# The Online Support Platform for Facilitating Effective Communications between Facioscapulohumeral Muscular Dystrophy (FSHD) patients and the Healthcare Network

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**2021.12**

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# Executive summary

Facioscapulohumeral muscular dystrophy (FSHD) is one typical type of chronic Neuromuscular Dystrophy. This type of disease necessitates network care because it is complex and necessitates a network of diverse healthcare expertise to reduce the negative effects of the disease and rehabilitate the patient to live a more normal life. As a result, effective communication and collaboration among various healthcare members become an important part of the overall patient experience.

Based on the user research, it can be found that patients often encounter problems during their treatment, but they often cannot get proper help quickly due to the slow reply time of the healthcare professionals. Also, because of the difference in the know-how of the disease, the communication towards the patient is not summarized as one diagnosis and support session and in the end, they cannot get a complete answer from the healthcare team. Therefore, I want to design an online support platform to help FSHD patients get the right help in time during the treatment of their disease.

The final design is an online support platform that aims to help patients solve their problems during the treatment and facilitate effective communications between patients and the healthcare network. The core of this service platform is to introduce a personalized coach to bridge the gap between the two sides. The platform has two main functions, treatment, and chat, which can meet most of the needs of a patient during the treatment process. In the treatment session, patients can follow the exercise videos based on their treatment plan made by the healthcare professionals. After they complete one exercise, the platform enables users to make a self-evaluation of their performance. When patients feel negative about the training, they can quickly inform this situation to the coach and the healthcare team by using the share function. Then they will receive comments on their recordings from the healthcare professionals so that they know how to adjust their actions. The chat function allows the patient to quickly ask questions and express their need when they encounter problems with their personalized coach. The coach will help to filter the question and inform the related healthcare professionals to discuss it in a chat group when needed. When the discussion ends, patients can get a summarized answer from the coach.

Based on the usability test, it can be validated that the design can bring benefits to people. The two main features of the online platform (chat and treatment) were useful to the test subjects, and they expressed a willingness to use the platform if it will be developed in the future. However, there is still room for improvement. In the future, we can further think about enlarging the user group, such as involving more patients of other neuromuscular diseases and expanding the service, such as helping the customer to build their healthcare team to add more value to more people.

# 1. Introduction

Chronic Neuromuscular diseases (NMD:s) are common diseases that impact the nerves that govern voluntary muscles as well as the nerves that relay sensory information to the brain. People with these diseases often not only suffer from physical disabilities, such as pain, muscle weakness, and sleep disturbance, but also they may experience some mental distress, such as frustration and nervousness. There are numerous types of neuromuscular disorders, while Facioscapulohumeral muscular dystrophy (FSHD) is one typical type of Muscular Dystrophy. Network care is needed for this type of disease because they are complex and require a network of different medical care expertise to help the patient to live a more normal life and reduce the negative effects of the disease in the patients' life. This results in effective communications and collaboration between different members becoming an important part of the whole process. Currently, many online healthcare platforms provide services for patients and healthcare professionals to enhance their life quality and communication efficiency. However, these platforms are in the early stages of development, so many functions are not yet perfect. Therefore, it is advantageous to design an ideal online healthcare platform for the target audience. In this project, people living with FSHD were set as the target audience and systematic research about the current situation of communications between the patients and the diverse healthcare professionals was conducted. Based on the results and analysis, an improved online healthcare platform was designed, followed by a user evaluation and future recommendations at the end of the report.

# 2. Project scope

### 2.1 Case description

According to the previous research by Samen Sterker, there are five high-level problem statements defined within the whole process of disease diagnosis and treatment of FSHD patients, which include:

1. Information – know-how is often lacking at the right time and place for best possible care.
2. Guidance – advice is not always as positive as it could/should be for patients to develop.
3. Holistic care – a complex care system is challenged to give holistic personalized care.
4. Location – the best care for NMD´s is often far away and requires traveling.
5. Exercise – the proven positive impact of the right form of exercise - is far from fully applied

