobin A1C

By measuring glycated hemoglobin (HbA1c), clinicians are able to get an overall picture of what the average blood sugar levels have been over a period of about 6-8 weeks.

Hyperglycemia (Hyper)

A too high blood glucose level, which is generally defined as a blood glucose level higher than 12mmol/L.

Hypoglycaemia (Hypo)

A too low blood glucose level, which is generally defined as a blood glucose level lower than 4.0 mmol/L.

IIT - Intensive Insulin Therapy

diabetes management method that requires multiple insulin injections per day to mimic the body's normal pattern of insulin secretion

NPO - Non Profit Organization

Pen therapy

insulin is injected via multiple daily injections with a manual pen.

Pump therapy

insulin is injected 24 hours a day via a portable pump that delivers insulin via a catheter placed under the skin.

T1D - Type 1 Diabetes

is the more severe form of diabetes is type 1 in which the pancreas of a patient does not produce insulin at all. Patients are dependent on multiple daily insulin injections. It is also called "juvenile" diabetes because type 1 usually develops in children and teenagers, though it can develop at any age.

T2D - Type 2 Diabetes

is a progressive condition in which the pancreas does not produce enough insulin and / or the insulin does not work effective enough any more. Type 2 diabetes is often associated as a "lifestyle" disease, caused by overweight, too little physical exercise and a diet high in carbohydrates and sugar and is mainly managed through lifestyle modification and (oral) medication.

T3D - Type 3 Diabetes

is an informal name for the people within a patient's support network - parents, partner, siblings, friends - that do not have diabetes themselves but are affected by the disease in different ways.

CONTENT

PART 3 - CONCEPTUALIZATION

PART 4 - DESIGN ITERATIONS & EVALUATION

PART 5 - REFLECTION & IMPLEMENTATION

LIST OF REFERENCES

PROJECT OVERVIEW

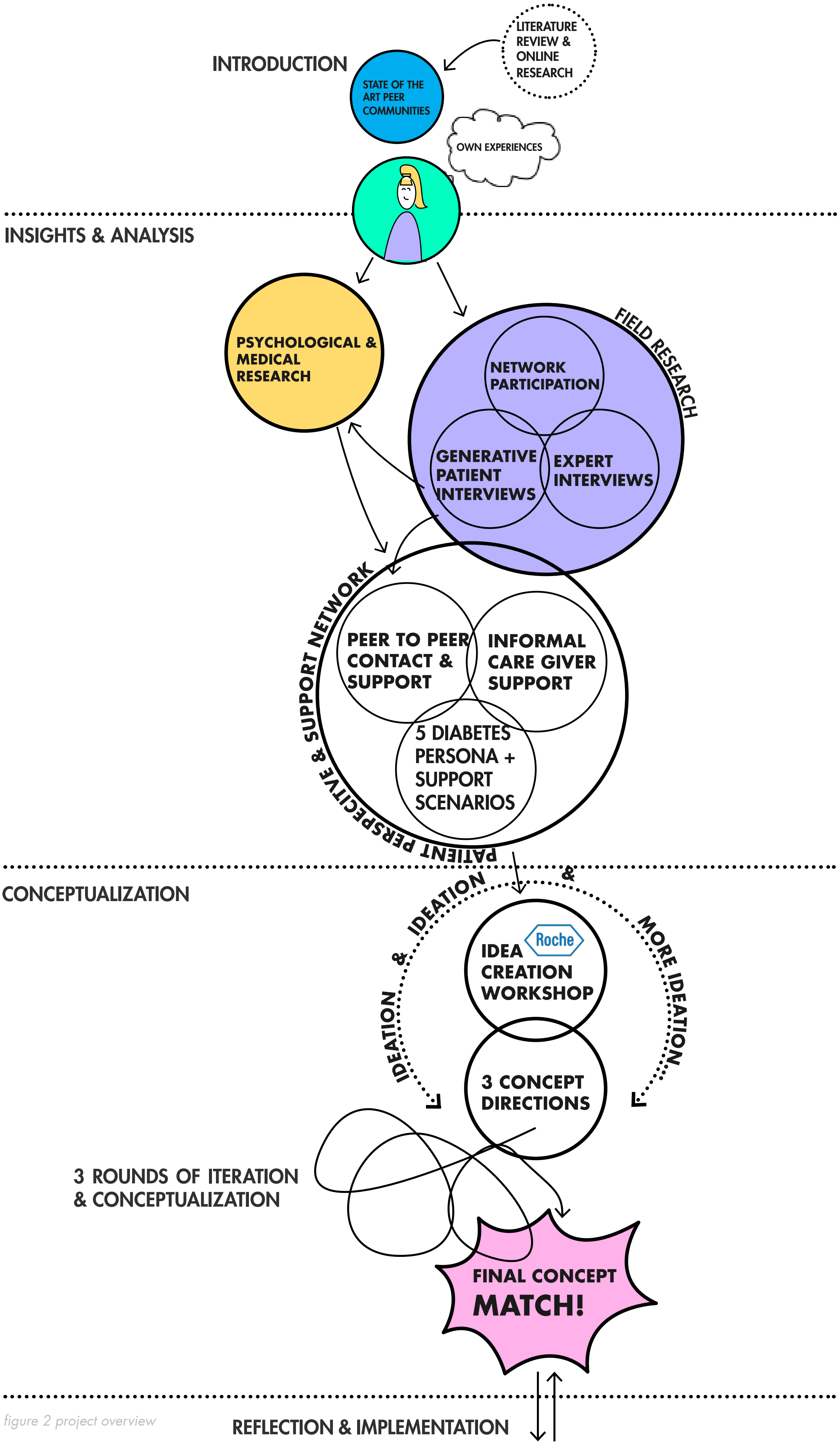


figure 2 project overview

ABSTRACT

This graduation project focuses on exploring the possibilities of facilitating peer support possibilities between diabetes type 1 patients, as a valuable addition to a patient's normal support network. This report presents the results of the analysis phase, the developed concepts and the final outcomes of this master thesis. **For a project overview see figure 2.**

The project started off with the participation in diabetes peer networks and expert interviews with employees of the diabetes industry, to understand the current efforts to connect peers and interactions within these networks. During the analysis phase several generative interviews with patients are conducted to identify emotional struggles related to diabetes management, understand their existing support networks and future peer support wishes. Part of the insights of these interviews were combined with insights of interviews with diabetes coaches and psychologists to be able to map out the emotional struggles of diabetes patients.

Diabetes is a disease that is mainly managed by the patients themselves. Improving or failing within this disease has various input on a patient's emotional balance. Having to deal with this disease every day, each patient develops an individual diabetes management style that is influenced by his/her personality, the surroundings and the relation with the professional care giver. As every patient has a different personality, the interviewed patients showed great differences within their management and mindset. As in real life when searching for new friends, the patients expressed the wish to get in contact with other peers, who would match their diabetes mindset, to be able to recognize problems and emphasize.

These detected influences and insights were then evaluated into personas and general support scenarios within a patient's life for a company internal idea creation workshop. These graphical tools served as empathizing tools and inspiration.

The ideas were analyzed and clustered according to the most overlap, to come up with concept directions that will be used by a great amount of young diabetes patients and is still adaptable to one's situation. Soon it was clear that the strong wish of all patients to be connected to mind like peers should be followed. The chosen concept direction focuses on the facilitation of peer contact according to patient's mindset.

Match! is an online patient platform that enables every diabetes patient to create an individual profile and display his/her diabetes mindset together with other additional info the patient would like to add that shows the person behind the diabetes. Match!'s goal is to let peers find contact points and similarities with other peers, in order to increase the chance of developing a friendship with the matching peer (see figure 3). The concept focuses on the profile creation process, the display of the mindset and facilitation between peers (see figure 4, 5 and 6).

Three design iterations are done and tested among fifteen diabetes patients, who positively responded to the new way of contacting and finding peers and the idea to facilitate this contact according to a patient's mindset.

Finally, the observations of the test sessions and feedback from patients are used to evaluate and reflect on the introduced concept. Further recommendations are made to optimize the flow, layout and to validate the psychological questions of the mindset test within Match! All insights within this project were summarized within the learning booklet that will help the company to develop the concept further towards implementation.

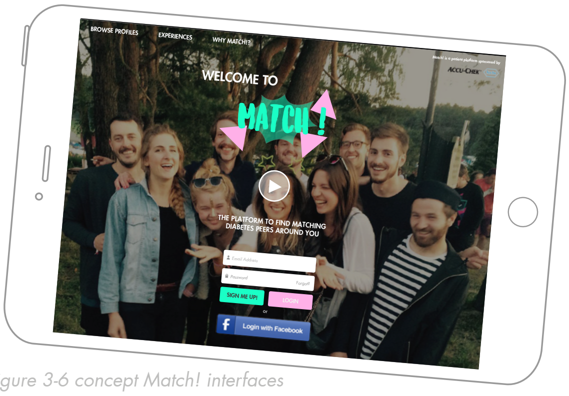


figure 3-6 concept Match! interfaces

„Inmiddels 10 jaar diabetes type 1, met 3 jaar een pomp. Aan het begin wilde ik geen pomp maar nu ben ik er heel tevreden mee. Het maakt alles een stukje makkelijker. Omdat ik vaak koolhydraat arm eet, zijn mijn bloedsuikers best wel stabiel en met mijn laatste hba1c van 55 was ik ook erg tevreden. Niettemin hou ik ook wel van snoepen en gewoon alles eten wat je wil."

„Hoi ik ben Bianca. Ik heb al best wel lang diabetes, maar sta altijd open voor nieuwe dingen leren, peers leren kennen te kletsen en uitjes. Verder hou ik van series, en architectuur, ben veel bezig met koken en hou van bakken. In het weekend bezoek ik graag nieuwe tentoonstellingen of ga gezellig iets drinken met vrienden."

„I have a normal relation with my DVK. She is friendly, but I also don't need that much help."

1.

INTRODUCTION

"A sufficient emotional and medical support network, which supports the patient in the preferred way, helps a patient to cope with a disease (diabetes)." (Gallanth, M.P. 2003)

Every chronical ill patient has individual support needs, but integrating the disease into one's surroundings can help a patient cope with the emotional side of his/her diabetes and the accompanying everyday tasks. This graduation project investigates how the individual support wishes of diabetes patients can be transferred into a new type of patient support tool. As diabetes is a disease that is mainly based on self-management, every patient has a quantity of diabetes related experiences. These experiences and "a problem shared is a problem halved" mentality provide the origin of this project. Within this project I want to investigate how patients and their support network can benefit from each other's experience and how a support tool could facilitate beneficial contact between patients.

Besides the wish to develop a concept that includes the wishes of the patients, I also wanted to design something that is feasible within the current health care industry and will be developed further after this project ended. To be able to approach the project from both sides, I cooperated with Roche Diabetes Care, a company widely known within the diabetes industry and interested in expanding their patient community themselves.

As the future community should be based on the wishes of the patients, I setup a qualitative research with both diabetes patients and professional care givers and employees from the diabetes industry. I evaluated the insights from the interviews into the key findings, a learning book and several graphical tools, to make them more tangible and easier for outsiders to emphasize with the patients.

This project introduction elaborates on the project origin and the research approach to look into the context from an interaction and business side.

1.1 PROJECT CONTEXT

The project context of this project involves an understanding of the medical context of the disease diabetes, in order to understand the effects on the patient's emotional wellbeing and support needs. Therefore I will first provide an overview of diabetes from a medical perspective and the support system for diabetes patients, to be able to dive deeper into the psychological context of diabetes and online support within later chapters 2.2 and 2.3.

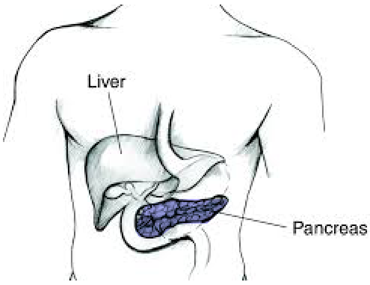


figure 7 location of the pancreas within the body

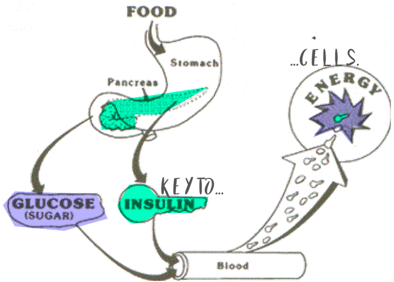


figure 8 insulin is the key to the muscle cells

figure 9 injecting insulin with an insulin pen

What is type 1 diabetes?

"Type 1 diabetes is an autoimmune condition in which the immune system is activated to destroy the cells in the pancreas which produce insulin." (Type 1 Diabetes., n.d.). These cells are situated in the pancreas, which is a small organ situated in the upper stomach between the stomach and the liver. (see figure 7) Insulin is a hormone, that is the main regulator of the sugar concentration in the blood (measured in BSL - blood sugar level).

The cells of a body need glucose (blood sugar) as energy to be able to function. Insulin therefore functions like a key for these cells to open, so the glucose from our food can be burnt within them (see figure 8). When this hormone is not produced any more, the concentration of blood sugar rises. Therefore, if these keys are not (or not enough) produced any more, patients have to inject insulin multiple times a day with the help of an insulin pen or insulin pump. Still, as the insulin is injected from outside the body and the onset of effect is delayed, it is hard to mimic the body's own insulin secretion and keep the blood sugar at a constant level. (see figure 9) (sources: DVN; DIABETER)

Diabetes self-management

As a patient's body cannot produce insulin any more, diabetes treatment involves measuring a patients blood sugar level multiple times daily, calculating how much insulin needs to be injected according to a patient's personal insulin ratio and controlling, if this dosage was correct. The blood sugar level is influenced by multiple factors such as eating food that contains carbohydrates, sport, stress, hormones, illness, the injected insulin or simply the weather.

As keeping the blood sugar level in range is dependent on so many factors, it is very difficult for patients to keep it in range. Furthermore, whenever a patient's blood sugar concentration is too high or too low, short or long term complications can occur. The threat of these complications is another burden on the mind of diabetes patients.

These difficulties patients are dealing with 24/7 is one of the main reasons for their increased support needs and what makes having diabetes such a burden to the emotional wellbeing. (More medical background knowledge about diabetes and diabetes treatment can be found in the appendix 1).

> *People around the patient, for example the parents, partner or friends, are often referred to as T3D - type 3 diabetes patients by online networks and doctors, to integrate them into the treatment and indicate the big effects on the patient's support network!*

figure 10 patients and doctors at Diabeter Rotterdam, a hospital for type 1 diabetes patient until the age of 30

Support for diabetes patients

In the Netherlands, a type 1 diabetes patient is forwarded to an internist specialized on diabetes and a DVK (diabetes verpleeg kundige). These two entities take care of the medical side of the disease, therapy adjustment and a checkup. Furthermore, a dietician can advice the patient on food and lifestyle choices (see figure 10).

As diabetes is for 98% a self management disease (Anderson et al., 2010), the direct network around a patient is also influenced by the disease and react upon it. The direct support network can provide emotional support and, with the right knowledge, also medical support. So far, this network is not actively approached within the diabetes treatment or online networks and patients and informal caregiver have to figure out their own personal way to handle and provide support from each other. (see chapter 2.3 for more information) The access to a professional psychological support is limited to patients with severe problems like an eating disorder or the fear of needles. Other possibilities for mental diabetes care are privatized. (Zorgstandaarddiabetes.nl, Diabetes type 1., 2017) Within this project the possibilities to strenghten the private support network of patients will be explored.

figure 11 injecting insulin with an insulin pen

Peer support among diabetes patients

Peer support provides a great addition to a patient's existing support network of informal caregivers. Patients get to know others that are dealing with the same problems and have enough background knowledge about the disease to provide a broad pool of improvements and advice to each other. Diabetes peer support is provided by multiple diabetes NPOs that organize group meetings, educational activities and online platforms to chat with other patients. Although the number of networks is growing, a great number of patients is not member of a network (see figure 11).

Little research has been done about the style and effect of the existing online peer communities and whether patients identify with the current support offer. Within the analysis phase multiple factors that on the one hand keep patients from getting sufficient support from their existing support network and on the other hand prevent them from actively participating within the networks were discovered. The possibilities to overcome these factors and increase peer contact within the new support tool will be explored.

1.2 DESIGN CHALLENGE AND BRIEF

Within a patient's support network there are two groups that can support the patient: the informal caregivers and other diabetes peers. Both of them have certain boundaries this project aims to overcome. If a patient does not manage to build up a sufficient support network that helps him/her during difficult times, a patient's emotional well being and efficiency in managing the disease can decrease. When defining the design challenge, the two different types of relations and roles of these three parties were analyzed (see figure 1.2a):

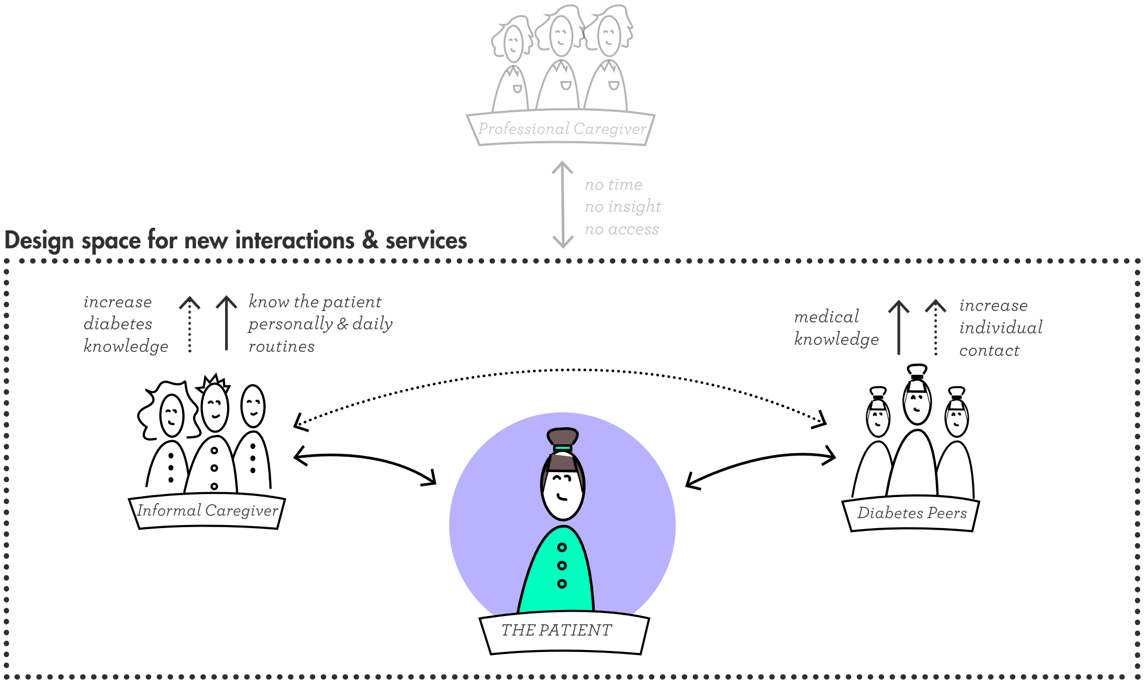


figure 12 design challenge of the project proceeding from the patient

The **informal caregivers**, for example partners, parents and friends have to find the right way and tone to support the patient. They have been there before the diagnoses or have to be "educated into the diabetes". There is no support manual and every patient has their own, individual support needs. As diabetes is a complex disease, informal caregiver need to be medically educated in order to support the patient and help implementing the disease into every day life.

As diabetes is a very individual disease, the challenge is find out how to provide them with the requested knowledge that is tailored to a patient's personal situation.

On the other side are the **diabetes peers** that do have the knowledge about the disease, but are not easy to find within the direct surroundings of a patient. As diabetes is an individual disease, the possibilities to do so are limited to online networks or diabetes community activities that facilitate contact. Without personal offline contact possibilities, patients have to rather connect to the diabetes groups and their view on diabetes than to individual peers (see figure 12).

The challenge here is to find out about other possible facilitation factors and moments to connect patients and transfer them into the new support tool.

In the current health system doctors often do not have the time and insights into the emotional world of a patient. Therefore this party will play a minor role within this project.

DESIGN BRIEF

In cooperation with both parties the following assignment is formulated:

> *"design a support tool that helps facilitating contact and exchange information between patients, in order to increase and strengthen the support network of T1D patients (aged 18 - 30 years)."*

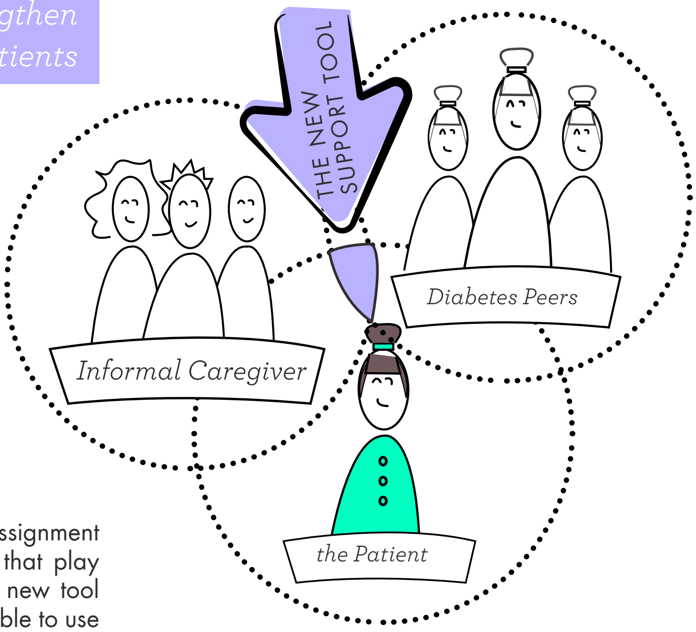


figure 13 Assignment of the project

Figure 13 provides a visualization of this assignment and introduces the different stakeholders that play an important role within this project. This new tool connects informal caregiver, peers, to be able to use other peers experience and knowledge to educate the patient's support network.

Determining the target group within this project

The target group for this project is limited to an age of 18 - 30 years old, which is also the age group of the participants within the generative interviews conducted. There are around 100.000 T1D patients within the Netherlands and around 10.000 between the age of 18-30 years. (Diabetes in cijfers. (n.d.).) This limit was determined after analyzing the existing networks (see chapter 2.1.2), and a patient's support network development. Below the age of 18 the parents of a patient are often the main support givers and afterwards, according to the interviewed diabetes industry employees *"these are the years when people have their first times: first time moving out, studying, first job etc. Those are exiting new situations where a lot of things change."* Combined with the extensive online activity inside this group and openness to social media and new ways to communicate (Newcom, Research & Consultancy, 2017), this group will be the focus group within this project.

USER INVOLVEMENT DURING THE PROJECT

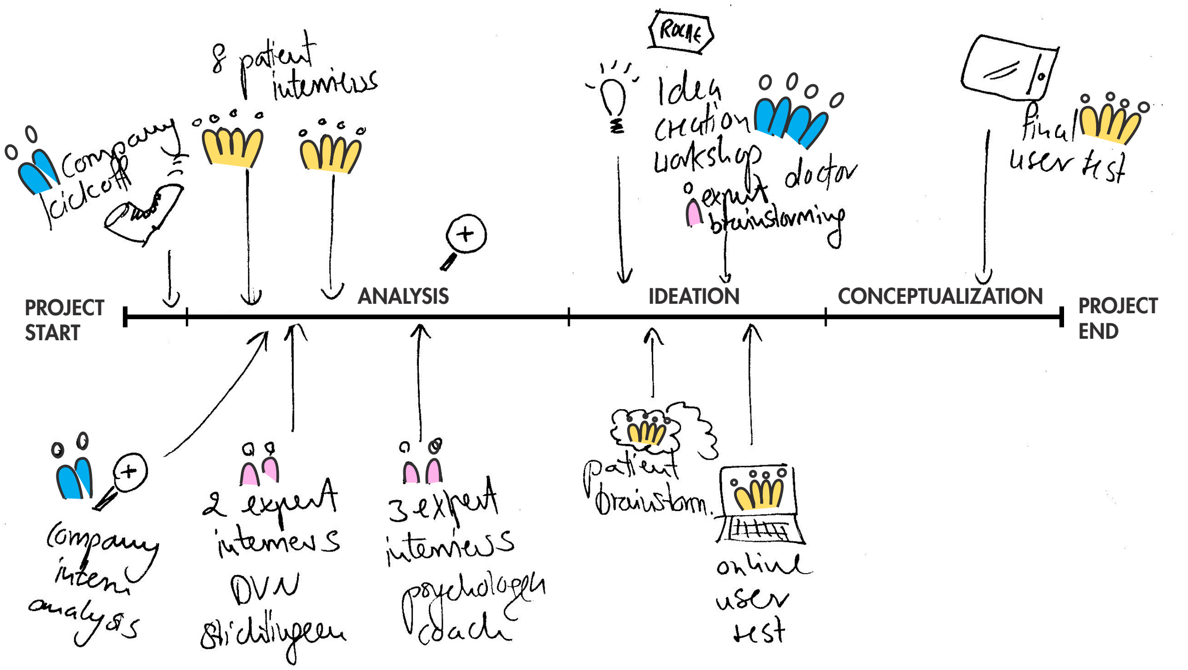


figure 14 - user involvement during the project

1.3 PROJECT APPROACH

HUMAN CENTERED DESIGN PROCESS

To meet the challenge of improving the support network of diabetes patients, the project is approached with a human-centered design process. Throughout the concept the targeted patients are involved in the steps taken, to deal with their expectations. Generative interviews enable them to directly contribute with their experiences as an expert of their context. Further in the ideation phase, co-creation methods with the company's employees and afterwards design iterations with the patients with validating prototype tests will ensure that the concept meets the needs of the patients. The most important goal of these co-creative moments is to raise acceptance for the new design both on patient's and company's side.
Figure 14 provides an overview of the moments users are involved within this project.

Generative research methods

Working on such a highly individual topic as a person's support networks was the origin to choose a generative method that involves as much user insights as possible, context mapping, a method developed within the TU Delft by Prof. dr. Stappers, P.J. and Dr. ir. Sleeswijk Visser, F. (Sleeswijk, 2005) All three layers of Visser's technique pyramid (see figure 15) will be included:

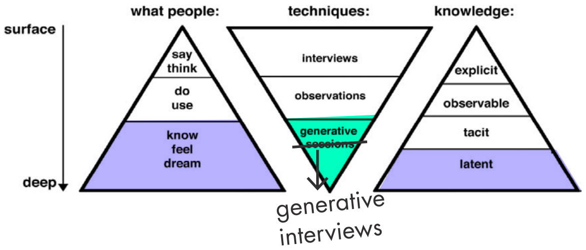


Figure 15 the generative patient interviews within this project will focus on the purple and green areas within the model (Sleeswijk Visser et al., 2005)

During this project, all areas within the pyramids are going to be tackled, with a focus on "know, feel, dream" and latent knowledge. This knowledge will be reached within the generative patient interviews that are conducted within this project (also see figure 16 next page). Within these interviews patients talk about their daily diabetes life, their support network and their wishes for the future regarding diabetes treatment and support possibilities. The interview is combined with different generative techniques, such as creating a collage.

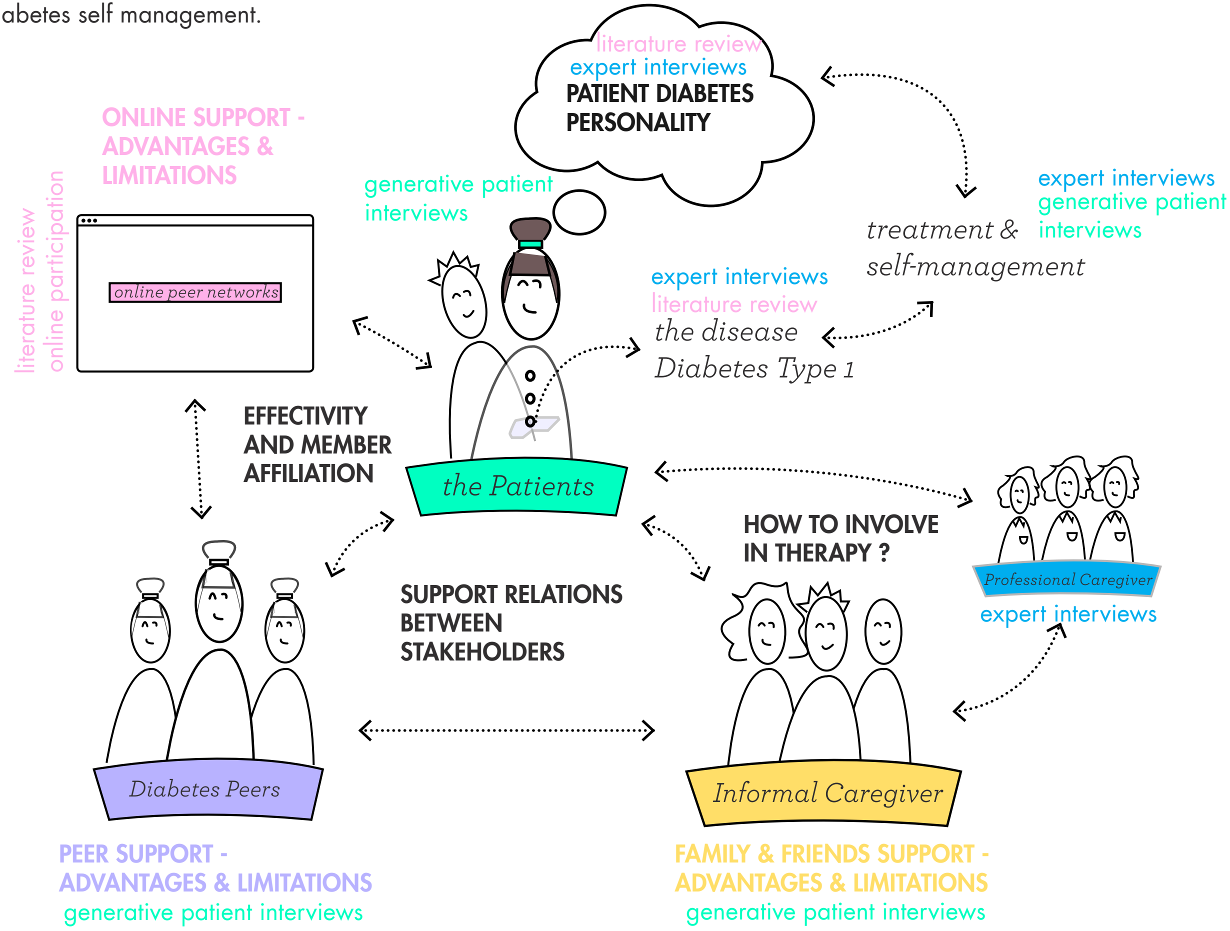
CONTEXT ANALYSIS

The main research question within this project is *„What kind of (peer) support do T1D patients, want and need and how can the new tool help to strengthen and extend their support network ?"* To be able to target all topics and areas around a patient's support network, the project scope is divided into different areas, all situated around the patient and his/her support network. The main research is parted into three areas: the patient and the individual psychological effects of diabetes, the informal care giver support network of a patient and (online) peer to peer support. Figure 16 provides an overview of all the topics that are investigated around the patient, to make sure to cover all aspects that play within a diabetes support network. The project mainly focuses on the different patient personalities and how they deal with their diabetes and support issues. Therefore the start of the project focuses on the emotional problems patients are facing within diabetes self management.

Afterwards the different support possibilities and support givers of a patient are analyzed and categorized into informal care givers (people around the patient without diabetes), diabetes peers and online support groups. Within these three areas the stakeholders, their roles, the type of support they provide and their advantages and limitations are analyzed. This was done to be able to use their advantages and try to tackle their limitations within the future support tool.

Before starting out with analyzing the different interactions within context, the state of the art of peer communities provides an overview of market opportunities within this the field. (see chapter 1.4).

Details of the research participants can be found in appendix 2.



LEGEND

generative patient interviews -interviews with a total of 8 patients and 1 informal caregiver support person.

expert interviews - interviews with industry employees, psychologists, diabetes coaches and PhDs.

literature review - psychological backgrounds & underlying principles of peer support and diabetes management

online participation - posting and reading posts online, searching participants and observing online activities within peer groups

figure 16 overview of the research areas & activities to examine them within this project

1.4 STATE OF THE ART PEER COMMUNITIES

Before analyzing the interactions within the communities, the status quo within communities was examined. the company's own efforts to gain access to establish themselves in the community business were analyzed within an internal analysis and compared to other diabetes communities. This was done to find out about possible market opportunities and pitfalls for Roche, which were also confirmed by the interviewed employees of two existing diabetes communities.

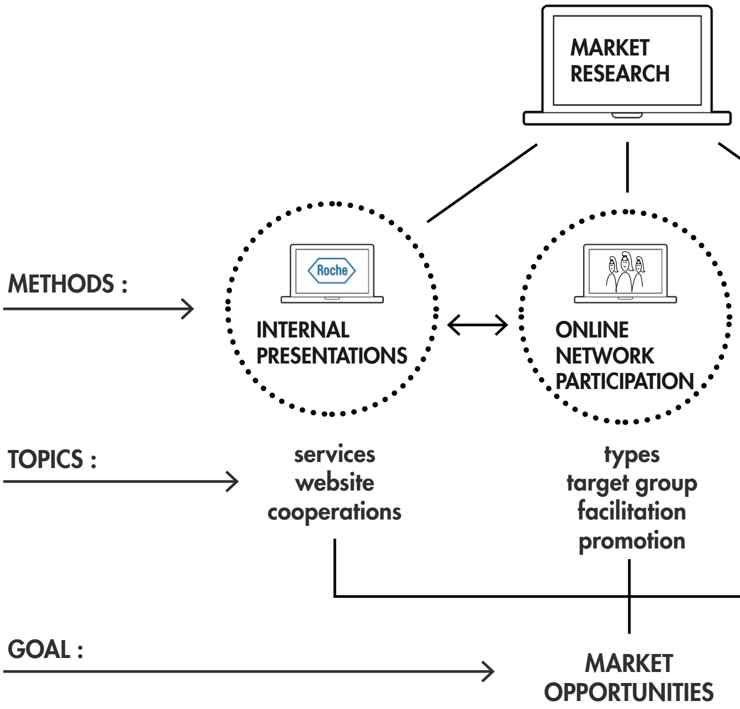


figure 16 structure of the market research

Research structure

The market research can be separated into three main categories: internal company research, external research within the existing peer to peer communities and interviews with peer network representatives. (see figure 16) The expert interview questions can be found in appendix 3.

Research Questions

How many patients are online and how are the networks promoted?

Why do patients identify with a network - connect to each other?

What topics are patients interested in?

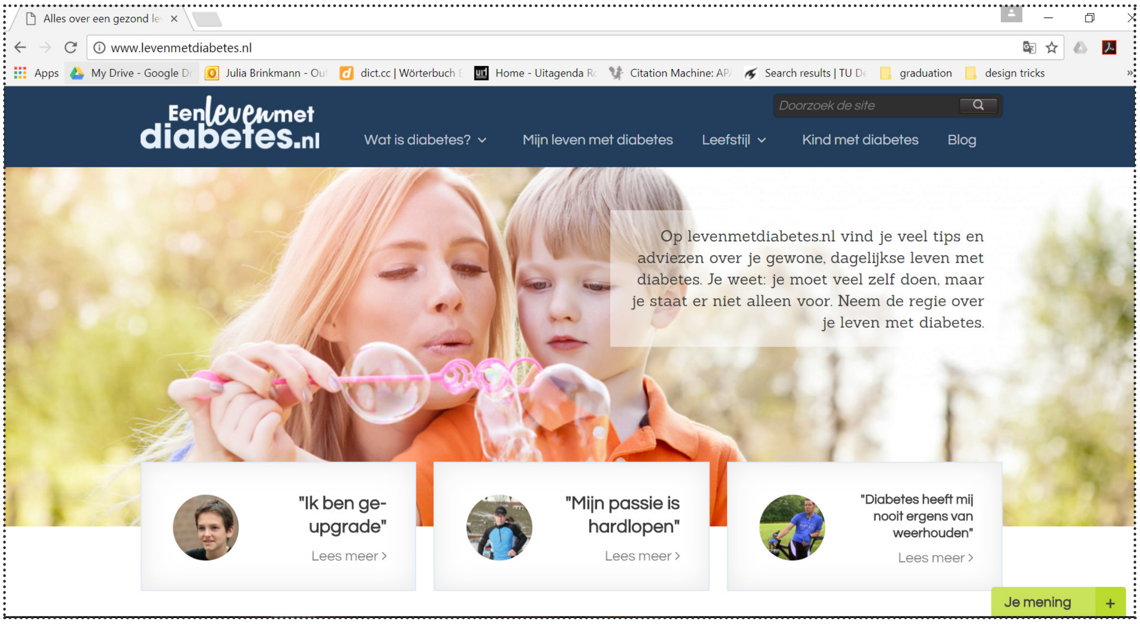
How do networks facilitate contacts / information?

Research tools

Company internal presentations and information exchange with the internship coordinator provided the needed insights for the internal analysis. Regarding the peer to peer communities, active online participation in the groups and analyzing the content and facilitation rules let to an overview of all networks. The interview with two communities web master lead to community industry insights and advice about the company's plans to start a community and their wishes.

Research results

The results are used to determine the market opportunities for the future community. These market opportunities are further taken into account within the idea creation phase in order to come up with feasible concepts. The insights of the expert interviews can be found in the learning books within appendix 4.



Op levenmetdiabetes.nl vind je veel tips en adviezen over je gewone, dagelijkse leven met diabetes. Je weet: je moet veel zelf doen, maar je staat er niet alleen voor. Neem de regie over je leven met diabetes.

"Ik ben ge-upgrade"

"Mijn passie is hardlopen"

"Diabetes heeft mij nooit ergens van weerhouden"

figure 17 screenshot of the company's website levenmetdiabetes.nl

THE COMPANY'S OWN COMMUNITY

Current service offer

With over 40 years of experience and a market share of about 41,1%, Roche Diabetes Care is the number one blood sugar meter provider in the Netherlands. The core strategy of the department is to provide patients with the tools for personalized diabetes management, which starts at educating the patients about diabetes and how to manage it, the right personalized products and the tools to efficiently manage the diabetes and assess one's management method

In order to increase direct customer contact , the company is also targets the diabetes therapy areas were patients decide for themselves. These tools include educational programs, data analysis tools for private use, and, since 2017, an own website for type 1 and 2 diabetes patients called "levenmetdiabetes.nl." (see figure 17) (see appendix 5 for company background information and additional service offers).

Website www.levenmetdiabetes.nl

The main goal of the website is to inform and show Roche's support with everyday questions. The website targets T1D and T2D patients and their surroundings and provides advice and tips on how to live with diabetes. Within the blogs patients are sharing their stories about their diabetes. As the community has just been started, most of the blog content is provided by the company and based on company intern information. The plan is to extend the community and open it up to patient participation within 2018.

Analysis content, idea, layout

In order to get some feedback on the current website, the website was analyzed within content, owner / author of the content and target group. This was done during the patient and expert interviews, where the participants were asked to comment on the website. The general impression was that the website is too general in the advice provided and users did not find out which target group should be reached. The complete findings can be found in appendix 6.

An FPO as an owner

As Roche would be the first to setup a community as a FPO, users and experts felt a little bit tensed about their data and what would be the goal behind this community as it was not perceived as something independent like other known communities. All interviewed experts agreed that within the health care industry patients and professional care giver have a rather suspicious picture of the pharmaceutical industry and their goals.

The content provided

As patients are used to patients being the owner of the provided content or scientific studies, there was a general mistrust whether the advice and tips provided were really applicable and useful. One patient compared the articles with the "too positive and too ambitious advice my doctor always gives me, that no one can ever follow."

The layout

The layout and pictures were received as nicely made, but not enough diabetes related and from the patients, more from the company's view with the included photos not showing actual diabetes situations or real patients.

STATE OF THE ART PEER COMMUNITIES

With the rise of e-health and virtual communities, an increasing number of peer to peer diabetes groups can be found online. In 2015 multiple new networks started, focusing on facilitating contact between diabetes patients and provide more recognition within the topics by clustering, especially for younger patients. Before these online networks the DVN - Diabetes Vereniging Nederland was the only one to organize diabetes camps for kids and teenagers and different diabetes activities and educational courses for grown-up patients to get together. Therefore the diabetes peer communities are all pretty young.

Types of communities

In order to get more insight into the status quo of diabetes peer communities in the Netherlands, the existing networks were categorized by type of participation, sponsor, size, target group and facilitation within the network. A total of 5 groups was identified. This was done to be able to identify gaps within the market, to be able to choose the right concept direction within chapter 3. (see figure 18 and appendix 7 for a more extended review of the four most important networks).

The biggest difference among the networks is their focus, who they include and “allow” into the network, who is the author behind the provided content, if patients can communicate and contribute within this network and what medium the network uses to facilitate this.

> The most successful communities for young people, the two facebook groups “Jongvolwassen en diabetes” and “Jong met diabetes” are either run by patients themselves or patients working within the diabetes industry. According to the owner of these groups, the reason for the success are the *“unfiltered emotions and feelings of patients, realness and recognition”*.

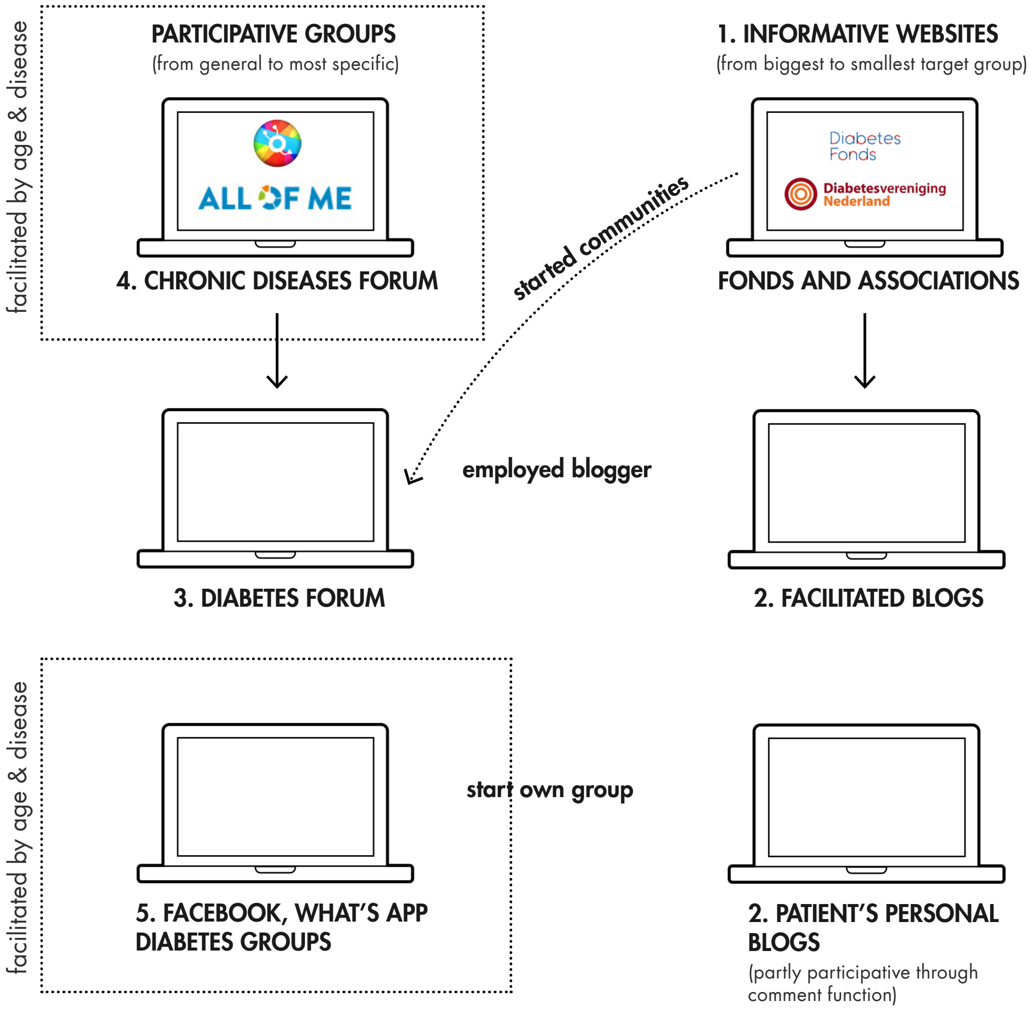


figure 18 diabetes communities categorized according to their owner, target group, patient participation and medium

HOW MANY PATIENTS ARE A MEMBER OF A DIABETES COMMUNITY?

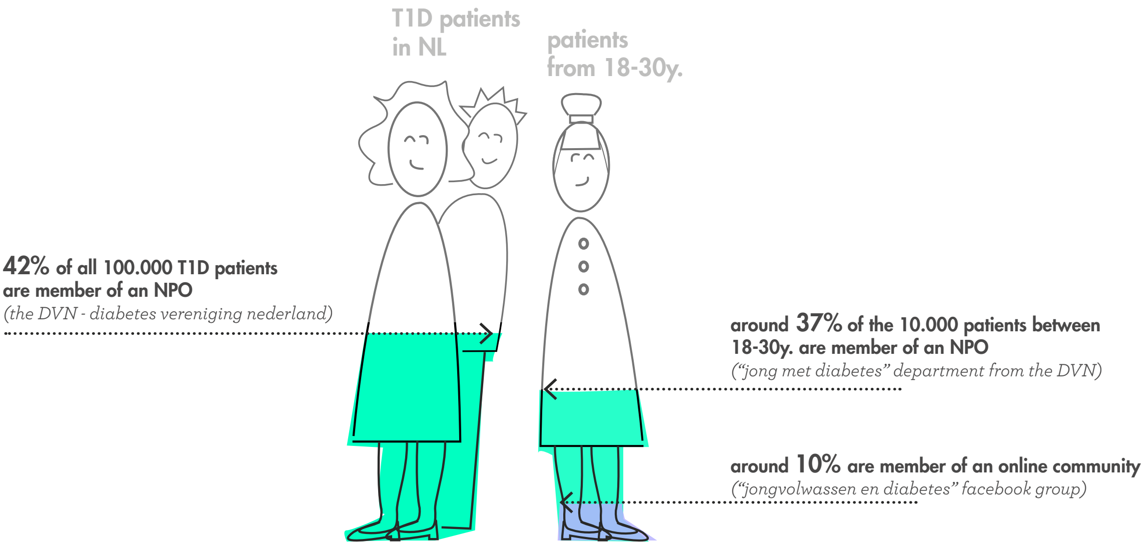


figure 1.4d target group analysis based on appendix 1.4 V - network analysis and interviewed industry employees

Facilitation within the analyzed groups

The more informative networks are open for everyone around the diabetes patient, the informal caregivers and professional health care, the other networks are more tailored support networks and have a clear definition of the group and a "door policy". This is also facilitated through the medium (request to join the group or register). The communities can be categorized into

1. **open to everyone, who's interested (1&2)**
2. **read anonymous, create an account to post (3)**
3. **door policy - for certain patients only (4&5)**

Door policy - only for patients!

The groups within 4 and 5 only allow "real" patients to become a member of the network to promote privacy and create a "safe-space" for patients.
According to the webmaster of the "Jongvolwassen en Diabetes" group, *"A door policy and clear rules for member leads to an intimate atmosphere in the group where people are willing to share their most intimate secrets since they know that friends and family cannot read it."*

Facilitation within the facebook groups is needed in order to make sure the posts and shared content are according to the network's guidelines and goals and fake user will be deleted. Within the closed networks, experienced user sometimes take over this task and comment on unwanted posts. It seems that the more facilitated the network is, the higher the feeling for responsibility among members.

Age limit for more specific content

So far, these facebook groups are only facilitated by age and type of diabetes. The age limit (18-35y. within the examined group) was introduced to dissociate from the existing networks that accepted everyone as a member: *"I wanted to talk about first time studying, moving out, first real job, a house, a baby, sex. Those are the relevant topics for this age group! That's why we focus only on younger patients."* according to the interviewed network owner. If more members in the group are the same age, these people are also more likely to experience the same problems within everyday life.

Steppingstone networks

To facilitate even more, patients use the free social media platforms (Facebook, What's App) to start their own groups, to find other patients that can relate even more to their specific medical or life situation. For example through the forum "diabetestrefpunt.nl," run by the DVN, the What's App group "Suikerklontjes" with newly diagnosed patients all over the Netherlands was started in 2016. This group was actively involved within this project and the user tests (see chapter 3.2) During this project another What's App group for students from the TU Delft was started by participants of the patient interviews. The backgrounds of this group will be explained further in chapter 2.4.

COMPARISON PEER COMMUNITIES

To sum up the advantages and pitfalls for the company within the peer community segment, the insights from the internal analysis and the existing networks are compared and combined with the opinions of the interviewed experts. This was done to be able to combine these insights with the patient's wishes for new support and to make sure the future support tool would be accepted and appreciated between the other networks.

INTERESTING INSIGHTS FOR THE ANALYSIS PHASE :

Advantages / Disadvantages NPOs
Existing peer communities

image of the communities = independent, trustworthy, doing good for patients

provided content = **from "patients" or scientific sources for patients**, reliable, usable, insider news, own opinions, **facilitate groups to provide more recognition "door policy"**

resources & budget = low/no budget, dependent on sponsors and **volunteers**, limited research resources to grow and improve

promotion = promotion through mouth-to-mouth, hard to gain access into professional health care environments and reach new patients, full potential of peer contact not exhausted yet

future development = little research what patients are looking for and to reach more patients

Advantages / Disadvantages Roche
Future peer community

image of the community = attentive & alert patients - be clear about the owner and what happens to the data / advertisement

provided content = not independent, still the company can provide valuable **insights in fields the company is an expert in**, no facilitation yet

resources & budget = high budget and big data, **existing customer circle as starting point and promotion**

promotion = use existing contacts within the industries and hospitals, **use hardware, educational courses and packaging provide** direct customer contact possibilities

future development = research about patient wishes / needs and promotion can be used to create a community that **ads true value for patients**

Big data chances

Worldwide operating companies as Roche, who have an extensive portfolio of diabetes related devices, a big circle of customer and data analysis apps are collecting big amounts of data from all kinds of stakeholders. The company is connected to hospitals, doctors, DVKs, user and pharmacies. Every stakeholder, by registering a new device, uploading the blood sugar values into online analyzing tools and visiting the doctor is contributing to the big amount of data Roche is collecting every second. Combined with their connections and their expert knowledge within the field, it seems like a logical step to make use of this data and provide the user with their inside knowledge and connect the stakeholder through their system. Following examples like the Philips "HealthSuite" platform or Siemens "Healthineers", the company can contribute the gathered data to improve the patient's therapy. Still, the company has to divide between the collected demographical & sensory data the patients and which one to use for what kind of further analysis to not violate any privacy laws.