To make my research and design more targeted, in this project, I will focus on one of these five directions and my option is problem statement 3, holistic care. This statement is more in line with the intention of this project, which is to investigate issues related to effective communication and collaboration between patients and healthcare professionals. To ensure the quality of holistic care of one patient, as a network, there are lots of different roles involved around one patient, such as a neurologist, a physiotherapist, and a rehabilitation doctor. Currently, many people visit the hospital or the doctor for a consultation, and they might ask if it is really important. Different roles of care professionals usually have no idea what the other is doing, which increases the likelihood of a mistake. As a result, the patient requires a single atmosphere in which he can interact with all his healthcare providers and has control of his data. To deal with these problems, there are lots of online healthcare platforms now. However, without good guidance on customer-centric design, there is a risk that these platforms are utilized in a suboptimal manner towards the end-user. Therefore, better understanding the needs and desires of the patients with NMDs and designing an online care platform for them is very valuable.

### 2.2 Stakeholders

This project is proposed by “Samen Sterker”, known as a network for quality care and quality of life for people with chronic Neuromuscular Diseases (NMD:s). They are now focusing on improving the current situation of these groups of people. They believe that ‘together we can be stronger and aim at improving the quality of life for millions of people that have any of the 500+ rare NMDs, especially for people and patients with Spinal muscular atrophy (SMA) and Facioscapulohumeral muscular dystrophy (FSHD). To be specific, they want to improve the services from 1-2-3 line medical and care professionals as well as a relevant extended network of services and support. In this project, they will act as one of the main stakeholders and actively participate during the whole process of the project.

# 3. Background

In this chapter, I did some literature review in terms of the disease, the healthcare network, and the current tools and methods that facilitate effective communications between patients and care providers. Understanding the characteristics of this disease will help me to gain a basic view of how it affects the patient's life. Understanding the necessity of communications in healthcare and investigating the current communication tools that improve patient experience help to provide insight and theoretical support for the subsequent research and design.

## 3.1 The disease of FSHD

### 3.1.1 General information

Facioscapulohumeral muscular dystrophy (FSHD) is a chronic disorder that causes muscle weakening and wastage in people's faces, shoulder blades, and upper arms (). The disease is named after the muscles in the face (*facies*), around the shoulder blades (*scapula*), and in the upper arms that are afflicted (*humerus*). Clinical observation and DNA testing are the common ways for FSHD diagnosis. The majority of cases are caused by chromosome 4 repetition (Statland & Tawil, 2016). The severity of symptoms depends on the size of the mutation of the D4Z4 repeats of the patients. The less the unit is repeated, the more severe the disease will be. Patients' treatment methods will also vary depending on the severity of their illness. In addition, FSHD is a hereditary muscle disease. About two-thirds of individuals with FSHD inherit the disease from an affected parent (Statland & Tawil, 2016). As there may be multiple individuals with this disease in the same family, this will help with the accuracy of the pre-diagnosis of the disease. This also provides the possibility for family members to help each other when there are problems.

### 3.1.2 The symptoms

Patients with FSHD often suffer from pain, muscle weakness, and sleep disturbance, which may lead to fatigue and physical inactivity (Mul, et al, 2016; Statland & Tawil, 2016). While some patients also experience joint and spinal abnormalities and hearing loss. As a slowly progressive muscular dystrophy, the signs and symptoms of FSHD usually appear in adolescence, with most people noticing some problems by age 20 (Muscular Dystrophy Association, 2009). In most people with FSHD, the disease progresses very slowly. It may take many years for patients to show some symptoms. Therefore, patients may ignore some of their symptoms in the early stages and do not seek medical attention until their shoulder or leg muscles get affected. The pain and inconvenience they experience are not only physical, but a large part of it is also psychological. During the progression of the disease, patients often experience some negative emotions such as depression and anxiety. This will affect their normal social participation and interaction with others. However, as a disorder of the nervous system, FSHD will not affect patients' learning abilities or sensations (Muscular Dystrophy Association, 2009). This means that patients can still learn and try new things within their physical ability.

### 3.1.3 The treatment

Until now, there is no therapy or cure for FSHD even through pharmaceutical drugs or surgery (Tawil, 2008; Statland & Tawil, 2016). However, some treatment activities may be

done to mitigate its consequences. Clinical research found that moderate aerobic exercise combined with cognitive-behavioral treatment reduced persistent tiredness in FSHD patients (Voet, et al, 2014). Exercise including aerobic exercise and strength training can help to strengthen muscles that are not significantly damaged and enhance an individual's total aerobic capacity. But it should be developed with the guidance of a professional physical therapist. During the daily training, patients need to pay attention to the exercise intensity to avoid hurt and overuse. Since patients vary a lot in their age, body condition, and disease severity, personalized training becomes even more important for FSHD patients (Muscular Dystrophy Association, 2009). Individuals should undertake baseline assessments of strength and exercise ability before commencing an exercise program, as well as provide a detailed account of their daily activities relating to personal care, home responsibilities, and work-related obligations. They should also discuss their favorite pastimes and personal ambitions that they hope to attain. A tailored program may be created using all of this information. While it should also include some instructions such as exercise repetitions, intensity, and duration. It is also important for healthcare professionals to monitor patients' daily activities and ask frequently about their condition since although patients will re-visit some care providers regularly, most of the time patients will complete their daily training alone at home. Patients were recommended to maintain a daily log documenting their daily activities and symptoms to provide useful feedback for the healthcare team (Muscular Dystrophy Association, 2009). And because the treatment process can be lengthy and patients often have many problems during the exercise, efficient care and support from the healthcare team become very important.

## 3.2 The communications between patients and healthcare professionals

### 3.2.1 The importance of communication

Studies have shown that excellent communication between doctors and patients, as well as among all caregivers who have direct contact with patients, resulted in improved clinical outcomes, lower costs, more patient satisfaction, and lower rates of physician burnout (Harrington, et al, 2004; Schmidt, et al, 2017). However, nearly half of all chronic illness patients (49.5%) report communication problems with their medical professionals (Henselmans, et al, 2015). Compared with other chronic diseases, FSHD is a relatively rare condition, not all the related healthcare providers have sufficient knowledge about it. Therefore, patients will have even more contact moments with various professionals for measurements and checks. During the process of consultation and treatment, there are multiple roles involved, such as the GP (general practitioner), the neurologists, the physiotherapists, etc. Therefore, a good patient experience is inseparable from the effective communication and cooperation of these people.

### 3.2.2 Current communication tools

Currently, there are many types of information and communication technologies aiming at improving communication quality between patients and healthcare professionals. Some commonly applied methods are communicating through text messages and video technology (Lindberg, et al., 2013). In terms of text messages, websites or web-based tools were utilized to deliver text messages. Patients utilized handheld platforms, such as mobile phones or laptop computers, to transmit and receive

information to and from the healthcare team (Finkelstein, et al., 2006; Darkins, et al. 2008. Self-care advice and an electric diary are typical examples that are often communicated through text messages. Such online communicating approaches allow different members to exchange ideas disregarding time and geographical limitations. Another commonly used form of communication is via video technology (Elliott, et al, 2008; Lindberg, et al., 2013). Examples of applications include instructing patients in the usage of medical equipment and improving their self-management through video-based home telecare services. Videoconferencing is another important application. Especially with the impact of Covid-19, virtual consultants through online video platforms rather than visiting the hospital are becoming more common, allowing for more easy access to experts. In short, both communication forms can contribute to communicating patients' data and managing their symptoms to help healthcare professionals achieve better home health monitoring. While there is no doubt that these tools still cannot replace the offline encounter between the patient and the healthcare professionals.

To promote remote home monitoring of patients with chronic diseases and effective communications between the healthcare team and patients, having a coach assisting the patients is also a common intervention. A review by Alders (2017) indicates that a personal coach can help to eliminate communication obstacles seen in the contact between the patient and the medical experts. Especially for those elderly who show poor information-processing abilities or health literacy (Alders, et al, 2019). While when it is in an online environment, it is still found that an e-coach can help patients to maintain a physically active lifestyle since it enables patients to receive quick feedback that can assist them in doing a sufficient amount of physical exercise while avoiding joint pain (Gupta, et al., 2018). A study by Allen (2008) shows that most patients (88%) who contacted the e-coach were interested in further coaching, which further demonstrates the positive effects of the presence of an e-coach in the treatment process.