Cooperations with known communities ?

Roche is sponsoring some of the biggest diabetes communities, therefore the possibilities to cooperate within the new community where also examined, in order to promote the new community. The biggest advantage would be to connect the new network to a trustworthy, known source within the diabetes community and offer the researched insights, promotion and budget. During the interview with the DVN, the webmaster showed great interest in a cooperation but only under the right circumstances, therefore this voiceless sponsor role would have to be rethought and a cooperation with two networks offering the same service could be difficult, as the organization wants to stay an independent information source. In any case could the network be promoted through advertisement within their magazines and through activities.

FIGURE 20 - EXISTING DIABETES RELATED SERVICES; SORTED ACCORDING TO OWNER AND TYPE

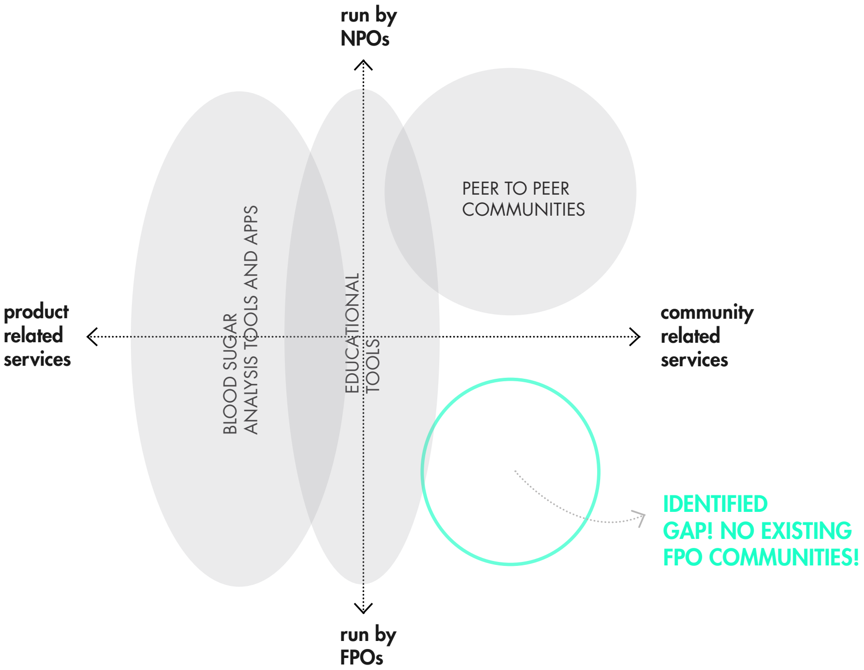
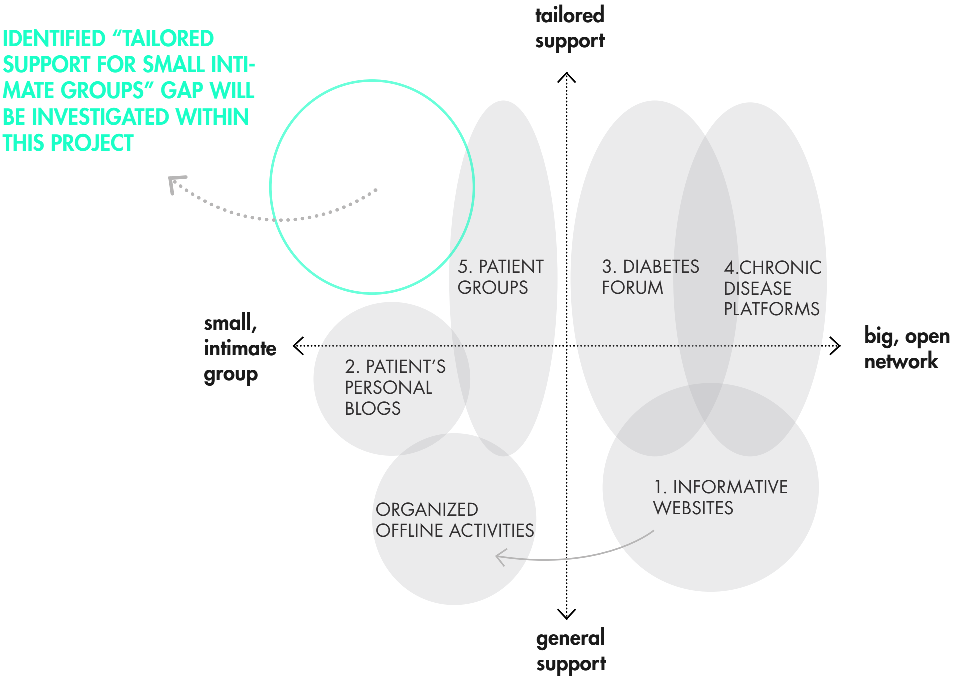


FIGURE 21 - EXISTING DIABETES NETWORKS; SORTED ACCORDING TO TYPE OF SUPPORT AND SIZE



MAIN RESEARCH INSIGHTS - FUTURE MARKET OPPORTUNITIES

To conclude the market research, two strategy matrix, to find service & types of community gaps, were developed, which can be seen in figure 20 & 21 During the research no existing FPO communities have been detected within the diabetes sector. It can be seen that so far FPOs only focus on product related services and add-ons to educate customer about their products and the disease and did not yet enter the community market. Therefore, Roche could make a good start within this sector. On the other side, regarding the focus of the existing communities, a gap within small groups that have a tailored service offer can be seen, as current networks facilitate the people, but only according to age and not to their service wishes.

2.

INSIGHTS & ANALYSIS

Chapter two focuses on the insights gained from the different research activities. The chapter is divided into the patient's diabetes management and diabetes mindset, the support possibilities for each patient - divided into informal care giver support, peer support and online peer communities and ends with the interviewed patient's future support wishes.

All findings are summarized within the 5 key findings within sub-chapter 2.5.

Each sub-chapter is structured in the research activities, the tools, insights and conclusions. All of the conclusions, marked through the green borders, will lead to the key insights at the end of this chapter.

2.1 DIABETES MANAGEMENT - MENTAL INFLUENCES

This chapter contains an overview of diabetes from an emotional perspective, to gain insight into the broader context of what it means to have to deal with diabetes every day. The main objective is to provide insights into the societal- and emotional impact of diabetes and understand the "act of balance" within this disease. This chapter first dives deeper into the everyday struggles regarding the diabetes management and its direct influence on a patient's emotional balance, these influences are then transferred to the patient's diabetes mindset.

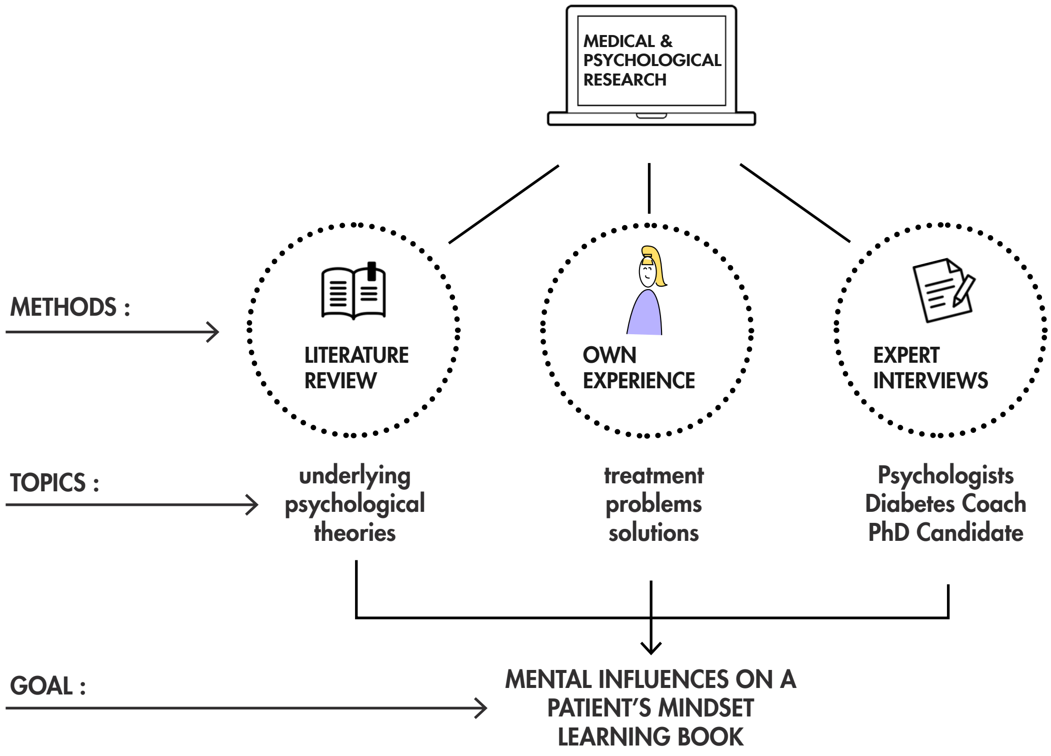


figure 22 structure of the medical & psychological research

RESEARCH STRUCTURE

The medical research within this chapter was partly started out of the researcher's own experiences and knowledge and completed by the literature research and interviewed experts. These insights combined lead to the complete picture of the influences on a diabetes patient's personal mindset (see figure 22).

RESEARCH QUESTIONS

What are the internal and external struggles diabetes patients have to handle?

What factors influences a patient's style of diabetes self-management ?

How can diabetes influence a patient's emotional wellbeing, short- and longterm ?

RESEARCH TOOLS

The researcher first analyzed her own diabetes path and underlying motivations with the interviewed psychologists and found out about other patient's influences and actions.

The expert interviews and the literature review completed the picture of the influences on a patient's mindset and reviewed other unknown behavior methods and effects to the researcher.

RESEARCH RESULTS

The results were mainly used to setup the generative interview tasks with the patients (see chapter 2.3), to be able to categorize them and determine the characteristics and differences within the mindset of the five created personas within chapter 2.3. The key insights of the expert interviews are summarized in the learning book in the appendix 4.

2.1.1 INFLUENCES ON A PATIENT'S DIABETES MANAGEMENT

Every patient builds up an individual diabetes mindset over time. A diabetes patient is shaped by internal and external influences displayed in figure 23. These influences were determined by the online platform "Stichting Eén Diabetes" within an internal user analysis. Before determining the internal influences on a patient's mindset, the external will be examined. This is done to be able to process them into realistic personas within chapter 2.3 and include the other influences within a patient's life into these personas, to be able to identify with a complete person instead of a diabetes patient. The following four influences were determined:

1. The patient's character

All interviewed expert stated that the character of a patient influences how this person will take the diagnose of this disease, what coping strategy the patient will use and how a person's diabetes management will look like. As the disease is so interwoven with the daily life of a patient, the personality influences all part of the diabetes management.

The network's webmaster confirms that *"Patients who have been chaotic before they were diagnosed are much likely to stay chaotic after the diagnose."*

How a patient's personality influences a patient's style of self management will be examined further within this chapter and summarized within the next chapter 2.3 - patient's mindset.

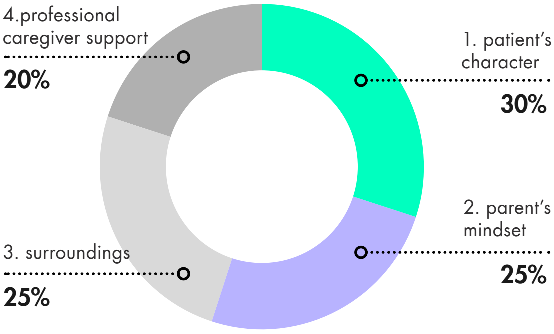


figure 23 influences on a patient's diabetes dealings

2. Growing up with diabetes - influence of the parents on self-management

"Diabetes does not just affect the person living with the condition – it has the potential to affect the whole family system too" (Holt and Kalra, 2013).

In general, once a person is diagnosed with diabetes, the existing support relations will not change in its style. The type of support they provided beforehand is likely to continue. Therefore if, for example parents have always been very pampering, it will be difficult for them to change this according to the diabetes. Depending on the age a patient is diagnosed with diabetes, the parents play a different kind of role within the system. Being diagnosed at a young age, patients have to not only take care of their child but also of the diabetes. Even though most patients, who grew up with diabetes, stated that they injected by themselves from an age of seven or when they started to go to the elementary school, parents stay on top of the diabetes, the doctor's visits and the insulin ratio the child has to inject. As within other areas of life, the parent's mindset influences the children. The mindset of the parents influences how self-conscious a child will deal with the diabetes later on. How scared the child is of the disease or how much it learned to handle difficult situations and ask for help if needed. If the parents handle diabetes as a "normal thing", the child will have less problems later on to accept the disease as part of his/her life.

3. The patient's other surroundings

Every situation in life is affected by the diabetes and also external factors as friends, room mates, the university and work will be influenced and influence back the diabetes management of a patient. These surroundings can have positive and negative influences on the adherence of a patient. 50% of the patients with diabetes state being nonadherent to their doctor's advice to a certain extend. *"Support from family and friends promotes adherence by encouraging optimism and self-esteem, which can buffer the stress of being ill. But they can also, if for example the partner does not want to follow the same diet as the patient, can have a negative influence on the patience adherence. See it as social pressure"* as Miller and DiMatteo state in the article about the "Importance of family/social support and impact on adherence to diabetic therapy." (Miller, T.A.; DiMatteo, R., 2013) Within the same study it was confirmed that if adults are living with others, this would have a positive effect on behavioral regimens through group motivation, in case the room mates encourage the patient to perform good and also stick to the therapy.

This combined practical and emotional support has a stronger effect than structural social support, therefore the quality of a relationship matters more than just the mere amount of people present in a patient's support network. Especially for patients who have been diagnosed a longer time ago, this support network can provide new, external motivation to handle the diabetes (see chapter 2.2.4) or help handling some tasks.

On the other side, the surroundings of a patient also influence how easy or difficult a patient experiences the disease, how much extra effort he/she experiences to be treated as normal and if certain barriers come up because of the disease.

4. Support from professional caregivers

A patient's DVK is the most important support person within the Dutch health system for diabetes patients. The DVK needs to know enough about the daily life and mindset of patient to get a complete picture of the patient's status. Breaking the mystery diabetes in small parts and showing the patients that diabetes can be integrated and balanced in one's life is an important part of the support network and professional health care providers. The interviewed diabetes coaches stated that the approach of DVKs to act as a "coach" rather than an expert and motivate the patient's autonomy has shown great successes within type 1 diabetes. With the basic principle of not undermining the authority of the patient within his/her own disease, they are coaching the patient, putting them in a central role and is his or her own principal caregiver. This new system stands in contrast to the old approach that was more focusing on acute care, making the patient the passive recipient of the changes made by the doctor. (Adapted from Bodenheimer et al., 2002). The most important aspects of this coaching approach are summarized:

role doctor / DVK = coach, even

doctor / DVK's task = inspire and coach the patient to solve the problems him-/herself

doctor's advice = implementing the patient's ability to change, mindset into treatment, triggering motivation, compliment on things that went good, asking for patient's opinion

patient's task= proactive, discuss, think along and ask questions

patient's reaction = internal motivation is triggered, feeling empowered, tackling problems and reflection on situations, recognize patterns

2.1.2 SOCIAL MISCONCEPTIONS

Before diving into the emotional world of the patient himself, the social status of diabetes was analyzed. This was done to be able to explain the double pressure that some patients might experience: the own expectations and ignorance of their surroundings that can cause extra frustration.

The distinction between the two forms of diabetes and the Dutch vernacular expression "suikerziekte" causes a lot of misconceptions in society about diabetes, which causes patients to having to explain and even to defend themselves for certain actions. There are around 10 times more type 2 diabetes patient and almost every person within the Netherlands knows someone, who has this disease, often causes bystanders to give unwanted advice or reflect things that one diabetes patient does or does not on another. Furthermore, as diabetes type 2 is mostly caused by an unhealthy lifestyle and overweight, type 1 patients are also often accused of it being their fault they got this disease.

Another obstacle, which diabetes patients often face is a lack of understanding and empathy that diabetes is a serious condition that affects the daily life and routine. As diabetes is at first glance invisible, patients are often dealing to "having to proof that either their disease is real or the other way round the patient tries very hard to proof that he/she is not sick through for example never missing a day at work or not admitting if your blood sugar is low and you need to eat something. Patients put themselves in competition with their healthy fellows, hiding this disease works until a certain point of medical harm. The most common misconceptions named during the interviews are listed within figure 23.

"Did you get "suikerziekte" because you ate too much sugar?"

No. Everyone can get type 1 diabetes it has nothing to do with your diet, weight, gender or age. Having to fight against the implication of an unhealthy lifestyle is one of the most confronting tasks.

"But you can grow old with that."

Even though this is often said to cheer someone up, the person saying this does not recognize the impact the disease has on the patient's life - every single day.

"My .... also has diabetes and he / she has no problems with that."

Everyone's diabetes is different and every patient reacts differently on certain food, situations or for example sport. Just because this isn't a problem for one, does not mean it isn't for the other.

"If you just stop eating carbohydrates and sport a lot you would not have to inject insulin any more?"

No. Almost all food contains a little amount of carbohydrates and your blood sugar will still rise. It is true that a low carb diet can help keeping your blood sugar more in range and avoid high peaks.

"Are you allowed to eat that? There's a lot of sugar in it."

Diabetes patients are allowed to eat everything, if they calculate how many carbohydrates are in there and inject the right amount of insulin for it. "Healthy" food as milk, bread and fruit also contains carbohydrates.

figure 23 social misconceptions of diabetes management

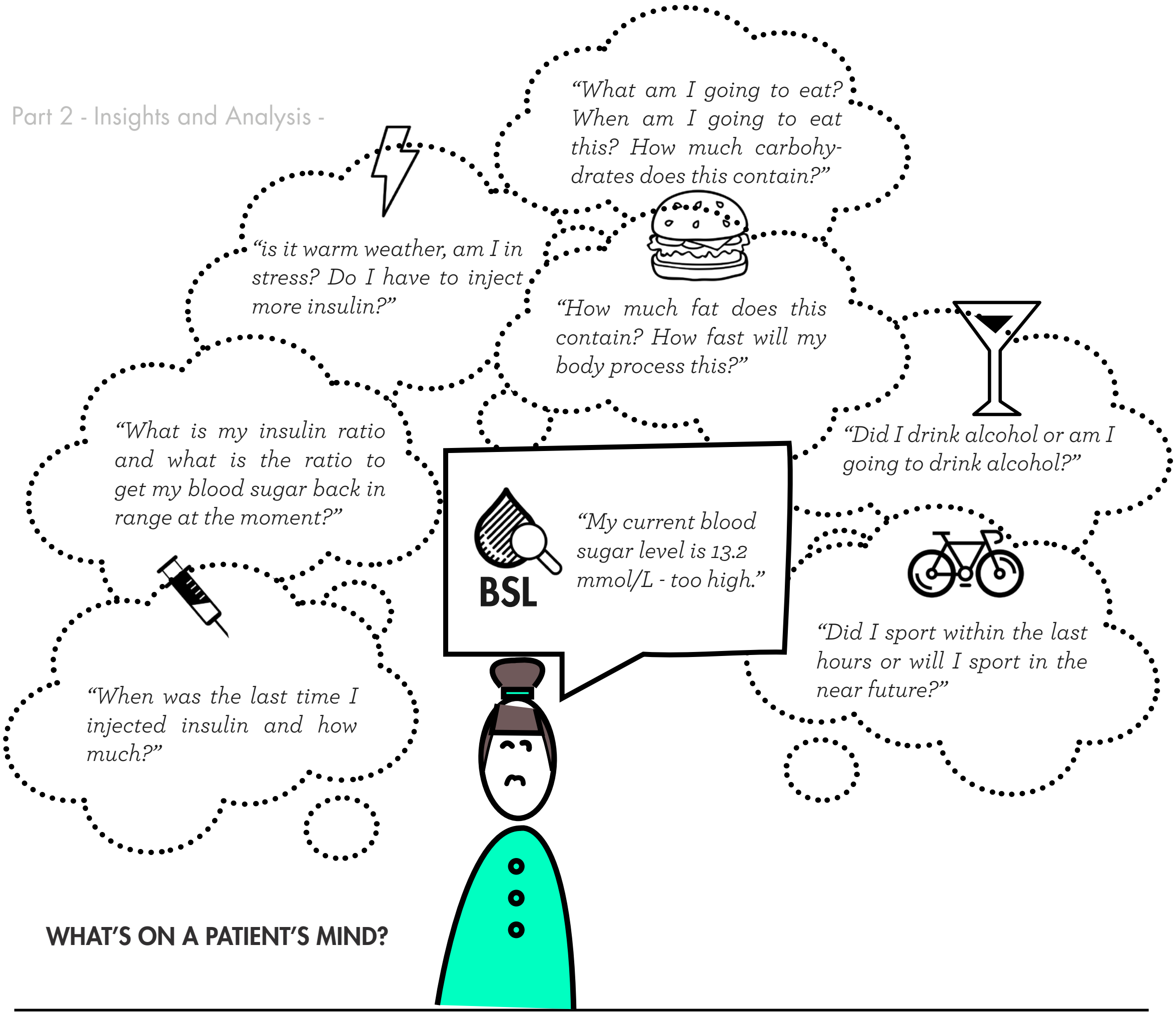


figure 24 questions a patient has to answer multiple times a day

2.1.3 DIABETES SELF-MANAGEMENT

As mentioned before, diabetes is for 98% a self-management disease. Therefore, as a first step within the project, the everyday struggles and long term problems that can be caused by diabetes will be examined and put into context of emotional disbalance and the personal struggles of patients. This was done to find out about possible problems and see how the interviewed patients deal with them and how patients could be classified according to their beliefs regarding diabetes.

Everyday tasks - everyday struggle?

Diabetes is a constant balance act between the right amount of insulin and the right amount of glucose in the body and balancing life and diabetes in a way that fits into a patient's way of life. To be able to calculate the needed amount of insulin and structure the day correctly, the patient always has to consider the following factors explained in figure 24.

These factor differ per season, time of the day, the blood sugar level, if the patient calculates everything correctly or simply if the patient did not forget any of these factors the last time he/she measured. Furthermore, the mood of the patient, stress, being sick, the weather and hormones can also affect the blood sugar level. These ratios and effects of the different causes vary from patient to patient and can often be misjudged. Keeping the blood sugar level in range is dependent on so many factors, patients often lack insight, simply because of the amount of influences that could have caused the blood sugar to rise or fall. To be able to keep it in range, patients have to recognize patterns within their therapy and behavior within every day situations. Every patient has a different method of doing it that is more or less effective. On the next page, the different influences on self-management next to adherence to the doctor's advice will be explained. The different persona in chapter 2.3 provide more tangible examples about these different methods.

2.1.4 PERSONAL INFLUENCES ON A PATIENT'S STYLE OF SELF-MANAGEMENT

How much has the patient integrated the disease into his/her life? How can his/her life be arranged with the diabetes and still keep a high quality of life? How and what motivates the patient? In order to find out about the support needs of patients, it first has to be clear what are the difficulties and influences within diabetes management, where patients could experience troubles. Through the expert interview and literature analysis the following three influences were filtered out:

1. Acceptance

2. Adaption

3. Motivation

These three factors are the most important principles when searching for a suitable way to handle one's diabetes and partly interwoven / dependent from each other.

1. ACCEPTANCE - INTEGRATING THE DIABETES

The state of how much a patient has "accepted" or integrated the disease into his/her life can increase and decrease over time. As Kubler-Ross describes in her model of the five stages of grief (see figure 25), every patient will go through multiple stages, and not in a particular order, after being diagnosed with diabetes, before reaching acceptance. This process can take months if not years and some patients will not reach this state at all. Within today's diabetes world, doctors and DVKs are trying refrain from calling it "accepting" the diabetes, but instead refer to "giving it a place in your life."

The emotional journey to give diabetes the right place in a patient's life is often a twisted road with many detours. Because patients have to take immediate action after being diagnosed, psychologists report that a lot of patients will first not go into denial but into "autopilot" and sometimes years later, when something in their life changes or their diabetes is not going so well, the actual acceptance process just begins (see green line in figure 25). As diabetes is a disease that goes on for years and follows a patient's natural life changes, the amount of acceptance can change along with the medical conditions. When the medical condition of a patient decreases and the diabetes seems unbearable, the acceptance can decrease. On the other side, new influences as new stakeholders or a new professional caregiver can provide new stimuli to care again. Therefore, in addition to Kubler Ross model, diabetes patients can switch between the stages, even years after the diagnose (see figure 26).

ACCEPTANCE WITHIN THE 5 STAGES OF GRIEF MODEL BY KUBLER ROSS

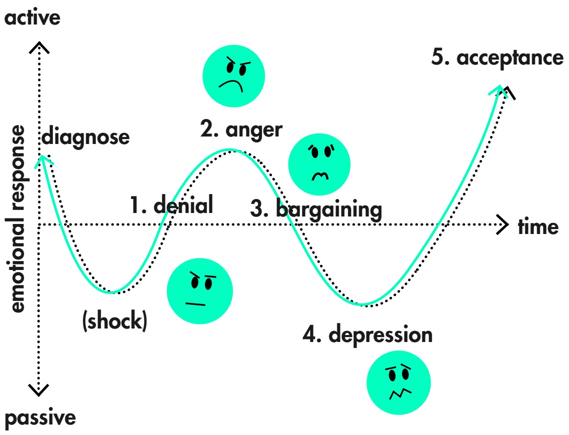
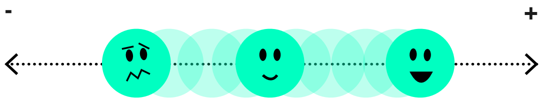


figure 25 five stages of grief model by Kubler Ross (1969)

ACCEPTANCE AS A DIABETES PATIENT

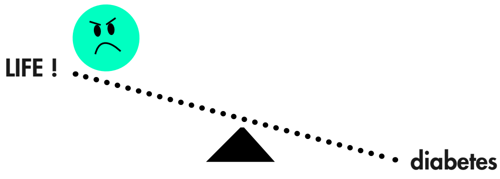
a patient can improve when finding the right balance with diabetes "I can do it!"



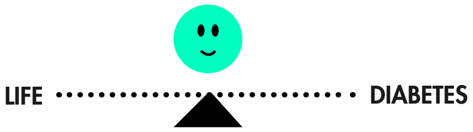
a patient can decrease when diabetes becomes more difficult to handle in new situations or the support network changes

2. ADAPTION - DIABETES TO LIFE OR LIFE TO DIABETES ?

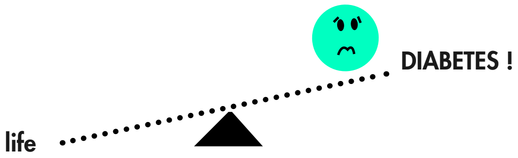
One of the biggest difference in diabetes management is the level of which patient are adapting their life to the diabetes or the other way round, they adapt the diabetes to their life. Each patient has an individual way that suites them. The amount of behavior change after the diagnosis differs between each patient and are also dependent on the amount of adherence and the perceived impact of diabetes on one's health. In general, diabetes psychologists and coaches advice to just continue living as beforehand and make changes in food intake for the cause of living healthier and not for the diabetes. This way, patients can integrate it more easy and continue living a normal life without being scared or focusing too much on the diabetes. The most important step for the patient is to find out how much he/she is willing to minimally invest into this disease and what is possible in the patient's daily life to adapt and change, without feeling like surrendering to the disease and draw on that. To give a better understanding of this type of adaption in everyday life, patients are divided into three broad categories according to how a patient balances life and diabetes: the ignorant, the balancer and the perfectionists. In the following paragraph these three types will be explained and back upped with quotes mentioned within the expert interviews:



1. The Ignorant: *"I sit in the car and I feel that I am low (low blood sugar level) and just eat a whole package of candy. Later on I forgot about that and I will have normal lunch and afterwards I will inject because I feel that I am getting tired as a result of a probably increased blood sugar level. So I react on it but I don't really think ahead or something."* Patients who did not adapt their life at all to their diabetes and only invest minimal time and effort to avoid severe consequences like hospitalization, to let diabetes have the least impact on their everyday life. These patients do not base their food, activities and everyday life decisions on their diabetes.



2. The Balancer: *"I will never not do something because of my diabetes, but I try to integrate it. For example if I want to eat candy I just do it. But beforehand I take certain steps to be able to do so and try not end up with a really high blood sugar afterwards. I don't want to let myself being limited by this disease"* Patients who found a balance between adapting their life to their diabetes and the way round. These patients will not let themselves be limited in their choices by their diabetes. This balance can differ in its effectiveness and amount of time consumption for every patient, the most important part is the feeling that these patient do not let themselves be limited through the diabetes and manage to stay healthy.



3. The Perfectionists: *"I often skip dinner invitations because I just don't feel like I can calculate the carbohydrates in a restaurant, where I did not cook the food myself. It's not worth the stress for me."* Patients who fully adapted their life to their diabetes and base all of their decisions regarding food and daily activities on their diabetes. These patients will often refuse to do certain things, are always aware how certain actions will affect their blood sugar and do not want to take the risk to find out. These type of patients are often scared about the diabetes and complications and will therefore stick to a clear structure to avoid extra, unpredictable influences on their BSL. These patients often feel very limited by the diabetes and the disease feels very time consuming to them.

3. FINDING & KEEPING THE MOTIVATION

The motivation to keep the blood sugar level in range as much as possible can vary and increase or decrease after the years. Motivation to do your best can come from the inside (internal), from the patient him-/herself and /or from the outside (external), from somebody or something else.

Whereas for some patients, it is enough to be responsible for their own health and scared of complications to be motivated, other patients need an external reason to find back or keep the motivation. The following list offers a summary of the reasons mentioned by the interviewed diabetes coach and psychologists:

"People who were fully motivated within the first 10 years to handle their diabetes in the best possible way and then something happens within normal life, that all of a sudden this is not the first priority on their list any more. The first years might be easier, but the thought that you will have diabetes until you turn 80 does not make people happy." "

interviewed psychologist
about motivation

Internal motivation:

- *Health and quality of life as a motivation, no limits tion from your body*
- *Negative health incidents and their effects (hospitalization) as a motivation to improve*
- *Being proud of yourself and your management skills, "keep the good path going"*
- *Thinking about the future and wanting to function correctly*

External motivation can be provided by:

- *Group motivation through competition and teaming up with other patients*
- *Compliments, empathy and acknowledgment of a patient's efforts and success by close ones (doctor, partner)*
- *Clear rules and steps to follow the doctor "simplifying and splitting up the problem" to provide success moments and stimulate self-consciousness*

"Even if a patient does not share anything at all with his/her surroundings, it is still good to say it out loud to be proud of your child / partner or friend. It is a burden every single day and often not recognized how much effort it takes to do it good." is the main advice coaches and psychologists give to the support network around a patient. Supporting the patient in a positive, motivating way is a crucial strategy to success and often underrated. Having to deal with an additional "burden" in life often feels unfair to patients, therefore pointing out the things that do go well, instead of the pitfalls, can make the patient proud of keeping it up. Further support behaviors will be evaluated further within chapter 2.2.

HOW CAN DIABETES IMPROVEMENT AND FAILURE INFLUENCE A PATIENT'S EMOTIONAL BALANCE ?

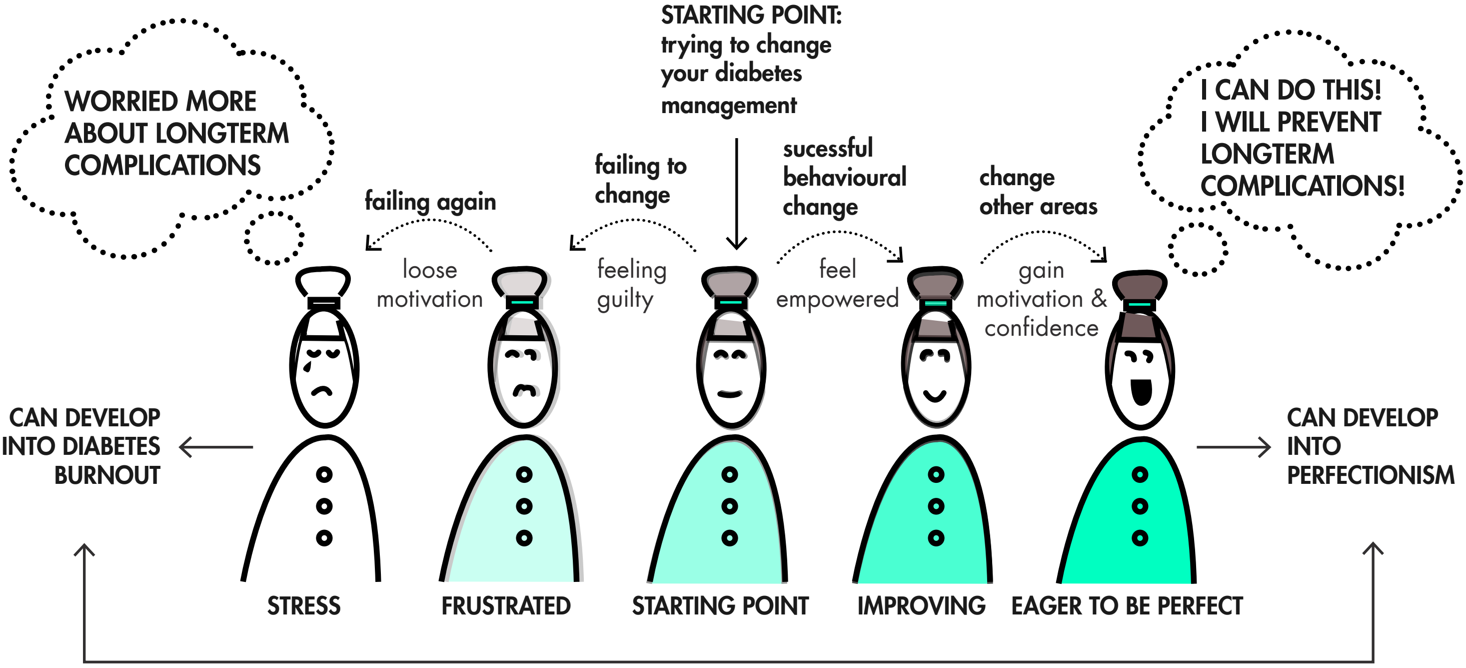


figure 27 correlation of the three emotional effects found - model based on expert interviews

2.1.5 INFLUENCES OF DIABETES MANAGEMENT ON EMOTIONAL WELL-BEING

The tasks and execution of a patient's self management are not only affecting the physical condition of a patient can but also, if things are not working out, have impact on the emotional balance. Patients have to deal with both medical management problems, behavioral management and handling the consequent emotional stress. Having multiple extra tasks every single day can become very exhausting. As (Anderson, R., Funnell, M. (2010)) puts it in his book "Patient Empowerment: Myths and Misconceptions:" *"Patients cannot surrender the control or responsibility they have for their diabetes self management no matter how much they wish to do so."*

The emotional balance of a diabetes patient is being influenced by the ability to implement changes and improve the diabetes management. On the other side, if the patient does not succeed to implement these changes he/she might feel guilty. The following two columns and figure 27 show a comparison of the correlations between succeeding and failing in diabetes management and emotional well-being:

1. IMPROVING OR FEELING GUILTY WHEN FAILING

SUCCESS	FAILURE
1. improving	1. feeling guilty
↓	↓
2. getting motivated	2. frustrated
↓	↓
3. perfectionism	3. diabetes burnout

1. FEELING GUILTY WHEN NOT IMPROVING

Every patient has different expectations about the diabetes therapy, patients vary in their personal goals. Still, every patient knows which levels should ideally be reached. Possibly being confronted with personal "failure" every time you measure your blood sugar, can have multiple effects on a patient's mind. Interviewed experts confirmed that *"Guilt conscience is often the reason why patients get stuck. Then patients don't go to the doctor any more. Still they also don't have the tools themselves to change this situation for the future"* Having diabetes for a longer period does not make it easier as insulin ratio and insulin sensitivity change and have to be adapted as the one's life also includes changes. Therefore especially patients, who have been diagnosed with diabetes a longer time ago and still haven't found their solution, have this feeling of guilt for not taking enough action towards their disease. Finding the right way to keep up the good resolutions can be difficult.

The feeling can be improved by strengthening the patient's self consciousness by letting the patient realize that he/she is not alone and is doing the best to perform well. A coaching approach and empathy of the support network and professional care giver can support this feeling.

2. GETTING MOTIVATED OR FRUSTRATED

Improving one's diabetes management and experiencing success can motivate patients and increase adherence to their therapy. On the other side, if patients experience that changes have not effect or they are not able to implement them in their daily life, they might feel frustrated.

3. PERFECTIONISM AS AN EFFECT OF UNSUITABLE DIABETES MANAGEMENT

Through the long term HBA1C and digital diaries patients constantly know how / good or bad they are doing. Through new information sources and patients posting their blood sugar levels online to compare, patients can feel pressured and competition. This can either develop in feeling frustrated again for "never being that good" or motivate patients to get even better blood sugar levels up to perfection.

3. DIABETES BURNOUT AS AN EFFECT OF UNSUITABLE DIABETES MANAGEMENT

On the other side, dealing with a chronic disease is never easy and there is a significant coherence between diabetes patients and depression, where 10-30% of all diabetes patients are dealing with depression, as Nefs, G. M. (2013) states in her PhD thesis "diabetes and emotional distress." Being "depressed" about your diabetes can show in various forms often described as a "diabetes burnout" (Polonsky, 1999). A diabetes burnout occurs when a person feels overwhelmed by diabetes and the frustrating burden of diabetes self-care. It does not have to have the same signs as a depression, but can show in a more passive approach.

Barnard and Lloyd (2012) describe a diabetes burnout as:

- Feeling overwhelmed and defeated by diabetes
- Feeling angry about diabetes, frustrated by the self-care regimen and/or having strong negative feelings about diabetes
- Feeling that diabetes is controlling one's life
- Worrying about not taking care of diabetes well enough, yet unable, unmotivated or unwilling to change
- Avoiding any diabetes-related tasks that might give feedback about consequences of poor control
- Feeling alone and isolated with diabetes

MAIN RESEARCH INSIGHTS - WHAT SHAPES A PATIENT'S SELF MANAGEMENT?

Every person has an individual style of self-management and attitude towards diabetes, a diabetes mindset. This attitude is shaped by the patient's state of acceptance, the internal and external motivation to keep the blood sugar level in range, the way a patient integrates the disease into his/her life and how much limitations result from this way of integrating. Finding the right balance of the named factors, to keep emotional balance and also finding out about the reasons why a patient is "out of balance", is a big step towards more "time in range" and better blood sugar levels. So far from the expert side, during the next chapter this scientific mindset will be fulfilled with the patient's personal opinion and how a mindset affects the patient's support network and support wishes.

2.2 PATIENT'S PERSONAL DIABETES MINDSET

In order to get deeper insights into the life of diabetes patients and their personal mindset, a small scale qualitative user research was set up with a total of 8 diabetes patients. Multiple research methods were used to access different levels of knowledge. Sensitizing booklets prepared the user for the interviews and find out about their daily life and how they handle their diabetes. This first exercise will be analyzed within this chapter and, combined with the insights of chapter 2.1, build the components for a patient's diabetes mindset. Based on this part of the interviews, 5 patient personas were developed, which will be introduced within this chapter and further evaluated within chapter 2.3.

RESEARCH STRUCTURE

The mindset research was started off with the participants describing their daily diabetes problems within the sensitizing booklet. Afterwards these daily problems were transferred to the patient's problems since the diagnose and how they solved them. All of the findings of the interviews were evaluated within the character of 5 personas and their own diabetes mindset. (see figure 2.2a).

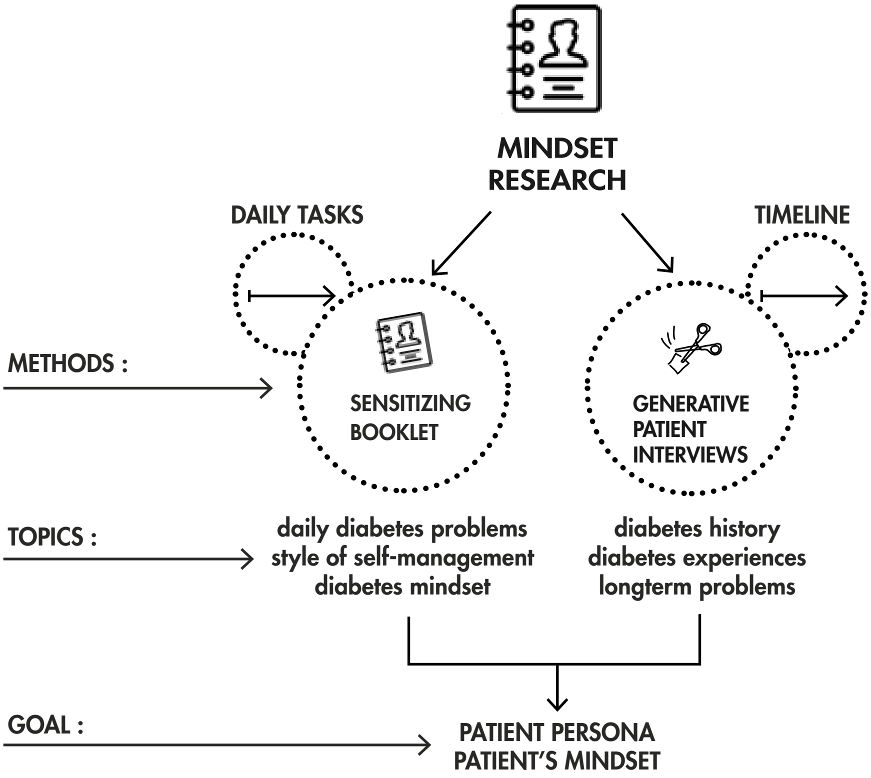


figure 2.2a structure of the mindset research

RESEARCH QUESTIONS

- *How do the different patients deal with their diabetes?*
- *What kind of diabetes mindset do the interviewed patients have?*
- *How can these patients be categorized and what are the differences / overlap?*
- *How does their character / experiences influence their diabetes self-management?*

RESEARCH PARTICIPANTS

A total of eight patients participated in the interview. To be able to compare positive and negative examples and find out about differences / overlap, both patients that were already “connected”, patients that had a blog, did videos or had a lot of contact within the diabetes community and patients that were “not connected” were recruited. This connection was not only based on being active online, but on how much the patients had integrated the disease into their surroundings. The non connected patients had an incomplete support network or no medical / emotional support at all (see figure 2.3c). All patients had a different lifestyle, diabetes mindset and diabetes history. This way, multiple dimensions of problems, networks and support wishes can be included within the project.

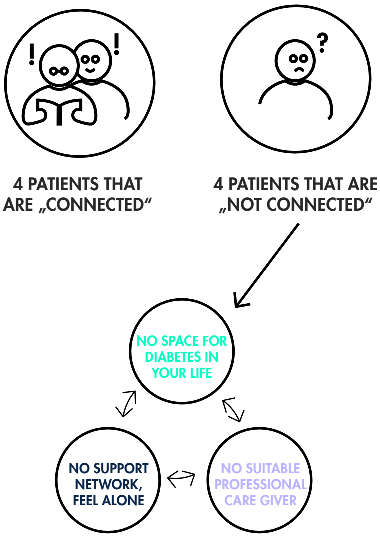


figure 2.3c not connected patients with an insufficient support network

RESEARCH TOOLS

The following research tools were used to analyze the patient’s diabetes mindset:

1. Daily tasks within sensitizing booklet

The participants within the generative interviews first received a sensitizing booklet to prepare for the interview. The purpose of the booklet is to prepare the interviewee for the upcoming interview and get them “into the mood” to think about their diabetes treatment, their support network and how they solve problems. The seven tasks in total went from concrete tasks like describing a day to steadily more abstract tasks and methods to solve problems or, as a forecast for the interview, how they think their diabetes future.

(see figure 2.3d & appendix 8 for sensitizing booklet with timelines).

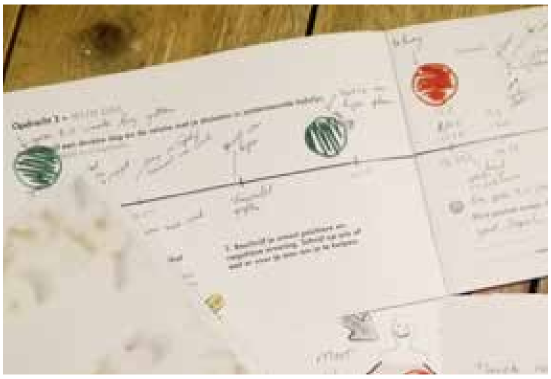


figure 2.3d booklet - daily timeline with positive and negative moments

2. Diabetes timeline

Within the interviews different tasks from the sensitizing booklet were presented and used to fill in the patient’s diabetes timeline (see appendix 9 for interview guide and appendix 10 for the individual timelines)

The sensitizing booklets covered one day within the patient’s life with diabetes, the goal of the interview was to dive deeper and cover the whole time since the diagnose. Each patient was asked to fill in the timeline and afterwards mark positive and negative moments and explain how they developed since the diagnosis. This was done to be able to understand the mindset every patient has towards diabetes and move from the small everyday problems to the “bigger” problems within his/her life and understand the connections between diabetes problems and life events.

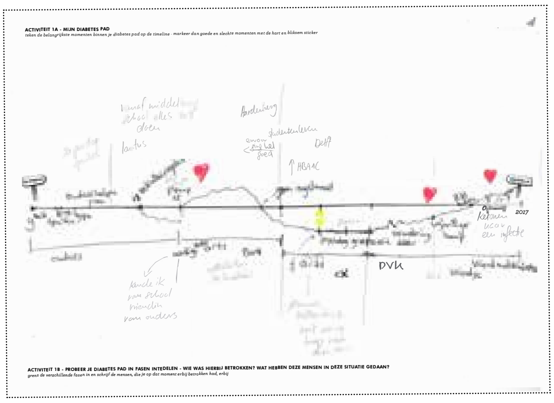


figure 2.3e diabetes timeline of a patient

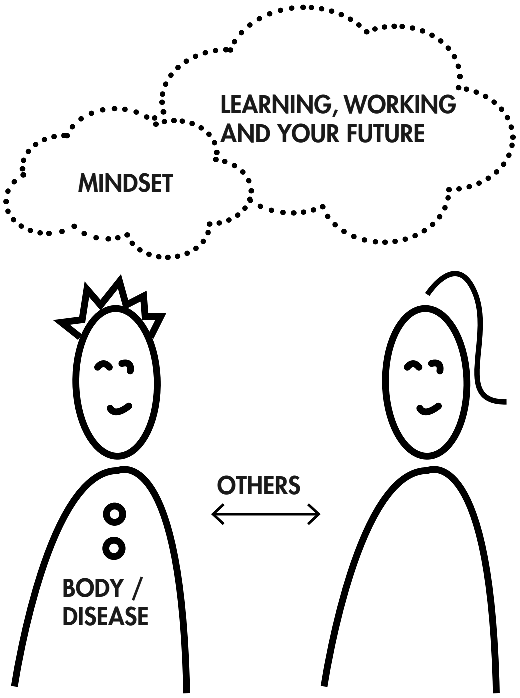


figure 32 important topics in every patient's lives

PREPARING THE INTERVIEWS & ANALYZING THE RESULTS

The interview setup and the gathered data was compared with the general topics within existing networks for chronical ill patients in order to be able to cover all aspects that are interesting for describing a patient's personality. Through analyzing the existing categorization of different platforms for young adults with a chronic disease, four meta themes (see figure 32) that keep young adults with a chronical disease busy, emerged (see appendix 11 for original categories of the different networks):

_the patient's mindset - Acceptance and integrating the disease into one's life, the balance between adapting life to the disease or adapting the disease to the patient's life

_the patient's body/disease - Time consumption and management of disease related tasks, recognizing possibilities & limitations, keeping healthy & trying to improve, "forbidden" pleasures in life and how to integrate them

_the patient & others - Being open & talk honestly about your disease, integrating others into your support network and searching & getting the right support, relationship, sex, friends, parents, doctor

_learning, working and your future - finding the right path, kids, new job, school, telling about your disease?, moving, preparing

RESEARCH RESULTS

5 Diabetes Patient Persona

The data gathered in the patient interviews was first transcribed and clustered into the characteristics of different diabetes patient persona. The goal of the personas is to help outsiders identify with the interviewed patients. Even though the mindset towards diabetes is not always on it, demographic data was introduced for the company intern idea creation workshop (see chapter 3.1). The illustrated comic figures portray a certain level of abstraction. Each persona has a different approach regarding:

Mindset towards life & diabetes

History with diabetes / milestones

Diabetes struggles

The mindsets of the interviewed patients were analyzed according to these 5 factors and, clustered into their overlap and differences. Within this chapter the personas will explain their diabetes mindset, within the following chapter their support needs and wishes will be examined further. These persona will guide the reader through chapter 2.3 and make the different sub chapter and topics more vivid by linking them to the different characters.

figure 33 overview of all 5 personas and their image

2.2.1 5 DIFFERENT DIABETES PERSONA

Keeping one's blood sugar levels in range puts great demands, that every patient is willing to follow at a different level. During the interviews it became clear that the patients differed within their diabetes management method and willingness to adhere to the prescribed therapy methods. All patients have individually integrated the disease into their life and created an unique support system around them, based on their diabetic support needs. The 5 main influences on the persona's mindset and influences that differ per person are:

From the patient's interviews and chapter 2.1:

A patient's character

Acceptance of the diabetes

Adaption - balance life / diabetes

Motivation

+

Influences of other stakeholders (parents, surroundings, DVK) on the diabetes management

The mindset of the 5 created persona and an overview of their character(see figure 33 for an overview), will be introduced. First the different personas and their visiting card are displayed to get a feeling of the persona (see figure 33 - 37 next three pages), then the persona's mindset are analyzed according to the three factors named in chapter 2.2: acceptance, adaption and motivation and the influences of their character and diabetes history. Here it can be seen that every mindset and personality brings different challenges with it. The chapter will end in a summary of all influences that shape a patient's style of self-management.