**3.3 The trend of online healthcare service**

Currently, the whole healthcare network in the Netherlands can be divided into two parts, the PGO (Persoonlijke Gezondheids Omgeving) and the ZNO (Zorg Netwerk Omgeving) (see the Figure below). PGO (Persoonlijke Gezondheids Omgeving) is the patients' safe online environment where they can store and share all their data about their health with their healthcare network. ZNO (Zorg Netwerk Omgeving) optimizes care for patients within a (regional) network of healthcare professionals. This kind of network enables care professionals to give a better service to the patient community. The online environment offers functions for communication, care coordination, and creating an integrated picture of the patient. A good patient medical experience and medical quality are inseparable from the effective cooperation between the two networks and the effective cooperation between different roles within the network.

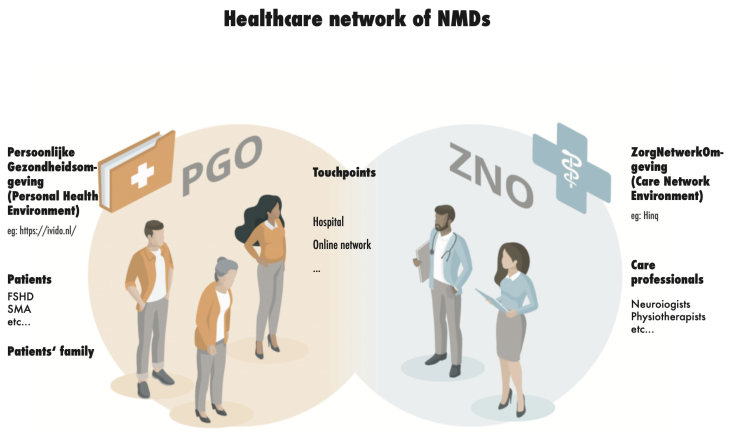



Figure 1. Healthcare network in the Netherlands

Currently, there are many online SaaS (Software as a service) platforms (a way of delivering applications over the Internet—as a service), such as “Hinq” and “Mighty networks”, which provide service for patients and care professionals to improve their life quality and the whole medical experience. However,  because the concept of the current healthcare network is still in the early stages of development, many problems have yet to be resolved, such as how to integrate different patient data and how to provide a way to help effectively communicate between different medical roles. Therefore, studying how to improve the user experience of these people, and design a medical network suitable for them is very valuable.

# 4. User research

After investigating some background information about the disease and communication tools for patients and healthcare professionals, user research was conducted to further understand the user needs and pain points. This chapter mainly describes the objective of the research and how the research was set and planned.

## 4.1 Research goal & questions

### 4.1.1 Research goal

From the user research, one of the principal goals is to gather data from the target audience to gain a deep understanding of their needs and desires. The main research method used was user interviews. By conducting user interviews, I can gain a clearer view of how patients are currently communicating with different healthcare providers and their feelings during communication.

### 4.1.2 Research questions

Since the main project focus is about improving the communication quality between FSHD patients and healthcare providers, the main research question was defined as:
*How to facilitate effective communication among different characters in the healthcare network?*

To answer this question, it is important to understand the latent reasons behind it, therefore, the sub-question was defined as:
*What are the main factors that affect effective communication among those people?*

## 4.2 Interview plan

### 4.2.1 Virtual interview

Due to the travel limitation of Covid-19, all of the interviews were conducted digitally. Although the virtual interview makes it kind of difficult for the interviewer to observe the participants' real feelings and reactions, especially for some older respondents, they are often not very good at using those digital tools, it is still a very sufficient method at this special time. One of the benefits is that it makes it more flexible in the choice of time and place for the participants to join the interviews. It saves lots of energy and effort of traveling from place to place. This is especially beneficial for our research objects since they may be affected by their diseases and have limited mobility. While they are at home and answer all the questions at their own pace, it also allows them to be more relaxed, so that the answer will be more truthful and insightful.

### 4.2.2 Generative session

In addition to the regular Q&A session in the interview, a generative session was also used in the interview. This approach was achieved by providing some toolkits and probes for the participants. These toolkits often contain some simple tasks for the participants to complete. By completing those tasks, I can gain deep and latent insights into how they feel and what they desire based on their deliverables, actions, and their explanations. The tasks can also work as triggers to help the participants easily tell their stories and elicit their emotions and memories.

#### 4.2.3 Corporation

In terms of the format of the actual interview, all of them were conducted based on close and organized cooperation with another Dutch student, who is doing the same project with a similar topic as I do. This is mainly because of two reasons. First of all, due to the impact of the epidemic, it has become more difficult to recruit interviewees, and I am unable to contact patients on the spot to communicate face-to-face. Secondly, due to the language habits of the locals, communicating in Dutch may be more effective. Therefore, in the entire interview of this project, he conducted the actual recruitment of interviewees in the early period and the interview in the later period. During the whole process, I completed the preparation of the interview guide with him, provided him with some suggestions from the perspective of the designer, and made some visuals. After the interviews, he shared with me the quotes of the participants with their consent. This made it easier for later analysis.

#### 4.2.4 Sample

The participants were all recruited based on some standards. The target audience of this project is mainly the patients and people with FSHD. We will take patients in the Netherlands as the main research object because that is the population targeted by Samen Sterker. Thus, all the people interviewed should be someone who has had FSHD in their life. We also try to make the interviewer's age cover all age groups of our target population. Since the context of this project was defined to be the healthcare network in the Netherlands, all the interviewees should be dutch people or who live in the Netherlands currently. While some insights can still be gained from people outside the Netherlands since there will be some similarities in different healthcare environments.

### 4.5 Practical setup

Since the entire interview was conducted online, I wanted to give the participants a more comfortable experience while ensuring the effectiveness and reality of the interview as much as possible. Therefore, a Miro board was created for better guiding our participants through the interview, where all the related tasks with some visuals were listed in one place. Zoom meeting was used as an online communication medium for the interview. It is safe and easy to use, thereby reducing the chance of users having problems when using it. An interview guide was made to help the interviewer better guide the participants through the whole session. (The full version can be viewed in the appendix).

Generally, the interview contains three sections. The first part is the introduction section. In this section, some questions related to the basic information about the disease and their life will be asked. For example, *How does your disease affect your life as it is right now?* This will also act as a sensitizing part that introduces the participants to the environment and helps them open their minds.

In the second section, some tasks with instructions and visuals were provided for the participants to complete (see figure below). The first task aims to understand the patients' current experience of how they experience the communications between

them and other roles in the healthcare network. A map of communication was made and the participants can select the elements/emojis from provided frames to make their map. After finishing, they were asked to explain what they made.