The complete persona characteristics can be found within the appendix 12.

THE EXECUTING LINE-WORKER

PIM, 30
T1D since he's 5 years old

„IT'S JUST DIABETES. MEASURING. INJECTING. JUST FOLLOW THE RULES AND YOU WILL BE FINE."

WHO IS HE AS A PATIENT?

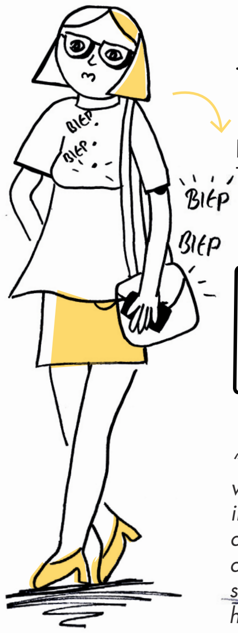
- Follow his doctor's advice
- does not want to waste much time on diabetes

WHAT IS DIABETES FOR HIM?

- something you can luckily grow old with. Everyone has their package and this is mine. As long as my blood sugars are OK I don't mind.

"Pim grew up with diabetes and is a very sober-minded person. Compared to the earlier times, today handling diabetes seems very easy for him. For him it's all not that bad as long as he sticks to some rules it's all going fine. Whenever he needs some advice he just contacts his doctor or visits his DVK. Pim has accepted his disease and is balancing life with diabetes very well. He does not make any compromises because of his diabetes as he does not know a life without. So far he stays motivated as it all does not seem so hard to handle at the moment."

figure 33 persona Pim



THE OBSESSED PROFESSOR

INGE, 28
T1D since she is 25 years old

„DIABETES IS LIKE A PROJECT. I LEARN NEW THINGS EVERY DAY. JUST THAT IT'S NEVER FINISHED CAN BE VERY FRUSTRATING."

WHO IS SHE AS A PATIENT?

- A scared perfectionist
- Fully adapted her life to diabetes
- Likes structure & keeping control

WHAT IS DIABETES FOR HER?

- a second full-time job. Something that is never perfect and that can be frustrating. Too many uncontrollable influences.

"Inge is a total control freak. She creates a lot statistics on her own and always wants to know exactly what is going on with her blood sugar. When she is not in range for some time, she gets frustrated. With her CGM sensor and analyzing apps she always has the total overview of her actions. Even though she spends a lot of time with the diabetes and lowers her side in order to have perfect blood sugar levels, she still did not completely accept the disease and tries to beat it her own way. Her biggest motivation is of course staying healthy and being very scared of complications."

figure 34 persona Inge

THE PUNISHED PRINCESS

MARJOLEIN, 25
T1D since she is 19 years old

„WHY DID THIS HAPPEN TO ME?
IT STILL FEELS LIKE ■AM CURSED.
I WANT MY OLD LIFE BACK."

WHO IS SHE AS A PATIENT?

- Somebody who likes to compare to the past and ignore her diabetes

- Not following the simplest rules

- Big problems to adapt and accept

WHAT IS DIABETES FOR HER?

- The worst thing that ever happened in my life. My whole life is ruined by it. I cannot accept this, I don't want this.

"Marjolein still hasn't given diabetes a spot in her life and does not really accept the fact that she has to deal with it. She is fighting the disease by ignoring it until she gets sick, then gets motivated again for her work - a doom loop. She desperately wants to get in contact with other peers and people that feel the same as she does and find new external motivation."

figure 35 persona Marjolein

THE WITHDRAWN MAVERICK

EMMELINE, 19
T1D since she was 1 year old

„IT'S MY DIABETES. I AM SO USED TO THIS, I KNOW BEST. WHAT CAN I LEARN FROM YOU?"

WHO IS SHE AS A PATIENT?

- Grew up in a non-connected diabetes world

- Shut herself off her support network

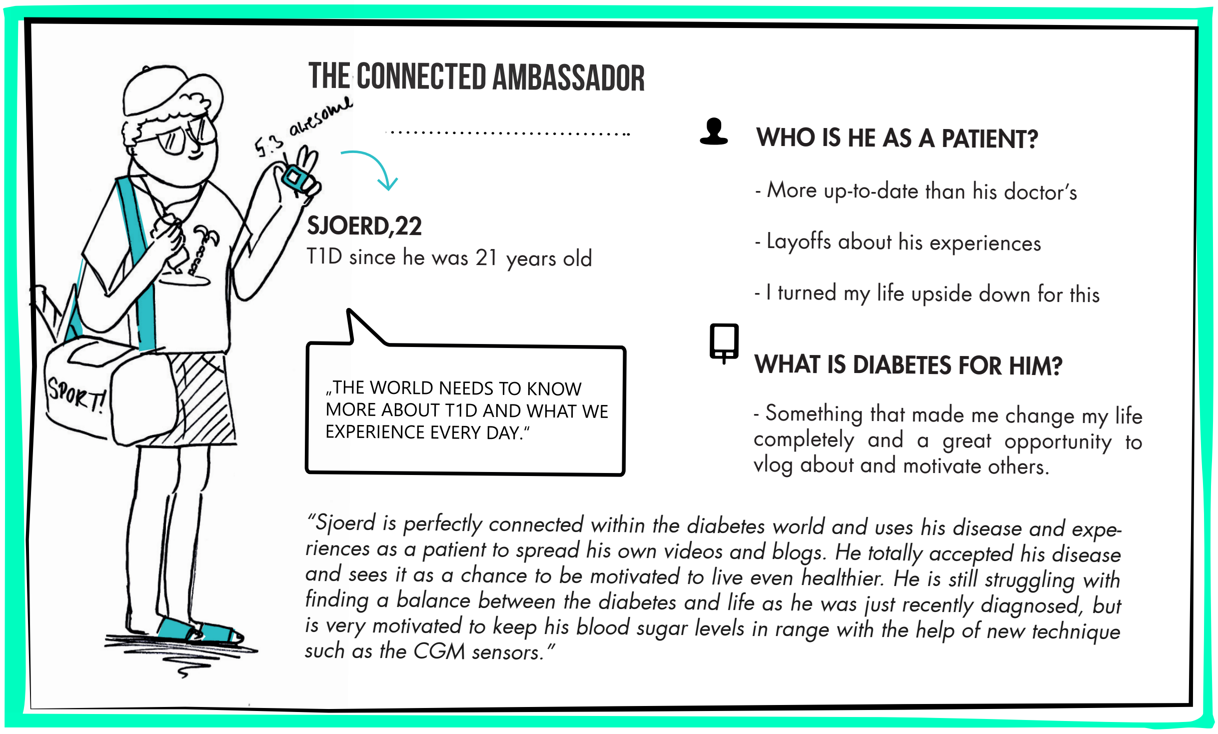
- Motivation waves

WHAT IS DIABETES FOR HER?

- Something that has always been there and I've gotten very used to dealing with it on my own.

"Emmeline grew up with diabetes thus she cannot remember a life without it. She has therefore accepted the fact that she has diabetes, but her internal motivation is going up and down like a roller coaster. She has integrated the diabetes almost too well in her life and sometimes forgets about it as she is so used to it. She lacks the step back and reflect on her situation to find new motivation to pick it up again."

figure 36 persona Emmeline



THE CONNECTED AMBASSADOR

SJOERD,22
T1D since he was 21 years old

„THE WORLD NEEDS TO KNOW MORE ABOUT T1D AND WHAT WE EXPERIENCE EVERY DAY."

WHO IS HE AS A PATIENT?

- More up-to-date than his doctor's
- Layoffs about his experiences
- I turned my life upside down for this

WHAT IS DIABETES FOR HIM?

- Something that made me change my life completely and a great opportunity to vlog about and motivate others.

"Sjoerd is perfectly connected within the diabetes world and uses his disease and experiences as a patient to spread his own videos and blogs. He totally accepted his disease and sees it as a chance to be motivated to live even healthier. He is still struggling with finding a balance between the diabetes and life as he was just recently diagnosed, but is very motivated to keep his blood sugar levels in range with the help of new technique such as the CGM sensors."

figure 37 persona Sjoerd

2.2.2 SUMMARY INFLUENCES DIABETES MINDSET

Within chapter 2.1, a total of 7 influences on a patient's diabetes self-management and diabetes mindset were identified:

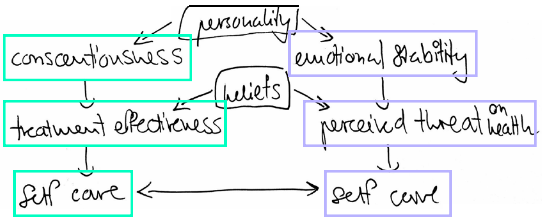
1. the patient's character
    1a) acceptance of the diabetes
    1b) adaption life-diabetes
    1c) internal of external motivation

2. growing up with diabetes - the parent's mindset
3. the patient's surroundings
4. professional care giver support

Number 2 is not applicable for all personas as not every persona grew up with diabetes and was shaped by the parents (only Emmeline and Pim did), number 3 will be evaluated within the following chapter - patient's support possibilities and number 4 is not within this project's scope.

When putting up the patient's mindset and determining the factors this mindset could be categorized and measure by, only the patient's own character will be taken into account and relations with other stakeholders left outside as they can also be influenced by other factors such as personal preferences.

The theory that a patient's personality determines certain aspects of self-management is also confirmed by Skinner, T. C., Hampson, S. E., & Fife-Schaw, C. (2002). Within their study they compared the 5 aspects from the Big Five Personality test (Goldberg, L. R. (1990), (testing personality on 5 factors: openness to experience, conscientiousness, extraversion, agreeableness, neuroticism) to the self-care performance of over 1200 young diabetes type 1 patients. The results showed that especially conscientiousness and neuroticism (emotional stability) influence self-care in the following way:

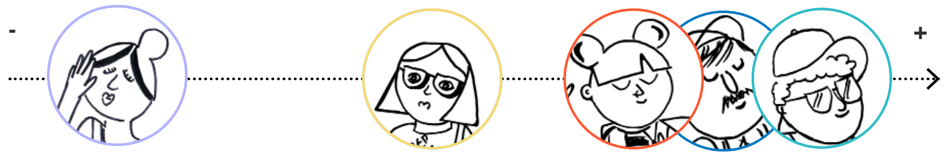


And that a person's health believes about the effectiveness of the treatment and the perceived threat on health are functioning as mediators between personality and self-care. Patient's with a high score in conscientiousness also often use a problem-focused coping strategy to tackle the diabetes and will therefore be very proactive about trying to improve their situation. Therefore these two influences have been integrated into a patient's diabetes mindset as:

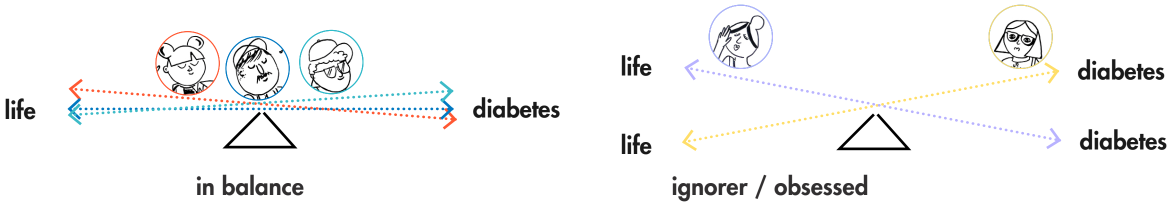
Neuroticism - emotional stability
Conscientiousness - adherence & proactive

Within figure 38 the personas are analyzed according to the six final factors: acceptance, adaption, motivation, emotional stability, adherence & proactive.

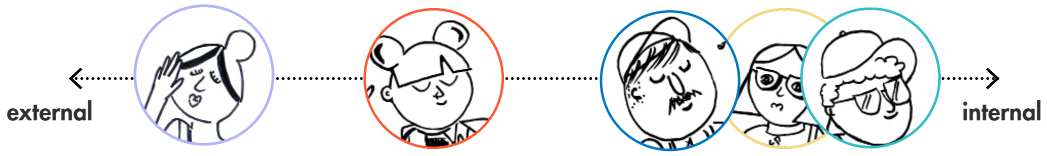
Acceptance of the diabetes *(figure 38 personas within the three factors of a mindset)*



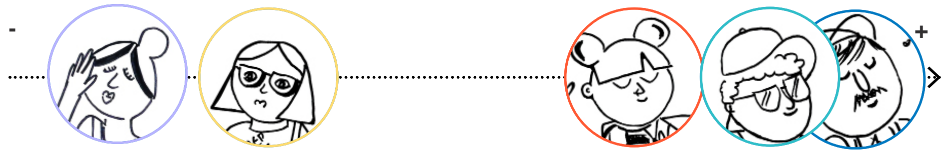
Adaption of life to the diabetes



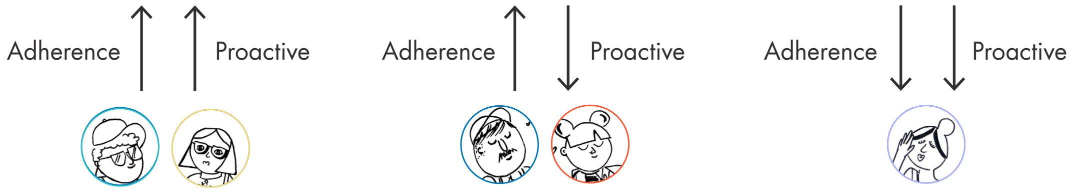
Motivation to keep it up & get good blood sugar levels



Emotional stability



Adherence & Proactive



Acceptance & Adaption: Whereas three of the personas (Pim, Sjoerd, Emmeline) are mostly in balance in all three factors, Marjolein and Inge are struggling with a lack of acceptance, which they both cover in different ways, an over adaption of their life to the diabetes or the other way round, trying to ignore the diabetes and not adapt the life at all.

Motivation: Regarding the motivation, Sjoerd and Inge are having a clear advantage with getting their motivation from themselves by wanting to live healthy or being scared of the consequences.

Emotional stability: In general, Pim has the most emotional stability whereas Marjolein has the least. Therefore Marjolein experiences the diabetes as more negative and unbearable than the rest.

Adherence to therapy and proactive therapy approach: Within these two factors two different approaches can be determined: patients who are very passive and do everything their doctor tells them (high in adherence and low in proactive), patients who do both - listen to their doctor and also develop their own skills and knowledge to be even better prepared and organized - high in proactive and adherence and patients who do not do what their doctor tells them - either because they cannot follow the advice or because they know better themselves - low in adherence and also low in proactive (very seldomly high in proactive - patients who do not believe in general methods and develop their own diabetes therapy). Within appendix 13 the individual mindsets are graphically displayed.

2.3 PATIENT'S SUPPORT POSSIBILITIES

To be able to analyze future support possibilities, the current support stakeholder within a patient's network have to be analyzed. This was done with different tasks within the sensitizing booklet and interview. With the generative interviews the goal was to first map out the patient's support network - based on the patients explicit knowledge, then the interviews moved on to the patient's relation with these stakeholders, their advantages sand problems regarding the type of support they provided. All insights are summarized within this chapter and divided into three groups: informal care giver, peer support and online peer networks.

RESEARCH STRUCTURE

The support research was started off with the participation within the online networks and find out about the support provided there. Through the generative interviews the researcher got in contact with more diabetes groups and was able to meet additional diabetes patients to confirm the findings of the interviews. The support findings of the interviews were evaluated within the persona's support networks and characteristica of each support group. (see figure 39).

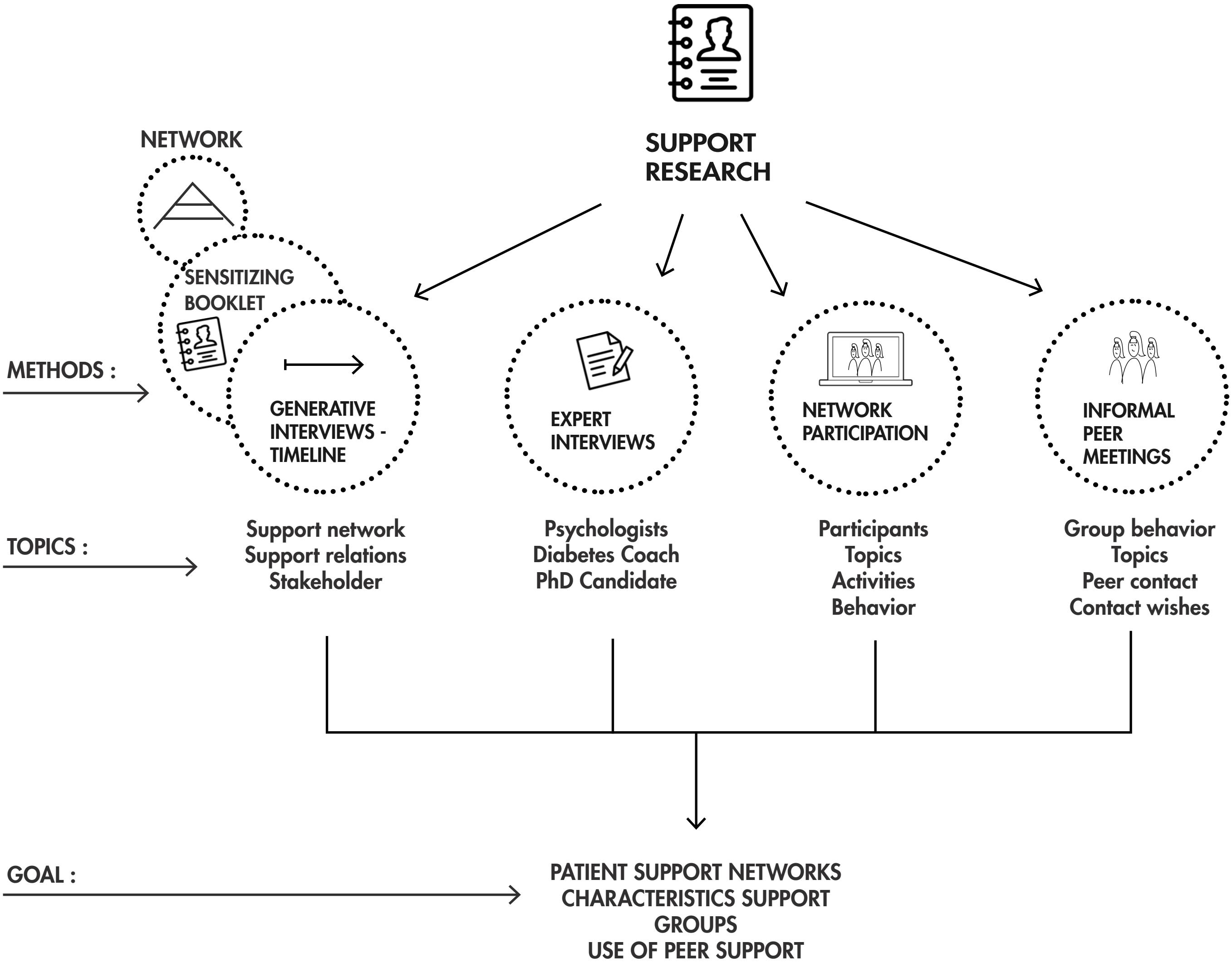


figure 39 structure of the user / field research

RESEARCH QUESTIONS

Support network

- *How does the patient's support network look like? Who are the stakeholders and what are their roles?*
- *What influences a patient's support network?*
- *What are their wishes for future support stakeholders?*
- *What is the role of informal caregiver within a patient's support network?*

Peer contact

- *What are the advantages and role of peer to peer contact?*
- *How do the online peer to peer networks support patients?*

RESEARCH PARTICIPANTS

As within the previous research activity, the same eight patients were interviewed. For this part of the interviews, one additional support person participated in the interview. This support person was included as a positive example for the researcher to learn from their effective support relation. The goal of the interview was to examine the patient's existing support network and find out about the relation of the stakeholders. The experts participating within the interviews provided the psychological background knowledge about the relation and role of the support stakeholders within the diabetes therapy. The expert interview guide can be found in appendix 14.

RESEARCH TOOLS

The following research tools were used to examine the interviewees support networks:

1. support network within sensitizing booklet

2. role during diabetes timeline

Each patient had to fill in the personal medical and emotional support work within the sensitizing booklet the patients received one week before the generative interview. During the interviews this network was analyzed and the participants explained the different relations between the stakeholder, the advantages and limitations and the buildup of their support network. Furthermore, the role of the trustee within every network was examined. During the interview, after mapping out a patient's diabetes timeline, patients were asked to explain how the different stakeholders have helped them within the different phases of their diabetes. (see figure 40 & appendix 15 for the patient's individual support network and appendix 10 for the patient's diabetes timelines).

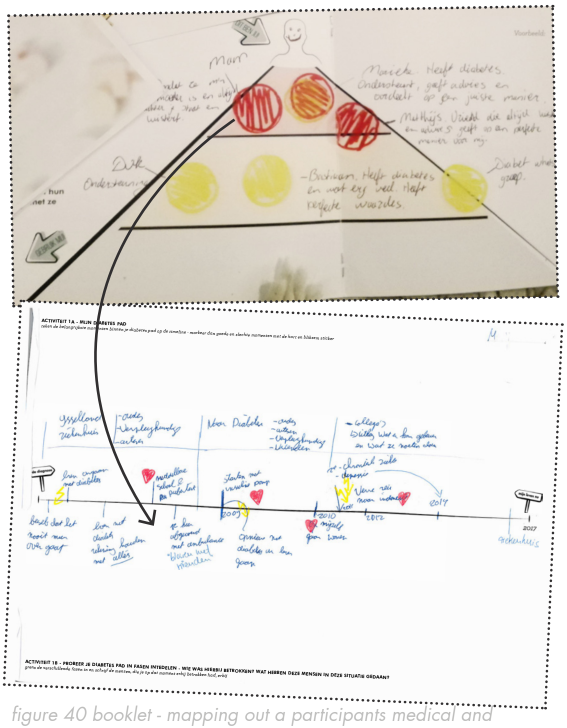


figure 40 booklet - mapping out a participants medical and emotional support network and diabetes timeline

Informal peer meetings

During the project, the researcher established a big network of T1D patients. The researcher participated in multiple online facebook networks and What's App groups with patients within the target group from all over the Netherlands, to get to know as many patients possible and be able to analyze their mindset and compare the persona to real life persons. The results of the analysis and personas were shared in informal meetings (see figure 41) with patient groups and diabetic friends to get feedback and recognition. The gathered information within these meetings was only used for validation and not for shaping the personas, as these patients had not participated in the interviews.

figure 41 meeting with the group "Suikerklontjes"

RESEARCH RESULTS

1. Patient's personal support networks

2. Characteristics and role of the different support stakeholder and groups

2.3.1 COMPOSITION OF A SUPPORT NETWORK

What influences a patient's support network? How is this network buildup? A support network is dependent on the patient's character and the support giver around him/her. The described support networks within the interviews were first analyzed according to how a patient's character influences the support network and on the next page, what is the correlation of the patient and support giver. This analysis was done in order to find out about influences and differences within the support systems, to be able to pay attention to them within the future support tool.

The mindset mentioned in chapter 2.2 was first summarized in figure 42. Looking back to the influences on a patient's mindset, the emotional stability seems to have most influence on a patient's support network. When looking back at the big 5 personality test, another area, the amount of "extravert" - how introvert or extrovert a person's character is, influences the size of the support network and how much a patient shares about his/her diabetes with the surroundings.

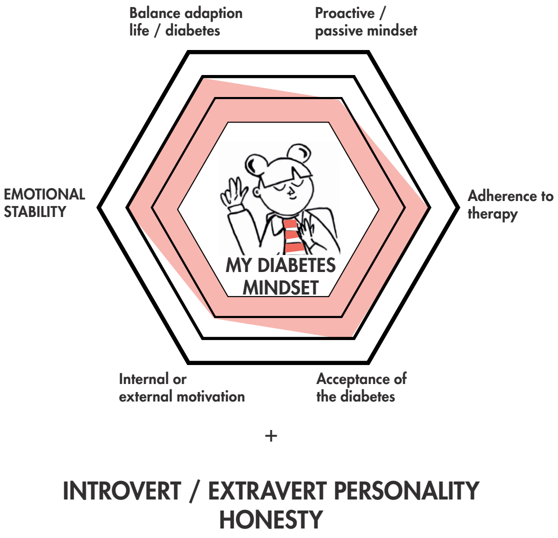


figure 42 overview infographic of all influences on a support network

As a third factor honesty about a patient's condition and self-picture was added. This sixth factor substantially correlates with the agreeableness domain according to Ashton, M. C., & Lee, K. (2005), but could also be measured separately. This factor is not only dependent on the patient's character and self-picture, but also on the reaction of the support network and surroundings.

Comparing the characteristics of a support network and how they are influenced by the patient's personality :

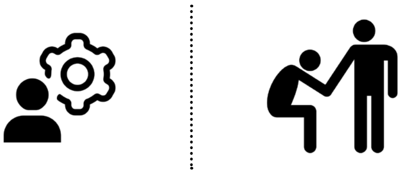
① **Type of support - emotional / practical support - emotional stability + extravert (from the 5 factor personality test)**

② **Amount of support - emotional stability + extravert**

③ **Size of support network: score in extravert**

④ **Depth of support provided by network: Honesty of the patient (**

On the following page the four different areas are evaluated:

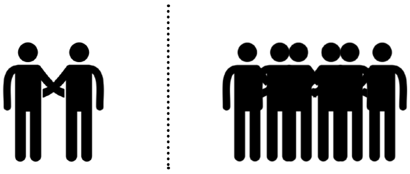


1. Type of support: Whether a patient is an emotional vs sober minded person. This project distinguishes between the emotional and medical support network of a patient, who provide emotional and practical support.

Emotional support involves help to cope with the emotions the disease evokes and fear of complications as well as motivating the patient, sympathizing and comforting. This type of support can also involve connecting the patient to the right support partners.

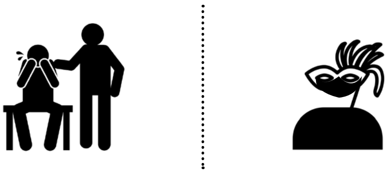
Practical / medical support involves providing information and instrumental / tangible support to the patient and helping with the tasks that an informal caregiver can take over. Practical support also involves education about the medical side.

2. Amount of support: Whether someone is a worried vs a stoic person. How people deal with the diabetes and how much it affects their emotional balance is very much dependent on a patient's character. Some patients would not let bad blood sugar levels affect their state of mind, while others reported to "feel down, grumpy and also unsatisfied with myself." This can be affected by how ambitious and forgiving patients are with themselves, but also how patients feel when their blood sugar level is out of range and if their blood sugar management matches their expectations. Especially the female participants stated a need for emotional support to cope with the stress of the diabetes, whereas the male participants were generally more sober-minded and stoic about this topic.



3. Size of support network: Whether a person is a sharing vs. loner person. As mentioned earlier in chapter 2.1, there are (at least) two categories of diabetes patients. One are the people that will talk about their diabetes and share information about it with their normal support network and the other group, that will only share information if being asked and otherwise keep the disease for themselves and their closest support network. The network of the interviewed patients consisted of an average of 4.25 people, ranging from 2 - 8 people. The size of this network is of course also influenced by the familiar situations of a patient, for example if the patient has siblings or not.

In general, the online platform Cyberpoli divides between two types of diabetes patients: open and closed patients. Patients that involve everyone in their disease and patients that keep the disease to themselves (Wat voor een type ben je? (n.d.).)



4. Depth of support: Whether a person is not afraid to honestly share what's on their mind or keeps a certain self image among their supporters. Some of the interviewed patients found it very hard to open up to new friends because of the feeling of getting pitied if they did or did not want to start the conversation about their diabetes since it did not seem to be something that stands for them as a person. These people have a limited amount of people that really know about their problems, often just the partner and the doctor. Others felt that diabetes was a part of them and their network should know about this to be able to support them on a deeper level. The depth of support also depends on how much support a patient wants and needs to be able to cope with this disease.

2.3.2 THE PERSONA'S SUPPORT NETWORKS

To transfer the insights of chapter 2.3.1 into reality, each persona got an individual support networks. Every persona has a different support network, tailored to their history. The spiderwebs show whether a persona prefers online or offline, how they use this support network, how many people they include etc

The networks exist of a medical and an emotional support network composed of 6 stakeholder groups. The gray fields mark the medical support within these infographics, the colored fields mark the emotional support. All contacts are ranked from 0-3. 0 marking no support at all, 1 marking only acute support if needed, for example if the persona is having a hypo and somebody needs to give her a glass of cola. 2 marking the level of thinking along and caring for the partner. Level 3 represents the mentioned "trustee", the person(s) this persona shares everything with. All networks are complemented with a short personal story of the persona.

The displayed infographics show that each diabetes patient has buildup an individual support network that is dependent on the patient's character and the four influences named in the last chapter:

① **type of support**
② **amount of support**
③ **size of support network**
④ **depth of support**

Furthermore the three other factors named in chapter 2.1:

(5. growing up with diabetes - the parent's mindset - only applicable for Emmeline and Pim)
6. the patient's surroundings
7. professional care giver support

are influencing a patient's support network. The support possibilities for each patients are divided into three groups:

① **informal care giver - called T3Ds**
② **peer friends**
③**online peer networks**

Figure 43 - 47 show the different support networks of all personas.

The characteristics, role, advantages and disadvantages of all three groups will be explained within the following sub-chapters.

EMMELINE - WITHDRAWN MAVERICK:

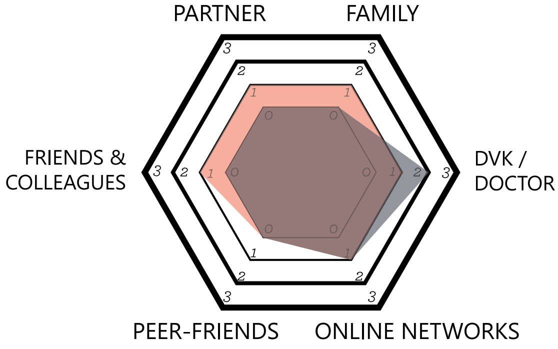


figure 43 Emmeline's support network

Emmeline: *"I am not sharing that much about my diabetes. It's just a normal thing that I have. And if I would talk to my mother she would only point out that my blood sugar levels aren't best. No thank you! I know that myself."*

Emmeline has problems trusting regarding her diabetes as she experienced the first support persons within her life, her parents, as being too nagging and judging out of concern. Therefore she mostly keeps her diabetes sorrows to herself now and does not have a real trustee.

INGE - OBSESSED PROFESSOR:

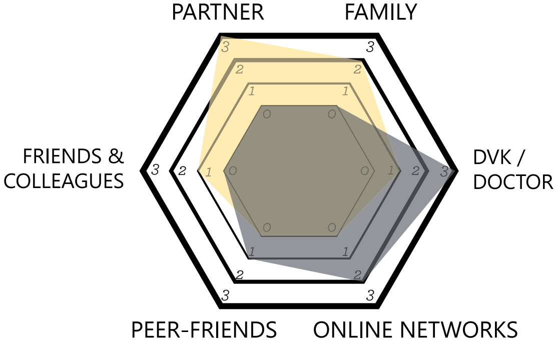


figure 44 Inge's support network

Inge: *"I am so stressed out by the diabetes. I need someone to calm me down and show me ways to handle it in a more relaxed way. Otherwise I don't know how long I can keep up with this. Or my partner."*

For Inge her boyfriend is everything. He is her trustee, the one person that always cheers her up again or calms her down, when things don't work out. Furthermore her family are very important to her and of course her doctor. Even though sometimes Inge read more about her problems online than her DVK.

MARJOLEIN - PUNISHED PRINCESS:

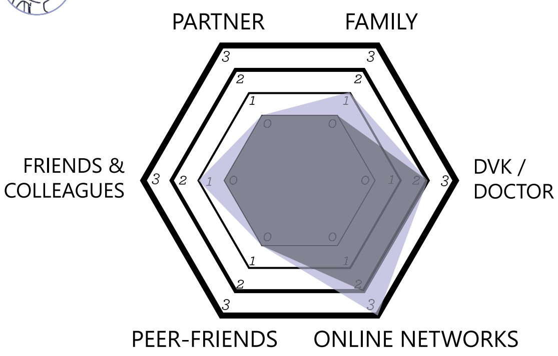


figure 45 Marjolein's support network

Marjolein: *"I cannot accept that I have this. I want people who feel and know how hard it is and can comfort me, when everything seems hopeless again. Diabetes is not manageable as everyone says. It's a miracle."*

As Marjolein does not let her friends and family support her accordingly, as they do not have diabetes and don't understand how it feels, she depends on her online peer friends from the networks. She spends a lot of time online, searching for recognition.

SJOERD - CONNECTED AMBASSADOR:

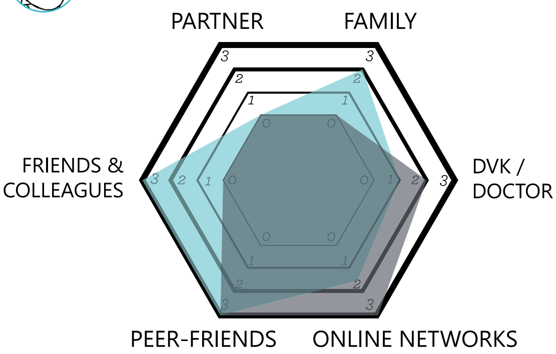


figure 46 Sjoerd's support network

Sjoerd: *"I already have so many friends within the diabetes community and offline, I could provide support to people. If anything I want to get to know more people through the diabetes and their life hacks."*

Sjoerd is the most connected person and has a lot of peer friends supporting him online and offline. He has multiple trustees as he shares his concerns very openly, but is on the same time such a positive person that he could rather provide support than is in need for support.

PIM - EXECUTIVE LINE WORKER:

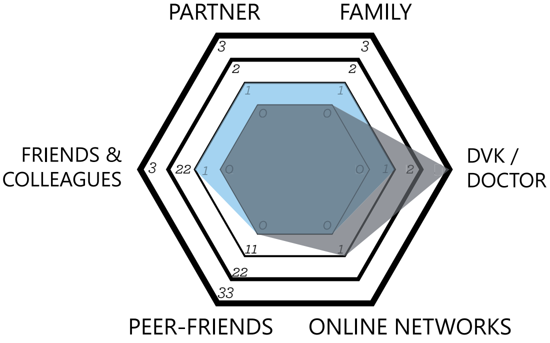


figure 47 Pim's support network

Pim: *"My doctor can actually help me with everything. If anything I also want life hacks and solutions for small problems. I am tired of all of these negative complaining posts. It's not that hard. get over it."*

Pim is a very sober-minded person that does not need much emotional diabetes support. He discusses all practical questions and problems with his doctor / DVK, who is also his trustee. For him, diabetes does not feels like a burden but something that he just has to deal with, like everyone has their problems.

2.3.3 INFORMAL CARE GIVER SUPPORT -

INDIVIDUALS WITHIN A PATIENT'S NETWORK

To be able to understand the support network of the different interviewed patients, the support networks within the sensitizing booklets were analyzed (see appendix 15). Six different groups were identified: the family, the partner, the DVK / doctor, the friends / colleagues, peer friends and peers the patient's contact within online networks. As stated within chapter 2.1, the general relation outside of the diabetes decides on this person's position within the support network. The support network was separated into three different layers: very close, middle and low to indicate how close this person is to the patient. Each patient could furthermore choose a trustee, he/she shares most diabetes issues with and describe the relation with this trustee. This was done to get to know the individuals involved within the support network and who could possibly be included into the future support tool.

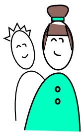
The trustee

A trustee is the main support person within a patient's network, the person that has the most insight into the patient's diabetes management and emotional well-being. Every patient had an individual trustee with a different function within his/her normal life. Within the analyzed support networks out of the sensitizing booklets, six out of eight participants positioned their trustee very close to them. The two exceptions stated that "nobody is as close to me within my network" and the other participant chose the DVK as a medical trustee and probably misunderstood the role of the trustee within the network.

Who was chosen as trustee by the interviewed patients?

Partner	III
Father	I
Mother	I
DVK	I
Best friend	I
Offline peer friend	I

The most striking differences was that three out of the four female participants chose their boyfriend as their trustee, whereas none of the male participants chose their girlfriend as a trustee. Unfortunately, it is not further known whether the male participants were single at the point of the interview or not. The role of these trustees will be explained further within the different stakeholder sub chapters. Within the following paragraphs the different support giver and their role will be examined further:



Partners

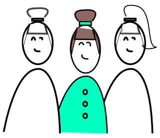
Three of the interviewed female participants marked their boyfriend as their trustee (one of them shortly ended the relationship, but before that the boyfriend would have also been her trustee). A reason for this that was the boyfriend "was always there" and "knew the most from me." Three of the four female patients put the boyfriend even higher within the hierarchy of the network than their parents. The trustees differed in the amount of practical support they provided as not all of them had enough medical knowledge about the diabetes. The interviewed informal stakeholder that did was appreciated very much by the participant, for having a complete overview of her daily routines and being able to analyze where her management went wrong. Totally relying on one single support source can be problematic in case this source disappears as one interviewee stated: "My ex-boyfriend did everything for me. He even helped me place my injection for my insulin pump and calculated how much I would have to inject, he had a better overview than me. Now that we broke up I have my father who helps me, but it's not the same.

Family

As parents are often the ones that knew the diabetes the longest, they are an important source of medical and emotional support. Seven out of eight participants named father, mother or both within their support network. One remarkable difference is that the participant that left the parents out of the network had been diagnosed with T1D as a child and had a father, who had been diagnosed with T1D shortly before. The patient therefore grew up with the disease and the influence from the parents on the disease during growing up has diminished. The biggest difference within the role of the parents is, as stated before, whether a patient had parents that supported him/her in a motivating, open way or if this relation was damaged in younger years and the patients backed away from support givers. One patient stated that whenever the parents commented on the diabetes management, because they were worried, this felt like nagging and judgmental. This resulted in hiding the diabetes and not trusting anyone any more within the diabetes management and not taking advice. For the patient, this loner attitude continued until the mid-twenties and it was hard to open up about the diabetes towards other support persons.

Integrating the autonomy of a teenager and transferring the responsibility for diabetes related tasks can be tricky according to the interviewed experts.

Other patients that were diagnosed later, stated that their parents are playing the most important support role next to the partner, if they took the time to deepen their knowledge about diabetes. Siblings were also named as a very important source of support, especially when they grew up with the patient already having diabetes.



Friends

Five of the eight interviewed patients stated to have friends that support them emotionally. These friends can be divided into two groups: Three of the eight had one friend that had deepened his/her knowledge about diabetes or, if the patient has not been diagnosed a long time ago, were integrated into the learning process about diabetes. Patients were then happy to be able to share their knowledge with someone and about the friend's interest. Even though none of these friends were received to provide real medical support, the patients that did include them into the diabetes learning curve, stated that these friends are useful when complaining about the disease, as they understand the topic and be able to give useful advice.

Two other patients that included friends within their network stated that these friends would know the basic things about the disease, to be able to react to dangerous situations, but would not really care about the diabetes. These patients kept these two networks separated on purpose. One conclusion is therefore that among the interviewed patients friends will only get as involved as the patient wants them to be. This conclusion is also supported within the relations model on page XX.

Doctor and DVK

The analysis showed that for most of the patients their doctor or DVK is the main source of medical support, there was only one participant, who did not mention both of them within the network. The DVK had the biggest difference in ranking. This person is for some patients very close, most patients placed the DVK in the middle within the middle section and two patients placed the DVK in the green section. The patients who placed the DVK lower than the rest of the network, had medical support from other sources like peer friends or a boyfriend that was really familiar with the medical side of diabetes or a bad relation with their DVK. All of the four female participants addressed their DVK by their surname and stated their good expertise and help, whereas the male participants simply wrote down "DVK" within the booklets. This could be a hint on an increased support need of the female participants and therefore more personal relationship.

MAIN RESEARCH INSIGHTS - SUPPORT INDIVIDUALS

Figure 48 provides an overview when the stakeholders enter a patient's support network. In general, the biggest advantage of informal caregiver is their closeness to the patient. These people are around the patient and know his/her background and daily routines. On the other hand, if a patient for examples moves out of the parent's house, this distance can interrupt the support within daily tasks. The moment patients moved out of their parents house new stakeholders, such as room mates and students from the student association, entered the support network. Serious relationships, where partners / friends start to really care about the diabetes were reported to start at an age of 22/23 years and often provide a substitute for the parents that no longer live close to the patient.

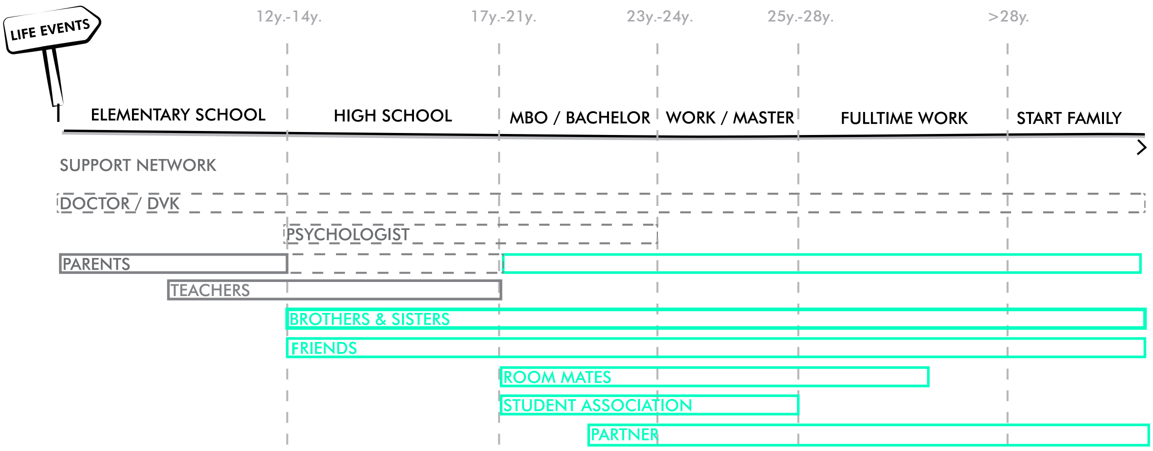


figure 48 Timeline of all stakeholders in a patient's life

IMPROVING THE DEPTH AND QUALITY OF THE SUPPORT

How can informal caregiver achieve this level of preventive support mentioned in on the previous page? What influences the support level? The following summary gives an overview of the reasons, patients mentioned, why they would not include some people within their diabetes support network or why it's difficult for informal caregiver to reach deeper levels of support:

From the informal caregiver's point of view:

- They forget about it
- Do not realize the support need and impact
- "none of my business"
- They wait until the patient shares something
- They are scared to ask the wrong questions
- Bad reactions within former interactions
- Lack of medical knowledge
- Unsure about patient's support preferences

From the patient's view

- Avoid "stupid" questions
- Tired of telling the same story over and over again
- Not to be perceived as pitiful
- I don't want to explain it again, no patience
- It's not such a big deal, it doesn't bother me
- I don't want to be known as the "diabetic"
- I do not want to be a burden to others
- Problems are too difficult for people to understand
- Others have a different mindset about it
- They don't understand the impact of it

MAIN RESEARCH INSIGHTS - RELATION SUPPORT LEVELS AND RELATIONSHIPS

Through analyzing the support networks of the interviewed patients and relations between stakeholders, the following relation was examined: The depth and quality of the support provided by informal care giver are dependent on the development of the relation of the patient and the caregiver, regarding interest and openness (see figure 49). These both factors have to be in personal balance for the caregiver to enter deeper levels of individual support. If the support person does not show interest into the patient's disease or does not gain the required medical knowledge, the support will stagnate at a certain level. On the other side, if a patient does not share information, the support giver can only gain more knowledge through external information sources, provided by the internet or the professional caregiver, which might not fit to the patient's situation.

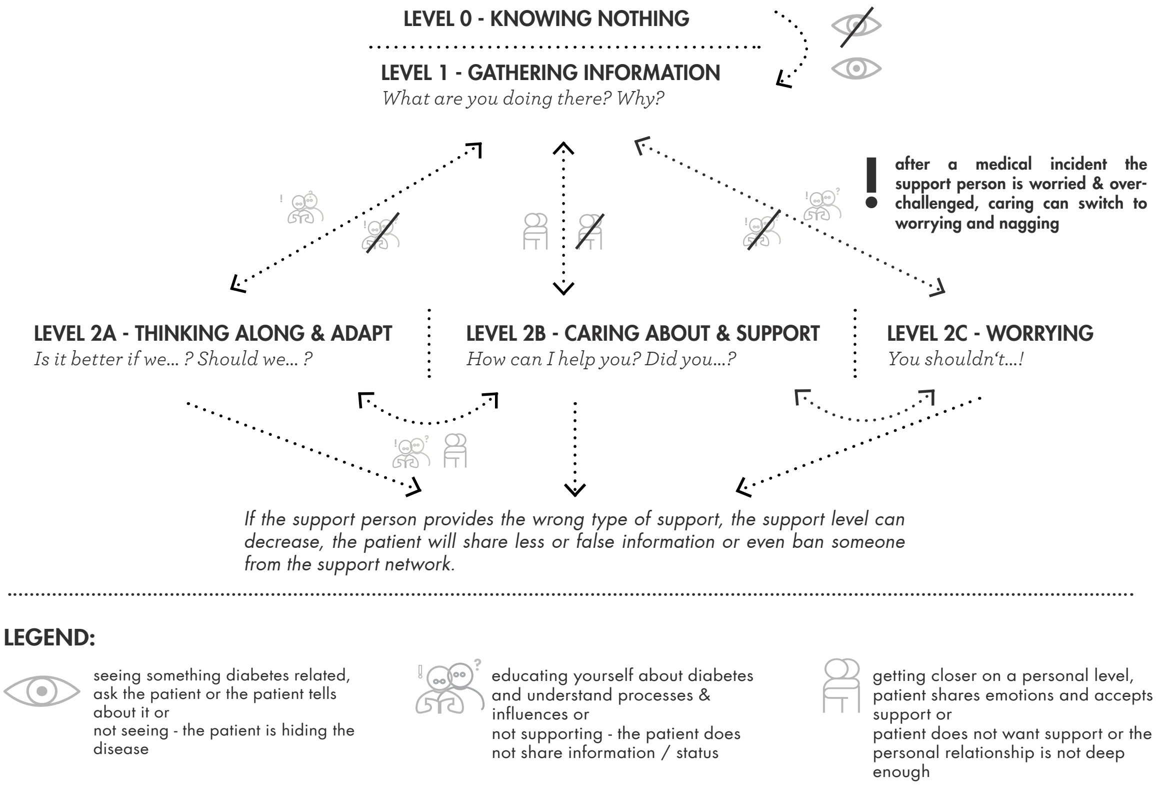


figure 49 model of support level relation within a patient's support network and informal care giver support - model based on generative interviews and patient's statements within this project

LEVELS OF SUPPORT

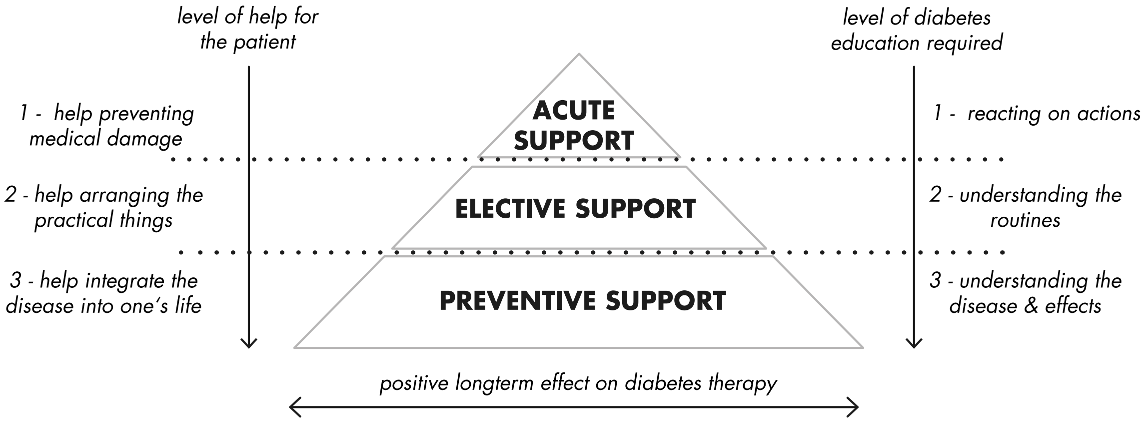


figure 50 informal care giver support levels and depth compared to professional health care support categories - model developed and based on the generative interviews and literature review within this project

What kind of support can informal caregiver provide? What support has the most positive effect on the patient's therapy? In order to analyze the support informal caregiver can give, the tasks named in the interviews were summarized and categorized. Afterwards these tasks were compared to a known support model within the professional health care sector, where support is divided into acute, elective, and preventive support. (see figure 50)

Acute care: the level of care in the health care system that consists of emergency treatment and critical care, also called secondary care. (Acute care, n.d.) Within the field of diabetes this would be acute help to prevent physical damage in case the blood sugar level is out of range, a hyper or hypo. Therefore the informal care giver is only reacting on actions the patient does.

Primary care - Elective support: Care that is chosen (elected) by the patient or physician and is advantageous to the patient but is not urgent, e.g. visiting a doctor specialized on diabetes and the DVK. (Medical Definition of Elective. n.d.) Transferred to diabetes this would be the second level, where informal care givers help with the practical things like organizing doctor's appointments or storing the medication at the right place. Therefore the caregiver needs to understand the daily routines and tasks a diabetes patient has to manage, like measuring the blood sugar level and injecting.

Preventive support: also referred to as "disease prevention" is separated into primary prevention: refers to actions aimed at avoiding the manifestation of a disease, while secondary prevention deals with early detection when this improves the chances for positive health outcomes. (Preventive care - medical definition, n.d.) Support within this category includes the most amount of knowledge about diabetes and its backgrounds but is also the most important one in order to be able to provide longterm efficient care and help integrating the disease into the patient's life. Without knowing the reasons behind the patient's actions, this behavior cannot be recognized by the informal care giver and therefore not be changed.

Advantages / Disadvantages informal care giver support:
Informal care giver know the patient's daily routines, personality and weaknesses. To be able to understand the patient's reasoning behind the diabetes related actions, the informal care giver has to gain as much diabetes related knowledge as possible (see figure 51) Only then he/she can reach the preventive support level, which has the most positive longterm effect on a patient's diabetes therapy and to learn how to cope with the disease.

[redacted] ▸ **DIABETES TYPE 1 (Nederland & Belgie)**
Vor 13 Minuten ·

Beste mensen,

Mijn vriendin heeft sinds haar 14e diabetes en sinds ik een relatie met haar heb maak ik de dagelijkse gang van zaken mee. De reden dat ik lid ben geworden(Dank hiervoor) is dus om meer kennis te creëren. Ik zie de dagelijkse problemen en voel de frustratie. Bij de uitzending van het diabetes fonds op Omroep Max was ik tot tranen geroerd. Uiteraard ben ik lid geworden om te hopen dat er een geneesmiddel gevonden kan worden.

figure 51 facebook post of an informal care giver within a diabetes online network

"The feeling of not being alone when something does not work out again" and *"they are the only ones that really know what this means"* was a statement that often came back during the interviews.

figure 52 informal peer meeting in the Hague, visited during this project, setup by a whatsapp group for newly diagnosed patients

2.3.4 PEER CONTACT & SUPPORT

In addition to the already examined informal caregiver, the interviewed patients were also in contact with other peers, offline and/or offline. Within this chapter, the characteristics of peer contact and the peer networks are analyzed. This was done to be able to compare all support sources and extract the advantages / disadvantages the new support tool could use and integrate. Peer contact among the interviewed patients:

online peer contact	**7/8**
peer acquaintance or friend	**5/8**
peer within family	**2/8**
own blog for peer contact	**2/8**

In the following paragraphs the biggest advantages of peer contact described during the interviews will be evaluated:

Group affiliation - a problem shared is a problem halved

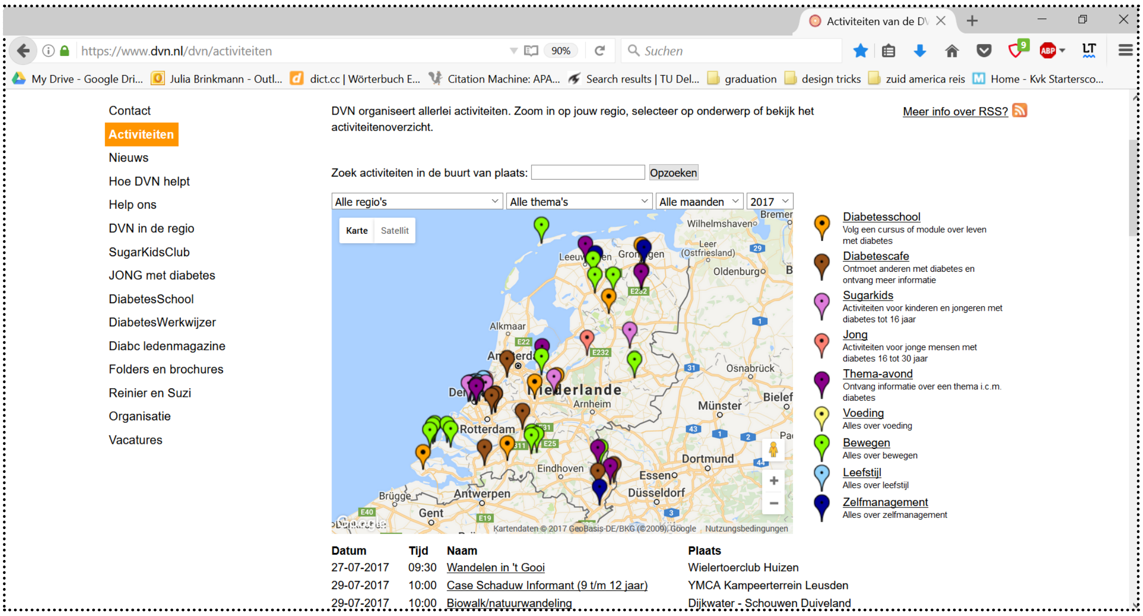
Peers provide support through increasing the feeling of belonging to a group and serving the saying "a sorrow shared is a sorrow halved." Even though there is little evidence for medical improvements through peer contact, phone-buddy studies with type 2 diabetics have shown that "social support and a positive action coping style increased significantly" after 3 month intervention and one year later these patients were still meeting on a regular basis (Rotheram-Borus, M. J., Tomlinson, M., Gwegwe, M., Comulada, W. S., Kaufman, N., & Keim, M. (2012)) for practical tips and to answer small questions and on the other side provides a lot of recognition with people experiencing the same (see figure 52).

Recognition & hands-on solutions

Peer contact provides a good addition to the professional health care, to answer questions that patients do not dare to ask their doctor or the doctor simply cannot answer simply because of the different angle he/she looks at the disease and make it possible for patients to come in contact with other patient's experience and how they handle situations. Recognition a problem and providing emotional support or even a solution is the biggest advantage of peer support.

Therapy inspiration

The contact to other peers is often used to compare gadgets before deciding on something new and getting advice and feedback from experienced users before entering new situations to take away the fear. Staying in contact with peers and seeing how they handle certain situations will also prevent patients of handling their diabetes in an inconvenient way.



- Contact
- **Activiteiten**
- Nieuws
- Hoe DVN helpt
- Help ons
- DVN in de regio
- SugarKidsClub
- JONG met diabetes
- DiabetesSchool
- DiabetesWerkwijzer
- Diabc ledenmagazine
- Folders en brochures
- Reinier en Suzi
- Organisatie
- Vacatures

DVN organiseert allerlei activiteiten. Zoom in op jouw regio, selecteer op onderwerp of bekijk het activiteitenoverzicht.

Meer info over RSS?

Zoek activiteiten in de buurt van plaats: Opzoeken

Alle regio's | Alle thema's | Alle maanden | 2017

Diabetesschool
Volg een cursus of module over leven met diabetes

Diabetescafe
Ontmoet anderen met diabetes en ontvang meer informatie

Sugarkids
Activiteiten voor kinderen en jongeren met diabetes tot 16 jaar

Jong
Activiteiten voor jonge mensen met diabetes 16 tot 30 jaar

Thema-avond
Ontvang informatie over een thema i.c.m. diabetes

Voeding
Alles over voeding

Bewegen
Alles over bewegen

Leefstijl
Alles over leefstijl

Zelfmanagement
Alles over zelfmanagement

Datum	Tijd	Naam	Plaats
27-07-2017	09:30	Wandelen in 't Gooi	Wielertoerclub Huizen
29-07-2017	10:00	Case Schaduw Informant (9 t/m 12 jaar)	YMCA Kampeerterrein Leusden
29-07-2017	10:00	Biowalk/natuurwandeling	Dijkwater - Schouwen Duiveland

figure 53 different activities provided by the DVN all over the Netherlands

Facilitated diabetes peer events
So far, if patients do not know a peer within their direct surroundings, they can relate on the diabetes organizations organizing peer meeting events. Until recently these events always involved an activity within a predefined setting (see figure 53). Therefore patients have to identify with the type of event, before even meeting the patients that will be present at these events. Among the interviewed patients almost everyone was member of the biggest diabetes organization - the DVN, but no one joined these events. The reason for the feeling that they would lack recognition with the patients present and not being able to know, who is coming to these events or not liking the event activity itself. But who is going to these meetings then?

The image of the interviewed patients is that only a very specific group actively participates in these events, and they cannot identify with the *"good diabetics, almost proud to show off their disease"* as one patient puts it. These events are mostly having a dusty image and are received as targeting type 2 diabetics. New concepts as the "Diaborrel" and patient photo shootings from patient-run networks are providing a more informal setting to get to know peers. The amount of young visitors at these event were reported to be increasingly higher than at the rest of the events.

Private peer contact
Six of the eight participants stated to have offline peer contact. These peers were either found per incident at school or in the neighborhood or the contacts were kept over from former peer activities like the diabetes camps for kids. Hereby it can be differed between patients that became friends with other peers on a personal level during these activities and patients that knew people within their circle of acquaintances that have diabetes. Within the second situation the pure fact that somebody else had diabetes provided enough connection to stay in contact. One exception provide the cases where patients had a peer within the close family, where the diabetes either did not influence the general support relation or negatively influenced the personal relation, causing competition and misunderstandings especially within the teenager years.

MAIN RESEARCH INSIGHTS - PEER CONTACT

To sum it up it can be divided between two different situations and influences: If multiple patients are meeting each other, only having diabetes is not enough to trigger people to an event or a connection. The event itself has to provide a valuable add-on for patients and patients want to know, who is joining an event from beforehand. The connection to other peers has to provide added value like tailored activities that patients would also do otherwise, new friendships or other identification factors such as the same age.

On the other side, if patients find each other per incident, outside of these networks in their daily life, for example at work, the connection of both having diabetes is enough recognition.

[redacted] ▸ DIABETES TYPE 1 (Nederland & Belgie)
Vor 1 Stunde ·

Goedenmiddag alle type 1 mede lotgenoten!
Mijn naam is jöran 24 jaar oud en al 23 jaar eigenaar van dit fenomeen. Ik vind het prettig om te weten dat er een groep bestaat waarin je jezelf kan herkennen. Ik hoop hier nog een beetje wijzer te worden net als jullie.

Hoelang heb jij db type 1 al?

7
47 Kommentare

[redacted] ▸ ALL OF ME - geheime groep
Vor 4 Stunden ·

wat heb ik toch al een mooie, leuke, soms verdrietige of ontroerende berichten voorbij zien komen.
het is voor mij altijd weer leuk om te zien wat de watsápp groep die ik heb opgericht vanuit deze groep nu betekend.
ik vind het erg geslaagd.
voor de gene die willen deelnemen kunnen zich hier onder melden of mij een bericht sturen.

5
4 Kommentare

[redacted]
20 Std.

Soms zijn opmerkingen best lastig als je een hypo hebt....
'Het komt vast door de warmte, ik heb er ook last van'...
Ik kan er niet meer aardig op reageren!

17

7 weitere Kommentare anzeigen

[redacted] Met zo'n warm weer moet ik niet al te veeel inspanning doen gegarandeerd hypo! Ook al mag ik soms minder inspuiten (maar dan is de kans dat je ook weer net iets te hoog ligt) in de winter als het echt vriest enzo juist hetzelfde.. tleven is toch simpel als diabeet..
Gefällt mir · Antworten · 2 · 18 Std.

Andy Bultheel hat geantwortet · 2 Antworten

[redacted] Gewoon van je af laten glijden.
Gefällt mir · Antworten · 17 Std.

[redacted]
25. August um 08:45 · Veldhoven, North Brabant

Ik heb echt zo ontzettend veel zin in vandaag, barst van de energie #not #

[redacted]
Am 18. Apr. um 7:18nachm. · Venlo ·

Vandaag heb ik het eventjes gehad. Beetje grieperig en erg misselijk en moe. Zit er eventjes doorheen vandaag. Ik ben blij dat ik dit kwijt kan aan mijn lotgenootjes!

Du und 2 weitere Personen
8 Kommentare

[redacted]
42 Min

Hba1c van 60 naar 58! We gaan de goede kant op!

8

[redacted] Lekker bezig!!
Gefällt mir · Antworten · 1 · 30 Min

figure 54 posts of peers within online facebook groups appreciating the peer contact possibility

2.3.5 ONLINE PEER TO PEER SUPPORT

Online networks and forums are providing an easy reachable and handy addition to offline contact with peers. As mentioned within chapter 2.3.4, seven of the eight interviewed patients were member of an online peer network and either actively posting and searching for advice or reading articles provided by other patients. After analyzing the current peer networks within chapter 1.4, the support interactions within these networks will be analyzed within this chapter. The goal here is to be able to compare the provided support with the support wishes of the patients and identify gaps for new types of support and increase the member affiliation within the to be designed support tool.

Target groups of the networks

The goals of the examined networks is to "inspire, inform and activate diabetes patients" and "to support people with diabetes in their daily life and improve the diabetes care." Patients should find new ways to positively deal with their disease, without underrating that having diabetes can be tough. According to the communities webmaster, the user can be categorized within four classifications:

1."The good diabetics": Patients that the networks want to keep updated and that are interested in diabetes related news and activities. This and group two are the main target group of the networks as they profit most from the provided information and support.

2. "The Patients where one thing is missing": for example insufficient medical care or no sufficient support network, they need inspiration and find people who understand their story and will provide tailored support and help. These patients need emotional and practical support to improve their therapy.

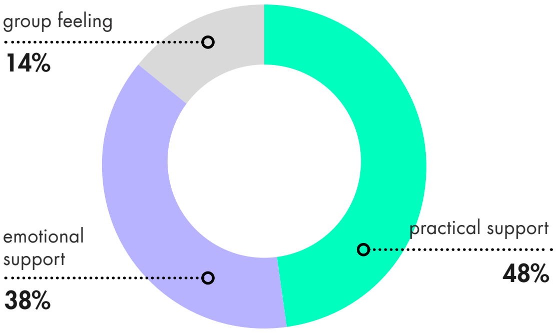
3. "The isolated ones": patients who are staying isolated and figuring it all out by themselves, they first have to be reached and included and show them that they don't have to go through this alone, there are multiple ways to get help outside of the doctor.

4. "The group that is really struggling": These patients are having deep anxieties and mental issues like depression or eating disorder. As the chairperson of a big Dutch peer network explains, "these groups cannot only be helped with a blog or an article, they need professional help." Even though these patients are welcome to read the websites and blogs, webmaster and forum user often actively encourage them to seek professional help or send personal messages, when heavy problems surface within the forum post.

As stated within the last chapter, the group that is mainly reached are the "good diabetics". Within the following chapter 2.4 it will be examined whether the interviewed patients identify with the support and information these networks provide and/or what is missing.

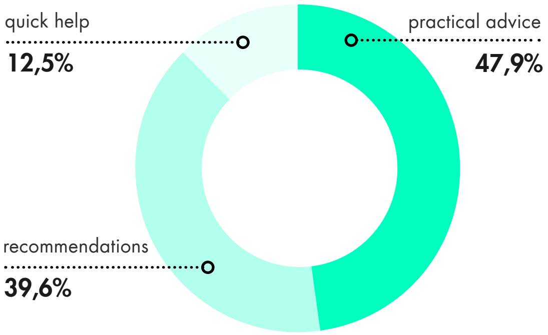
Types of support provided within peer communities
To be able to classify the network's support offer and compare it to the support provided by informal care giver within the next chapter, the topics within the most frequently used network among the target group, the facebook group "Jongvolwassen en Diabetes", were analyzed. The last 100 posts within the network were categorized into their internal motivation/goal and psychological background and how many posts served this goal. All topics and wishes were then clustered into three different categories based on the main support categories used within this project: emotional and practical support. A third category, that can only be provided by other peers was added: group feeling among patients. The division of the three main categories can be seen in figure 54 and will be examined further within figure 55-57.

Figure 54 - Support division within the network:



Types of practical support: providing solutions, life-hacks & inspiration but also "quick help" at this very moment, when patients ran out of insulin for example, this advice is mainly used to get inspired and solve small, everyday problems, recommendations about new products, gadgets and lifestyle choices are also a big part of this group (see figure 55)

Figure 55 - types of practical support:

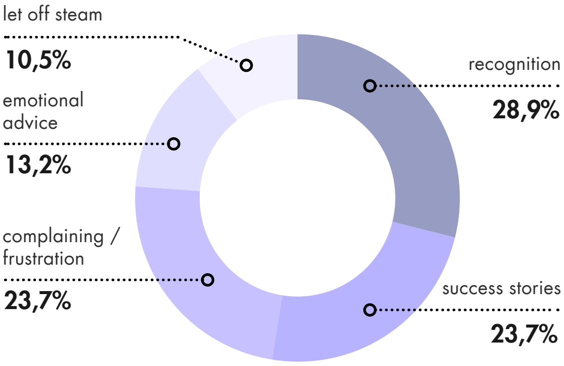


Within the analysis it can be seen that these networks mainly provide practical support. Regarding the fact that people within these networks do not know each personally neither each other's medical data, this advice can have both advantages and limitations:

Peer to peer networks have the advantage to quickly solve acute problems. Compared with professional caregiver with fixed working schedules, these networks have multiple communication possibilities and, because of the high amount of user, more potential patients that can answer questions 24/7. Because of the high amount of recognition, user can provide a diverse range of solutions to a problem and inspiration. Still, patients have to realize that online peers do not know their medical background and are not professional care giver. Patients miscalculate the power of online peers and will ask specific medical questions from peers, instead of consulting their doctor. This can be dangerous, especially for newly diagnosed, unexperienced patients. Whereas for some patients the advice given might work as an inspiration, others will include this advice one to one and cannot handle the possible consequences.

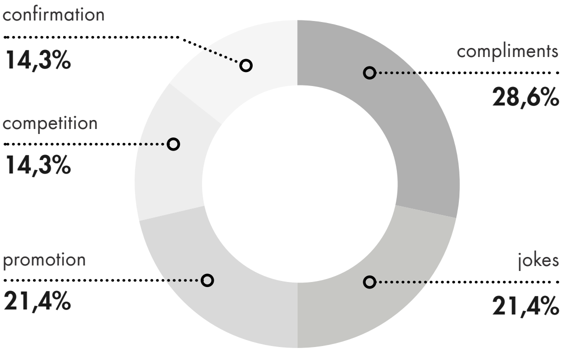
Types of emotional support: this type of advice is mainly used to let off steam after a bad day, share stories & frustration & sarcasm, patients are look for recognition and other's who can relate & understand a problem more than the professional caregiver, but on the other side also to share positive stories, to get compliments from other peers (see figure 56)

Figure 56 - types of emotional support:



Enhance group feeling: patients upload their blood sugar levels for comparison & motivation, are seeking for confirmation about choices and share jokes to cheer up other members (see figure 57)

Figure 57 - types of group feeling:



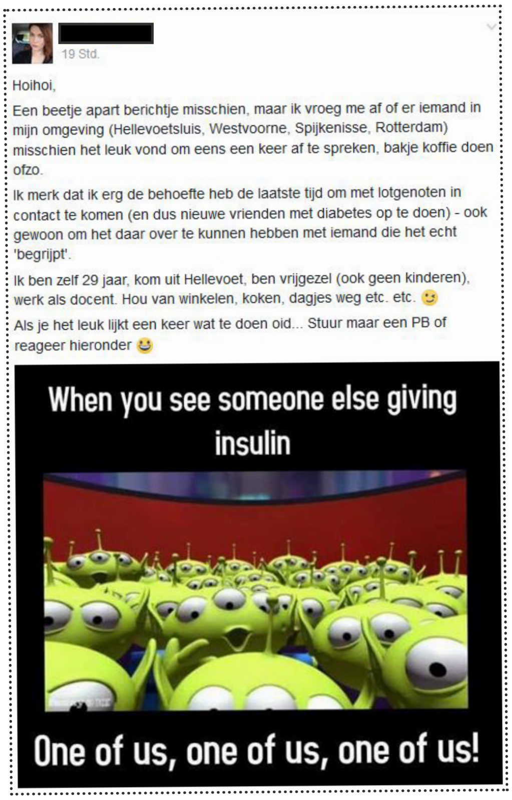
Only online help?

During the interviews one participant, who in general had a very negative attitude towards her diabetes, stated to be very attached to the online peers, but furthermore was not trying to find a way to integrate the disease into her life. This form of support, to post severe problems online and find recognition, instead of seeking professional help, is a phenomenon that multiple interviewed experts have also encountered and try to tackle by referring to professional psychologists and diabetes coaches when reading posts and facilitating.

Facilitating offline contact through the networks

Within offline facilitation it can be distinguished between the networks that have been started by organization, who focused on offline activities beforehand, like the diabetes vereniging nederland and online networks that were started for purpose of communication online. These networks occasionally try to setup offline meetings but also stated that this was difficult to combine with patient's personal agenda, preferences for meeting locations and cities. Still, once patients would come to these meetings they would all be very happy to make new friends and talk to other patients. One meeting that does get a lot of visitors is the annual "Stichting Eén Diabetes" photo shooting, as this meeting provides the mentioned add-on advantage of getting a nice picture of yourself.

Patients, who privately search for offline contact within their living area, do occasionally, timidly post invocations (see figure 58).



[redacted]
19 Std.

Hoihoi,

Een beetje apart berichtje misschien, maar ik vroeg me af of er iemand in mijn omgeving (Hellevoetsluis, Westvoorne, Spijkenisse, Rotterdam) misschien het leuk vond om eens een keer af te spreken, bakje koffie doen ofzo.

Ik merk dat ik erg de behoefte heb de laatste tijd om met lotgenoten in contact te komen (en dus nieuwe vrienden met diabetes op te doen) - ook gewoon om het daar over te kunnen hebben met iemand die het echt 'begrijpt'.

Ik ben zelf 29 jaar, kom uit Hellevoet, ben vrijgezel (ook geen kinderen), werk als docent. Hou van winkelen, koken, dagjes weg etc. etc. 😉

Als je het leuk lijkt een keer wat te doen oid... Stuur maar een PB of reageer hieronder 😄

figure 58 patient's searching for contact offline within online networks

Barriers to post something online that were named by the interviewed patients included:

- *"I do not want to look desperate"*
- *"I am unsure about the people I will meet"*
- *"the people, who will answer do not fit my criteria "*
- *"online networks feel too anonymous to do so"*
- *"nobody else does it - I would feel awkward"*
- *"I don't need this - I have enough support online"*

Within the few times people were looking for offline contacts, they mostly stated their age, their location, what they wanted to do with the peer (mostly drinking a coffee or a beer), what kind of work they do and sometimes their hobbies. In some cases, peers also mentioned a certain diabetes related problem they wanted to talk about and therefore limited their search to other diabetes patients with the same problem. It can therefore be concluded that if patients are searching for offline contact, they are either searching for sort of friends that fit their own life situation or others who can help them solve one specific problem. These criteria will be evaluated further within the following chapter - patient's support wishes.

Another interesting aspect was the topic "quick help", where patients ask other patients for help on the spot, if they happen to live in the same region, for example if a patient forgot the diabetes kit at home or ran out of insulin. This is a point where online and offline help is already facilitated.

Advantages & Limitations (online) peer support

To sum it up, peer support is very helpful to solve medical and very specific diabetes related problems. Online peer to peer support can provide short term relief, recognition and solutions for small / little problems, but as patients do not know each other, the depth of support is limited as the medical background knowledge and life situation of people is unknown. On the other side, if peers would be able to meet offline friends, this knowledge about each other's daily life could be enhanced, the support could even be more tailored and qualitative better.

This assumption was also confirmed by the interviewed patients, where the patients that had actual offline peer friends instead of acquaintances, placed them higher within their support network and / or choose them as their trustee.

2.3.6 COMPARING (ONLINE) PEER SUPPORT AND INFORMAL CARE GIVER SUPPORT

To be able to find out about the pros and cons of each support giver examined, (online) peer support (purple within the model) was compared to the task the informal caregivers could provide (green within the model) (see appendix 16 and figure 59) The results are implemented within the model used in chapter 2.3.3 on page 55.:

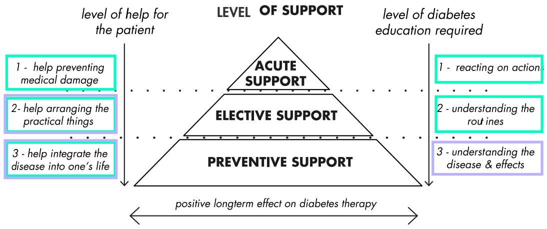


figure 59 comparison support provided by informal care givers (green) and peers (purple) within the developed model

Acute support: informal care givers as they are the ones present offline if something happens, the online peers can be contacted through the networks but are location wise too far away

Elective support: peers can give advice, how patients can arrange practical things offline, as they understand the routines. Informal care giver first have to learn the routines and can afterwards take over practical tasks and help implementing the solutions.

Preventive support: Most overlap within this category, as the online network peers have most experience within the disease and can provide solutions. On the other side, as they cannot help the patient to implement these solutions into his/her offline life, this support stays limited. the informal care giver do not have as much medical knowledge, still they are around the patient within daily life and can help recognizing behavior implement solutions.

Quality of a support network

The support possibilities for a person are dependent on this person's relation with his / her diabetes, how much support this person will allow and how the existing support network is build up. According to the patient's own character and support wishes, these medical and emotional support networks can be kept separated, partly overlap, with caregivers providing both emotional and medical support or in some case completely overlap, if some stakeholders have both the medical knowledge and discretion into a patient's emotional world. When comparing the support networks of the interviewed patients and analyzing according to their satisfaction, emotional balance and efficiency, the patients that had supporters that could support them both medical and emotional to a certain extent, were the most satisfied and had the best emotional balance (see appendix 18 within the red box). Whereas the patient within the blue box, where the trustee had not sufficient knowledge did not use the support network's full potential and therefore got less useful feedback and help from their trustees. Regarding peer contact, the integration of peers into the network only seems to be efficient when integrated into the offline network and more on a personal level (see difference in percentage in appendix 17 - red and blue box patients). This theory is also supported by diMatteo's research about the importance of family support, which states that *"functional social support (combined practical and emotional support) had stronger effects on adherence than did structural social support, suggesting that the quality of family-patient relationships matters more than just the mere presence of individuals within a patient's network of support."* The pure presence of a big amount of peers within the online networks did not show a big effect on the patient's emotional balance regarding the diabetes.

Comparing these results back to a model of patient support categorization developed by (Bloem, S., 2012) (see figure 60 and appendix 18) which states that dependent on their amount of acceptance and control over the disease, patients want different types of support, it can be seen that two of the support categories he suggests (stimulating pride and emotional support) are best achieved through online networks, the transition of getting online support and having to implement this support offline works for small changes and for problems that can be solved immediately. Practical help, planning & structure and personal coaching are offline activities that can be best taken over by the informal care givers. Crucial changes within a patient's behavior, routines and mindset, a deeper analysis of the backgrounds of a problem, more regular support and checkups are needed to succeed over a longer period.

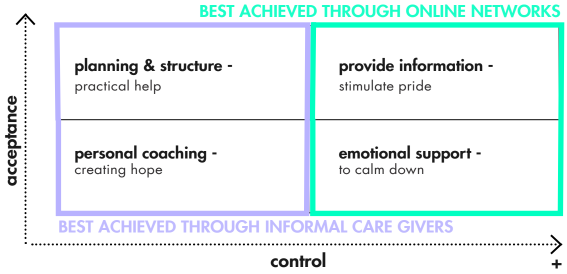


figure 60 support target group

MAIN RESEARCH INSIGHTS - SUPPORT EFFICIENCY & QUALITY - Figure 61 shows an overview of all stakeholders and the missing pieces.

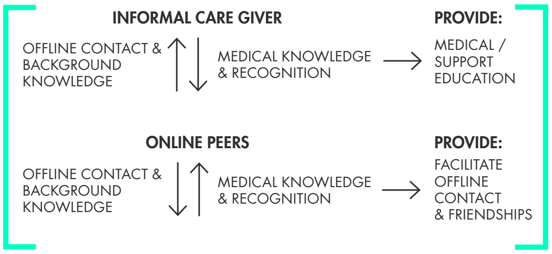


figure 61 support target group

2.4 PATIENT'S SUPPORT WISHES

In order to get deeper insights into the life of diabetes patients and their support surroundings, a small scale qualitative user research was set up with a total of 8 diabetes patients. Multiple research methods were used to access different levels of knowledge. Sensitizing booklets prepared the user for the interviews and find out about their daily life and diabetes mindset. With the generative interviews the goal was to first map out the patient's diabetes history and support network - based on the patients explicit knowledge, then the interviews moved on to the patient's feelings and dreams about their future support, in order to reach the underlying latent knowledge of the users. Based on the user interviews, 5 patient personas were developed, which will be introduced within this chapter and further evaluated within chapter 2.3.

RESEARCH STRUCTURE

The support research was started off with the participation within the online networks. Through the generative interviews the researcher got in contact with more diabetes groups and was able to meet additional diabetes patients to confirm the findings of the interviews. The support findings of the interviews were evaluated within the persona's support networks and support wishes and the special support moments within patient's life. (see figure 62).

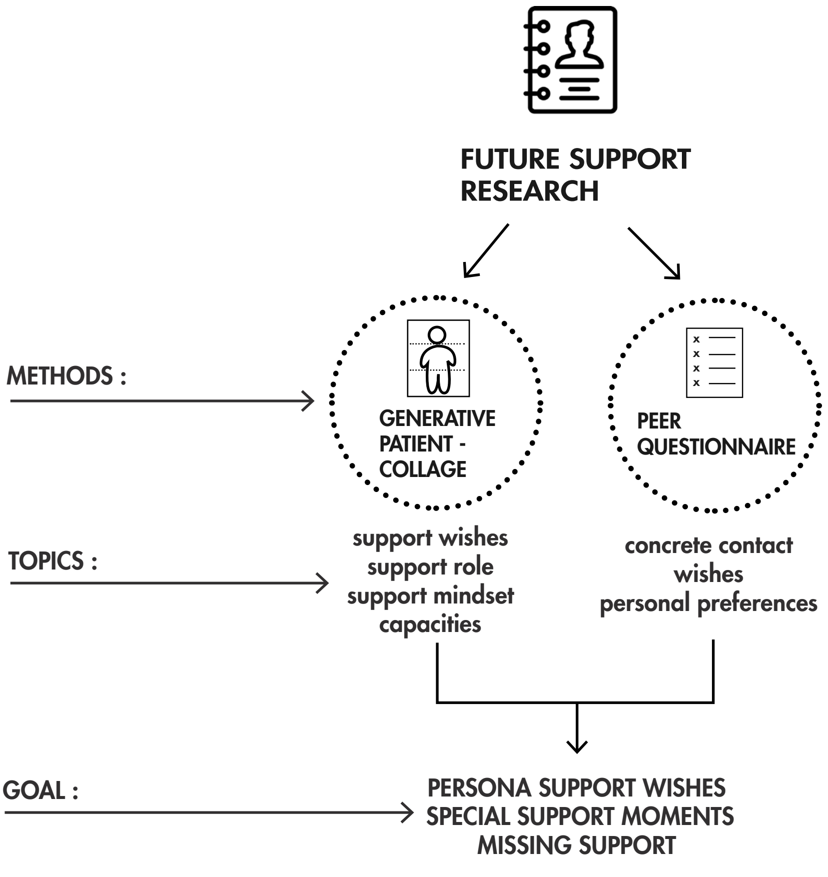


figure 62 structure of the user / field research

RESEARCH QUESTIONS

- *How are the interviewed patients in contact with other peers?*
- *What characteristics should the interviewees future dream peer have?*
- *How do the interviewed patients use the online peer to peer communities*
- *What are their patients wishes for future support stakeholders?*

RESEARCH PARTICIPANTS

As within the previous research activity, the same eight patients “connected” and “not connected” patients were interviewed.

RESEARCH TOOLS

The following research tools were used within the generative interviews:

1. peer support dream collage

2 questionnaire about the patient’s peer support preferences

The final goal of the interview was to find out about patient’s wishes for people that could fulfill this existing network. What kind of peer do patient want as a support person? What characteristics should this person have?. (see figure 63) A collage of this peer’s mindset, personality and capacity was created.

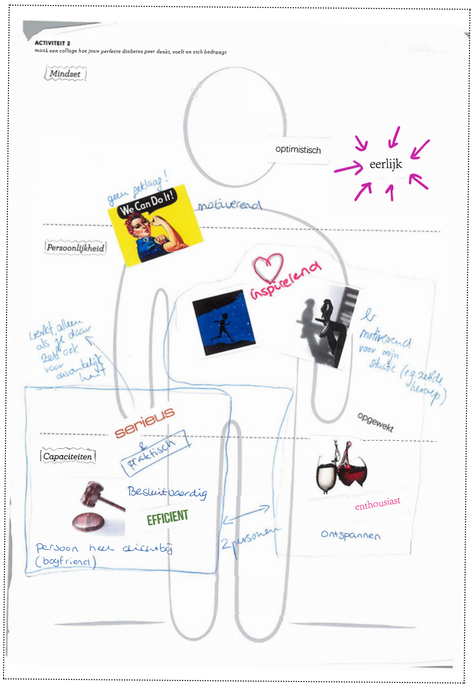
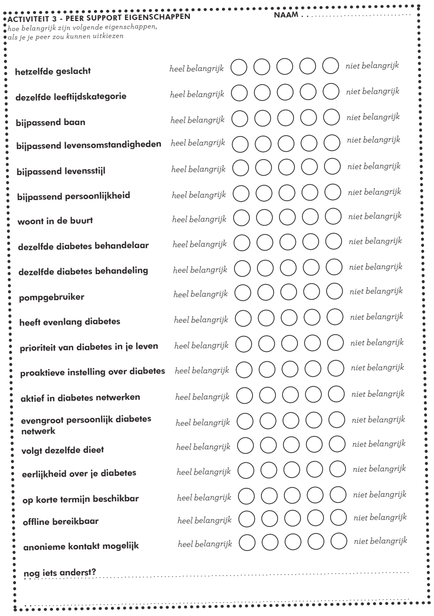


figure 63 a patient’s dream support person

This collage was then used to walk through the timeline (see chapter 2.3 - research tools) and let the patient think about how this person could have helped him/her in difficult situations. At the end the people had to fill in a questionnaire and answer questions about their preferences regarding peer to peer contact (see figure 64). See appendix 19 for the patient’s collages and appendix 20 for the results of the questionnaire.



ACTIVITEIT 3 - PEER SUPPORT EIGENSCHAPPEN NAAM . . . .

hoe belangrijk zijn volgende eigenschappen,
als je je peer zou kunnen uitkiezen

hetzelfde geslacht	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
dezelfde leeftijdskategorie	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
bijpassend baan	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
bijpassend levensomstandigheden	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
bijpassend levensstijl	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
bijpassend persoonlijkheid	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
woont in de buurt	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
dezelfde diabetes behandelaar	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
dezelfde diabetes behandeling	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
pompgebruiker	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
heeft evenlang diabetes	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
prioriteit van diabetes in je leven	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
proaktieve instelling over diabetes	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
aktief in diabetes netwerken	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
evengroot persoonlijk diabetes netwerk	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
volgt dezelfde dieet	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
eerlijkheid over je diabetes	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
op korte termijn beschikbaar	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
offline bereikbaar	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*
anonieme kontakt mogelijk	*heel belangrijk*	○	○	○	○	○	*niet belangrijk*

nog iets anders? . . . .

figure 64 questionnaire about the patient’s preferences regarding the future peer’s characteristics - what factors are most important?

The goals of the different tasks can be found in the appendix 21.

RESEARCH RESULTS

1. Patient’s personal support preferences

The wishes stated by the interviewed patients were summarized within three types of support person the patient’s are looking for: a friend, a role model and an antipole. These roles are combined with the type of support a person wants.

2. Support moments timeline

Throughout the patient interviews, special support moments within a patient’s life were recognized and connected to different events in life. The results of this timeline are evaluated in an infographic that includes moments of change. For the idea creation workshop within the company the personas were connected to special moments within the support timeline to guide the employees ideas and let them think about certain moments they had also witnessed within their own life, for example moving out or starting to study in another city.

3. Support opportunities

Finally, the patient’s support wishes and activities within the online networks are compared to the support the networks provide and analyzed for support opportunities that can be implemented in the future support tool.

2.4.1 WHAT TYPE OF SUPPORT DO PATIENTS WANT?

What kind of support do patients want? What parts of the diabetes mindset influence the type of support patients want? To be able to answer these questions, the collages and statements of the interviews were analyzed and compared to each other. It can be summarized, that all of the interviewed patients were searching for practical advice, but only some participants would also appreciate more emotional support. The others had a very sober minded character and did not experience the disease as so heavy. This factor also corresponds with the finding The results are displayed within the figure 65:

1/8 patient was looking for only emotional support

4/8 were looking for both emotional and practical support

3/8 patients were looking for only practical support

These support wishes are also represented by the personas and their character / diabetes mindset: having accepted the disease and being more sober minded Pim and Sjoerd are looking for practical support to improve their diabetes management even more. Emmeline wants both type of support to open up to support again and find a way to pickup her motivation again. Inge and Marjolein are dealing with the diabetes in a wrong way and need emotional support to be able to either comply with their perfectionistic standards (Inge) or start accepting this disease and perform minimum amount of tasks required (Marjolein).

How the diabetes mindset influences the type of support

Looking back at the diabetes mindset displayed within chapter 2.2 (see figure 65)

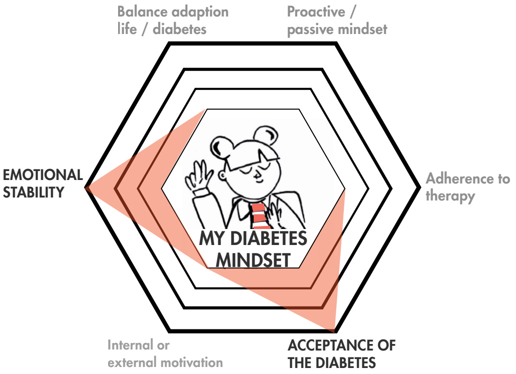
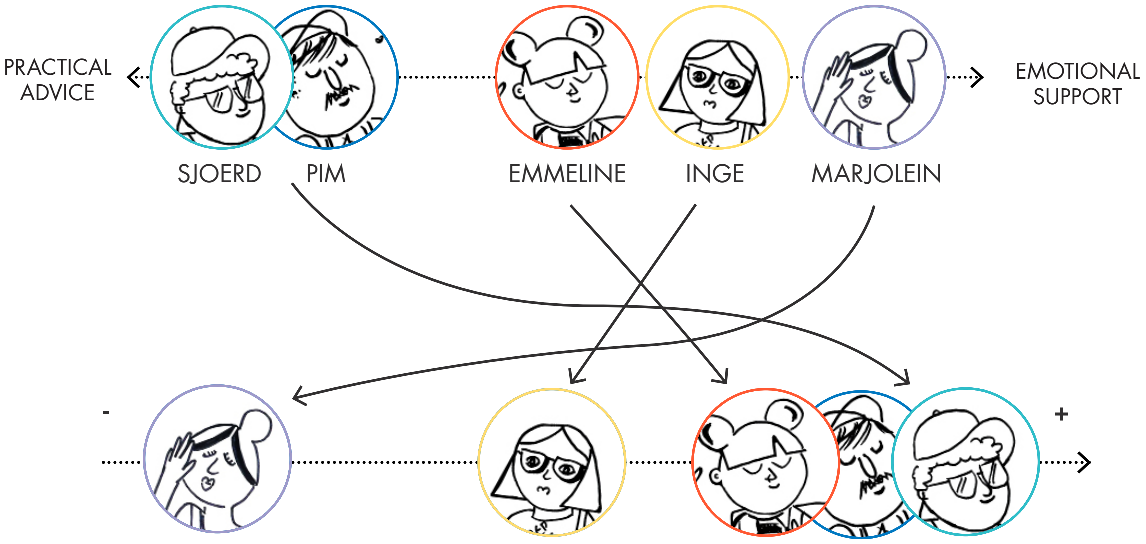


figure 66 diabetes mindset summary

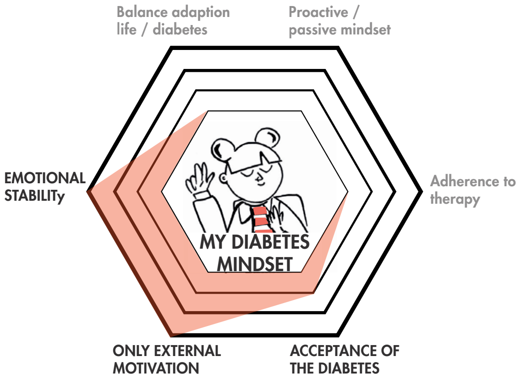
The type of support wanted is very dependent on the amount of acceptance / integration of the diabetes into the patient's life (see figure 66) and emotional stability, as mentioned within chapter 2.3. This assumption is based on the theory that once a patient starts to accept the disease, the blood sugar levels will increase and the patient will feel emotionally more stable. Patient that do not accept the fact that he/she has to deal with this disease, the support will differ in amount, type and tone from a patient that has accepted the disease. The support for persona Marjolein has to deal with basic psychological principles as motivation and comforting the patient, whereas support for a patient who is dealing with the practical problem of the disease, for example Sjoerd, can be more solution oriented.

Relation of type of support wanted and acceptance; (figure 65)



Relation diabetes mindset and support

EMOTIONAL SUPPORT CAN HELP WITH...



PRACTICAL SUPPORT CAN HELP WITH...

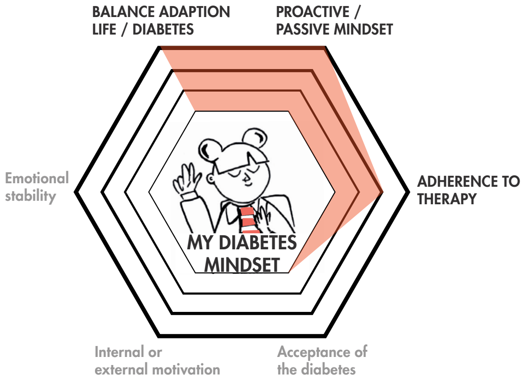


figure 67 diabetes mindset practical and emotional support

The support network can provide external motivation through group affiliation or rewards, but not internal. Internal motivation is a result from successful managing the diabetes and a positive, problem approaching mindset.

2.4.2 WHO SHOULD PROVIDE THIS SUPPORT?

The mindset that will benefit a patient is dependent on his own mindset and support needs. Within the interviews, the patients expressed different wishes for the type of person they would like to have in their life (see appendix 22 for comparison)**:**

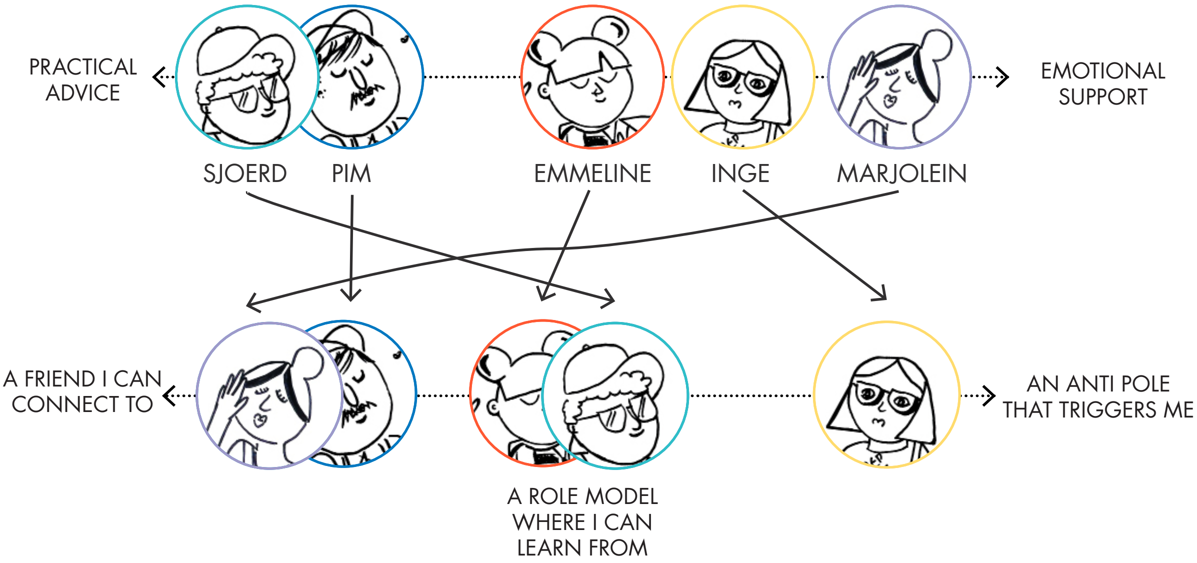
3/8 patients wanted to find a friend that could integrate in their normal friend group and had the same mindset about diabetes as they had. This person should react on problems and challenge similar to the patient and can provide tailored advice.

4/8 patients were looking for a role model with a "better" mindset, who had already solved the problems they are encountering and can provide expert advice, motivate them and inspire.

1/8 patient was looking for an antipole that has the exact opposite diabetes mindset and can provide new input and help reflecting on the diabetes mindset by being completely different. This "wakeup" effect was desired by a patient that needed a new, more relaxing way to deal with the diabetes.

Looking back at the diabetes mindset (see figure 67), the preferred role can again be set into context with their amount of acceptance, motivation and adaption and the type of support they wish for. As the personas demonstrate within figure 68, the patients with a negative attitude towards their diabetes either wanted a friend that will "complain along" or like Inge, realized that their mindset isn't the best and want to be triggered to change and therefore search for an antipole. The patients in balance on the other side also searched for a friend that has the same mindset or were motivated to meet their role model and get inspired to perform even better.

Relation of type of support and who should provide this (figure 68)



DYNAMIC SUPPORT SYSTEM

As diabetes is a disease that goes on for years and follows a patient's natural life choices and changes, the support system will not likely stand still. The relation of support givers and receivers is a dynamic system that is influenced by internal and external factors and that support roles and they type of support needed and provided can and will change over time. Patient who first only wanted emotional support, could, once they proceed with the disease also need practical advice how to cope with situations (see figure 69). The other way round, patients who first stated to have no need for emotional support could, once their disease changes to the worse, need emotional support after all. Therefore, the first, very static model to analyze the patient's support wants was dismissed (see appendix 23).

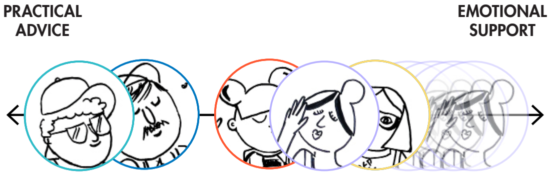


figure 69 changing support wishes

Moaning vs. motivation

The support role that patients want can also change according to their own mindset towards the diabetes. Patients, who have a negative attitude towards their diabetes were often looking for a friend with the same negative mindset, who understands them and to "moan together" or get them out of this negative vibe. Once these patients start turning their negative into a more positive approach by supporting each other and get motivated themselves, this mindset can change from recognition and moaning to a more coaching, motivating approach (see figure 70).

From the other side, most patients with a more positive mindset were looking for people that could help them solve their remaining problems and were not particularly interested in being with negative patients that could "demotivate" them again. **Patients therefore prefer contact with people that are sharing their mindset and not people who will drag them down with a negative attitude.**

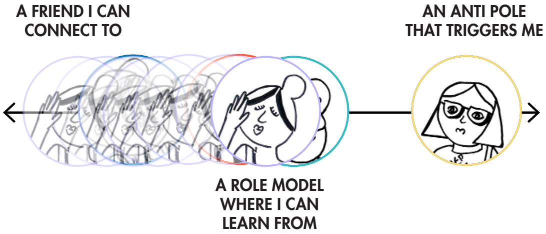


figure 70 changing support wishes

2.4.3 COMPARING ONLINE SUPPORT WITH THE PATIENT'S SUPPORT WISHES

To be able to analyze the effectiveness and whether the online support fits the patient's wishes, their online activities were analyzed and summarized. They can be categorized into three categories:

1. Regular poster, (1/8 interviewed patients), who provide and search for advice and need both the emotional and practical support of others. They regularly post updates of their condition and questions either within the networks or through their own channel. These patients also answer other's questions and/or comfort others by providing emotional support.

2. Infrequent poster, (2/8 interviewed patients), who don't want emotional support by these networks and only use them for practical advice. This group uses the networks for practical advice and inspiration by reading and answering the posts that are appealing to them. These patients subconsciously connect to the patients that they can relate to and ignore the others.

3. Lurker, (5/8 interviewed patients), who are lid within some of these networks but never post anything and only read online. These people like the feeling of being in a community but cannot are less emotionally affected by the disease and therefore cannot relate to other patient's problems. **2 of the 8 patients had their own channel / blog to post diabetes related information to avoid the other groups.**

Connecting to the peers online

The main reason patients join a network is to find people that can relate to their problems or thoughts and provide support, solutions or inspiration on how to solve them. For a lot of patients the networks also provide a great source or emotional support and a place to get rid of negative thoughts and feelings. Still, the positive aspect about group support, recognition and relating to other people is at the same time the reason 6 of the 8 patients are inactive within the networks or completely stay away. Patients who do not struggle with the same problems or cannot relate to the amount of emotional baggage diabetes brings for other patients, receive the platforms as being too emotional, too negative and too much nagging within the posted threads. The negative posts often overshadow the practical aspect of having a source of fast help and inspiration next to professional health care.

Looking back at the analysis of the types of support provided online within chapter 2.3.5, this comes as a surprise insight. Even though the practical support, the positive stories, the jokes and recognition stories outweighs the emotional support and letting off steam posts within the network, a lot of patients still have the feeling of the networks are being too negative and too much "complaining about how hard it is and feeling miserable of asking for attention and being pitied" as one patient puts it in the interview.

CONCLUSION - PATIENT SUPPORT WISHES

Regarding the patient's recognition with the online network, it's not only the type of posts that people find annoying but in general the mindset of other patients online how much they care for a certain topic and if they can recognize this amount of care and acknowledge a problem as being "legit" to care about or not. Patients have a different need for support and worry about things in a different way and amount. As the power of peer contact is to recognize or provide solutions out of the own horizon, it is hard for patients to care for problems that are not affecting themselves and they cannot relate to.

This lack of empathy and recognition was also realized by the interviewed expert: Harsh judgment and patients condemning each other for not feeling the same instead of keeping out of a topic. Patients, who don't share this feeling of recognition can either misbehave and be banned from the networks or, as the interviewed patients, stay quiet and don't use the full potential of the support networks. On the other side, all of the interviewed participants agreed on being interested in more contact with peers, but only with peers they can connect to on a personal level.

MAIN RESEARCH INSIGHT - MATCHING MINDSET AND LIFESTYLE

The results of the questionnaire about the patient's peer contact preferences are matching the results that were discovered so far (see figure 70 and appendix 20):

8/8 patients were looking for somebody empathic, open and honest

7/8 thought it was very important that the future peer has a diabetes mindset that fits the mindset of the patient - especially regarding adaption life / diabetes, time consumption and how limited a patient feels through the diabetes

7/8 patients wished to have a click with the future peer, like within friendships outside of the diabetes

6/8 would prefer getting in contact with peers that have a matching lifestyle, e.g. being a student

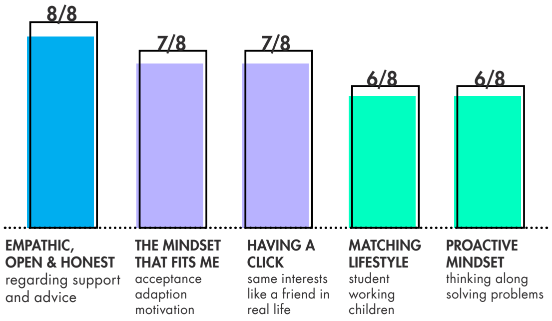


figure 70 results questionnaire, conducted with 8 diabetes patients - extended results can be found in appendix 21.

and 6/8 of the patients was looking for somebody who also pro actively deals with his/her diabetes meaning to actively trying to improve and searching for solutions fro problems instead of only listening to the doctor in charge.

The results can be divided into two categories: patients are looking for people with the same diabetes mindset and on the other side patients looking for more general patients that are within the same state of life and life situation, comparable to searching for friends or meeting new people at other occasions in life and sharing experiences.

This fits to the finding within the chapter 2.3 peer contact that if patients would find another peer per incident, within another group they could identify with, for example in the same friend group or studying at the same university, the mindset would not matter that much any more, if they have a personal connection. Furthermore, according to the interviewed experts it is most valuable for reflecting and behavior change, if patients with different mindsets are connected. Tensions and discussions within a group can facilitate new insights about routines and inspiration.

2.4.4 MOMENTS OF CHANGE

During the interview the generated collage for the future dream peer was used to walk through the diabetes timeline of each patient, to find out when patients need / want most support and what moments of transition were difficult for each patient. This was done to be able to map out contact points for the new support tool and targeting patients at the moment they are most open for new connections.

Including new people

Including new people into the support network and openly talk about your diabetes is not easy for every patient. While some patients keep the disease a secret as long as possible, others talk about it the very first time they meet someone. This also depends on the relation to the person that will be included and how close this person already is to the patient. In a poll on the online platform Cyberpoli.nl (see figure 71 and appendix 24) among youngsters with a chronic disease, 43% agreed to inform their classmates about their disease alone, with the help of their parents or with the help of the teacher, 35% would only tell it to their friends within the class and 12% would not tell it at all. This poll is also transferable into a university or work setting, where new colleagues and students or room mates could be integrated into the disease or not.

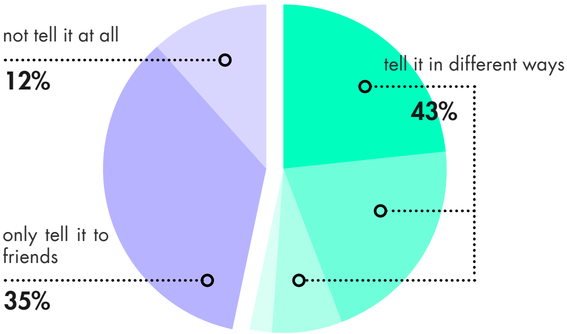


figure 71 questionnaire from platform cyberpoli.nl - how do you tell your classmates about your diabetes?

All of these different reactions demonstrate that every patient has a different mindset and opinion about whether he/she wants to integrate new "strangers" into the disease if the disease is not immediately visible, or prefers to only include the friends or keeps it completely to him/herself. The reasons behind this can both be shame, not making a big deal out of it or as a lot of patients mentioned *"being tired of telling the same story over and over again. So I just wait until people ask me."*

Moments of change within a patient's life

Within the interviews patients stated certain moments within their lives that were crucial within their support network and further development. Those moments always involved a change in one's location or at least moving to another house within the same city and starting a new function and / or involving new people in the support network, marked with red stars within figure 73 on the next page)

Summing up the patient's timelines, the most determining moment in a young diabetes patient's life is the period when he/she leaves the house of the parents to start an apprenticeship or study, moves to another city and lives on his/her own for the first time. (see figure 72)

[redacted] ▸ **Jongvolwassen en diabetes**
Vor 10 Stunden · Bemmel ·

Hiiiii lieve mensen!
Het is zover, deze Stef stuntpiloot gaat over een paar weken op kamers! Ongeveer 32 m2, ruimte genoeg voor al mijn diabetes rotzooi. Geintje, nu een serieus iets. Hebben jullie wat ervaringen voor mij, van op jezelf wonen? Ik heb wel drie huisgenoten, maar toch voelt het alsof ik alleen ben. Nu woon ik thuis, en mijn ouders en zusje weten bij alles wat ze moeten doen. Ik ben benieuwd naar ervaringen!

👍 1 18 Kommentare

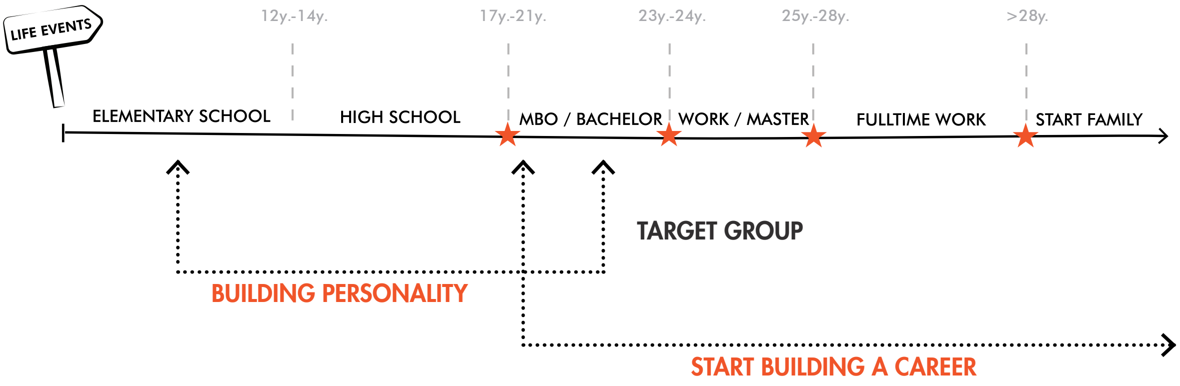
figure 72 patients reporting about their moment of leaving their parent's home

Living alone can be difficult at first, with a lot of new responsibilities, having to care for everything alone and keeping up the structure the parents provided at home. As students tend to have very different daily routines and not take as much time and money for the food a parent's home can provide 3 times a day. The step out of the care of the parents and moving out of the parent's house was a big step for each patient. The gap of not having the parents around any more and *"having no routine any more, nobody who cooks for me, nobody who keeps my meds"* to quote one patient, has to be filled with the patient's own responsibility to take over these tasks. Four out of eight participants agreed that the moment they moved out of their parent's house was the beginning of a chaotic roller coaster period regarding their blood sugars. But also before this point a certain amount of handling the diabetes autonomously and less attachment took place.

On the other side, regarding the support network, new people, who have to be educated to a certain amount, will join the support network. The same happens when someone else leaves the support network or a contact diminishes. The chosen target group is within the most developing life phases with the most changes and developments. Therefore factors such as building the personality, personal development, autonomy and attachment towards the parents, play an important role within the support network. Therefore these moments of change mark moments of an increased need for support, which is difficult to find in a new city in a short amount of time.

★ MOMENTS OF CHANGE IN THE PRIVATE NETWORK

...involve a change of one's location
and / or a change in one's daily life
and / or a change in one's support network.



MAIN RESEARCH INSIGHTS - PEER SUPPORT MOMENTS

The moments of change within a patient's life also represent moments where patient's stated to have an increased need for support and are open to meet new peers and friends. Patients described these moments of change as being difficult regarding their diabetes and they needed some time to find back people that could support them with their diabetes. For some of them it took years before they opened up again or found a new partner they could share everything with as personal relations have to grow again after moving to another place. Patients described that during that time they spend a lot of time searching for information online for example for a suitable doctor within the new location or talking to their online peer friends. Figure 2.3aa shows stereotypical moments of change within peer contact.

★ MOMENTS TO CONNECT TO PEERS

...involve a change of one's location
and / or having to buildup a (new) support network.

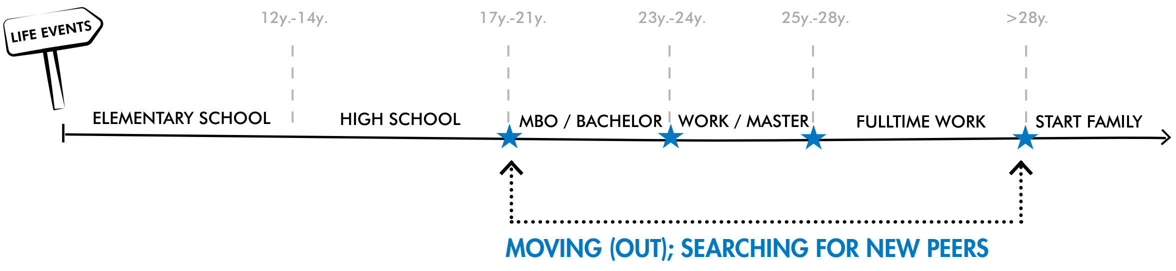


figure 73 - moments of change and enhanced need for support

2.5 KEY FINDINGS & DESIGN OPPORTUNITIES

Both interviews, network participation and market research form the researcher's opinion and interpretations about the support wishes of young diabetes patients. The collected insights within chapter 2 lead to five key insights for the research phase that were validated by the user. These key insights will be taken into account for the functions and goal of the future support platform. After each insight is explained, the potential for the future support tool is mapped out. An overview of all insights can be found within appendix 4.

Clustering the findings

Looking back at the main research question posed in chapter 1.3 *„What kind of support do T1D patients, aged 18 - 30 years, want and need and how can Roche help to strengthen and extend their support network?"* , this question can be separated into the same 4 parts as within chapter 1.4, when the current support networks were analyzed (see figure 74).

As the key findings are supposed to help answering these questions within the future support tool, each finding corresponds to one or more of the 4 named topics:

Trigger - *Who is interested in such support and what could be the trigger to join this network?*
Connection - *Why do patients feel connected to each other and how can these factors be enhanced?*
Topics - *What topics are patients interested in? Where do they benefit from?*
Facilitate - *How should the network facilitate the contact and should the network offer additional services?*

By clustering the insights into these topics, they can also serve as design requirements within the next chapter.

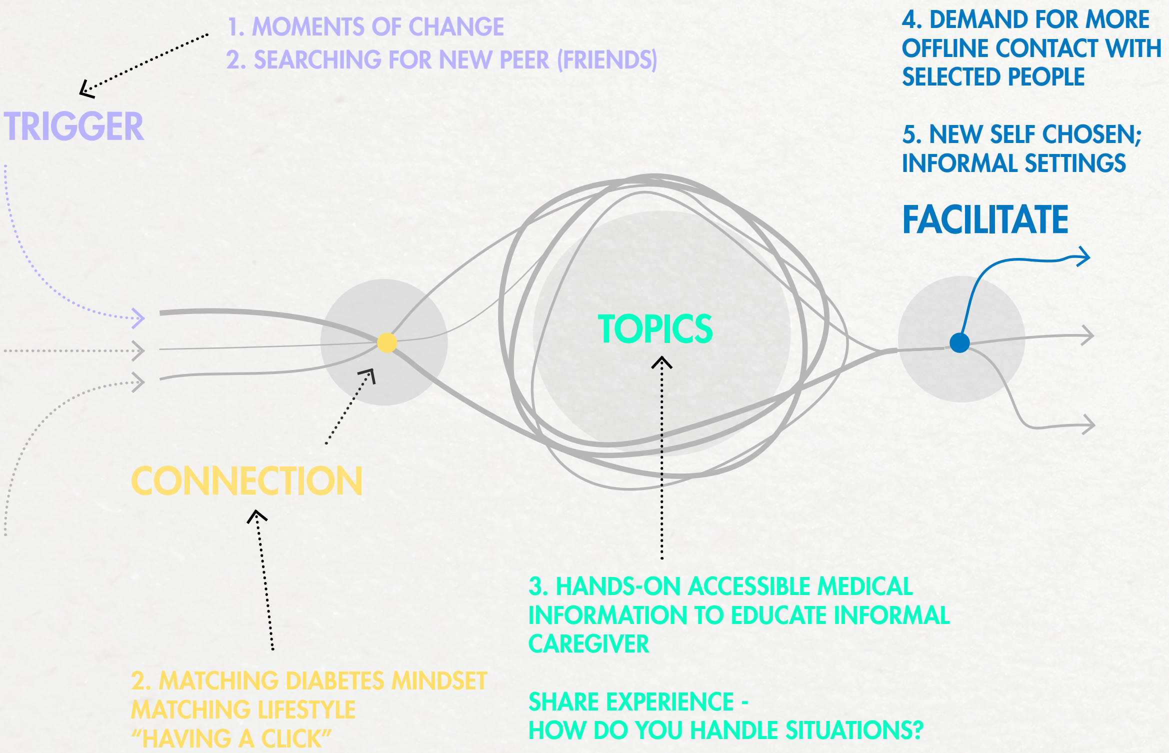


figure 74 questions around the future support tool

1

TRIGGER - PATIENTS HAVE AN INCREASED NEED FOR SUPPORT WITHIN THE "MOMENTS OF CHANGE"

- patients named multiple moments when their amount of support increases by changing location, new support stakeholders enter their network or their daily life changes

- these moments provide insecurity and new orientation within the life of a patient, they need to find new friends, a new doctor, new daily life / routines

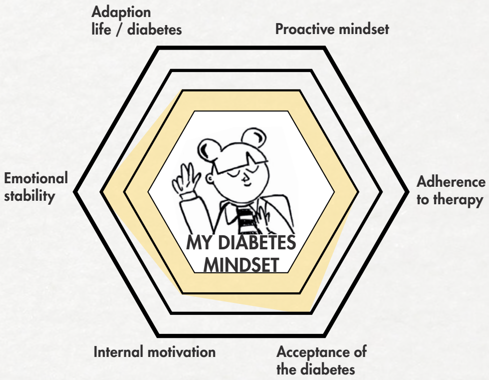
- moments of change provide new chances of building up a new support system but also having to integrate new people and reacting to changes within the old support system

figure 75 starting to study in a different city

Regarding potential to reach a lot of diabetes patients, the new support tool can take the important dates for students and young people into account and provide information / contact points within the facilities these moments include, for example use the national student enol platform "Studielink" or the target the universities themselves (see figure 75).

2

TRIGGER & CONNECTION - SEARCHING FOR PEERS THAT MATCH A PATIENT'S DIABETES MINDSET AND LIFESTYLE



- existing networks only facilitate according to age and disease and the mindset displayed online is often perceived as too negative by the patients, if a patient does not share the mindset displayed online, the desired recognition effect does not take place

- each patient has a personal diabetes mindset is and the poll (see chapter 2.4.3) showed that patients are searching for someone with a mindset that fits them

- the diabetes mindset of a patient is shaped by his/her normal personality (big 5 personality test), how the patient copes with the disease and the motivation behind it (see figure 76)

- users furthermore connect with others in the same situation within life e.g. also studying and somebody they are having a click with

- each patient is, dependent on his/her mindset, looking for a different other peer - three roles have been detected 1. friend, 2. role model, 3. antipole

- further tests have to determine the relation between a patient's personality and diabetes mindset and if the six developed factors are fitting for this test

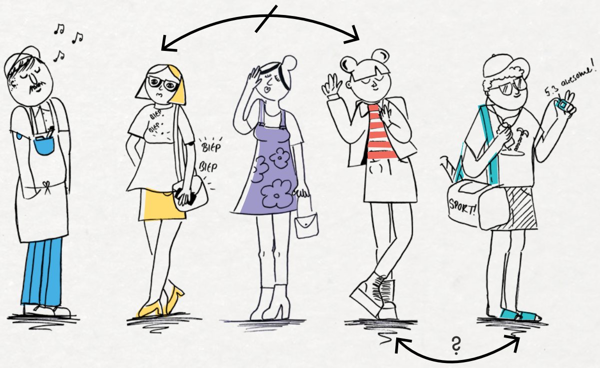


figure 76 starting to study in a different city

Having a matching lifestyle, having a click and a matching mindset is also what attracts people within normal life, the people they become friends with. The new support platform could therefore aim to facilitate new peers that also fit on a personal level and develop new friendships. The tool should therefore detect a patient's own mindset, see what this patient is looking for and what could provide the click / contact point for users.

3

TOPICS - PROVIDE MEDICAL KNOWLEDGE TO INFORMAL CARE GIVER; USE PATIENT#S EXPERIENCE AS KNOWLEDGE SOURCE

- support by informal care giver is most valuable because of the daily contact with the patients and as they know the patient's daily routine

- education if often gained by experience or by asking the patient directly, no external help to educate; informal caregiver therefore only have one source of information - their "own" patient and the internet, where information is not facilitated or clustered

figure 77 provide specific practical information by patients for patients and informal care giver

- to be able to provide most valuable support "preventive care" (see model in chapter 2.3.3), informal care giver need to gain the medical knowledge to understand the cause of the diabetes related effects and help the patient to better adhere to his/her therapy

- informal caregiver do not have their own network so far, they mingle between the patients and have to process the diabetes specific information (see appendix 25)

- within the current support networks, patients highly appreciate content created from other patients, as it is more "reliable, honest and accessible". Therefore the new platform should also try to integrate patients and informal care giver as content owner and / or focus on topics the company is an expert in (see figure 77).

Research has shown that informal caregiver play a very important role, yet they are not specifically targeted by the existing support networks. Information is often tailored for patients themselves and informal caregivers do not know what might be important for "their" patient. Informal care givers and patients should be able to gain inspiration by looking at hands-on examples from other patients instead of scientific knowledge.

SUMMARY - HOW TO SUPPORT A PATIENT

The future support tool should try to enhance these support do's and dont's that were collected within the expert and patient interviews. The table in appendix 26 and the learning book in appendix 4 provide further support insights:

- **putting emphasis on the autonomy of a patient and letting them explain his/her choices instead of confronting the patient with advice and failure**

- **find out why and how a patient already changed other things in his/her life and what is the patient's change potential**

- **Don't comment on blood sugar levels or health habits before asking the patient - this can cause a feeling of guilt and shame**

- **try to bring back the things that went good when talking about times past and remember them instead of the bad things**

- **try to analyze what causes the problem very specifically / personalized, to be able to diminish or avoid the reasons why the patient acts this way**

4

FACILITATE - OFFLINE CONTACT & SUPPORT HELPS PATIENTS IMPLEMENT CHANGES AND COPE WITH THE DISEASE IN DAILY SITUATIONS

- the limitations of online peer contact, to not be able to detect daily routines and patterns as patients stay anonymous, can be downscaled by meeting peers offline - see figure 78

- online help is based on patients recognizing problems and acting appropriately - if the recognition effect fails, patients are not interested in helping each other - this effect can be turned around when meeting offline - by using group dynamics and personal contact

- patients expressed the wish for more offline contact with matching peers within their proximity, who know their life circumstances and background

- predefined diabetes events have the image of being only for the "good diabetics" - no recognition among the participants - patients want to identify with the meeting and have control about the setting - participants

- patients want to know beforehand who they are going to meet to see if they can have an advantage from this conversation

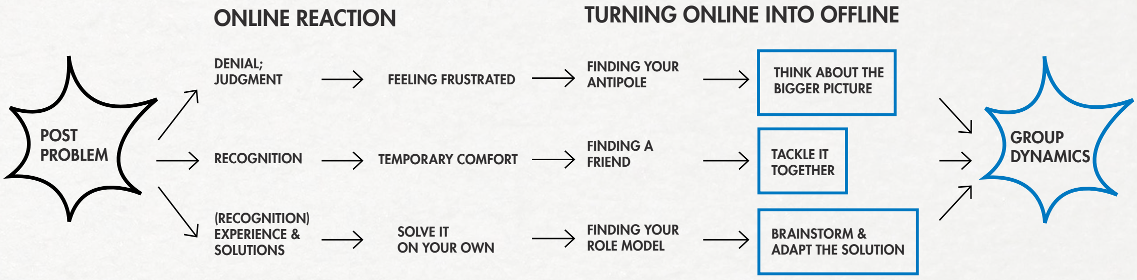


figure 78 turning online into offline - advantages of the different roles

Offline contact will result in discussing with peers instead of only posting a text without knowing the person behind it online. Through offline facilitation, patients within the different roles can contribute helping the problems and derive a benefit from the dynamics within a group discussion.

5

FACILITATE - MEETINGS IN PATIENT'S PREFERRED SETTING

figure 79 meeting for a drink with the What's App group "Suikerklontjes" within a relaxed beer garden

- Predefined events and settings, where people connect because of the diabetes are too linked to the disease and often evoke negative feelings

- Recognition and participation should be based on other more positive things, like sharing the same hobby or going to the same school

- Meetings should have more advantages than just talking about one's disease, like friendship, doing fun things, following mutual hobbies

- Meetings should be setup by the patients themselves to be able to fit their criteria (see figure 79)

- Frequency and means of contact should be determined by the patient himself and adjust to the patient's regular contact habits.

How the support stakeholders will be contacted, how often and where the users will meet up depends on the users individual preferences. Common communication tools outside of the platform make it easier to integrate advice into a patient's everyday life and implement it.

3.

CONCEPTUALIZATION

This chapter is moving from the analysis into the idea generation phase. Within two company intern idea creation workshops, the 5 personas introduced within chapter 2.2 were combined with special support moments identified within the analysis in chapter 2.4.4. The employees of the company were triggered to come up with feasible concepts tailored for the personas.

These ideas were then clustered according to their overlap and formed three concept directions. Within these concept directions, the ideas were clustered again according to the list of requirements to form the final concept. Within several ideation rounds, the concept was evaluated and validated within a final user test.

The final concept "MATCH!" is a platform for T1D patients, that facilitates contact between patients based on their personal preferences regarding diabetes and personality. This mindset will help patients finding new peers just like friends, connect on a personal level and meet up with them offline in their desired setting.

3.1 DESIGNER'S VISION

This chapter provides the designer's personal view on the analyzed results context as a patient and interaction designer and points out the most promising design insights. As this chapter focuses on the subjective opinion and is not based on objective facts, it will be written in the first person.

Thinking back about the original research question *„What kind of (peer) support do T1D patients want and need and how can the new tool help to strengthen and extend their support network ?"* and looking at the 5 key insights within chapter 2.5, it became clear to me that all interviewed patients had very different support needs, deeply related to their situation in life and own diabetes mindset. So far, these needs are mostly served within big online groups, where different patients with different mindsets are supporting each other. All of the interviewed patients were a member of these groups, but five of the eight did not actively use the online help to pose questions or provide support. The reason for this was the tone of the posts within these networks, that was perceived as *"too nagging, too much suffering with the diabetes and taking it all too hard, instead of just being like: OK I have this and it is part of me. But it's not what defines me."* to sum up the patient's statements.

The biggest advantage of peer support, recognition and having enough medical inside knowledge, does not work, if the users cannot relate regarding importance, impact and severity of a problem. The style of diabetes self management is highly interwoven with a person's daily life and dependent on a person's character. People, who perceive this disease as being very severe and limiting are already served within these online groups.

Patient's, who seem to have a more relaxed mindset about diabetes feel out of place within the current groups and support tools. Everyone was interested in more peer support, but only with people that share their mindset and lifestyle. Connecting based on the diabetes works, as mentioned earlier, when meeting someone per incident within daily life, but not when connecting to peers online, here more specific diabetes related factors influence the contact and support efficiency (see figure 80). Therefore, the second insight, to facilitate contact between patients based on their mindset seems the most promising design insight as this principle is not done yet.

The third insight, the need to educate informal care giver with specific, targeted knowledge that is clustered for each patient's situation, therefore seems like a logical extension of the fact that patient's do not have a sufficient peer support network. As the patients often do not know offline peers that fit their criteria, informal care giver provide most support and are confronted with problems they often cannot help to solve. Offline peers can provide this missing link.

Context opportunities
When combining this insight with three other insights: to use the moments of change, to facilitate more offline contact and to leave the choice for the setting and communication mean over to the patient, it becomes clear that every patient has his/her personal preferences not only who to talk to but also where, how and when. Picking out people on one's own preferences and getting in contact with them the way you want and meeting them at places you like, are the exact same things that play when searching for new friends. Most people connect because of a common interest, a common place they visit or something they experience together that serves as an ice breaker. After the first contact is made, the character, contact opportunities and the will to invest time will decide about whether people become friends or not.

Within this chapter I want to explore how patients can find new peers like friends that happen to also have diabetes and fit their mindset, to be able to talk about the same types of problems. Following the assumption that if friends are trying to help, patients are more likely to listen to them than reading online advice from unknown peers.

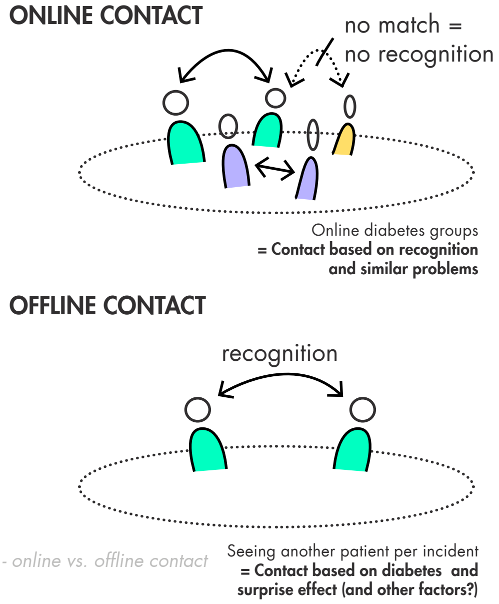


figure 80 - online vs. offline contact

3.2 REVISED DESIGN GOAL & INTERACTION VISION

Revised Design Goal
The findings from the analysis phase, the context of a digital platform and the designer's vision are the origin for this revised, more specific new design goal. The ideas and concepts generated within this chapter will be evaluated according to this design goal.

The main objective of this design goal is the process to find new (peer) friends that will connect to a patient's character and diabetes mindset. As diabetes self-care is very much dependent on a patient's personality (see chapter 2.2), other factors can also provide recognition among patients. The same as friends don't have to handle situations the same way and can also connect based on other factors such as listening to the same music or visiting the same places. The diabetes will be used as an incubator to connect people, the personal preferences of a patient will steer the search and the support tool helps facilitating the offline surprise effect when ,for example, peers find each other at school. Therefore I want to combine the advantages of online help, to easily find other and the offline surprise effect of finding people within the same location and connecting because of other influences such as visiting the same place, going to the same school or doing the same sports (see figure 81)

The final design goal is therefore

> *"Design a support tool that uses the mindset of T1D patients to facilitate contact between peers, in order to increase the support efficiency and provide support within a patient's daily life."*

Interaction vision
The interaction vision for the future support tool will accomplish the presented design goal. This vision is used to display the envisioned interaction qualities of the future service. Figure 82 shows the picture of the film premiere, where an older actress spots a younger singer wearing the same dress expresses all characteristics of the future interaction - at first surprising ("Huh, she/he also made the same choice / also has diabetes"), yet familiar and engaging. Using that one random thing they have in common as a conversation opener and turn strangers that would normally not talk to each other into a match.

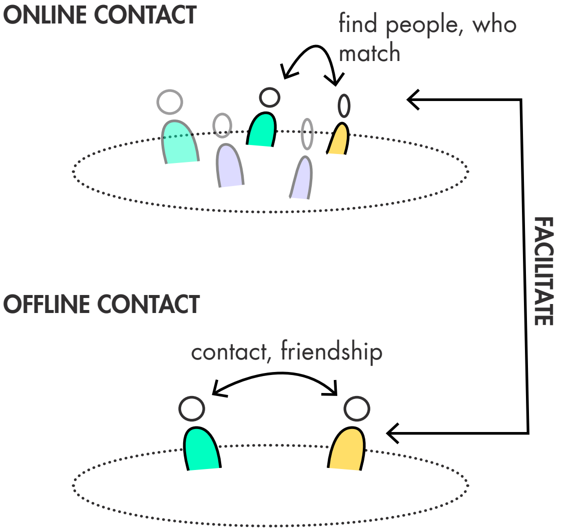


figure 81 pointing out the invisible to create a connection between random people

figure 82 pointing out the invisible to create a connection between random people

3.3 DESIGN GUIDELINES

To be able to translate the design vision into a service and user experience, the five key insights are split up and reformulated into a total of fourteen guidelines. These guidelines are used to evaluate the design ideas on their overlap regarding the most relevant research findings and help to evaluate the final design. The guidelines together cover the targeted user experiences within the context of patient contact.

The original starting point and personal goal of this project is to develop a tool that helps to strengthen and extend a patient's support network. To find out what support patients are looking for and how peer contact can support a patient in handling the disease was the springboard of all research activities. Therefore, most guidelines origin from the facilitation process and which provides the most beneficial contact and information for patients, the guidelines are clustered into the five categories of the key findings plus the longterm support impact (see figure 83). These guidelines are used to develop three concepts from the ideas of the workshop presented on the next page.

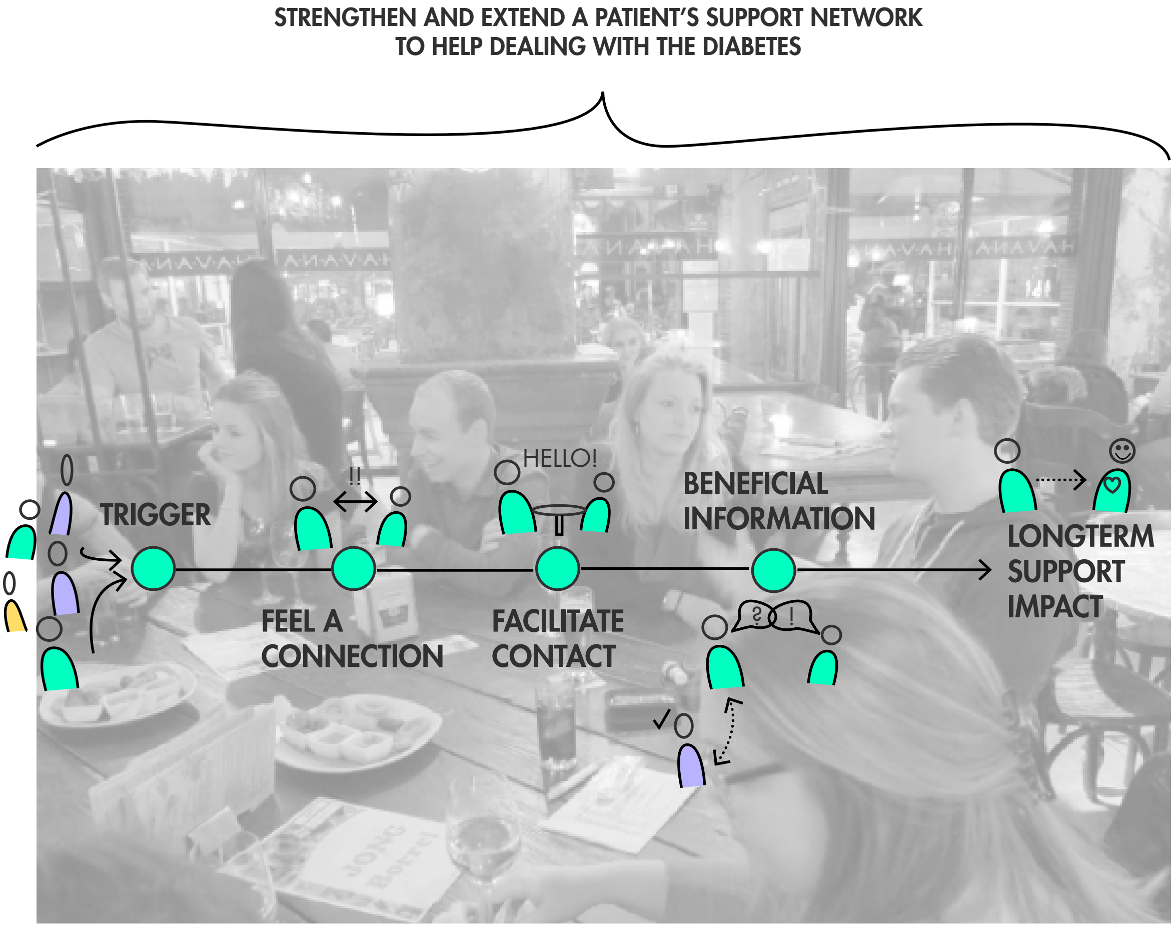
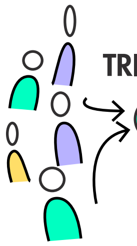


figure 83 guidelines clustered according to the facilitation process and longterm support impact

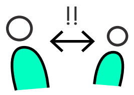


TRIGGER

NEW MEMBER
The concept should trigger / address patients that are not actively online yet into the network by providing a clear advantage

TARGET MOMENTS
The concept should help patients to deal with the moments of change and offer information / support

UNIQUE ADVANTAGE
The concept should have a clear distinction from existing networks by targeting a different, new form of contact

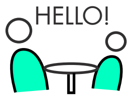


FEEL A CONNECTION

MINDSET AS CONNECTOR
The concept should make it possible to steer the connection with new peers according to a patient's mindset and personal preferences

DISPLAY MINDSET
The concept should make it possible to display a patient's mindset, to be able to see if this person fits the patient's contact preferences

CONNECT TO THE RIGHT PEERS
The concept should make it possible for patients to filter their search according to their own wishes

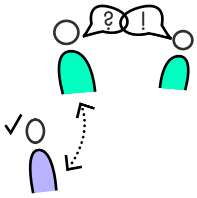


FACILITATE CONTACT

CONTACT PREFERENCES
The concept should enable patients to contact other peers according to their own contact preferences regarding communication mean, location and frequency

ENHANCE OFFLINE CONTACT
The concept should make enhance offline contact between patients by enabling them to provide and use location based data of other patients

ENHANCE BENEFICIAL CONTACT
The concept should enhance beneficial contacts in order to improve a patient's integration and dealing process



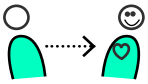
BENEFICIAL INFORMATION

RELIABLE CONTENT SOURCES
the concept should only provide own content that shows the expertise of the company within this field, otherwise other experts and patients should use a mediator to provide reliable content

TAILORED CONTENT
The concept should make it possible to tailor content according to a patient's own wishes and situation

HANDS-ON PRACTICAL ADVICE
The concept should provide content that is implementable within the patient's daily situations

INCREASE DIABETES EDUCATION
The concept should provide inspiration and solutions for daily "offline" problems and include the support network in the problems, in increase therapy adherence and provide qualitative better help



LONGTERM SUPPORT IMPACT

STRENGHTEN SUPPORT NETWORK & CREATE NEW FRIENDSHIPS
The concept should enable longterm - outside of the network - contact and possible new friendships to become part of the patient's future support network

figure 84 employees looking at the persona characteristics

3.4 IDEA GENERATION WORKSHOP

As one of the personal goals for this project was to develop a feasible concept that also reflects the ideas of the company, the ideation phase was kicked off by two company intern idea generation workshops. This was done to spread the knowledge of the project within the whole department and get feedback. After presenting the results of the analysis phase, the employees got creative within multiple small exercises.

A total of twelve employees, including marketeers, manager, customer service and sales person were present for the analysis presentation. To make the analysis results more accessible and deepen the knowledge of the employees, the personas were presented through an extended characteristics poster (see figure 84). By giving a detailed explanation of the mindset of a potential user and a moment where this user stands in life, the main support research question was a divided into:

1. How does the current support network of this persona looks like?

2. What is his/her biggest challenge with the diabetes - where does he/she need support?

After the employees familiarized themselves with the persona and their characteristics, the personas were combined with the examined moments of change of chapter 2.4.4, to think about the question:

3. What is going to change for this persona within this new situations?

4. What places / people is this persona going to meet within this new situation?

By triggering the co-workers to think about places this persona is going to and connecting the persona to situations the employees had once experienced themselves (for example moving out of their parents house, starting to study), they could empathize with the personas, even though they don't have diabetes.

The personas were combined with a moment of change according to their age, their personality and who of them would experience most changes within this period. The specific support moments are displayed on the following page in figure 85.

PERSONAS AT THEIR PERSONAL MOMENT OF CHANGE:

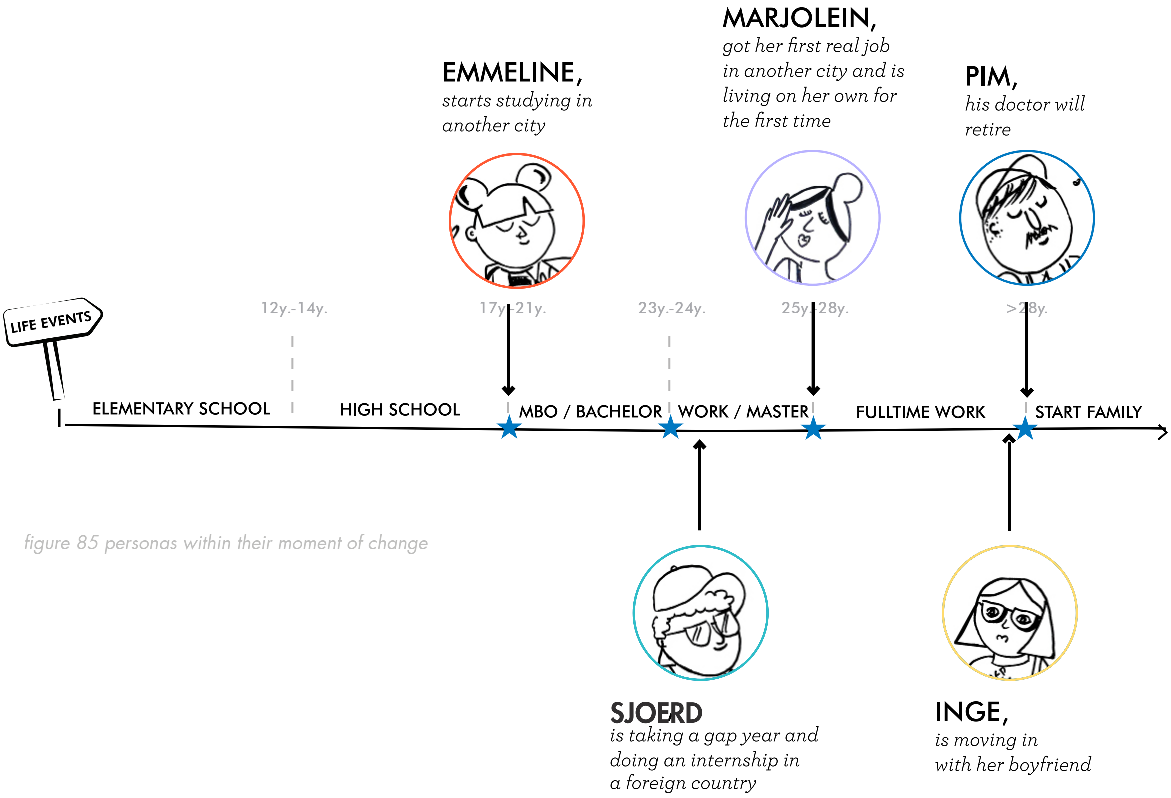


figure 85 personas within their moment of change

After the employees put themselves into the persona's shoes, two activities were done to capture the support ideas:

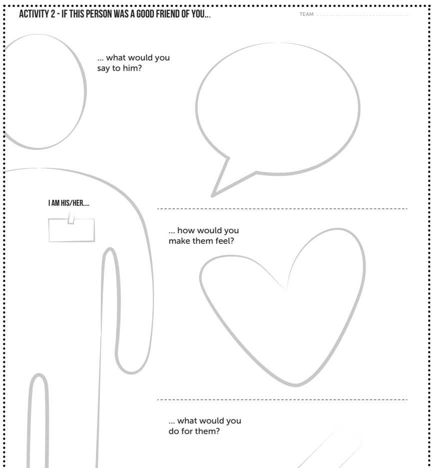
Activity 1 - *How would you support this persona if it was a friend of you? (see figure 86)*

This activity triggered the empathy of the employees and put them into the position of this persona's personal support network

Activity 2 - *What support could Roche provide this persona in this situation? (see figure 87)*

This activity directly targeted the company's resources and how they could be used to help this persona in this situation. Each activity was done for every persona and situation, the ideas were captured on the sheets and afterwards transferred to post-its. After the workshop, the post-its were clustered according to the most overlap regarding mindset and how adjustable the idea was to the different mindset. The ideas were then fulfilled with additional ideas from brainstormings with patients. Three concept directions evolved from this workshop. These directions will be evaluated further within chapter 3.5.

The brainstormings from this workshop and clustering steps can be found in appendix 27.


ACTIVITY 2 - IF THIS PERSON WAS A GOOD FRIEND OF YOU...

TEAM

... what would you say to him?

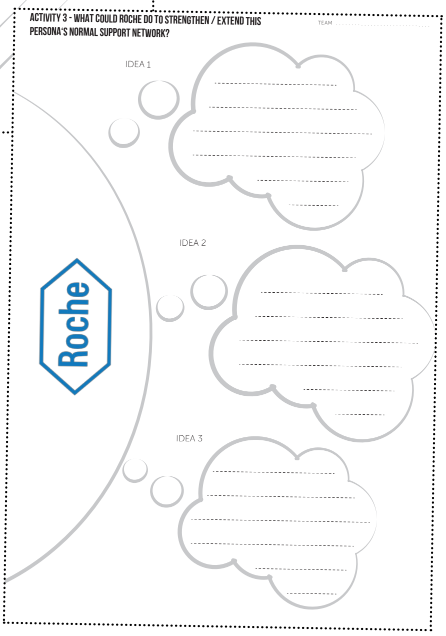
I AM HIS/HER...

... how would you make them feel?

... what would you do for them?

figure 86 activity1 - supporting a friend

figure 87 activity 2 - support from the company


ACTIVITY 3 - WHAT COULD ROCHE DO TO STRENGTHEN / EXTEND THIS PERSONA'S NORMAL SUPPORT NETWORK?

TEAM

IDEA 1

IDEA 2

IDEA 3

3.5 IDEATION

The ideation phase marks the transition from the research- into the design process and shows different ways of translating the design goal and analysis insights into the context of patient support. All persona ideas from the idea creation workshop were first combined and clustered. Afterwards the most overlapping ideas, that also fit the guidelines presented in 3.3, were combined into three design directions. An example of each direction is illustrated and briefly explained.

5 key insights and corresponding design opportunities were presented within chapter 2.5 (see page 70-73 for more details).

1. Use the moments of change to provide support and information
2. Use a patient's mindset and personal preferences to facilitate contact and / or information
3. Involve informal care giver and inform them about the small-scale medical details of diabetes
4. Focus on small - scale peer contact, to increase the support efficiency within daily life
5. Include the support tool into a patient's contact and communication preferences

Within the designer's vision for the future support tool, the focus was mainly put on the fact that patients are specifically searching for other peers that correspond with their mindset and use the information / support these peers will provide. Therefore all three directions revolve around a patient's mindset (2.), combined with other insights.

②+④ *“Diabetes tinder” - use the mindset to filter peers and find friends that match*

The lack of recognition of the displayed mindset within the online groups is the main reason, the interviewed patients are not actively using the support tools. As diabetes is such a highly personalized disease and every patient handles situations and life differently, patients should be enabled to search for other peers that exactly match their criteria (see figure 88.

The concept of having a diabetes tinder - where patients can fill in who / what they are looking for and then find matches to be able to connect to each other's lifestyle and problems each peer is struggling with, also serves the principle of searching for new friends. If a patient gets the possibility to pick out peers that he/she feels a connection with, the step to include this peer into the short list of support stakeholders.

One requirement for this concept is to find out what patients are looking for and narrow down the results, but not display people as objects within a catalogue and / or still enable making contact based on things outside the mindset.

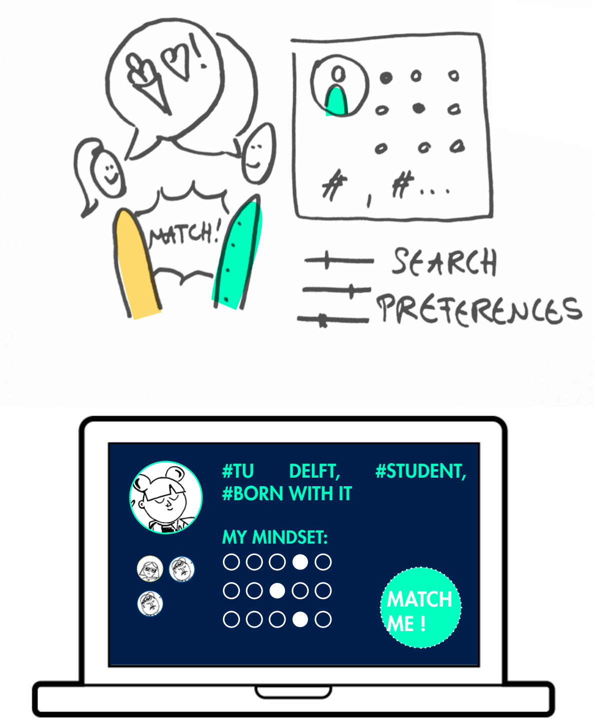


figure 88 idea direction 1

2 + 3 *“Diabetes Pinterest” - collect stories that match and educate others according to a mindset*

Diabetes is a complex disease that takes a long time to fully understand and relate back to daily situations and influences on the blood sugar level. Patients stated that friends and partners would often ask them about diabetes related information they saw online and do not see diversity between patients or understand the impact on a patient’s life.

To facilitate this process, the ideas within this concept include the patient and / or the support giver creating a profile and updating it with relevant diabetes information and tips and tricks. The T3Ds around the patient should be integrated into the therapy and fed with relevant information the patient will preselect.

Displaying the patient’s mindset through the stories that are provided can also help to take away stereotypes from new support givers. Whenever new people will enter the network, the tool can be shared and learn together (see figure 89).

A downside with this idea is that a lot of patients stated to not want to invest so much time in the diabetes itself and the main contact person within this concept are the patient and his/her informal caregiver - not the peers.

figure 89 idea direction 2

2 + 1 + 5 *“Mindset Google” - search and provide information based on a mindset*

During the interviews patients often stated to not want to read about stories and problems they cannot identify with and are missing practical, problem-focused inspiration for daily situations. As every patient has his/her own spectrum of experience and stories, this concept focuses on facilitating the provided stories according to different filters such as location (e.g. providing information to the menu of a restaurant) or per hash tag (e.g. finding everything about how to count carbohydrates in a restaurant) and to leave notes during daily life situations and locations.

This concept could also help patients within the moments of change, when everything is new within a city and / or if patients need to help each other out and can find other patients around them (see figure 90). A point of criticism within this contact is the lack of constant contact between peers to improve longterm support.

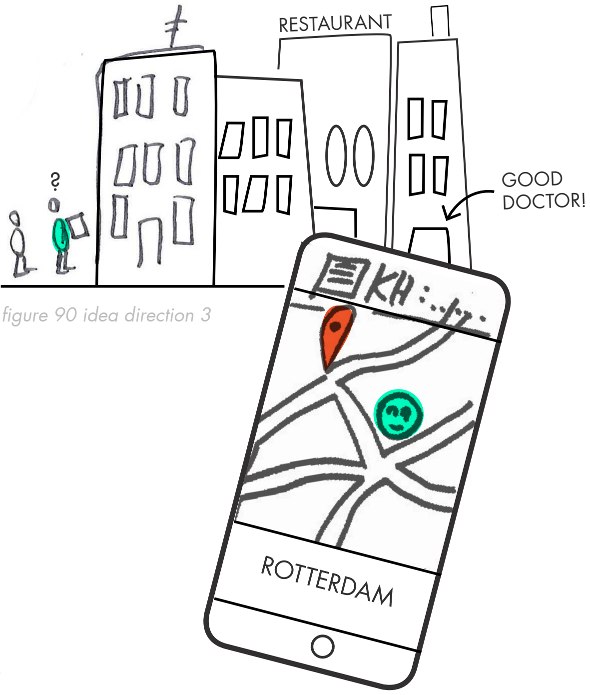


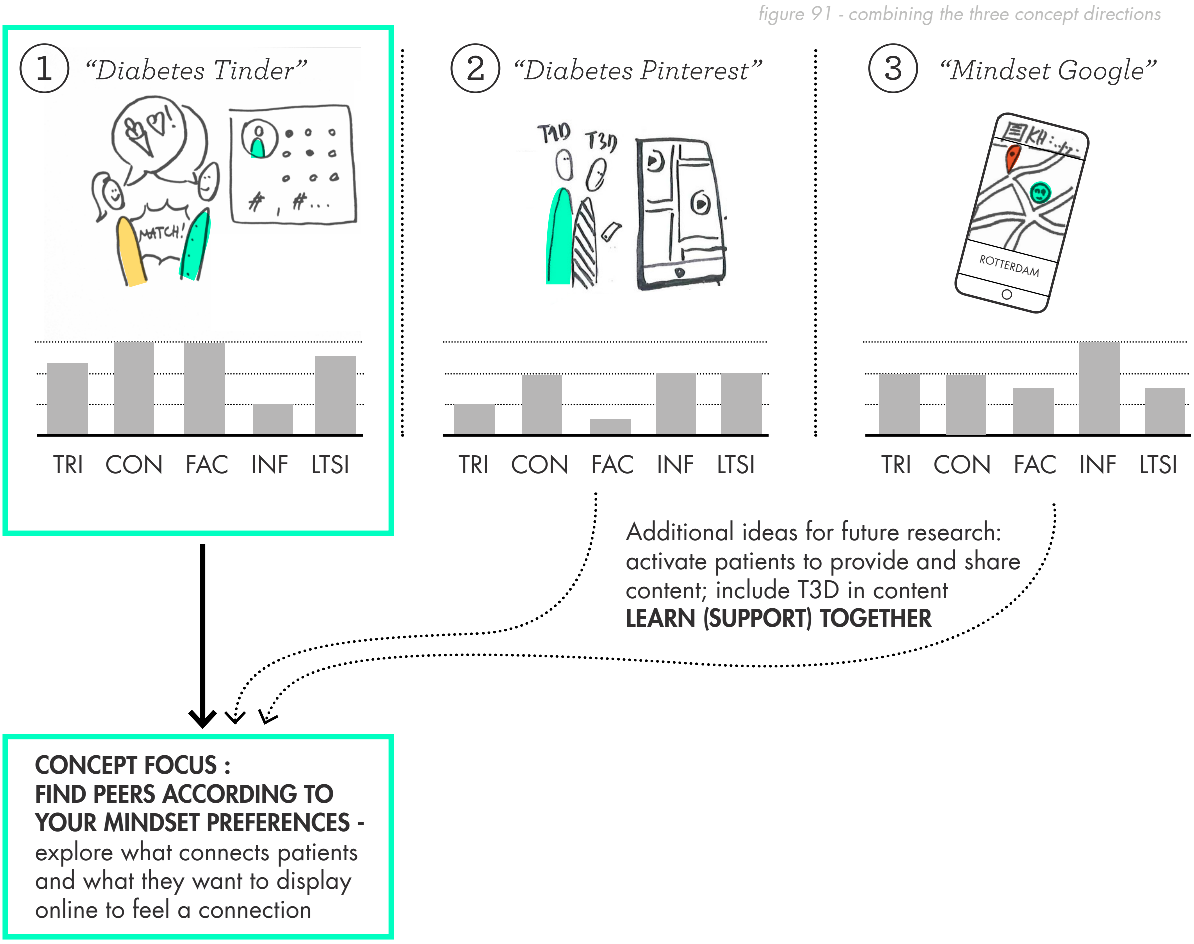
figure 90 idea direction 3

3.6 CHOOSING A CONCEPT DIRECTION

The three directions are compared on the basis of the guidelines presented within chapter 3.3 (see page 79): Trigger (TRI), Feel a Connection (CON), Facilitate Contact (FAC), Beneficial Information (BEIN), Longterm Impact Support (LTSI), patient feedback and the designer's own evaluation. The directions were first discussed with the internship coordinators and the final choice was confirmed by the positive feedback within another brainstorm session with diabetes patients.

After looking at all the ideas within the concept, it became clear that one direction did not cover the whole process the platform would involve - trigger, connection, contact, information and longterm effect. Therefore, one direction was chosen to focus on and evaluate and parts of the other directions would be included within the recommendations and for further research after the project has ended (see figure 91).

figure 91 - combining the three concept directions



Additional ideas for future research: activate patients to provide and share content; include T3D in content
LEARN (SUPPORT) TOGETHER

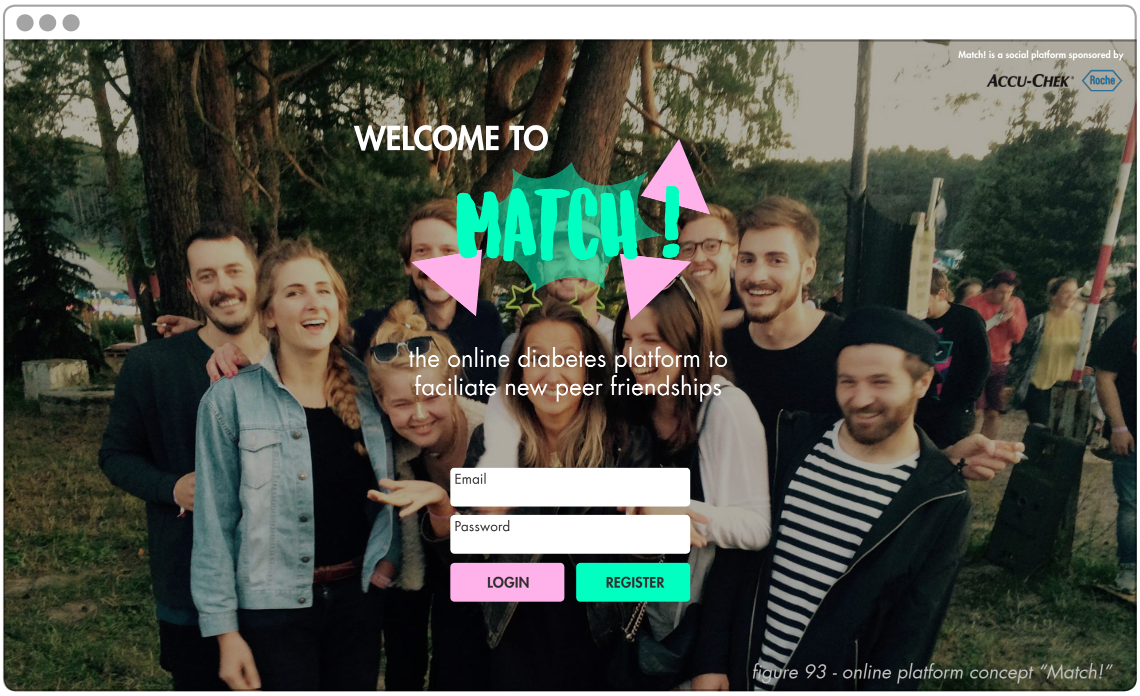
CONCEPT FOCUS :
FIND PEERS ACCORDING TO YOUR MINDSET PREFERENCES -
explore what connects patients and what they want to display online to feel a connection

Figure 92 on the right page shows the clustering of all used ideas into the 5 steps displayed in chapter 3.3:

1. Trigger patients to create a mindset profile
2. Facilitate the contact and match function
3. Trigger patients to meet up offline and / or stay in contact as they wish
4. Provide content that is useful for both patients and their private support network and share experiences
5. Longterm support effect

To be able to stay within the time and contentual limit of this project, the iterations of the concept will focus on steps 1,2 and 3. Step 4 and 5 will be included into the recommendations for future development within chapter 5. Therefore the guidelines regarding "beneficial information" will not be used to rate the concept within the concept reflection in chapter 5.1.

figure 92 - clustering all chosen ideas into the final concept


Match! is a social platform sponsored by

WELCOME TO MATCH!

the online diabetes platform to faciliate new peer friendships

figure 93 - online platform concept "Match!"

3.7 MATCH!, THE PLATFORM TO FACILITATE NEW PEER FRIENDSHIP

Based on the selected concept direction (page 84) the concept "Match!" is developed. The online platform aims to facilitate peer contact according to the patient's preferences - see storyboard in figure 94.

Display mindset
The platform helps patients to find other peers that they can connect to regarding their diabetes and possibly become friends outside of the platform, to be able to integrate more peers into their close support network. To help displaying a patient's mindset and find matching peers, patients create an online (diabetes) profile, figure 93 gives an indication of how this new platform could look like. By sharing insights of a patients offline (diabetes) life, hobbies or other details, it becomes easier for patients to see whether a peer could be interesting to get in contact with and take away the anonymity and lack of background knowledge of the other online networks. What patients want to share within this platform will be explored within the future iteration steps.

Peer search
Some of the information within the profile will be testable or comparable to be able to search for peers that match and / or filter the search. As it will be new to patients to be able to specifically find other peers, the search preferences and search scenarios will have to be explored. This will be done within the iteration steps, whether this is diabetes specific or more general, for example demographic data like age, location.

Offline contact
During the brainstormings with diabetes patients and also during the patient interviews, the wish to find other peers within a patient's proximity often offured. Therefore the concept will specifically explore the possibilities to find other peers within the same city / work / sports club or according to other sports preferences. This third part will also intervene with the main function of the platform to display your "mindset" online and possibly connect this mindset to offline activities and include these places within the search for other patients.

The main functions of the concept, that will be evaluated within the future iteration steps, are:

① **show your (diabetes) mindset online**

② **find matching peer based on personal preferences**

③ **facilitate offline contact by searching for contact points (locations, people etc.)**

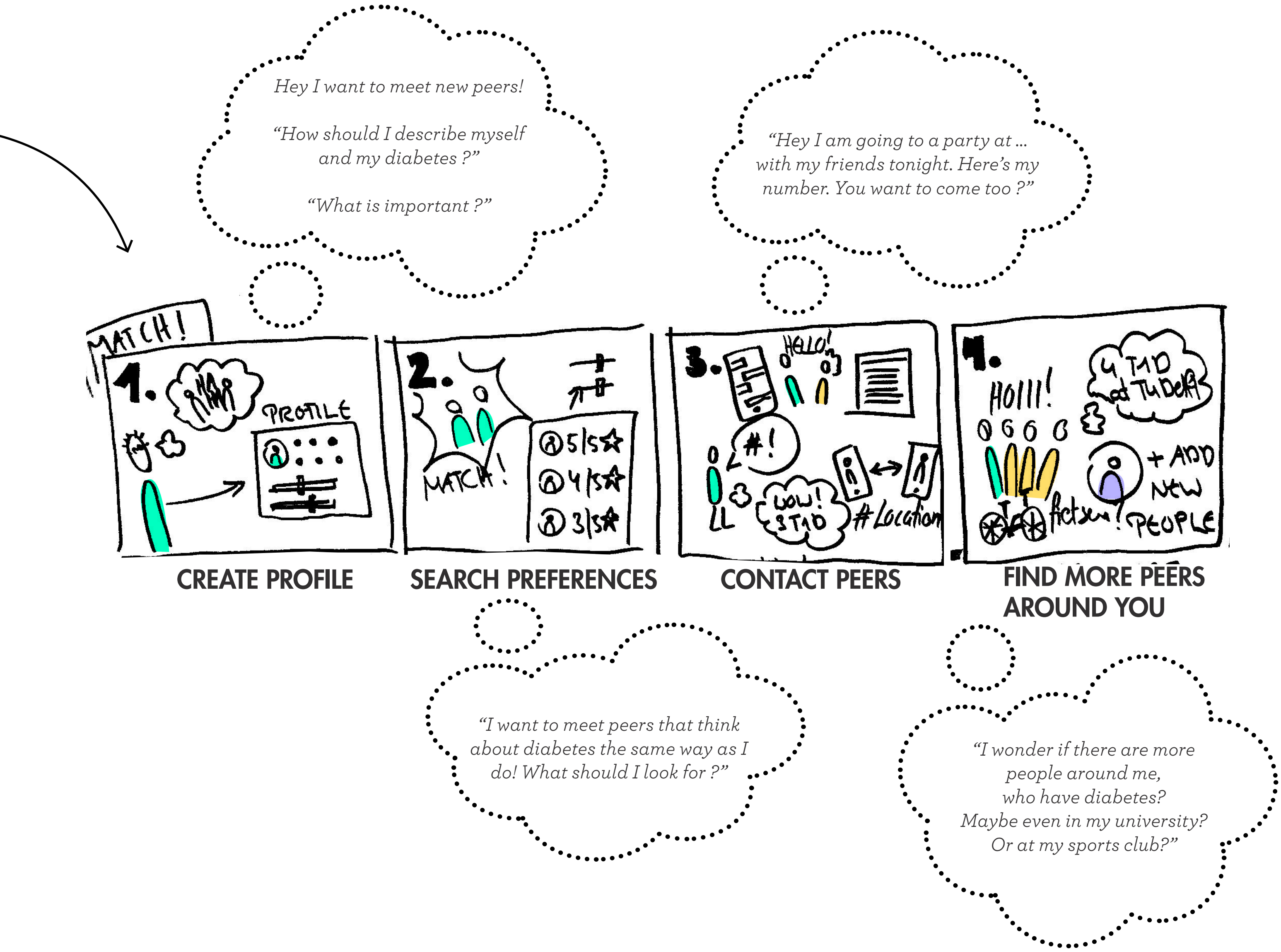


figure 94 - concept scenario "Match!"

4.

DESIGN ITERATIONS & EVALUATION

The developed service focuses on four different aspects: sharing data, the mindset test, how to match and what patients want to read within other profiles. Three iterations of different extent are accomplished to develop the chosen concept direction and translate the design goal and interaction vision into the final concept of a patient platform. A total of 15 different diabetes patients took part in the three iteration rounds.

Each iteration focuses on the interaction between the patients themselves and the patients and the platform and the experience towards the matching function and getting in contact with other peers. Within different questionnaires and short patient interviews, the patients were asked for their feedback on the concept, different styles of mindset tests and the profiles.

This phase will elaborate on the created questionnaires, the accomplished user tests and the developments made to optimize Match! into the final design. At the end of each iteration round an evaluation will sum up the findings and changes within the service.

4.1 What to iterate on?

4.2 First Iteration Round

4.3 Second Iteration Round

4.4 Final Iteration Round

4.5 Concept Evaluation

4.6 User Scenario

4.7 Service Details

4.1 WHAT TO ITERATE ON ?

How do people display their mindset online? Is a mindset measurable? How do people know whether somebody matches their mindset? To answer these questions, an online research on different social platforms on how people display their mindset online and how someone's personality and mindset can be tested brought inspiration before starting off with the iterations. An additional literature research shed light on the psychological principles of becoming friends. These three areas form the room for iterations (see figure 95)

4 FIELDS TO IDEATE ON:

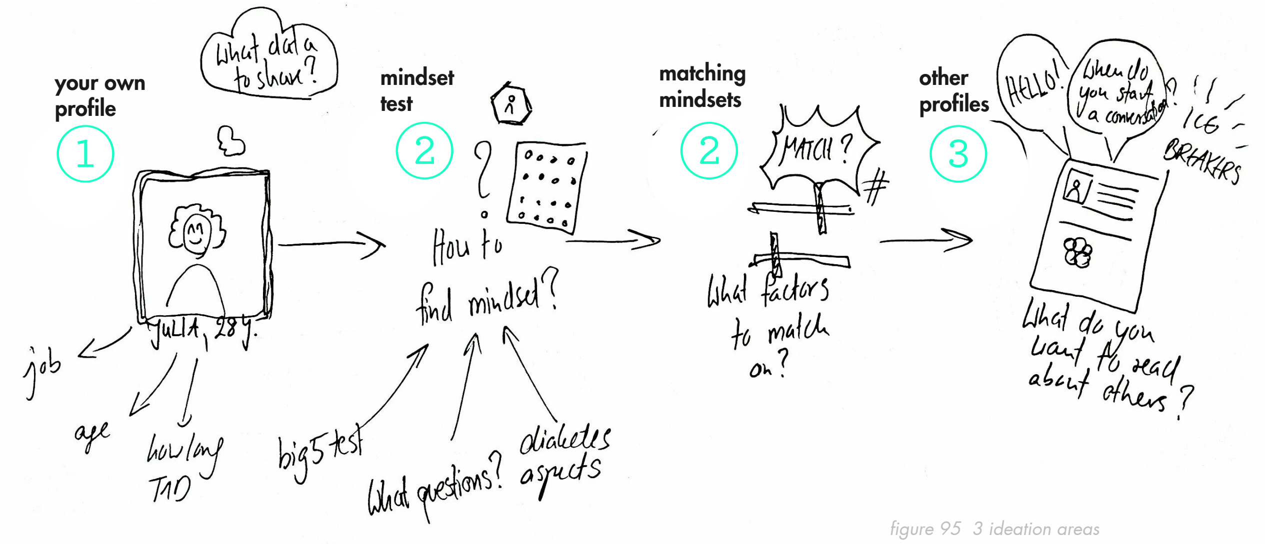


figure 95 3 ideation areas

HOW DO PEOPLE DISPLAY THEIR MINDSET ONLINE?
Four big social media platforms were analyzed to get an overview of how people convey personality traits online to match a user's desired self-presentation (see Counts, S., & Stecher, K. B. (2009, March) and appendix 30) The self-concept can be categorized according to William, J. (1890) into the material (i.e., physical), social (i.e., social and occupational roles) and spiritual self (i.e., perceived abilities). The networks let user display themselves through all of these three categories whereas the "material" part can be seen through the photos user post online - see figure 96.

Within their paper "Self-presentation of personality during online profile creation", Counts S. and Stecher, K. examine what types and attributes contribute most to creating a profile that represents personality traits. As a general conclusion, descriptive items like the photo and about me statement along with other more free-form items like quotes, movies and books had the most impact on personality trait ratings. Therefore, next to the mindset test, the patients should have the possibility to fill in these fields to have a feeling of accurately displaying their personality online.

On the next page the different possibilities to fill in a profile are summarized.

figure 96 - concept scenario "Match!"

Looking at current online networks, the following parts of a profile and means can be summarized:

① **signalment with basic (demographic) data**

② **pictures and videos for personal preferences**

③ **likes and hashtags for personal preferences**

④ **open text questions for personal preferences**

⑤ **links to other networks for extended personal preferences**

⑥ **friends in the network to confirm identity information (Donath & boyd, 2004) and providing social context (boyd, 2006),**

⑦ **status updates to display current mood / actions**

⑧ **testimonials of things and places**

HOW CAN YOU TEST A MINDSET / PERSONALITY?

The two personality tests that are mainly used within research, as mentioned earlier on page 44, the five factor model of personality and the Myer Briggs Type Indicator test. As a patient's diabetes mindset is widely dependent on a patient's personality, these tests could be combined with certain diabetes specific questions. Both tests use different forms of questionings such as "How much do you agree with the statement...?" "How...would you describe yourself?" and questions about how participants would react in certain situations as metaphors for underlying factors that are tested.

WHY DO PEOPLE BECOME FRIENDS ONLINE?

Anagnostopoulos, A., Kumar, R., & Mahdian, M. (2008, August) point out two influences that are important for the correlation within the future social networks:

① **Homophily,** which means that individuals often befriend others who are similar to them, and hence perform similar actions. Sias, P. M., & Cahill, D. J. (1998) confirm this within their study that coworkers move from acquaintance to friend based on "perceived similarity" - the feeling that the other one has the same values, ideas and taste within things in life.

only photos and videos + hashtags

figure 96 - photo feed on social media platform instagram

Therefore next to matching patients based on their diabetes mindset, other influences as taste within music, hobbies and personal preferences can be used to match people.

② **Confounding factors / external influence,** where external factors are correlated both with the event that two individuals become friends and also with their actions. e.g. people living in the city, visiting the same place, therefore having the same interest.

Considering these factors within the future network, the location of people should also be included to make it possible to find the people around them. Looking back at the analyzed social network, another factor adds to homophily based on taste - having common friends. As said before, this can provide social context (Boyd, 2006) and help skipping the first contact barrier. Within the following iteration rounds, finding out how people "break the ice" to contact someone based on his/her profile will be included. Will having diabetes be enough or do people need another conversation starter?

MAIN RESEARCH INSIGHT - MINDSET

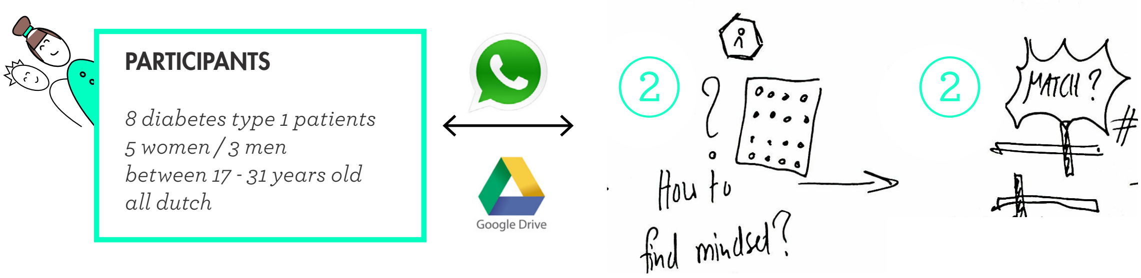
To sum it up, the future network can test the diabetes mindset with the help of a personality test, a person's interest / hobbies can provide an additional connection (homophily) and help participants displaying their preferred picture of themselves online. Combined with a patient's demographic data such as hometown, age and for example employer as confounding factors, these factors can help starting a conversation with other patients. Now that I know the existing possibilities, I want to iterate on what real patients want to fill in online, what questions about diabetes they prefer and what they are interested to see on other people's profile.

4.2 FIRST ITERATION ROUND

After being inspired by other online platforms, I started exploring the real patient's opinion about diabetes mindset tests. What kind of aspects need to be tested to have a full picture of a patient's mindset? How do patients want to display their mindset online? This iteration round focuses on the mindset test part and how to match people and is separated in two parts. The round is divided into two parts that both led to the development of the first graphical prototype of the platform.

USER RESEARCH

A total of 8 people were recruited from the 2 diabetes What's App groups I participate in: "Suikerklontjes" with diabetes patients all over the Netherlands and "Diabetes Type 1@TU Delft" and formed a new What's App test group with them. This way I was able to reach a lot of participants who live quite far away from each other and the open "group" setting simulated the feeling of being in a sort of group online - like the platform.


PARTICIPANTS

8 diabetes type 1 patients
5 women / 3 men
between 17 - 31 years old
all dutch

PART 1 - INTRODUCTION

As an introduction I posted three basic questions about the topic mindset. The goal was to have people start a discussion about these questions, the same as people posting things online within the platform and get to know each other:

① *What is a diabetes mindset?*
6/8 patients correctly described what a diabetes mindset is although with different interpretations about the extent of a mindset. **The word mindset therefore has to be explained within the platform to make people understand what is going to be tested.**

② *What do you want to know of somebody's diabetes mindset?*
The answers differed regarding content and profundity and can be categorized into three topics:

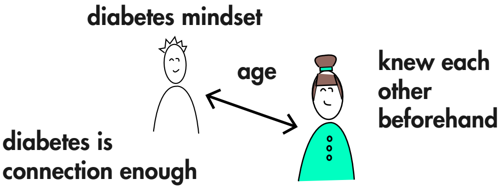
1. basic (demographic) data - how long do you have T1D, what do you do in your daily life?

2. diabetes data - HBA1C, measurable scores

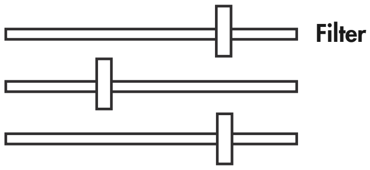
3. psychological data - dealing with diabetes everyday and positive / negative experiences

As the answers differed so much, the questions within the test should be adaptable and / or be able to be skipped, when patients are not interested in the data they would create. **SKIP**

③ *Did you ever make new friends through your diabetes and why did you have a click?*
Answers to this question can be summarized to 4 types of connections people felt:



Patients all have different demands regarding their match, this finding corresponds with the paper of Anagnostopoulos, A., Kumar, R., & Mahdian, M. (2008, August) that people connect based on homophily and external influences and the mentioned "surprise effect" when patients find each other offline within chapter 3.1. **Some user will search for more specific people within the platform while others might just browse profiles and look for more basic similarities. The search settings within the platform should therefore be able to be adjusted.**



PART 2 - QUESTIONNAIRE

Afterwards the participants took part in an online Google drive questionnaire that tested three different styles of mindset - tests. Each test involved 6 questions that were based on the 6 factors that were determined within chapter 2.2.2 (see figure 97)

Based on the researched assumption that the style of a patient's diabetes management is directly influenced by a patient's personality, the questions did not directly asked about these particular 6 factors; but were concluded back to other situations and metaphors that aimed to test the same aspect. E.g. internal motivation was being tested by asking about other unpleasant things that require motivation in a patient's life, like doing the taxes (see figure 98).

CONCEPT 1 - Two extreme procedures within a situation were described and participants only had two choices to choose from.

CONCEPT 2 - "How much do you agree with the following statement?" - participants had 5 graduations to choose between "totally not agree" and "totally agree".

CONCEPT 3 - Abstract - which photo describes your choices / your personality the best?

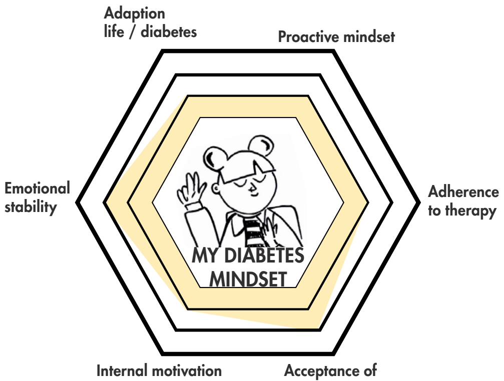


figure 97 - concept scenario "Match!"

**not testable
instead tested: factor extravert from big 5 personality test**

CONCEPT 2 WAS CHOSEN BY THE PARTICIPANTS TO BE THE BEST TO MATCH ON WITH THE MOST NUANCES TO CHOOSE FROM

Suikerklontjes
Anne, +31 6 14244632, +31 6 15854121, ...

en iedereen bedankt voor het meedoen. 👍 18:40

+31 6 57934865 ~Ton groot roessink
Wat houden de concepten in waar ik mijn mening over moet geven? 18:46

Dat zijn de vragen die je moet beantwoorden. 18:49

Alle concepten hebben een verschillende style van vragen 18:50

+31 6 37560559 ~Ilss💕
Gaat het nou over de vragen zelf of over hoe je de manier van vragen vind? 😅 19:52

+31 6 16724286 ~Rik Schoeman
Allebei toch? 19:53

+31 6 37560559 ~Ilss💕
Ik heb het ingevuld 19:59

Diabetes type 1 @ TU
Pierternella, Pim, Yvonne, linde, +31 6 105...

ok dit is de form. eindelijk klaar met de test haha. 18:39

Match! online user test
Hellooo! bedankt dat je wil meedoen aan mijn mini user test. Zoals je misschien w...
docs.google.com
https://goo.gl/forms/U3wWewQRcsjqUPuk2 18:39

jullie mogen hem invullen en ik zegdan welke richting is gekozen en wat jullie erva vinden. 18:39

en het is maar een klein voortestje. niet het eigenlijke ding. 18:40

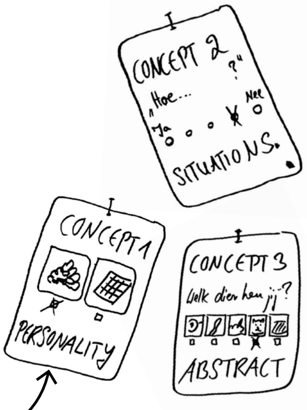
en bedankt dat jullie mee doen :) 18:41

linde
Ik heb hem ingevuld! Hoop dat je er wat aan hebt 19:18

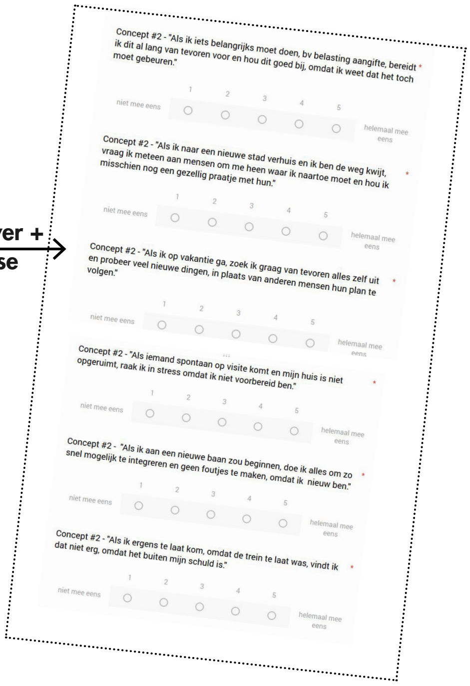
Thanks :) 19:41

GOOGLE DRIVE - QUESTIONNAIRE

FEEDBACK VIA WHAT'S APP



answer + choose



Concept #2 - "Als ik iets belangrijks moet doen, bv belasting aangifte, bereidt ik dit al lang van tevoren voor en hou dit goed bij, omdat ik weet dat het toch moet gebeuren." *

niet mee eens 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ helemaal mee eens

Concept #2 - "Als ik naar een nieuwe stad verhuis en ik ben de weg kwijt, vraag ik meteen aan mensen om me heen waar ik naartoe moet en hou ik misschien nog een gezellig praatje met hun." *

niet mee eens 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ helemaal mee eens

Concept #2 - "Als ik op vakantie ga, zoek ik graag van tevoren alles zelf uit en probeer veel nieuwe dingen, in plaats van anderen mensen hun plan te volgen." *

niet mee eens 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ helemaal mee eens

Concept #2 - "Als iemand spontaan op visite komt en mijn huis is niet opgeruimt, raak ik in stress omdat ik niet voorbereid ben." *

niet mee eens 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ helemaal mee eens

Concept #2 - "Als ik aan een nieuwe baan zou beginnen, doe ik alles om zo snel mogelijk te integreren en geen foutjes te maken, omdat ik nieuw ben." *

niet mee eens 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ helemaal mee eens

Concept #2 - "Als ik ergens te laat kom, omdat de trein te laat was, vindt ik dat niet erg, omdat het buiten mijn schuld is." *

niet mee eens 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ helemaal mee eens

figure 98 concept 2 was chosen as preferred question option

PART 3 - THE PLATFORM LAYOUT

After they had answered the questionnaire, one concept was chosen and I included this style of questions in a (non working) digital prototype, to test the content and layout. Then I posted three screenshots within the What's App group to hear about the patient's opinion about their choice. (see figure 99)

A complete overview of the procedure, the questions and results is given within appendix 28.

RESEARCH INSIGHTS

Connecting the 6 aspects to other situations

The answers within the aspects emotional stability, internal motivation and adaption gave a realistic picture of the participant's answers. The other three factors: acceptance, proactive and adherence were too difficult to find suitable situations as they are very unique to the diabetes management. Patients furthermore stated that they understood the aspects these questions were aiming, for but were still missing some "hands-on" diabetes questions like "How much effort do you put in your diabetes?" "How big is the role of diabetes in your life?"

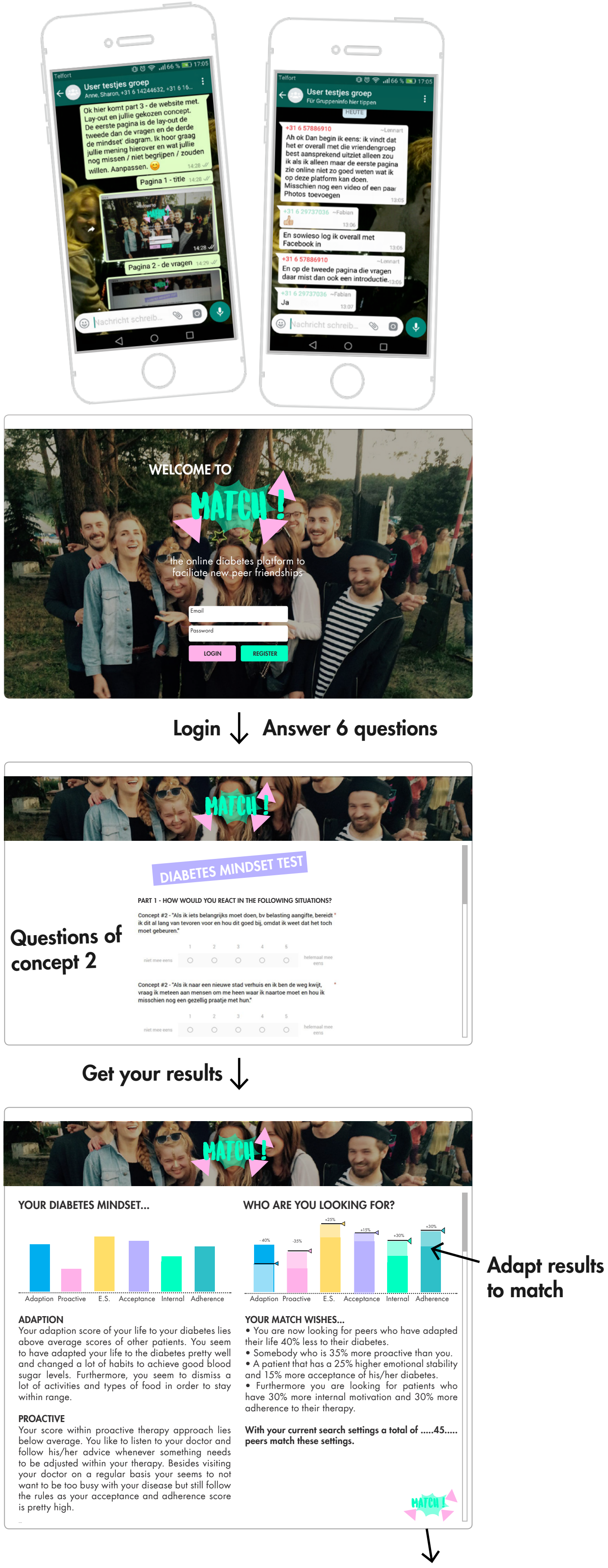
The test has shown that the assumption to be able to cover all aspects of the mindset by turning them into situations cannot be done for all influences and a diabetes mindset is broader than the six found aspects. The test is still lacking some general question about the diabetes, what role diabetes plays in a patient's life and how big this role is and needs to be extended.

Mindset Test

The patients choose concept 2 - situation questions with 5 nuances between "totally agree" and "do not agree" as being the most accurate to fill in as it had the most nuances to choose from (although an even number would be better to avoid neutral answers). They enjoyed thinking about the diabetes in a more abstract way, but were concerned that this way they could not find the correct match they wanted. The concept that was perceived as being the most fun to fill in was concept 3. These questions are not matchable as every participant interpreted the pictures differently. Still, as filling in your profile should also be a pleasant activity and the interaction vision includes the quality "being pleasantly surprised", they can be used as ice breakers to display within a profile as a conversation opener.

Match Function

The patients stated that additionally to the mindset test they would like to know the age and location of a person, an idea was to be able to fill in the profile of the person you want to match with and more focused questions to be able to find a more accurate match within the given answers.



Ok hier komt part 3 - de website met. Lay-out en jullie gekozen concept. De eerste pagina is de lay-out de tweede dan de vragen en de derde de mindset' diagram. Ik hoor graag jullie mening hierover en wat jullie nog missen / niet begrijpen / zouden willen. Aanpassen. 😊 14:28

Pagina 1 - title 14:28

Pagina 2 - de vragen 14:29

+31 6 57886910 ~Lennart
Ah ok Dan begin ik eens: ik vindt dat het er overall met die vriendengroep best aansprekend uitziet alleen zou ik als ik alleen maar de eerste pagina zie online niet zo goed weten wat ik op deze platform kan doen. Misschien nog een video of een paar Photos toevoegen 13:05

+31 6 29737036 ~Fabian
👍 13:06

En sowieso log ik overall met Facebook in 13:06

+31 6 57886910 ~Lennart
En op de tweede pagina die vragen daar mist dan ook een introductie. 13:06

+31 6 29737036 ~Fabian
Ja 13:07

the online diabetes platform to faciliate new peer friendships

DIABETES MINDSET TEST

PART 1 - HOW WOULD YOU REACT IN THE FOLLOWING SITUATIONS?

Concept #2 - "Als ik iets belangrijks moet doen, bv belasting aangifte, bereidt ik dit al lang van tevoren voor en hou dit goed bij, omdat ik weet dat het toch moet gebeuren." *

Concept #2 - "Als ik naar een nieuwe stad verhuis en ik ben de weg kwijt, vraag ik meteen aan mensen om me heen waar ik naartoe moet en hou ik misschien nog een gezellig praatje met hun." *

YOUR DIABETES MINDSET...

WHO ARE YOU LOOKING FOR?

ADAPTION
Your adaption score of your life to your diabetes lies above average scores of other patients. You seem to have adapted your life to the diabetes pretty well and changed a lot of habits to achieve good blood sugar levels. Furthermore, you seem to dismiss a lot of activities and types of food in order to stay within range.

PROACTIVE
Your score within proactive therapy approach lies below average. You like to listen to your doctor and follow his/her advice whenever something needs to be adjusted within your therapy. Besides visiting your doctor on a regular basis your seems to not want to be too busy with your disease but still follow the rules as your acceptance and adherence score is pretty high.

...

YOUR MATCH WISHES...
- You are now looking for peers who have adapted their life 40% less to their diabetes.
- Somebody who is 35% more proactive than you.
- A patient that has a 25% higher emotional stability and 15% more acceptance of his/her diabetes.
- Furthermore you are looking for patients who have 30% more internal motivation and 30% more adherence to their therapy.

With your current search settings a total of .....45..... peers match these settings.

figure 99 - what's layout test of three screens

MATCH !

FEEDBACK FROM PARTICIPANTS

The positive feedback was that the website looks inviting and friendly. The picture of the friend group displayed the image of searching for new friendships, without being too much of a dating website.

The function of the website was generally understood, still the patients stated that without the explanation of the mindset beforehand and the abstract questions they would be not quite sure of the goal of the website, therefore the front page needs to provide a clear explanation or a preview of what is going to happen before creating an account.

Most comments were made regarding the mindset display. The bar graph was experienced as being "too serious" - too much like a test. Patients worried whether people with a negative mindset would be so happy about seeing their exact scores. The future mindset should be somehow more "vague" in displaying the scores but more clear about what the scores mean, what they refer to.

All in all, patients reacted very positive on the basic idea of the concept but were concerned about it being "too serious". The final concept should be more fun and have a more social, engaging approach to find new friends rather than only relying on scientific matches. Within appendix 32, the most important quotes out of the What's App group are linked to the different parts of the website.

> *"I don't understand the factors within the diagram in relation with the questions I just answered. So I don't know what they mean and how I scored. Then if I should adjust them for the person I am searching for I just don't know who I am looking for?"*
>
> **feedback of the mindset diagram**

MINDSET MATCH - QUALITIES AND LIMITATIONS

This iteration round targeted the 4 of the 6 connection and contact guidelines. Therefore it will only be evaluated within these.

MINDSET AS CONNECTOR
The concept makes it possible to change the search preferences according to personal wishes; still the displayed 6 factors are not clear and therefore it is not clear who patients should search for

DISPLAY MINDSET
The concept displays 6 aspects of a patient's mindset. This is not enough and has to be fulfilled with personal interests, more demographic data and other diabetes related information

CONNECT TO THE RIGHT PEERS
The effect is not achieved yet as patients do not know what kind of peer they are searching for as the mindset factors are not clear

ENHANCE BENEFICIAL CONTACT
The mindset can be changed according to a patient's wishes and patients can search for their "role model" - the part where patients actually contact each other has not been tested yet

DESIGN RECOMMENDATION

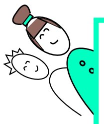
- explain the word diabetes mindset on platform
- include demographic data (confounding factors)
- include other interests to match on to make the platform about friendship (homophily)
- make it able to skip questions and adjust search settings for mindset
- more direct diabetes questions to provide more nuances within a user's mindset
- display results in a friendlier, more positive way to avoid patients "judging" each other
- make the mindset accessible for other users - provide contact points to talk about - "funny facts" of question concept 3 as conversation starters

4.3 SECOND ITERATION ROUND

The second iteration round focuses on the other part of the concept - what do patients want to display within the profile and how much details do they want to share ? What is important within other profiles to reach your goal? When do patients feel a connection when reading another peer's profile and contact the other peer? To answer these questions I let the participant fill in their own profile and rate other profiles I sent them.

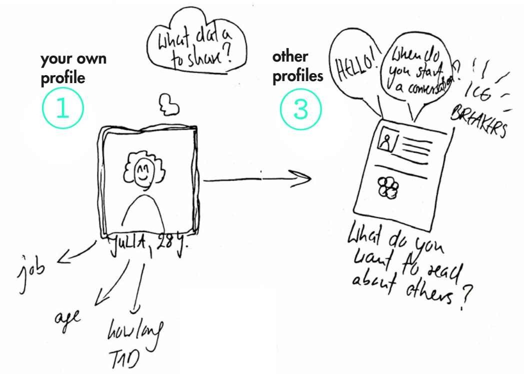
USER RESEARCH

Six of the eight people from the previous round participated during this second round. Again, they participated via whatsapp and filled in an online profile I send them. After collecting the forms I evaluated them into three quick graphical concepts I posted in the group to get some feedback on what the patient's preferences were for the final profile.



PARTICIPANTS

8 diabetes type 1 patients
5 women / 3 men
between 18 - 30 years old
all dutch

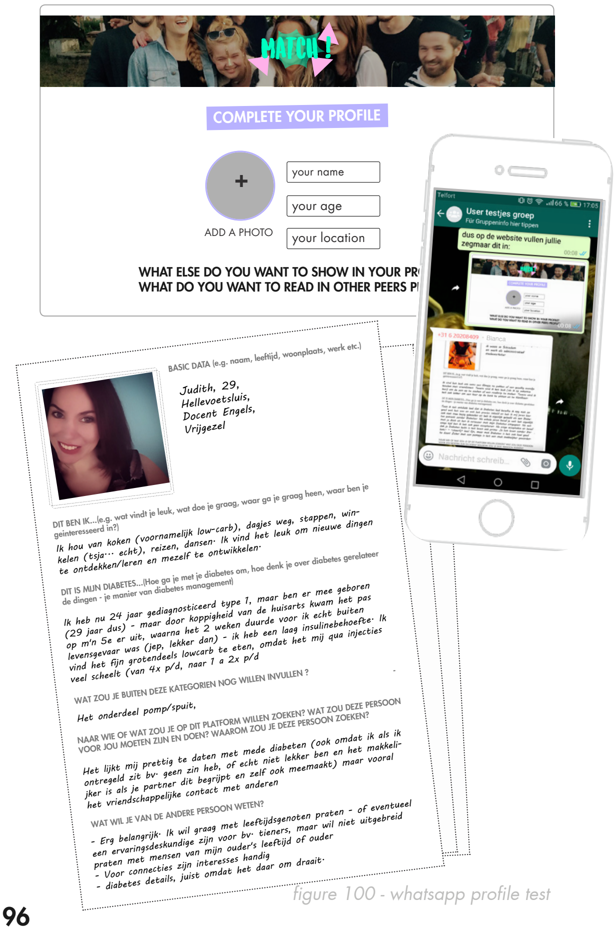


PART 1 - FILL IN YOUR PROFILE

To be able to provide real, realistic profiles within the final concept, I wanted to know from the patients what they would fill in their profile when thinking about the online platform and what they want to read about from others. Therefore I send them a screenshot of the website, where they would fill in these details (see figure 100) and an empty profile with open text questions and asked them to fill in the four sections:

① *basic data*
② *about me*
③ *this is my diabetes*
④ *What do you want to know from the other peers?*

Additionally the participants can fill in things they are missing and how important they rated these three sections. Furthermore, as the questions within the last iteration round were not satisfying for the participants, they could freely state how they would like to fill in their diabetes mindset online. These additional questions and informations the peers provided within these profiled were used within the final iteration round to setup the questions and fill in some profiles as matches.



WHAT ELSE DO YOU WANT TO SHOW IN YOUR PR
WHAT DO YOU WANT TO READ IN OTHER PEERS P

dus op de website vullen jullie zegmaar dit in:

BASIC DATA (e.g. naam, leeftijd, woonplaats, werk etc.)

Judith, 29,
Hellevoetsluis,
Docent Engels,
Vrijgezel

DIT BEN IK...(e.g. wat vindt je leuk, wat doe je graag, waar ga je graag heen, waar ben je geinteresseerd in?)

Ik hou van koken (voornamelijk low-carb), dagjes weg, stappen, winkelen (tsja… echt), reizen, dansen. Ik vind het leuk om nieuwe dingen te ontdekken/leren en mezelf te ontwikkelen.

DIT IS MIJN DIABETES...(Hoe ga je met je diabetes om, hoe denk je over diabetes gerelateerde dingen - je manier van diabetes management)

Ik heb nu 24 jaar gediagnosticeerd type 1, maar ben er mee geboren (29 jaar dus) - maar door koppigheid van de huisarts kwam het pas op m'n 5e er uit, waarna het 2 weken duurde voor ik echt buiten levensgevaar was (jep, lekker dan) - ik heb een laag insulinebehoefte. Ik vind het fijn grotendeels lowcarb te eten, omdat het mij qua injecties veel scheelt (van 4x p/d, naar 1 a 2x p/d

WAT ZOU JE BUITEN DEZE KATEGORIEN NOG WILLEN INVULLEN ?

Het onderdeel pomp/spuit,

NAAR WIE OF WAT ZOU JE OP DIT PLATFORM WILLEN ZOEKEN? WAT ZOU DEZE PERSOON VOOR JOU MOETEN ZIJN EN DOEN? WAAROM ZOU JE DEZE PERSOON ZOEKEN?

Het lijkt mij prettig te daten met mede diabeten (ook omdat ik als ik ontregeld zit bv. geen zin heb, of echt niet lekker ben en het makkelijker is als je partner dit begrijpt en zelf ook meemaakt) maar vooral het vriendschappelijke contact met anderen

WAT WIL JE VAN DE ANDERE PERSOON WETEN?

- Erg belangrijk. Ik wil graag met leeftijdsgenoten praten - of eventueel een ervaringsdeskundige zijn voor bv. tieners, maar wil niet uitgebreid praten met mensen van mijn ouder's leeftijd of ouder
- Voor connecties zijn interesses handig
- diabetes details, juist omdat het daar om draait.

figure 100 - whatsapp profile test

PART 2 - THE PROFILE LAYOUT

After looking at the profiles the participants send back to me, I went over to test possible layouts of the future profile. Should it be more functional or more informal? What is the most easiest profile to start a conversation with? As most participants indicated within their profiles that their diabetes mindset is the most important part within the profile, I developed two small cards with two different layout styles and posted one after another in the group. After each screenshot the participants had the possibility to comment on the layout and indicate the positive and negative point about each section. During this discussion the questions about the lack of hobbies and interests within the profiles came up so in the end I added a third postcard with a layout example about how the interests could be portrayed. The third layout was not compared with the first two as the card was about a different topic (see figure 101).

A complete overview of the procedure, the questions and results is given within appendix 29.

RESEARCH INSIGHTS

Filling in the profile

The three provided categories were fitting and each participant filled in the profile in his/her preferred way and extent. Six of the eight participants provided a profile picture and all of them filled in all four questions. In addition to the given questions the patients would like to know why other peers registered for this platform, who they are looking for and to be able to add more diabetes specific things to match on for example which pump a patient is using or if he/she has additional diseases.

Type of questions

Multiple participants mentioned to prefer partly premade options for different aspects and tick boxes and partly free text questions. This would save a lot of type work and it is easier to fill in or you might see options that you would not have come up with yourself to make the process of creating a profile quicker.

Most important topics

All three categories were rated evenly important with slight differences between patients who preferred the diabetes section and others who preferred the interests section. Therefore these sections should be, as mentioned earlier, adjustable to the amount of data the participant wants to fill in. Same applies for the type of person the participants want to meet up with. Six of the eight participants were focusing on the diabetes details, two were more looking into the hobby section. All of them wanted to know the basic data of their new peer friend. When specifically asked about the basic data, all participants again agreed that age was something that should be displayed very clearly, followed by location.

Nu als tweede deel heb ik even een paar antwoorden in een profiel gezet (wel van een nep persoon) en wil van jullie weten wat jullie van de lay-out style vinden en hoe goed Jullie met zon profiel zouden kunnen herkennen wat voor persoon dit is. 00:22

hier komt de eerste persoon: 00:22

dit is niet het hele profiel - het gaat meer om de informatie en wat voor beeld jullie dan krijgen van deze persoon 00:23

HEY ! I AM ROBIN; I AM 24 YEARS OLD, FROM ROTTERDAM AND I STUDY #ARCHITECTURE AT THE #TU DELFT.

DIABETES IN MY LIFE :

I AM A T1D SINCE ... YEARS, MY HBA1C IS #7.3 - I MEASURE MY BLOOD SUGAR LEVEL 5-7 TIMES A DAY - I USE THE OMNIPOD PUMP FOR MEASURING, PUMP AND DIARY. I COUNT CARBS 70% OF THE TIME. I WOULD NEVER NOT EAT SOMETING BECAUSE OF MY DIABETES. #IT'S JUST A NUMBER.

Layout 1 - functional diabetes
basic data: name, age, location,
education, work
mindset infographic and
diabetes facts

HEY ! I AM ROBIN; I AM 24 YEARS OLD, FROM ROTTERDAM.
I AM A T1D SINCE ... YEARS.

DIABETES IS FOR ME ...

the „best" thing about diabetes... having a legit reason to eat candy in class, haha.

My diabetes is a... *a loyal dog haha. Never leaves you. but then not so nice&cute.*

This is my diabetes kit... *only my omnipod pump that's also my meter and diary. As little things as possible.*

My white knight(s)... *everyone around me knows I have diabetes so they give me dextro when I need it.*

Since the diabetes I... *nothing has changed, I live the same life as before the diagnose.*

I still cannot get used to... *when I am in stress I tend to neglect my diabetes. I am too distracted.*

The most difficult thing for me... *remember to count carbs. I am mostly correct with guessing but sometimes I am totally wrong.*

My doctor knows me for ... *knowing how I should handle things, but still cannot manage 100%.*

Layout 2 - informal diabetes
basic data: name, age, city
diabetes photos, quotes,
personal stories

Layout 3 - additional interests
basic data: name, age, city
education, work
only hobbies, photos, quotes, hashtags

HEY ! I AM ROBIN; I AM 24 YEARS OLD,
I LIVE IN ROTTERDAM AND I STUDY #ARCHITECTURE AT THE #TU DELFT.

Hobbies... *I like to football in the weekend and watch football with my friends.*

Interests...(van fb) *#Drake, #Feyenoord, #NikeSB, #Dumpert, #Rotterdamdansparade, #RestaurantBokaal, #vicemagazine*

In my freetime... *I often go to the beach in summer and to the skihall in the winter. #SCHEVENINGEN*

My last vacation... *adventure vacation in India, super awesome and crazy!*

In the weekends... *I go out with my friends. #BIERGARTEN ROTTERDAM #ANNABEL #BEACH PARTIES*

A random fact about me... *People often tell me I look like JD Unfortunately I am as funny as a piece of bread haha.*

figure 101 3 different layout concepts

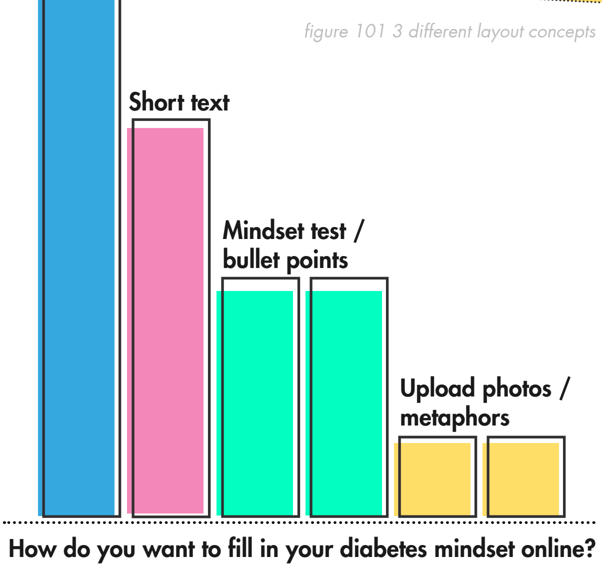


figure 102 - results of participant's mindset questionnaire preferences

Layout preferences

The three introduced layouts reflected the patient's choices within the questionnaire in part 1 - how to fill in your mindset online. Patients preferred to simply answer questions and write a short text about their diabetes. Within the two layouts the decision was not clear between layout 1 and 2. Layout 1 was experienced as very clear, but also a bit cool and not very accessible to send a message to. Layout 2 on the other side was first experienced as very inviting and open. Therefore no clear decision could be made between the two layouts, it seemed to be a question of taste.

Some patients also marked that putting all pictures within a bubble form could be confusing as the profile pictures are also mostly in a circular form and the form cuts away a lot from the picture. Therefore a square form was preferred. Within appendix 33, the most important quotes out of the What's App group are linked to the layouts.

FEEDBACK FROM PATIENTS

When asking about connection between the profile the participants had to fill in and the layout choices, if they would really want to fill in these questions and upload the pictures, most people said they would only want to upload a picture of their diabetes kit. The other metaphors could be interpreted different and seemed difficult to match on. The general feedback was to prefer clear, easy and fast possibilities to fill in the profile but not make it look too formal and cool (see figure 102 on the previous page).

Almost all participants agreed that the open questions of layout 2 should be kept as an option to fill in as they provided easy "conversation starter". Same goes for layout 3. As a voluntary add on these photo / quote / funny fact questions were definitely appreciated as they made the profile less about diabetes only and more about the person itself. Therefore a sort of middle way has to be found for the final profile.

> *"I like to answer these questions and think about my diabetes but I don't know what to write for some things. Maybe if you would see some other profiles and get some inspiration you could fill it in faster and with more details or have some prefilled in questions?"*
>
> **feedback of the profile**

FILL IN PROFILE - QUALITIES AND LIMITATIONS

This iteration round targeted the 5 connection and trigger guidelines. Therefore it will only be evaluated within these.

MINDSET AS CONNECTOR

The profiles let the patient fill in personal preferences very freely within the open type questions, but patients also wished for some guidance and inspiration.

DISPLAY MINDSET

The new spiderweb mindset was preferred as it is a little bit more vague and not as judgmental combined with open text questions and one picture of the diabetes kit.

NEW MEMBER

the patients enjoyed filling in the profiles and typed in very extended answers, still the real attractiveness of the concept can only be tested within the last test round.

TARGET MOMENTS

The concept enables to fill in demographic data such as location and school / work, therefore patients can adjust their search preferences in case they move to a new city or start a new job.

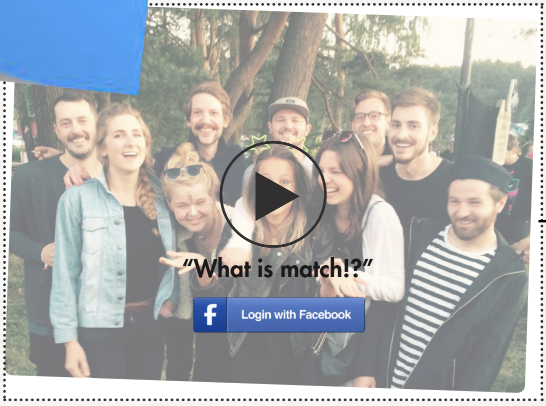
UNIQUE ADVANTAGE

The participants stated that they are member within some forums but were never asked to fill in a profile, for them this felt like the addition to facebook only that within this concept you can find other peers, which is an idea they appreciated very much.

Figure 103 provides an overview of all design recommendations taken from the two iteration rounds.

SUMMARY OF DESIGN RECOMMENDATION ITERATION ROUND ONE AND TWO - figure 103

TITLE PAGE



→

FILL IN QUESTIONS

"definition of mindset"

Concept #2 - "Als iemand spontaan op visite komt en mijn huis is niet opgeruimt, raak ik in stress omdat ik niet voorbereid ben." *

niet mee eens ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 helemaal mee eens

Concept #2 - "Als ik aan een nieuwe baan zou beginnen, doe ik alles om zo snel mogelijk te integreren en geen foutjes te maken, omdat ik nieuw ben." *

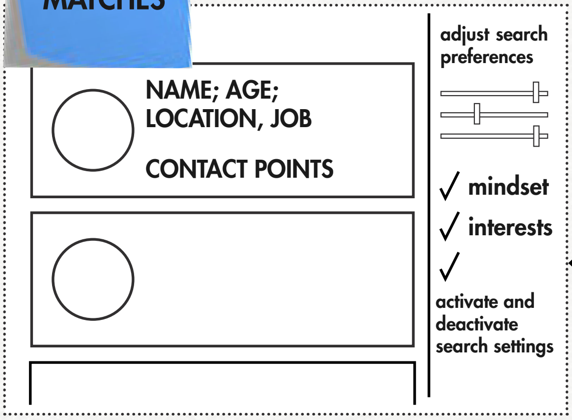
niet mee eens ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 helemaal mee eens

+ more diabetes questions
+ free text questions

SKIP questions

↓

LIST MATCHES



NAME; AGE;
LOCATION, JOB
CONTACT POINTS

adjust search preferences

✓ mindset
✓ interests
✓ activate and deactivate search settings

←

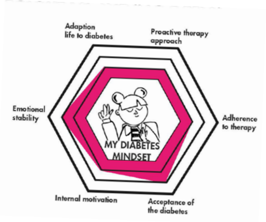
↓

YOUR PROFILE

square photo

basic data
NAME; AGE;
LOCATION, JOB

my diabetes...



+ free text questions
friendly, not negative mindset

+ photo diabetes kit

about me...

adjustable
able to skip this part
ice breaker - funny fo
interests

↓

+ home page
+ main menu?
+ navigation
+ order?
+ why did you visit match?!

use data from iteration round 2 for final profiles to provide "real" matches

BASIC DATA (e.g. naam, leeftijd, woonplaats, werk etc.)

Judith, 29,
Hellevoetsluis,
Docent Engels,
Vrijgezel

DIT BEN IK...(e.g. wat vindt je leuk, wat doe je graag, waar ga je graag heen, waar ben je geinteresseerd in?)

Ik hou van koken (voornamelijk low-carb), dagjes weg, stappen, winkelen (tsja... echt), reizen, dansen. Ik vind het leuk om nieuwe dingen te ontdekken/leren en mezelf te ontwikkelen.

DIT IS MIJN DIABETES...(Hoe ga je met je diabetes om, hoe denk je over diabetes gerelateer de dingen - je manier van diabetes management)

Ik heb nu 24 jaar gediagnosticeerd type 1, maar ben er mee geboren (29 jaar dus) - maar door koppigheid van de huisarts kwam het pas op m'n 5e er uit, waarna het 2 weken duurde voor ik echt buiten levensgevaar was (jep, lekker dan) - ik heb een laag insulinebehoefte. Ik vind het fijn grotendeels lowcarb te eten, omdat het mij qua injecties veel scheelt (van 4x p/d, naar 1 a 2x p/d

WAT ZOU JE BUITEN DEZE KATEGORIEN NOG WILLEN INVULLEN ?

Het onderdeel pomp/spuit,

NAAR WIE OF WAT ZOU JE OP DIT PLATFORM WILLEN ZOEKEN? WAT ZOU DEZE PERSOON VOOR JOU MOETEN ZIJN EN DOEN? WAAROM ZOU JE DEZE PERSOON ZOEKEN?

Het lijkt mij prettig te daten met mede diabeten (ook omdat ik als ik ontregeld zit bv. geen zin heb, of echt niet lekker ben en het makkelijker is als je partner dit begrijpt en zelf ook meemaakt) maar vooral het vriendschappelijke contact met anderen

WAT WIL JE VAN DE ANDERE PERSOON WETEN?

- Erg belangrijk. Ik wil graag met leeftijdsgenoten praten - of eventueel een ervaringsdeskundige zijn voor bv. tieners, maar wil niet uitgebreid praten met mensen van mijn ouder's leeftijd of ouder
- Voor connecties zijn interesses handig
- diabetes details, juist omdat het daar om draait.

4.4 REQUIRED FEATURES & INTERFACE DESIGN

To be able to setup the final prototype for the final iteration round, first the required features within the platform are determined (see figure 104) and afterwards transferred into an interface design. (The extended flowchart and additional screens that are not displayed within this chapter can be found in appendix 30). Note that the final test will not be about the layout itself, but a generative interview to determine the final order, flow and functions of the platform. Therefore the layout will be kept basic to keep the functions in the foreground.

MATCH!

REQUIRED FEATURES

CREATE PERSONAL DIABETES MINDSET PROFILE	login / facebook login and create personal profile	answer diabetes mindset questions and see personal mindset	preview profile and adjust / edit in case something changes
MATCH PROFILE / CONTACT PEERS	list of peer profiles with match details to compare mindset	display demographic data, interests and mindset details within peer profiles	contact possibilities / ice breaker within a profile
ADJUST MATCH SETTINGS	free #search and interest search to increase personal	demographic data search (location, age) to be able to find peers that are close to you	edit mindset search preferences to find the preferred peer (antipole, role model, friend)

figure 104 - overview required features within the platform

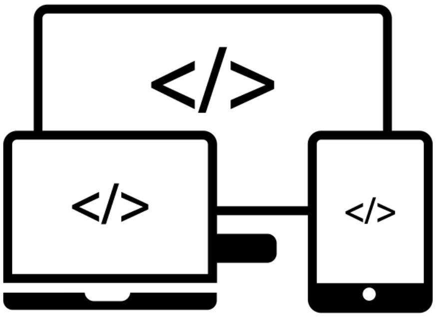


figure 105 - responsive design for all devices

PLATFORM MEDIUM
The platform will be started off as an internet website , responsive to different devices - desktop computer, laptop and tablet (see figure 105). Further mobile developments will be discussed within chapter 5.3 - future recommendations. To keep an overview and simplification the interface will only be displayed on a tablet within this report. The final iteration round will also be done with a paper prototype, tailored to the size of a tablet with a touchscreen, to make it easier for the participants to pretend to move around the website.

FLOW OF THE WEBSITE

The website is divided into two parts: the first part are all first use register screens, everything that contains the questions, the profile, the mindset each user fills in. Afterwards this profile will be matched with the other peers within the platform. The second time the user will visit the website he/she can login and is forwarded to the home screen with the main functions of the website. From the home screen the user can take a look at the matches and new peers, edit his/her own profile and see if they have received any new messages. When leaving the home screen, a slide-in menu on the upper left corner of the screen helps the user to navigate through the website. Here all main features, message, matches and own profile can be reached. The search settings can be edited within the list of matches screen (see figure 106)

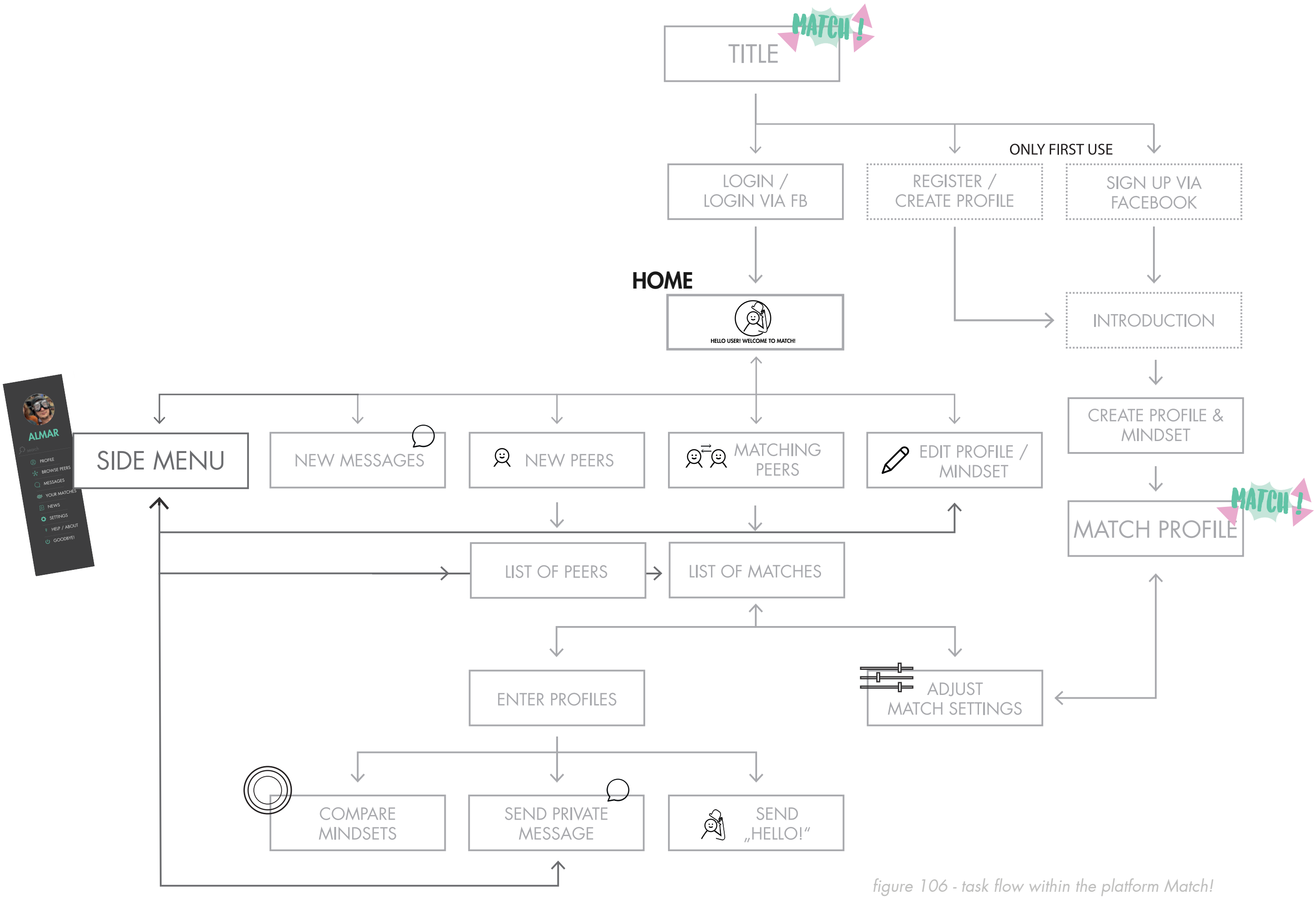


figure 106 - task flow within the platform Match!

LAYOUT CONCEPT

The intended image of the platform is to facilitate new friendships and that meeting diabetes peers can be great fun. Therefore, when visiting the platform at first, the user should get the feeling of being welcomed and arouse curiosity of the features within this website. The movie that plays in the background of the title page will show sceneries of diabetes peers finding matches, meeting up and hanging out with their new friends. The focus of the platform are the peers as people and not as diabetes patients. The bright colors and peer icons reflect this new, fun way to meet peers (see figure 107).

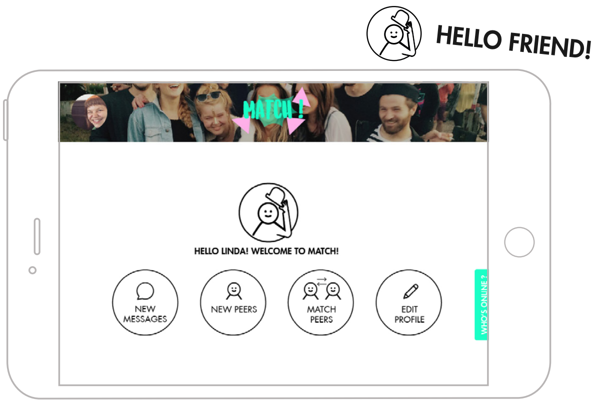
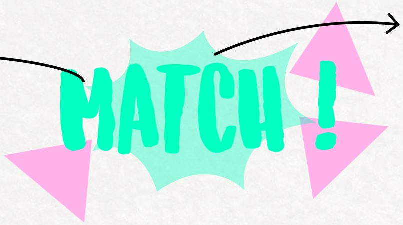


figure 107 - inviting home screen

LOGO CONCEPT

NAME : find your "matching" peer online, match with other diabetes patients



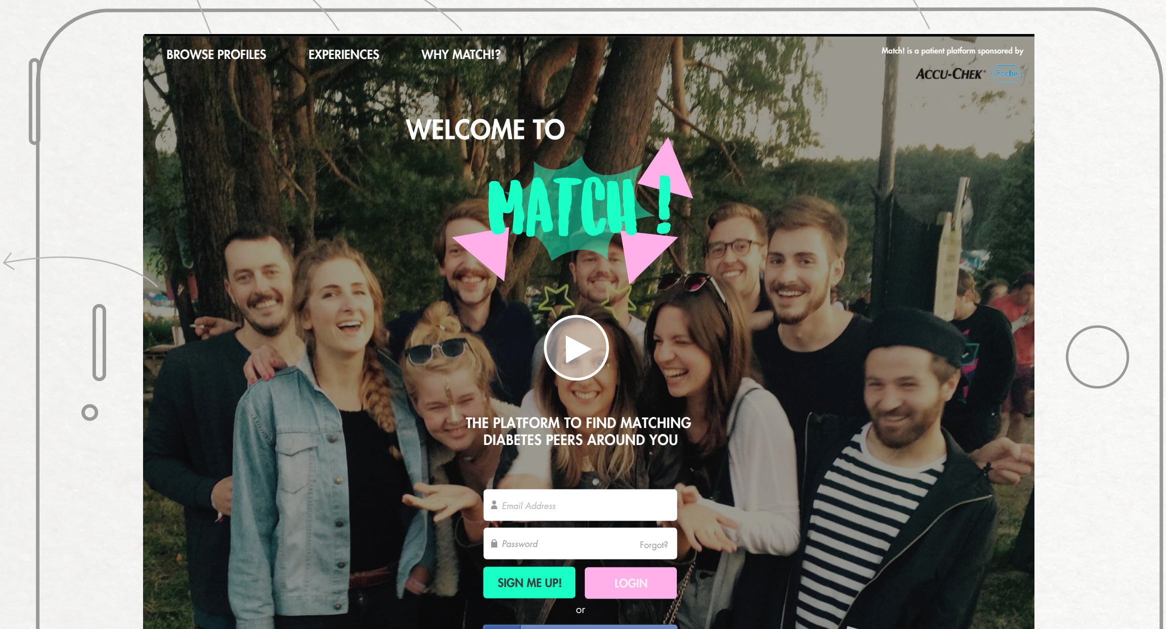
LOGO: Bam!, Explosion!
_new way to meet peers
_away from the dusty image of peer meetings
_find matching peers with one click

= HERE COMES YOUR MATCH!

LAYOUT CONCEPT

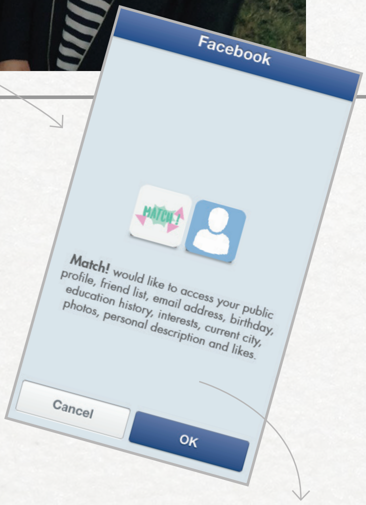
before signing in - browse profiles or read about experiences to understand concept and trigger user

clearly indicate Accu-Chek as the provider of the platform to enhance trust and ensure privacy



video in the background starts playing automatically

figure 108 - title screen of the website with sign up and (facebook) login function



Match! would like to access your public profile, friend list, email address, birthday, education history, interests, current city, photos, personal description and likes.

sign in via facebook
- common friends / likes makes finding matches even easier
- speed up the profile creation process

INTERFACE DESIGN

Within the following pages, the designed interfaces of the Match! patient platform are presented and their components are explained.

title page - triggering new user and login

The title page greets the user with a movie of a group of diabetes friends that met each other via Match! and are having fun with each other hanging out. Before signing up for the platform, users can browse the profiles of a few peers that agreed upon this for their privacy or read stories of experiences and the background of match. The title screen has two main options, the user can either sign up for a new account or, in case he/she is already registered, login to the platform (see figure 108). The possibility to sign up via facebook enables the platform to use part of the user's data for the profile and display common friends with other peers and likes.

CREATE A PROFILE

In order to find other matching peers, each peer has to create a personal profile. After signing up for the platform an introduction page explains the user the procedure. Then the user is guided through 4 different parts to fill in (see figure 109):

① **Diabetes mindset**
② **Interests**
③ **Basic Data**
④ **Upload profile picture**

Afterwards the profile can be previewed and adjusted if needed. The questions are partly free text questions, partly the user can choose between nuances of 1-6 to aggree on certain statements. The provided questions were taken from the information the participants provided within the profiles in the second iteration round.

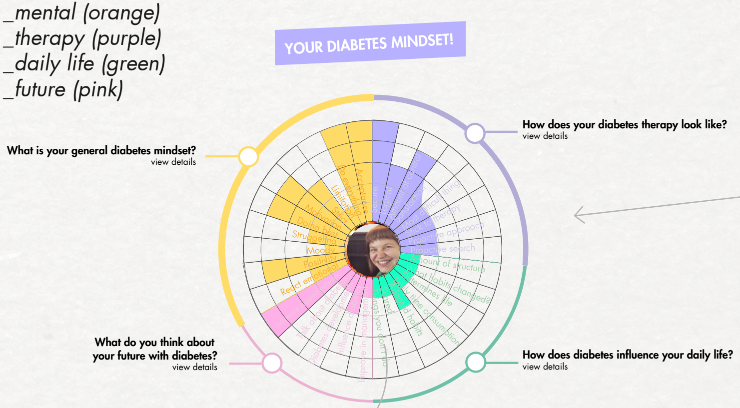
Through the button in the down right corner the user can forward to the next question. Each question can be deleted throughout the questionnaire, to enable skipping questions that are not applicable or possibly too confronting.

Within the profile the demographic data such as name, age, location, education is displayed on top, as it is the most important to look at within a profile. In the middle of the profile the diabetes mindset infographic and quotes from the free text answers will be displayed together with possible photos the user uploaded. On the bottom of the page the interests of the user are shown as text, icons and possible snapshots.

Each profile contains two buttons to either send the peer a message or send a hello smiley as a contact entrance point. After the user has checed his/her profile, he/she can be matched with other peers (profile see figure 110).

DETAILS MINDSET

divided into 4 categories:
_mental (orange)
_therapy (purple)
_daily life (green)
_future (pink)



answers can be given from 1-6
mindset has 6 circles to indicate nuances
each answer has an apart slot - 30 slots in total

figure 109 steps to fill in the profile

HI! WELCOME TO MATCH!

WE AT MATCH WANT YOU TO FIND THE PERFECT PEERS. IN ORDER TO MATCH YOU; WE ASK YOU TO FILL IN YOUR PROFILE FIRST AND ANSWER THE DIABETES MINDSET QUESTIONS.

DELETE THE QUESTIONS, THAT ARE NOT RELEVANT TO YOU.

THERE IS NO RIGHT AND WRONG ANSWER. IT'S ABOUT HOW YOU HANDLE THINGS.

TURN KEYWORDS INTO HASHTAGS, TO MAKE THEM SEARCHABLE FOR OTHER PEERS.

YOUR DIABETES MINDSET
GENERAL

THE FIRST QUESTIONARE ARE ABOUT YOUR GENERAL DIABETES MINDSET. YOUR ANSWERS TO THESE OPEN QUESTIONS WILL BE DIRECTLY DISPLAYED IN YOUR PROFILE.

1. Shortly describe your diabetes mindset. What kind of diabetes person are you?
Your answer

2. What was your last HBA1C?
Your answer

3. What are you interested in learning regarding diabetes? What is your current diabetes question(s)?
Your answer

4. What would you do if you had 1 day off diabetes?
Your answer

5. Describe the craziest / funniest thing that ever happened to you with diabetes.
Your answer

6. What role does diabetes play in your life?
☐ the little sister that you have to look after
☐ the big fat monster that scares you
☐ the naive family dog that always follows you
☐ the mean big brother that suddenly punches you
☐ the strict mother that doesn't allow anything
☐ the creepy witch that cannot be trusted
☐ the old acquaintance that has always been there
☐ Other:

YOUR DIABETES MINDSET
THE MENTAL SIDE

THE NEXT QUESTIONS ARE SEPARATED INTO 4 AREAS - DIABETES MENTAL,THERAPY, DAILY LIFE AND YOUR FUTURE. THESE QUESTIONS ARE GOING TO BE INCLUDED INTO AN OVERVIEW INFOGRAPHIC WITHIN YOUR PROFILE. .

18. How much do you aggree with the statement "you can do everything with T1D"
1 2 3 4 5 6
do not aggree at all ○ ○ ○ ○ ○ ○ totally aggree

19. How much have you "accepted" your diabetes?
1 2 3 4 5 6
not at all ○ ○ ○ ○ ○ ○ I have accepted and deal with it

20. How limited do you feel through your diabetes?
1 2 3 4 5 6
not at all ○ ○ ○ ○ ○ ○ very limited

21. How "strict" are you with you with yourself regarding your diabetes?
1 2 3 4 5 6
not at all ○ ○ ○ ○ ○ ○ very strict

22. Where do you get your motivation to do your best from?
1 2 3 4 5 6
internal motivation (from yourself and for your health) ○ ○ ○ ○ ○ ○ external motivation (motivated through

23. How much are you doing your best to have good blood sugar levels (on a daily basis)
1 2 3 4 5 6
never ○ ○ ○ ○ ○ ○ always do my best

24. Do you often have (or had) difficult times regarding your diabetes?
1 2 3 4 5 6
yes all the time ○ ○ ○ ○ ○ ○ no almost never

25. How much do bad blood sugar levels influence your mood?
1 2 3 4 5 6
not at all ○ ○ ○ ○ ○ ○ very much

26. How sober-minded / emotional would you describe yourself regarding diabetes?
1 2 3 4 5 6
pretty sober-minded ○ ○ ○ ○ ○ ○ pretty emotional

27. How positive or negative do you think about your diabetes?
1 2 3 4 5 6
pretty negative ○ ○ ○ ○ ○ ○ pretty positive

overview questions

introduction to the mindset questions

adding #hashtags enables specified search preferences

start test

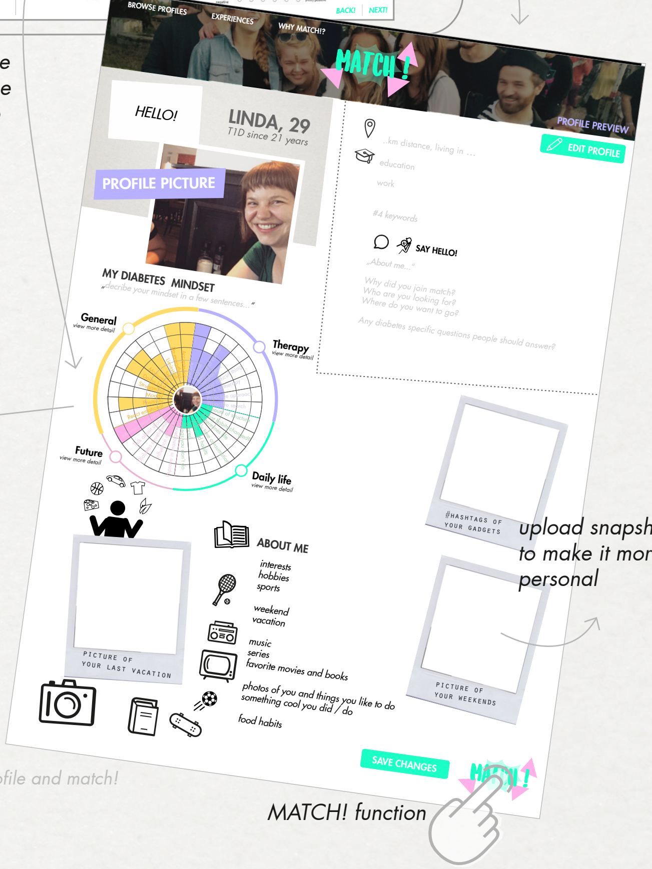
answers to these questions will be directly displayed within the profile

5 categories:
GENERAL
MENTAL
THERAPY
DAILY LIFE
FUTURE

next page

diabetes mindset +basic data +interests are displayed within the profile

answers to these questions will be progressed into the mindset infographic



HELLO!

LINDA, 29
T1D since 21 years

..km distance, living in …
education
work
#4 keywords

„About me…"
Why did you join match?
Who are you looking for?
Where do you want to go?
Any diabetes specific questions people should answer?

MY DIABETES MINDSET
„decribe your mindset in a few sentences…"

ABOUT ME
interests
hobbies
sports
weekend
vacation
music
series
favorite movies and books
photos of you and things you like to do
something cool you did / do
food habits

upload snapshots to make it more personal

MATCH! function

figure 110 - preview profile and match!

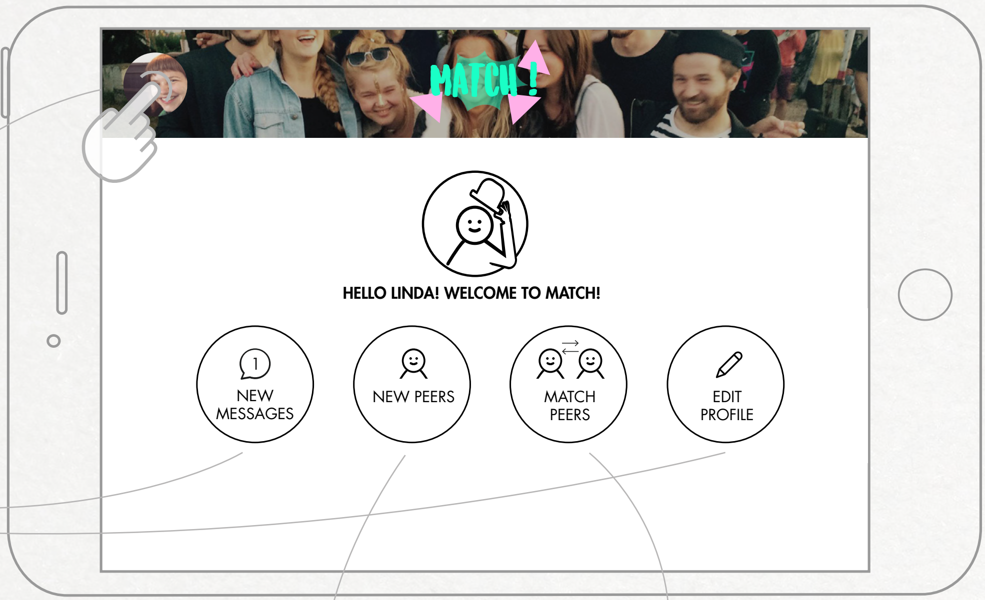


figure 111 - home screen with main menu

SLIDE-IN MENU

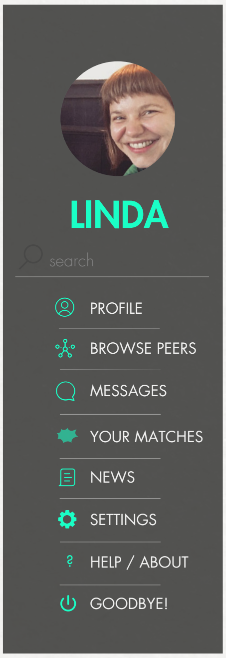
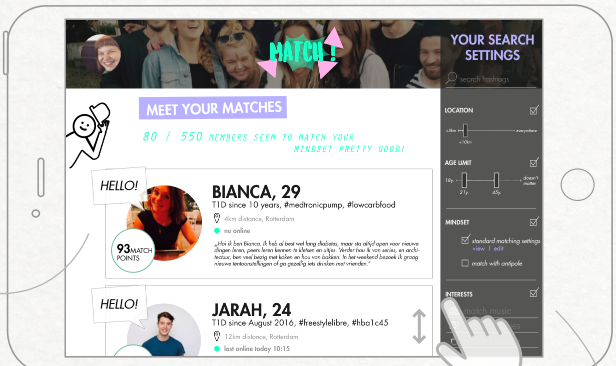


figure 112 - slide in menu

name, age, distance is most important
diabetes #

LIST OF MATCHES / PEERS



BIANCA, 29
T1D since 10 years, #medtronicpump, #lowcarbfood
4km distance, Rotterdam
nu online

„Hoi ik ben Bianca. Ik heb al best wel lang diabetes, maar sta altijd open voor nieuwe dingen leren, peers leren kennen te kletsen en uitjes. Verder hou ik van series, en architectuur, ben veel bezig met koken en hou van bakken. In het weekend bezoek ik graag nieuwe tentoonstellingen of ga gezellig iets drinken met vrienden."

JARAH, 24
T1D since August 2016, #freestylelibre, #hba1c45
12km distance, Rotterdam
last online today 10:15

browse through profiles

DETAILS MATCH

MICHAEL, 25
T1D since 22 years, #medtronicpump, #freestylelibre
8km distance, Schiedam
last online yesterday

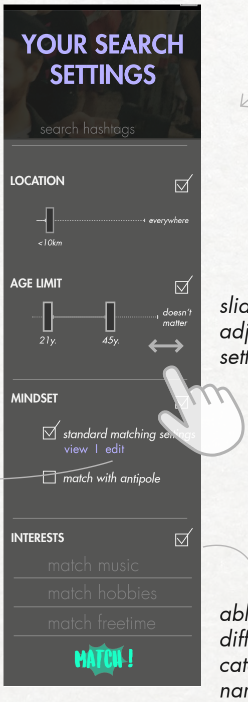
„Hoi ik ben Bianca. Tja diabetes...wat moet je daarover zeggen. Het is niet makkelijk maar je went wel. haha stomb uitspraak. Ik ben het inmiddels wel gewendt. Maar het blijft een kutziekte. Toch denk ik dat het leuk zou zijn om lotgenootjes te vinden waar je over speciale dingen kan praten - ik struggle bv nog steeds met sporten en hypos. "

summary about me text

amount of similarity based on mindset test

click gesture to enter profile

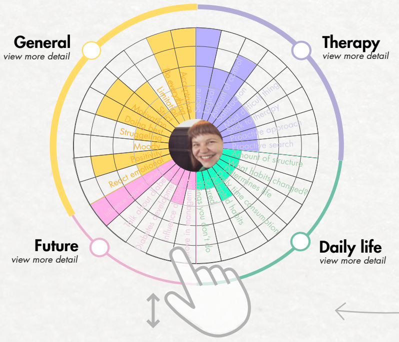
edit mindset search settings
- *standard search for a similar mindset*
- *search for role model*
- *search for antipole of your mindset*



slide gesture to adjust search settings

able and enable different search categories to narrow down or broaden search preferences

figure 113 list of peers with search settings



increase or decrease slot score with slide gesture

HOME SCREEN & MAIN MENU

After the user has logged into the platform, all functions are displayed within the home screen. From here, the user see if there are new messages or if new peers had signed up. Besides that the matches can be reached or the profile can be adjusted (see figure 111). Whenever the user moves around the page, all of these functions can be reached through the slide in menu that can be opened through touching the round button on the upper left corner with the profile photo of the user. Here the functions profile, browse peers, messages, your matches, (in the future news), and the settings are displayed. Through this menu each user can also logout of the page again (see figure 112).

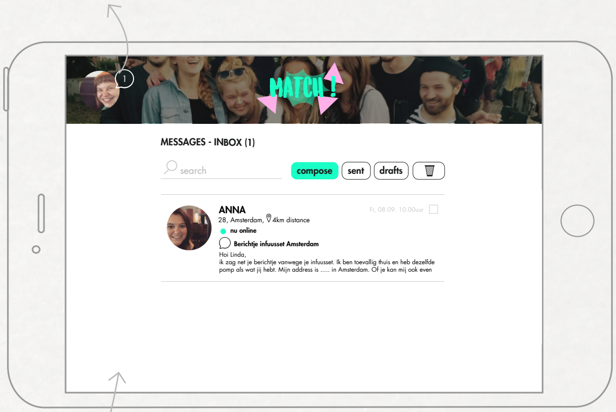
The content that should be displayed within this home menu will be brainstormed within the final iteration round.

PEER PROFILES

Each peer will have his/her own personal profile with all information that is provided and the diabetes mindset infographic (see figure 113). When looking at other profiles the user can immediately see how good this peer matches, compare the diabetes mindsets too each other and send a message or a hello sticker to make contact. When pressing the message button the user will be forwarded to the inbox (see figure 114) Each profile consists of a mix of quotes, pictures, text and hashtags.

Possible ice breaker to make it easier to contact peers will be brainstormed within the final iteration round.

new messages popup



MESSAGES - INBOX (1)

ANNA
Fr, 08.09. 10.00uur ☐
28, Amsterdam, 4km distance
● nu online
Berichtje infuusset Amsterdam
Hoi Linda,
ik zag net je berichtje vanwege je infuusset. Ik ben toevallig thuis en heb dezelfde pomp als wat jij hebt. Mijn address is ..... in Amsterdam. Of je kan mij ook even

figure 114 inbox with new messages from peers

HELLO!

BIANCA, 29
T1D since 10 years
● nu online

4km distance, living in Rotterdam
BA, bedrijfskunde, Hogeschool
public service & administration employee
#spoor, #NS
#relaxed, #funny, #social, #caring

SAY HELLO!

ik ben Bianca. Ik heb al best wel lang
etes, maar sta altijd open voor nieuwe
en leren, peers leren kennen te kletsen en
Verder hou ik van series, en architectuur,
n veel bezig met koken en hou van bakken.
In het weekend bezoek ik graag nieuwe
tentoonstellingen of ga gezellig iets drinken
met vrienden."

YOU AND BIANCA HAVE...
93 MATCH POINTS
mental 90
future 95
daily life 85
therapy 91

MY DIABETES MINDSET

„Inmiddels 10 jaar diabetes type 1, met 3 jaar een pomp. Aan het begin wilde ik geen pomp maar nu ben ik er heel tevreden mee. Het maakt alles een stukje makkelijker. Omdat ik vaak koolhydraat arm eet, zijn mijn bloedsuikers best wel stabiel en met mijn laatste hba1c van 55 was ik ook erg tevreden. Niettemin hou ik ook wel van snoepen en gewoon alles eten wat je wil."

Relation with your dvk / doctor
„I have a normal relation with my DVK. She is friendly, but I also don't need that much help."

I measure my blood sugar between
5-7 times a day

„If I had one day off diabetes, probably not that much would change. But still I would eat a lot of candy."

„craziest thing that ever happened to me with diabetes is that I was at the train and had to look at my pump because I thought it was clogged and all of a sudden a lot of people went inside and somehow somebody pulled the katheter out of my stomach...there was blood everywhere and people were in shock...and it was painful. outch!"

#MEDTRONIC PUMP,
#FREESTYLELIBRE

ABOUT ME

interests - reading, museum, history, food, architecture
hobbies - food, books, photography
music - pop, 60s rock, hippie music
weekend - going for a drink with friends, cooking dinner for friends, going to museums and exhibitions
vacation - city trips, beach vacation, camping in the wild
food habits - „I spend a lot of time with my food, trying out new receipes, I mostly follow the paleo diet (low in carbs, high in proteine), that works good with my blood sugar levels."

#KAJAK, #PORTUGAL
#LEKKERZONNETJE

#EXHIBITION
#TATE GALLERY

figure 115 filled in peer profile

show details

send private message
or send "hello!" sticker

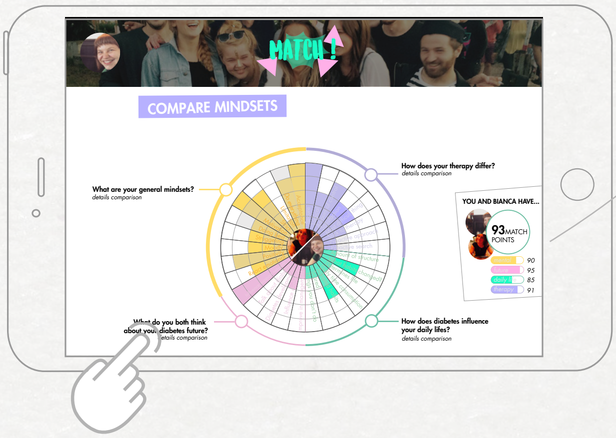
MATCH PEERS

Peers are standard matched according to similarity to the users own mindset. The more similarity a peer has within the diabetes mindset, the higher the match points. The total match points are a summary of the match points within the 4 stated categories - mental, therapy, daily life and future (see figure 115).

Within the search settings the mindset search preferences can also be adjusted according to the user's wishes by dragging the different slots and increasing or decreasing them. This way the user can not only search for similar minded peers but also for role models and eventually antipole, peers who have a total different mindset as the user, if wanted (see figure 116).

Furthermore peers can also be matched on demographic data such as distance, age and education or work or based on interests, to include the basic factors of how people become friends that were mentioned within 4.1 - homophily and confounding factors.

COMPARE 2 MINDSETS



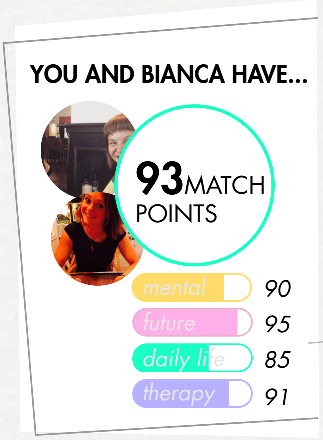
What are your general mindsets?
details comparison

How does your therapy differ?
details comparison

What do you both think about your diabetes future?
details comparison

How does diabetes influence your daily lifes?
details comparison

YOU AND BIANCA HAVE...
93 MATCH POINTS
mental 90
future 95
daily life 85
therapy 91



YOU AND BIANCA HAVE...

93 MATCH POINTS

mental 90
future 95
daily life 85
therapy 91

4 categories of diabetes mindset to compare

figure 116 compare your mindset with other peers

figure 117 overview tested screens

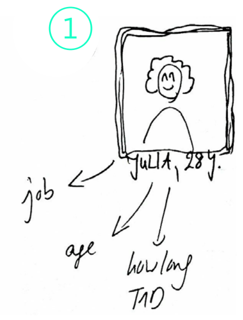
4.5 FINAL ITERATION

The final iteration is focused on combining the insights of the first two iteration rounds and testing the interaction and experience when using the complete website. A paper prototype of the order and content of the platform is tested (see figure 117 - 121) with five new diabetes patients within the TU Delft or at the participant's home. (see figure 122 - 125 on the next page) The content and layout of the platform is based on the insights of the first two iteration rounds and design recommendations.

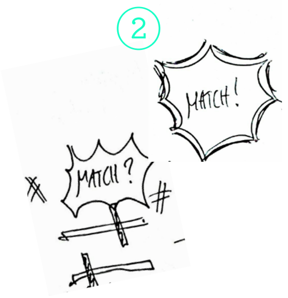
FINAL USER RESEARCH

As the previous two iteration rounds tested only parts of the concept and mostly created content, this test is also setup as a generative interview with different tasks the participants has to walk through. Through the use of a paper prototype instead of a digital one, the order and content can be directly adjusted on the spot. The findings were used to come up with a (within this project) final order and layout and to give further recommendations regarding content and future development. The findings will be processed into an experience prototype and a platform toolbox the company can use for future development (see chapter 4.6 and 4.7).

create profile on platform



find matches filter matches



contact matches

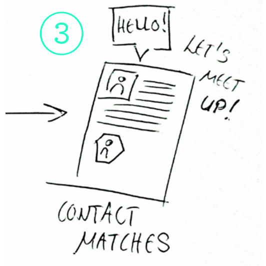


figure 118 5 paper prototype sets

TEST SETUP AND TASKS

The participants each got 5 different tasks to fulfill during the task. The screens of the platform were all personalized for the patients with their photo and printed out, to be placed in the cardboard tablet. Whenever a participant would indicate of pressing a button on a screen within the prototype I placed the new screen in front of them. The five tasks and their goals are as follows:

① **"create a profile" -** this task tests the order of the questions, the aptitude of the questions

②**" find a matching peer and contact him / her"** - this task was done to see what participants are looking for and how easy / difficult it is to contact new, unknown people - possible ice breakers were brainstormed

③**"imagine you are on a trip and you forgot your meter - how could this website help you?" -** this task helped to figure out whether the participants understood the search settings and how to change them

④ **"imagine you are lacking structure within your diabetes management - how could this website help you improve this?" -** this task helped to see whether participants understood the mindset search and infographic and how to change it

⑤ **"choose a persona you find interesting and think about how this persona would use the website** - this task was introduced to see whether the personas are realistic and could be validated by the patients to be used in the toolkit for the company.

A complete overview of the procedure, the questions and results is given within appendix 31.

figure 119 main platform features

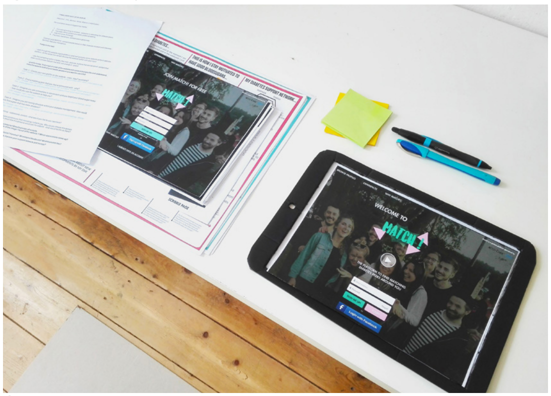


figure 120 preparing paper prototype

figure 121 carton tablet

figure 122 participant filling in the questionnaire

figure 123 participant rearranging the order of the questions

RESEARCH INSIGHTS

Performance within the tasks

Task 1 - create profile
5/5 participants were able to walk through the task without any problems and were able to find all buttons and use cues. The general impression was that the order was not right and there are too many questions to answer, which would lead to skipping a lot of questions.

Task 2 - search for a matching peer and contact him/her
5/5 participants were able to directly go to their matches from the title page. When asked about what they were searching for 3/5 participants indicated to only look for the location, 2/5 looked for the photos, 2/5 looked at the match points and only one of them read all personal description texts and then chose for a person. All users agreed that they would find it challenging what to write to the match as a first message. It felt a little bit awkward of contacting someone simply because they have the same mindset. Multiple ideas for possible ice breaker and contact possibilities were created. These ideas can be found within the recommendations in chapter 5.2.

Task 3 & 4 - change (mindset) search settings
Only two participants were able to find and understand the search setting status bar as it was very hidden and too dark. Afterwards the location setting was clear, but the mindset search was not fully understood because of the lack of use cues how to change the mindset.

Task 5 - validate personas and their use of the website
All participants were able to find a persona they could identify with or indicated to be "between two personas." Some of the users experienced the personas as being very stereotypical patients. The participants expressed ideas for 4/5 personas and how they would use the website. The only persona that was not thought to be interested in the website is Emmeline - as she does not want to keep herself busy with her diabetes and would not want this type of contact that is based on the fact that both have diabetes.

The content and icebreaker brainstormings will be evaluated within chapter 5.2 - future recommendations.

Use experience
Even though some parts the interface still have a lot of things to improve regarding a fast, logical and fluent order, the participants were all engrossed into reading the information about other matches and having the possibility to contact single peers. Every user found something interesting within the website and browsed the profiles of the others. Even though it was a simple paper prototype, every user filled in their real mindset and took some time to think about appropriate answers to the diabetes questions. The developed functions within the last two iteration rounds were all confirmed to be legit and expected within the website. The biggest limitations were found within the process of filling in the profile which was experienced as being too long-standing and dry. The general flow of the website was well understood even though participants were not sure whether they would include another home page or not.

Interface experience
The interface of the website was experienced as being friendly and open, the group of friends indicated the desired use of the website. The biggest points of criticism were within the display of the mindset graphic, which is not clear yet and too detailed and the search settings which are too hidden within the website. Most participants indicated to be familiar with the structure of the website, the main menu hidden within the left upper corner and to be able to filter the search results as other search platforms such as 222.marktplaats.nl use the same kind of system.

DESIGN RECOMMENDATIONS

The design recommendations and the patient's generated ideas and feedback are presented in the implementation phase and reflection (chapter 5.1 and 5.2

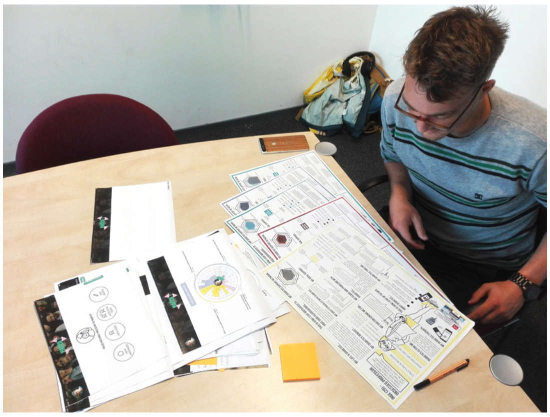


figure 124 emphasizing with the personas and discussing them

figure 125 discussing the order of the platform

4.6 USER SCENARIOS

Although the platform Match! can be used for different purpose to be used in various ways, some similarities among the purpose of usage were observed during the final iteration and are displayed within this scenario.

① 4/5 user agreed to only look for peers that live close to them, to be able to easily meet up with them (see figure 126).

② 3/5 user would also browse random profiles and see "who else has diabetes - out of curiosity" instead of focusing on the mindset match, and enjoy the possibility of conveniently finding other peers offline. The other two user were more interested in exploring how far other peers would match their mindset and explored the details the infographics (see figure 127)

③ 3/5 user mentioned the idea of using the platform in case of emergencies when for example they are away from home and forgot their meter (see figure 128)

This scenario mainly clarifies the interactions during the search for peers. The overall goal of Match! is to facilitate peer friendships and offline contact. In the scope of this last iteration round, too few insights are gathered about what happens after patients have contacted each other and met up. The longterm effect will be evaluated within the next chapter.

① LOOK FOR PEERS IN YOUR AREA AND SCHOOL - EASY TO MEET UP WITH

80 / 550 MEMBERS SEEM TO MATCH YOUR MINDSET PRETTY GOOD!

☑ standard matching settings view I edit

☐ match with antipole

BIANCA, 29
T1D since 10 years, #medtronicpump, #lowcarbfood
4km distance, Rotterdam
● nu online

„Hoi ik ben Bianca. Ik heb al best wel lang diabetes, maar sta altijd open voor nieuwe dingen leren, peers leren kennen te kletsen en uitjes. Verder hou ik van series, en architectuur, ben veel bezig met koken en hou van bakken. In het weekend bezoek ik graag nieuwe tentoonstellingen of ga gezellig iets drinken met vrienden."

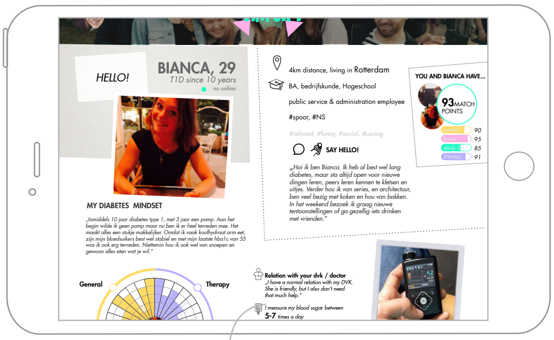
JARAH, 24
T1D since August 2016, #freestylelibre, #hba1c45
12km distance, Rotterdam
● last online today 10:15

"oh she lives only 4 km away, I would meet up with her. That's around the corner."

"I think I would first narrow down the location search setting and see who lives around me and has diabetes. Maybe there is somebody here in the university?"

figure 126 - diabetes friends meet each other within lunch break

② GENERAL INTEREST TO SEE WHO ELSE HAS DIABETES AROUND YOU



"I would first look read the texts and look at the profile and just then look at the mindset details."

"I like the mindset idea but I would also look for other things and just browse, who is on that website."

figure 127 - diabetes friends meet each other within lunch break

③ LOCATION MATCH - HANDY FOR EMERGENCIES

"I can imagine that the gps function also comes in handy when you are away and you realize you forgot something or your insulin is empty. Then you can search for peers around you they sometimes do on facebook."

"Maybe you can send an emergency pop-up to every patient that is near you and then everyone sees it on their mobile phone?"

figure 128 - diabetes friends meet each other within lunch break

4.7 CONCEPT EVALUATION

The previous user scenarios concludes the three design iterations and shows the most overlapping activities patients are planning to do with the platform Match!. The three previous content and flow iterations all provided the possibility to develop the concept further with input from real users. This makes it possible to evaluate the concept based on their verbal feedback.

Throughout the first two iterations, parts of the concept was evaluated based on the applicable guidelines that were formulated based on the design brief. The complete concept was tested within the final iteration round. The written feedback within the What's App iteration rounds and oral feedback during the last iteration round are of significant value within this evaluation of Match!.

Therefore within this chapter the complete concept will be evaluated on the general participant feedback. Additionally, two main objectives of the design goal and interaction vision will be evaluated. The fulfillment of the guidelines will be analyzed within chapter 5.1.

> *"you know that you will get in contact with a person that fits your mindset, therefore you already know that this person is, in my case, more sober minded and is also interested in other things besides diabetes - I want to get something back from this match and not listen to somebody else complain all the time."*

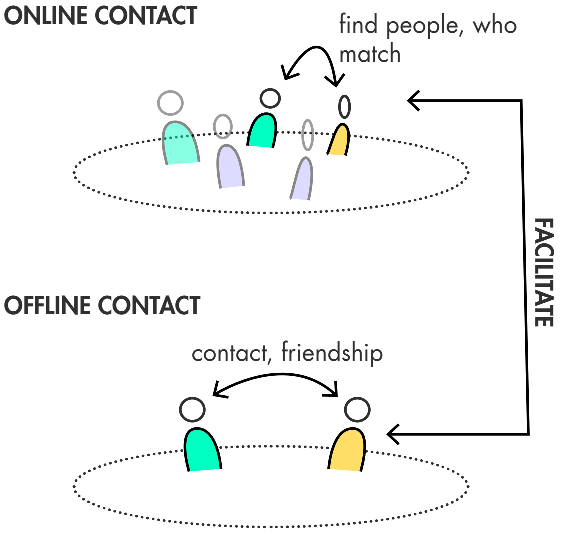


figure 129 design goal - "design a support tool that uses the mindset of T1D patients to facilitate contact between peers, in order to increase the support efficiency and provide support within a patient's daily life."

The main objective of the design goal is the process to find new (peer) friends that will connect to a patient's character and diabetes mindset and lateron become friends (see figure 129).

General feedback of the concept

4/5 participants were very enthusiastic about the idea - one of them was recently diagnosed and knew noone else with diabetes, another user did not know anyone else, who had the same mindset as him and the other two were mostly excited about the location search function, to be able to meet other people around them to have a coffee with and *"talk about diabetes in a normal, relaxed way."* and not having to take the detour via facebook or randomly see people that also carry an insulin pump on the streets.

One user indicated that he would probably not use the concept in real life, as he already had a quite broad network of diabetes peers and felt fully supported. He indicated that this way to contact peers would still focus too much on *"getting in contact purely because of the fact that you both have diabetes and not as real friends."*

He therefore preferred to keep the earlier mentioned surprise effect to meet peers per incident.

Facilitate contact with matching peers
Throughout the three iteration rounds, patients were excited about the thought to be able to meet other peers personally and specifically search for matching peers as this is something that does not exist within the current networks. Within the final evaluation round all participants found a peer they would like to contact within the website. Considering that the displayed profiles were based on real patients, the goal to facilitate contact with matching peers seems theoretically reached. Hereby it has to be indicated that not the fitting mindset as it was displayed in the infographic was the most exciting matching point for the participant but more the demographic data and to be able to check a patient's profile before getting in contact with him/her. Here, patients mostly paid attention to the age, distance and photo of the other patients. As the peers within the list of matches would match anyway, the details of the mindset seemed less interesting.

Increase support efficiency and provide support within patient's daily life
Three of the participants had no real peer support network and agreed on the convenience of having someone close to them that could help them solve their problems. Therefore again, the short distance to other peers was the biggest advantage within the concept. Patients would mostly contact peers that live in the area to be able to meet up with them like with their other friends. All participants agreed that for some of their diabetes issues, like gathering experiences about certain topics and asking very specific questions, could be solved through this website. As most diabetes problems correlate with daily life situations, the hobbies and common interests like sports or going out help facilitating the contact between peers with similar problems.

Therefore, as these participants stated the use of the concept for this intended purpose, it can be concluded that for patients who do not have a lot of peer contact yet, this concept will help improve their support network. For patients do not want to keep themselves busy with diabetes, this type of contact will still feel too much focused on the disease and therefore forced.

Longterm goal - facilitate peer friendships
The chances that this contact will develop into a friendship were partly confirmed by the participants. Some stated that having the same hobbies and mindset would definitely increase the chances, while others indicated that still you have to first get to know the person behind the profile to be sure about that.
As a final conclusion it can be stated that this concept can be a good start for patients who do not have a good support network yet. The overall experience of the platform was inviting and positive and none of the participants was repelled by the "moan-image" that other networks carry.

figure 130 interaction vision

Surprising, yet familiar and engaging
The described interaction vision of figure 130, the surprising incident of meeting other peers was experienced as followed within the concept: The concept displayed a number of peers that theoretically live within the location of the test person. This amount of 550 peers was the most surprising effect for the participants. The possibility of finding peers within the same city was only a surprise to the participants who did not know any other peers yet. All participants agreed of feeling a certain connection with the matching peers, especially because of the same age.

The engaging factor of the concept could still be improved. All patients showed certain hesitation how to contact a peer after looking at the profile. The mindset itself did not seem to work as a contact point. When sending a message all participants would pick up a different detail from the profile, still a certain contact barrier remained. Within the final iteration round all patients participated in a brainstorming about possible ice breakers that could ease the contact moment. The results of these brainstormings are summarized within chapter 5.2.

5.

REFLECTION & IMPLEMENTATION

After evaluating the final iteration round and service concept, this chapter will look beyond the value of the new peer support platform. Starting with the concept reflection, the concept will be evaluated according to the determined guidelines within chapter 3.3. Afterwards, as the final iteration round was a generative interview, the ideas and recommendations of the patients will be evaluated within chapter 5.2 - future recommendations. Conclusions are drawn and recommendations are given as an advice for Roche Diabetes Care on how to continue the project. Furthermore, a roadmap is created to define a strategy for the future implementation steps. The chapter ends with my personal reflection on the project and acknowledgment to everyone who support it.

5.1 CONCEPT REFLECTION

The three iteration rounds with five teen different patients have provided rich insights into the way diabetes patients want to use the platform Match! and how they want to get in contact with other peers. During the final iteration the patients reflected on the tasks through verbal feedback. These comments are valuable to, in addition to all the observations, assess the user experience of the introduced service. This chapter reflect on the complete concept Match! and the support possibilities it introduces within diabetes patients through the guidelines of chapter 3.3 - see page 78,79.

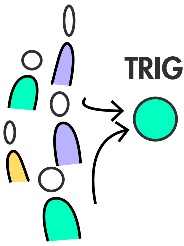
GUIDELINES

Following the formulated guidelines, the concept will be evaluated on the trigger, the amount of connection the peers felt, the contact facilitation and longterm support impact. As mentioned earlier, the iteration rounds and final concept did not focus on the content and information part as this part was included into the generative interview within the final iteration round. Therefore the guidelines regarding beneficial information will not be evaluated but will be further touched upon within chapter 5.2, where the brainstormings of the patients will be discussed.

A scale from 0 - 3 is used to indicate if and to what extent the guidelines are fulfilled by the concept Match!

(○○○ not at all up to completely ●●●)

The guidelines that are not fully met shall be referred to in the following chapter 5.2 - future recommendations.



TRIGGER NEW PATIENTS

●●◐ **ATTRACT NEW MEMBER**

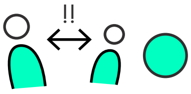
Four of the five participants indicated that they would be interested in joining this platform. The participants stated that this type of communication did not trigger the pitfalls they experienced within the other online groups, such as negative tone and moaning. Only one participant would not want to use it.

●●● **USE TARGET MOMENTS**

The location match function was highly appreciated by the participants and, combined with the hashtags of university or work can easily connect peers to new peers when moving to another city.

●●○ **UNIQUE ADVANTAGE**

The only comparable concept at the moment are the diabetes facebook groups with the facebook profiles of the members. The advantage of Match! is the possibility to determine beforehand whether a patient would fit within the mindset. Still, as the participants were also a little bit hesitant in contacting the other peers, this guideline could be improved.



FEEL A CONNECTION

● ◐ ○ MINDSET AS CONNECTOR

All participants agreed that the displayed mindset of other peers makes them more interesting to contact with as you can know from beforehand that this person will share your opinions. The thing that is still missing are the contact points that make it easy to switch from the profile to an actual conversation and send a message. As mentioned earlier, all participants agreed that there has to be some sort of openings moment.

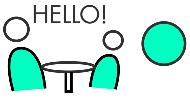
● ● ◐ DISPLAY MINDSET

Even though the questions were clearly too much, all participants agreed that the topics and categories were sufficient to cover the full mindset. Together with the basic data and interests, the full personality of a peer would be covered. The matching points made it very clear to all participants how much another peer matches their mindset. Still, a few graphical things would have to adjusted to make the overview and especially the comparison of two mindsets more clear. Two participants stated that the layout was too much detail and should be more summarized / simplified.

● ● ◐ CONNECT TO THE RIGHT PEERS

The possibilities to filter the peers within the concept are stated to be sufficient for the demographic data and interests, the layout of the mindset facilitation part was not quite understood by four of the five participants. As this is only a minor change within layout the guideline is almost reached. The general setting of connecting to similar peers was appreciated, the concept of the antipole was something that peers did not understand within first use but wanted to explore. The role model function and increasing the different slots was understood by all participants but experienced as clear enough.

……



FACILITATE CONTACT

● ● ○ CONTACT PREFERENCES

The concept included a message system to make the first contact. All of the patients agreed with the advantage of the connection with facebook would have if there would not be the privacy concerns. The intended transfer to other communication means was not recognized by the participants.

● ● ● ENHANCE OFFLINE CONTACT

Even though this part was not tested with the paper prototype, the patients were mostly excited about the location search as they could look for peers that would live close to them to be able to meet up with them.

● ● ◐ ENHANCE BENEFICIAL CONTACT

The role model search function was understood by most participants, still as stated earlier, the function of increasing one slot randomly did not bring a secure feeling of actually searching for somebody that is better within certain thing. One patient stated that the pure contact with other peers would ensure him help, he did not search for somebody that is better on purpose. Still, every patient was able to search for his/her preferred peer.

LONGTERM SUPPORT IMPACT

● ◐ ○ **STRENGTHEN SUPPORT NETWORK & CREATE NEW FRIENDSHIPS**

Three of the participants were very enthusiastic about this new way to contact peers. Combined with their preference to find friends that live close, the requirements for new friendships are almost given. Still, as the concept did not test any longterm effect nor whether these contact would really result in friendships, this guideline still needs further development.

SUMMARY REFLECTION

When looking at the guidelines it can be seen that the concept is clearly not finished and needs testing regarding the longterm effect of the new way to contact peers and whether this platform really increases the support efficiency within a patient’s support network. Still, within the parts that were already pretty evaluated within the last test round, the concept scored quite good with only three guidelines that had two dots or less. Those scores were caused by a lack of graphical guidance within the layout and can also be solved by further layout tests and psychological background search about the content of the questions and which possibility to display a mindset online the participants would prefer.

As the last iteration round was a generative interview, the participants created a lot of interesting ideas on how to develop the concept in the future and already tackled some of the biggest concerns within the brainstormings. The results will be presented within the next chapter.

5.2 FUTURE RECOMMENDATIONS

During the last iteration round the participants created a lot of inspiring ideas about the missing parts of the concept and the issues that require more attention. Within this chapter these ideas are presented as recommendations for the company on how to further optimize Match! The results of the brainstormings with the participants about the different topics can be found in appendix 32.

CONTENT

During the final iteration round each participant was asked to brainstorm with me about the possible content this website cold provide and asked to rate possible ideas that were created during this project.

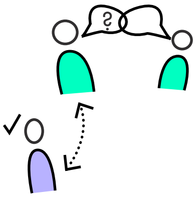
The mistrust against content that was provided by a company, that many participants expressed within the interviews was only shared by two of the asked participants. Three of the participants stated that they would not particularly be interested to see any news or content within the website as the match function should be in the front. One participant who was newly diagnosed with diabetes and not really connected within the diabetes world suggested that it would be nice to have scientific information, tips and new contacts within one place; to easily be able to keep an overview.

The two ideas that were developed within this project to provide small-scale situational videos and trigger patients to join the videos was seen as a nice opportunity by all patients, even though they all agreed to rather watch videos instead of submitting. One nice example a participant brought up were the Instagram / Youtube challenges, where famous blogger post a video and ask their followers to post their experiences as an answer. This idea would require Roche Diabetes Care to cooperate with influencer and already have a bigger amount of member, to create a video domino effect.

The other idea of using the global position of the company to provide content from diabetes patients around the world was found interesting but also dependent on the content. Patients then would prefer really different stories or short videos instead of simple articles.

The here presented guidelines resulted from the generative interviews at the beginning of the interview. Within the final test round patients only agreed on the advantage of hands-on practical advice, furthermore they seemed supersaturated by the amount of content that other websites already provide. As patients are very picky about their choices of content, the company should stick to the guidelines when developing new content ideas and first test them with the target group before posting content on their future platform.

GUIDELINES REGARDING BENEFICIAL INFORMATION AND CONTENT



RELIABLE CONTENT SOURCES

the concept should only provide own content that shows the expertise of the company within this field, otherwise other experts and patients should use a mediator to provide reliable content

TAILORED CONTENT

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

HANDS-ON PRACTICAL ADVICE

The concept should provide content that is implementable within the patient's daily situations

INCREASE DIABETES EDUCATION

The concept should provide inspiration and solutions for daily "offline" problems and include the support network in the problems, in increase therapy adherence and provide qualitative better help

figure 131 what content to display within the website?

FACILITATE CONTACT

ICE BREAKER - CONTACT POINTS

The website was experienced as being very handy for finding people, still the biggest challenge remains how peers will contact each other to meet up offline. All participants agreed that it would have to persuade themselves to simply send a message because of the same mindset and they would have to think about a fitting openings sentence. As this part was not developed at all, one task within the final iteration round was to came up with several ideas for ice breakers.

Facebook connection

Four of the five participants compared the platform with facebook with the only difference that diabetes is the connector. Facebook's idea of using common friends (homophily) as a conversation opener or being able to add someone as a friend seemed like a suitable ice breaker. Another patient came up with the idea to be able to like a person's mindset to first show appreciation before starting to talk with each other.

On the other side only two of the five participant logged into the platform using facebook. This was mainly due to the privacy concern that not all facebook contacts should see the mindset score of a patient even though that would not be possible anyways. As a future recommendation, as it would be very handy to find common friends on facebook and having a contact point, the website has to emphasize the facebook connection option, but clearly indicate where the profile can be found.

Furthermore, regarding privacy., it has to be clear that only diabetes patients can create a profile and ensure privacy even when connecting via facebook. This could be done within a small test about the users diabetes knowledge or whether he/she is registered at a certain hospital or within another community. Another finding within the expert interviews was also the need for a webmaster that checks the website for fake user.

Match! would like to access your public profile, friend list, email address, birthday, education history, interests, current city, photos, personal description and likes.

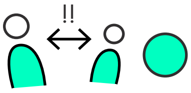
ensure privacy when logging in via facebook!

figure 132 privacy concerns

Starting a group

Another promising idea that was taken from the interviews would be the possibility to form a group with peers who live close or have the same mindset and then invite people into a certain group or to an event. This group will work as a mediator between patients and take away the difficult first contact moment. This idea also corresponds with the findings of the analysis phase. Even though the website is already displaying the interests, education, job and location of a user, the focus should be on more specific mediators between the user like common places he/she visits or maybe also connect the events a user is going to on facebook with the website.

Because of the high concerns regarding privacy, this option should also be tested before implementing.



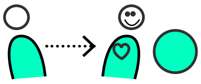
FEEL A CONNECTION

THE MINDSET

The questions within the final iteration round were based on information that patients shared within their profiles of the second iteration round. These questions have been evaluated according to their similarity and as patients complained about the amount of questions, been shortened to a total of 30 questions. The connection between a patient's personality and his/her diabetes management was touched upon within chapter 2.2.2.

The questions would have to be tested among the existing customer circle of the company to see whether the questions are too confronting and work for a big amount of different thinking patients. Within this test the result of the questions should be displayed as a mindset infographic at the end to get feedback whether patients whether think their result correlates with their mindset in reality.

In addition, to complete the validation process, a psychological longterm study about the influences of a patient's mindset on his/her diabetes management and how to correctly display this mindset through the questions would have to be done to validate these final questions.



LONGTERM SUPPORT IMPACT

LONGTERM STUDY

As the concept was not finished within the first two iteration rounds, the longterm effect could not be measured within this project. Within the final iteration round patients could only give indications about whether they think they could find a suitable peer within this platform, which five of the five participants positively confirmed. Still the longterm effect is not proven nor confirmed yet.

To be able to do that the company should, before launching the platform, test the efficiency about the created contact, including feedback of the participating peers after a certain amount of time about the development of the contact. Furthermore, as friendship is a broadly researched topic, existing statistics about the chance of creating friendships with a certain amount of peers.

The amount of friendships that are created correlates with the amount of member the platform has, therefore the longterm study should also continue once the platform has been launched. The company could send out regular questionnaires even after the platform already begun to see the effect developing. Only this way the concept can be tested regarding the facilitation of friendship.

5.3 IMPLEMENTATION

The company Roche Diabetes Care recently setup their own diabetes website that will be developed further with the the insights that were gathered within this project. Together with the internship coordinator, a rough implementation plan was developed. What steps have to be taken to validate the findings of this project and develop the platform further? How should the platform be promoted to trigger enough members?

DESIGN RECOMMENDATIONS

In addition to the recommendations made in 5.2, design iterations should follow on aesthetic and flow level. Some initial recommendations can be made that evolved from the final user test sessions (see figure 133-.

Layout: Starting off with the questions, the participants stated that the process of filling in these questions has to be clearer, preferably only having one question at one page. The suggestions on the first page, to add hashtags and be able to delete questions should be automatically implied within every page, otherwise users will forget about these features.

The biggest difficulties were experienced during the search settings tasks. Two of the participants did not recognize the field on the right side as it remains is remains unobtrusive with the dark background. Below the original version a design proposal of how the feature could look like within the future platform was made (see figure 135). By moving the feature to the top, it directly jumps into the users eye when opening the page and remains there when scrolling downwards.

Mindset display

The mindset infographic is based on the amount of questions that were originally posed. As the questions have already been narrowed down, the future infographic would contain less slots as the users wished for. The separation of the mindset into so many slots did not provide a clear overview especially when comparing two mindsets. The colors did not indicate enough difference between the two mindsets. One participant expressed the idea that whenever a user wants to change the mindset preferences, it would be easier to increase the whole mindset. A statement as "I am looking for someone who is 20% better" would be appreciated rather than dragging the different slots (see figure 136).

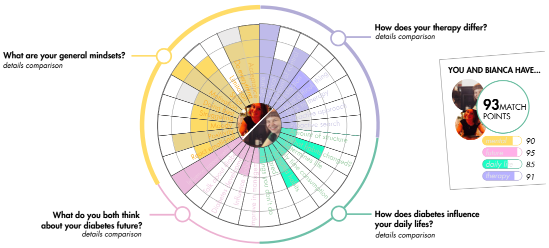
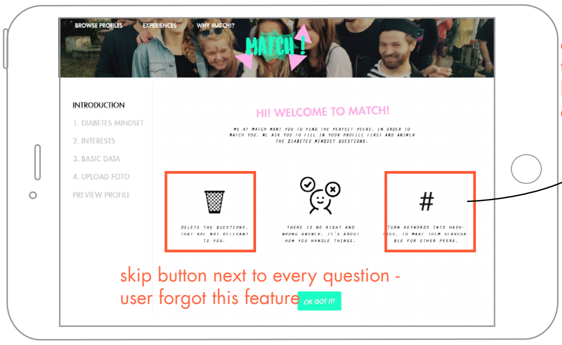


figure 136 too detailed mindset



WE AT MATCH WANT YOU TO FIND THE PERFECT PEERS. IN ORDER TO MATCH YOU, WE ASK YOU TO FILL IN YOUR PROFILE FIRST AND ANSWER THE DIABETES MINDSET QUESTIONS.

DELETE THE QUESTIONS, THAT ARE NOT RELEVANT TO YOU.

THERE IS NO RIGHT AND WRONG ANSWER. IT'S ABOUT HOW YOU HANDLE THINGS.

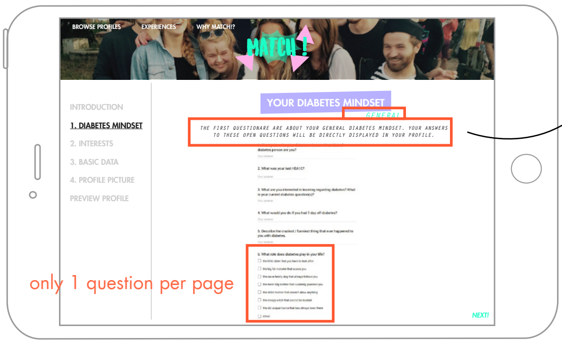
TURN KEYWORDS INTO HASHTAGS, TO MAKE THEM SEARCHABLE FOR OTHER PEERS.

skip button next to every question - user forgot this feature

automatically turn things into hashtags - users forget about this

figure 133 front page questionnaire - changes

not big enough - more clear which category you are in - in between page?



THE FIRST QUESTIONARE ARE ABOUT YOUR GENERAL DIABETES MINDSET. YOUR ANSWERS TO THESE OPEN QUESTIONS WILL BE DIRECTLY DISPLAYED IN YOUR PROFILE.

2. What was your last HBA1C?

3. What are you interested in learning regarding diabetes? What is your current diabetes question(s)?

4. What would you do if you had 1 day off diabetes?

5. Describe the craziest / funniest thing that ever happened to you with diabetes.

6. What role does diabetes play in your life?

only 1 question per page

figure 134 changes questionnaire

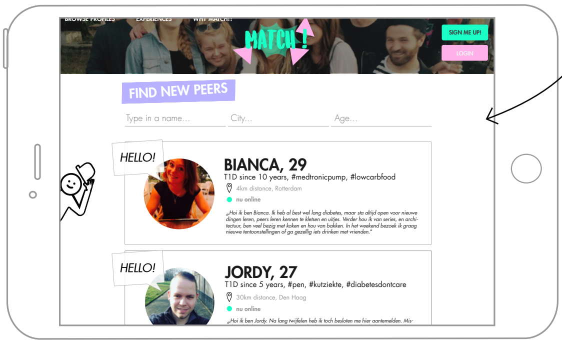
80 / 550 MEMBERS SEEM TO MATCH YOUR MINDSET PRETTY GOOD!

BIANCA, 29
T1D since 10 years, #medtronicpump, #lowcarbfood
4km distance, Rotterdam
nu online
„Hoi ik ben Bianca. Ik heb al best wel lang diabetes, maar sta altijd open voor nieuwe dingen leren, peers leren kennen te kletsen en uitjes. Verder hou ik van series, en architectuur, ben veel bezig met koken en hou van bakken. In het weekend bezoek ik graag nieuwe tentoonstellingen of ga gezellig iets drinken met vrienden."

JARAH, 24
T1D since August 2016, #freestylelibre, #hba1c45
12km distance, Rotterdam
last online today 10:15

too dark - remains hidden, too many details no overview

DESIGN PROPOSAL



BIANCA, 29
T1D since 10 years, #medtronicpump, #lowcarbfood
4km distance, Rotterdam
nu online
„Hoi ik ben Bianca. Ik heb al best wel lang diabetes, maar sta altijd open voor nieuwe dingen leren, peers leren kennen te kletsen en uitjes. Verder hou ik van series, en architectuur, ben veel bezig met koken en hou van bakken. In het weekend bezoek ik graag nieuwe tentoonstellingen of ga gezellig iets drinken met vrienden."

JORDY, 27
T1D since 5 years, #pen, #kutziekte, #diabetesdontcare
30km distance, Den Haag
nu online
„Hoi ik ben Jordy. Na lang twijfelen heb ik toch besloten me hier aantemelden. Mis-

figure 135 design proposal search settings

FLOW - FINAL ORDER PAGES

After filling in the first task within the generative interview, all patients were asked to rearrange the website screens and write down their preferred order of the slides. The preferred order of all participants were analyzed and compared and resulted in this final order (see figure137). The website should start off asking for the basic data as they are easy to fill in, afterwards the participants wished to see the profile they were about to fill in to have a better overview of what is going to happen. Starting off from the profile the different questionnaires could be answered. The questions were also limited to 30 questions in the order: basic data - mindset - interests (see appendix 31).

FLOW - MAIN MENU

Some participants expressed the wish to get rid of the home page and directly start off by seeing their matches when entering the website as that is the most important function within the website (see figure 138). All other functions displayed on the home screen such as "edit profile", "new peers" should be hidden within the slide-menu. Other peers thought it was nice to be greeted by the icon on a home screen and then being able to search for new matches. The button "new peers" was experienced as not being interesting to all participants as they would only contact their matches anyway.

"If a new peer is a match he/she will appear in my matches list, therefore I don't need that function." as one participant explained.

As Roche plans to display content within the platform, the home screen has to stay a sort of news feed. To which extend other features should be excluded would have to be tested in future iteration rounds.

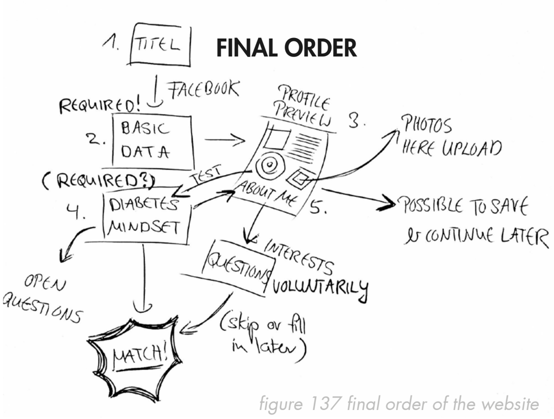


figure 137 final order of the website

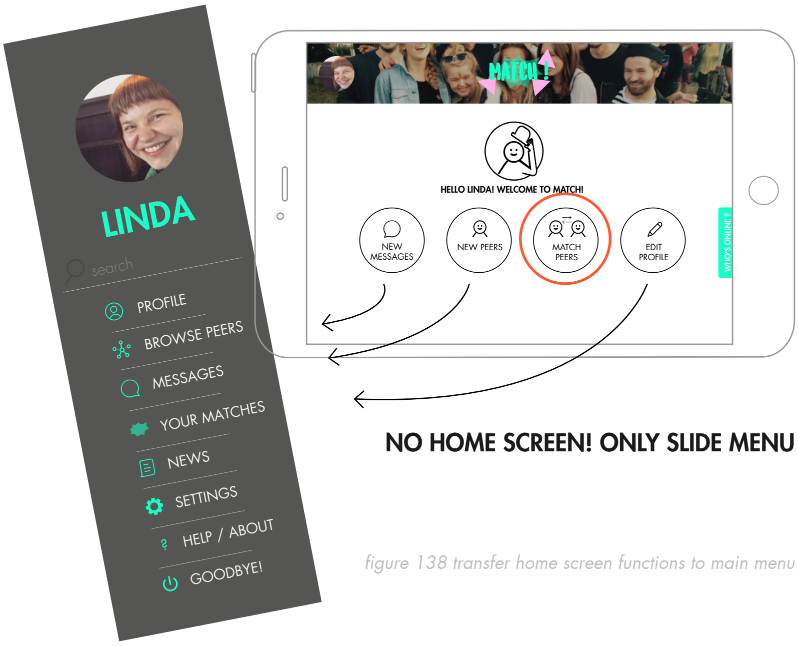


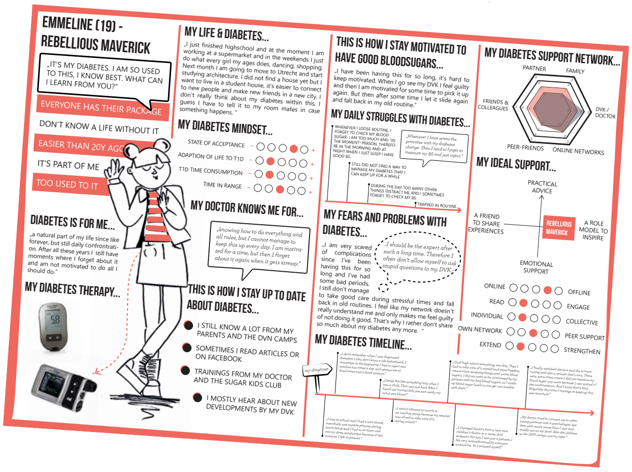
figure 138 transfer home screen functions to main menu

PLATFORM DEVELOPMENT TOOLKIT

This main goal of this project is to inspire the company how to develop their existing community within the future months. Therefore all generated insights within the analysis phase and infographics will be delivered to the company as an additional platform development toolkit, to be able to validate future development ideas with the help of the findings within this project.

The platform development toolkit consists of the characteristics of the 5 diabetes personas, the discovered moments of change timeline and all findings that have been generated within the expert interviews, summarized in the learning book - see appendix 4 (see figure 139). The personas were tested with the patients within the last iteration round to be able to validate their use of the support platform.

This way new ideas can be checked for feedback the experts provided to this topic, the employees of Roche can think about whether the idea would fit the persona and how the moments of change could help promoting or targeting the target group with the developed ideas. Furthermore, the tasks from the idea creation workshop can be used to develop new ideas.



EMMELINE (19) - REBELLIOUS MAVERICK

„IT'S MY DIABETES. I AM SO USED TO THIS, I KNOW BEST. WHAT CAN I LEARN FROM YOU?"

EVERYONE HAS THEIR PACKAGE
DON'T KNOW A LIFE WITHOUT IT
EASIER THAN 20Y AGO
IT'S PART OF ME
TOO USED TO IT

DIABETES IS FOR ME...

„a natural part of my life since like forever, but still daily confrontation. After all these years I still have moments where I forget about it and am not motivated to do all I should do."

MY DIABETES THERAPY...

MY LIFE & DIABETES...

„I just finished highschool and at the moment I am working at a supermarket and in the weekends I just do what every girl my ages does, dancing, shopping. Next month I am going to move to Utrecht and start studying architecture. I did not find a house yet but I want to live in a student house, it's easier to connect to new people and make new friends in a new city. I don't really think about my diabetes within this, I guess I have to tell it to my room mates in case something happens."

MY DIABETES MINDSET...

STATE OF ACCEPTANCE – ○ ○ ○ ● ○ +
ADAPTION OF LIFE TO T1D – ○ ● ○ ○ ○ +
T1D TIME CONSUMPTION – ○ ● ○ ○ ○ +
TIME IN RANGE – ○ ○ ● ○ ○ +

MY DOCTOR KNOWS ME FOR...

„knowing how to do everything and all rules, but I cannot manage to keep this up every day. I am motivated for a time, but then I forget about it again when it gets stressy."

THIS IS HOW I STAY UP TO DATE ABOUT DIABETES...

- I STILL KNOW A LOT FROM MY PARENTS AND THE DVN CAMPS
- SOMETIMES I READ ARTICLES OR ON FACEBOOK
- TRAININGS FROM MY DOCTOR AND THE SUGAR KIDS CLUB
- I MOSTLY HEAR ABOUT NEW DEVELOPMENTS BY MY DVK

THIS IS HOW I STAY MOTIVATED TO HAVE GOOD BLOODSUGARS...

„I have been having this for so long, it's hard to keep motivated. When I go see my DVK I feel guilty and then I am motivated for some time to pick it up again. But then after some time I let it slide again and fall back in my old routine."

MY DAILY STRUGGLES WITH DIABETES...

WHENEVER I LOOSE ROUTINE, I FORGET TO CHECK MY BLOOD SUGAR. I AM TOO MUCH AND "IN THE MOMENT" PERSON. THEREFORE IN THE MORNING AND AT NIGHT WHEN I JUST SLEEP I HAVE GOOD BS.

„Whenever I have stress the priorities with my diabetes change. Then I tend to forget to measure my BS and just inject."

STILL DID NOT FIND A WAY TO MANAGE MY DIABETES THAT I CAN KEEP UP FOR A WHILE.

DURING THE DAY TOO MANY OTHER THINGS DISTRACT ME AND I SOMETIMES FORGET TO CHECK MY BS.

TRAPPED IN ROUTINE

MY FEARS AND PROBLEMS WITH DIABETES...

„I am very scared of complications since I've been having this for so long and I've had some bad periods. I still don't manage to take good care during stressful times and fall back in old routines. I feel like my network doesn't really understand me and only makes me feel guilty of not doing it good. That's why I rather don't share so much about my diabetes any more."

„I should be the expert after such a long time. Therefore I often don't allow myself to ask stupid questions to my DVK."

MY DIABETES TIMELINE...

my diagnose

„I don't remember when I was diagnosed therefore I also don't know a life beforehand. I remember in the beginning I had to inject mix insuline two times a day and always eat at fixed times and a fixed amount."

„I was at school and I had a sore throat, everybody was outside playing during lunch break and I had to sit down and eat my three sandwiches because of the insuline. I felt so piteous."

„Candy felt like something holy when I was a child. That was just bad. After I found out normal kids just eat candy my mind was blown!"

„I wasn't allowed to switch to an insuline pump because my teacher was afraid to take care of it during school."

„Until high school everything was fine. Then I had to take care of it myself and more freedom meant more tempting things and worse blood sugars. I did not want to be confronted by my parents with my bad blood sugars, so I made up blood sugar levels to not get into trouble with them."

„I changed doctors from a very nice children's doctor to a mean drill sergeant. For him I was just a patient, I felt very misunderstood by everyone around me. So I isolated myself."

„I finally switched doctors and she is more caring and also a woman that's nice. There were some times where I did not measure my blood sugar any more because I was scared of the confrontation. And I know that's bad. Hopefully this time I manage to keep up this new structure."

„My doctor tried to connect me to other young patients with a psychologist, but they were much worse than I was and totally not on my level. Also the children at the DVN camps...not my type."

MY DIABETES SUPPORT NETWORK...

MY IDEAL SUPPORT...

ONLINE ○ ○ ○ ● ○ OFFLINE
READ ○ ● ○ ○ ○ ENGAGE
INDIVIDUAL ○ ● ○ ○ ○ COLLECTIVE
OWN NETWORK ○ ○ ● ○ ○ PEER SUPPORT
EXTEND ○ ● ○ ○ ○ STRENGTHEN

PERSONAS AT THE MOMENT OF CHANGE:

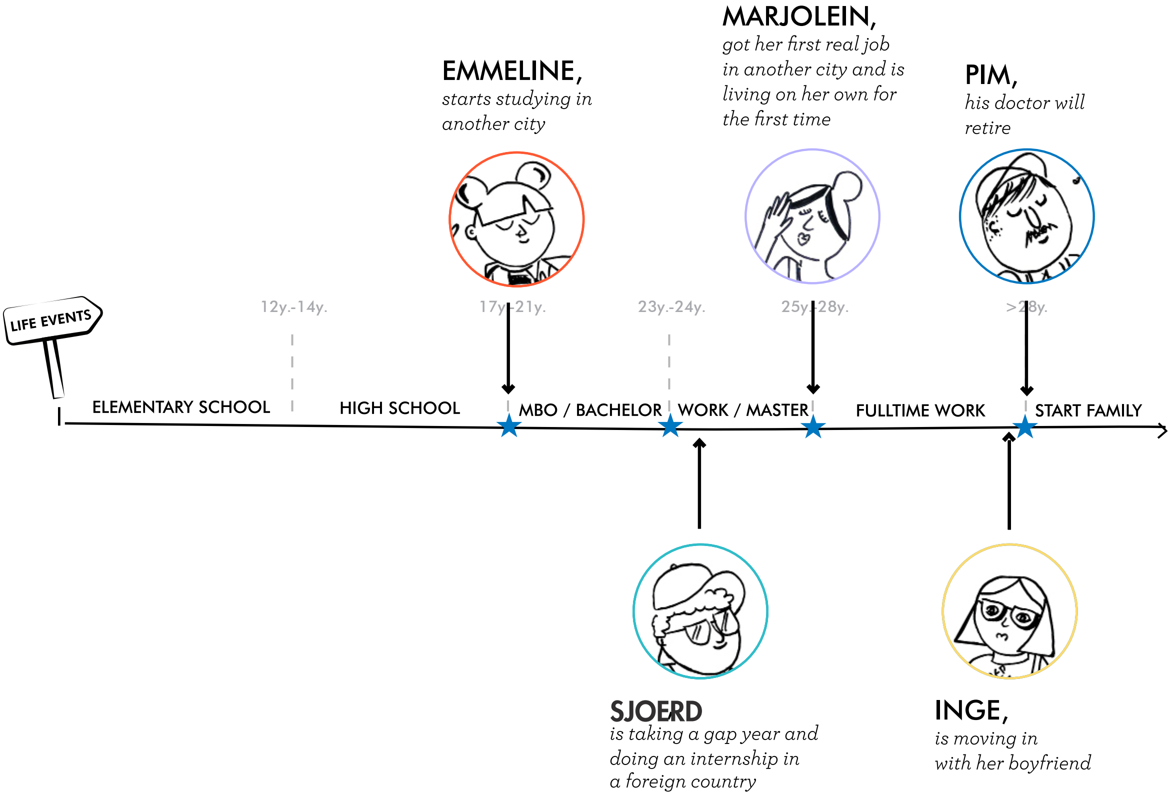
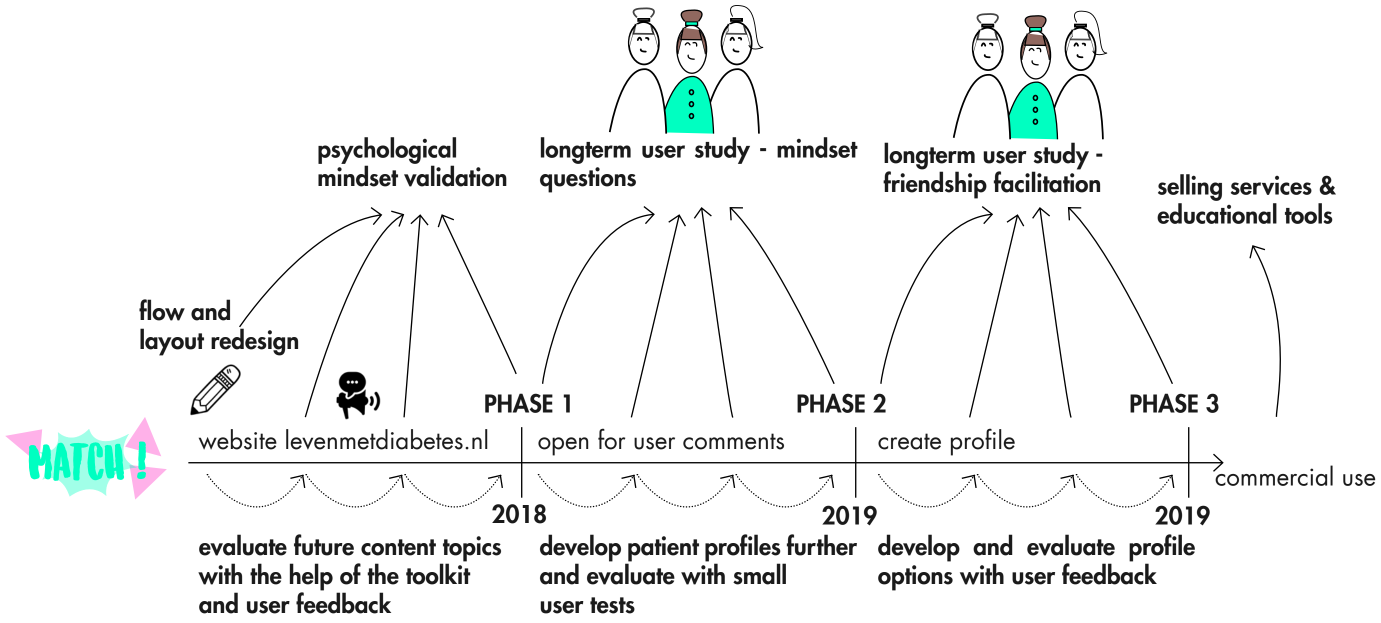


figure 139 parts of the toolkit

ROADMAP TO IMPLEMENTATION

The company is planning to turn the existing website into a community in 2 phases, starting at the beginning of 2018. Within phase 1 users will be able to comment on the provided content and blogs and within phase 2, parts of this project will be implemented and user will probably have the possibility to create their own profile. Within figure 140 the most important implementation steps are summarized.



As the company already has a quite big customer circle through the product registration and registration for the newsletter, the platform should be promoted within this circle to be able to provide enough profiles to find sufficient matches before opening the platform to the public. Accu-Chek has 70.000 diabetes patients within their online patient data base and 6000 insulin pump user. These users can be contacted within the newsletter or through the existing website. Furthermore, through the newsletter questionnaires regarding the mindset and for user feedback can be send out.

The following ways to promote the platform have been developed together with the intern ship coordinator of Roche Diabetes Care:

Online promotion
_newsletter
_website Accu-Chek - levenmetdiabetes.nl - Roche
_google search engine marketing
_fb group advertisement

Offline promotion
_diabetes education evenings & foundation activities
_suppliers (mediq, diactueel)
_diab magazine of the DVN
_goodiebag at different activities
_fairs - register directly and find matches on site

Promotion moments / chances
_Packaging of blood sugar meters & pumps
_courses for Aviva expert blood sugar meter + pump user
_DVK can promote platform during course
_doctor's waiting room - match directly by scanning

5.4 PERSONAL REFLECTION

I started this project out of the ambition to become active as a patient and contribute to the development of diabetes support possibilities. As I had experienced myself that being sufficiently supported helps handeling the disease this was my biggest motivation to give more than 100% within this project. Looking back being a patient myself provided a lot of advantages but also brought some struggles with it. Within this page I want to reflect on the project's ups and (small) downs.

When searching for patients, being a patient myself opened a lot of doors and patients immediately trusted me to tell their story and understand their struggles. At the beginning of every interview I told my own story to make clear that to some extend I had experienced a lot of troubles myself and was free of judgement. I was able to dig very deep within the interviews and brought up topics like trust issues, feeling exhausted and hiding the disease, some patients even talked about depression and attempted suicide. Some patients were grateful to be able to tell their complete story for the first time, since a doctor often only focuses on the medical side of the disease and psychological help is not easily accessible for adult patients any more. Sometimes, by putting the story into a timeline, patients were able to draw new conclusions and understand why they acted that way.

During the interviews I realized that subconsciously I enjoyed the interviews with the patients I could connect most to, the most. I wanted to contact them afterwards but wasn't sure if that would be in favor of my project to stay objective and not mix personal contacts with the analysis.

On the other side, when I was interviewing patients that had negative attitude towards their diabetes or being ignorant I was afraid that they could pull me down again and bring back my old patterns, if I spend too much time with them. I also catched myself secretly thinking that they were moaning too much and should stop complaining since having diabetes is not that bad for me and they have not been having it for so long as I have.

Getting in contact with so many peers was a very inspiring new experience that I would not want to miss. Even though, to be honest, after a while I realized that being a member of at least 10 diabetes group provided too much input and made me continuously think about my own disease, which is not something I desired. Still, it was good to therefore think about the project the whole time as well. Being a patient and expert at the same time provided a lot of motivation to give more than 100% within this project but also brought some pitfalls and limitations. I was constantly thinking about myself as a patient and asking myself "would I really use this concept?" "Would this be something I want to do?". Reflecting back at the interviewed patients and insights that were collected along the way I feel like I got so much into this topic that I could not answer this question out of the perspective of me as an external diabetes patient. Therefore my personal guideline to use my expertise as an expert but still keep neutral functioned pretty well in the end.

The two most important things I learned for myself within this project was that first of all even though you plan your project very well and put up a strict time schedule and even book a trip as a motivation after the project, you can never fully calculate all possible things that could happen. Having a close relative pass away destroyed my planning and it was a lot of work getting back on track with the project afterwards. Therefore within future projects I will plan more buffer inbetween different phases.

The second thing I learned about myself as a designer is that even though I really enjoyed using the contextmapping methods and basing the whole concept on real user feedback, the other part of concluding findings back to literature remains a tough one. Having done my Bachelor at a school that was completely focused on a designer's intuition and personal opinion, the switch of having to provide reasoning for my decisions was difficult. This is something I want to furtherly improve within future projects, as I understand the value of being able to easily "sell" your results to company employees once they are backed with literature and user opinions. Within this final thesis I felt like I already made a lot of progress implementing and developing findings to become waterproof, but I know that the ladder of high class scientific research is high within the Netherlands.

Overall this project has been great pleasure and challenge to me and confirmed my decision to work on projects that would really enrich the life of others. Even though being a patient since 24 years, I have learned so many new surprising insights that I am now even more persuaded that no design concept can ever be developed without the feedback and testing with real users.

Words of appreciation

I consider this graduation project a wonderful collaboration with people I was able to learn so much from, which resulted in an outcome that inspired me as a patient and designer. This project has been a great learning opportunity for me, about my personality as a designer and as a patient.

This ton of work would have not been possible without a wonderful team of attentive and creative people that guided me through the project and helped me whenever I got stuck. I got to know a company that is really caring for their patients and people that could really emphasize throughout the project without even having diabetes themselves. My sincere thanks to Marianne and all employees that participated in the company workshops and feedback rounds. Thanks to Stella and Quiel for keeping me sharp and attentive throughout the whole process and especially Quiel for your open ear whenever I was hesitating or got stuck.

Furthermore I would like to thank all the diabetes peers that supported me throughout my project and provided me with fresh insights and feedback. Their input guided the project towards a realistic outcome, and will hopefully helps many peers in the future.

Last but not least, thank you to everyone who listened to my endless stories about my graduation support, showed interest in my project without being a peer and tried to understand more about the medical backgrounds of diabetes in order to understand what I am working on. You are the best. :)

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