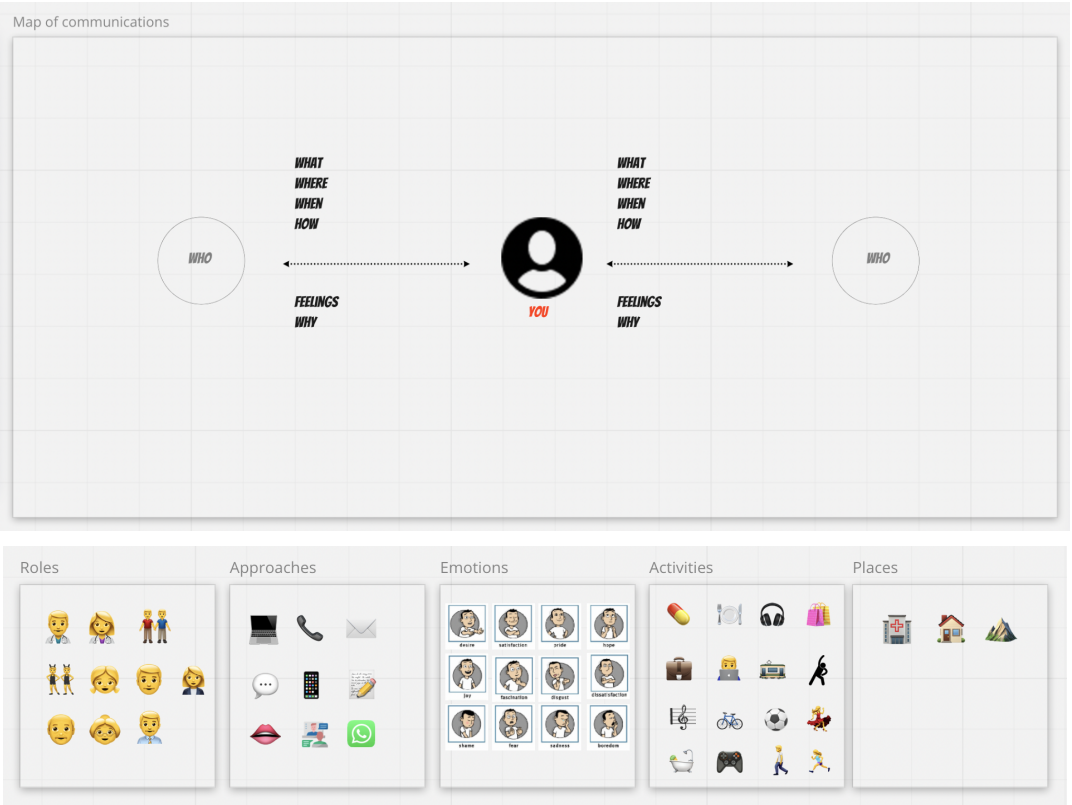



Figure 2. The toolkits for participants

The second task is to let the participants imagine their desired future. They were asked to change the map they made into an ideal one based on their personal feelings and preferences. Compared with the first task, this task seems to be much more difficult. It is also common that it is not that easy for people to know what they need and want. Therefore, in the third section, some possible solutions with visuals were provided for them. They were asked to talk about their opinions about each solution. By doing this, we make it much easier for the participants to imagine and create the desired future scenario.

# 5. User research analysis

### 5.1 User segments

In total, six people participated in this interview aged from 44 to 71 years old. Based on the user interview, some general features of the patients can be gained. Generally, FSHD will have direct adverse effects on their physiology, such as muscle weakness, sleep disturbance, and so on. This will affect the patient's normal life to a certain extent. They can no longer continue their hobbies as before, especially some sports. This physical pain will also have some negative effects on their psychology, for example, they often feel depressed and become unwilling to socialize. In terms of the communications in their care process, all participants think it is important to ensure easy and effective contact with the healthcare team and they want to be actively involved in the process. Among these participants, half of them have lived with this disease for a long time (>5 years), and half of them are relatively short diagnosed patients (<5 years). Therefore, the six testers were further classified into two groups based on their common features. By segmenting the users, it helps to make the design more relevant and beneficial to personalize the experience.

Short diagnosis (<5 years)

1. They are unfamiliar with the disease and the whole treatment process and need more guidance and help.
2. Have more negative emotions such as frustration.
3. Have more motivation about the treatment. They will be more likely to follow the instructions of the healthcare providers in the training program.
4. Don't know many people who have the same disease

Long diagnosis patients (>5 years)

1. They are getting used to living with the disease and know how to deal with some basic problems.
2. They become a little negligent to the treatment plan. They are not as enthusiastic as at the beginning, and more often do not complete training on time.
3. They have their understanding of the treatment and prefer to exercise in their way. They will try more things in their daily treatment.
4. They know more patients who are in the same situation, but the communication is not very frequent.

### 5.2 Customer journey map

Based on the user interview, a customer journey map from the patient's point of view was made (see figure below). The target audience is all FSHD patients within the dutch medical care system. This map covers their entire medical process from the initial diagnosis to the later treatment. Generally, the patient journey was divided into three stages, before diagnosis, during diagnosis, and after diagnosis (treatment). Different actions in each stage, users' emotional changes, and key touchpoints were indicated in this map. This visualization helps to dive deep into the target user and gain insights into common customer pain points. So that I can better tailor the customer experience to

their needs. And by elevating the user experience at the lower points and optimizing the experience at higher points, I can make the whole experience ideal.

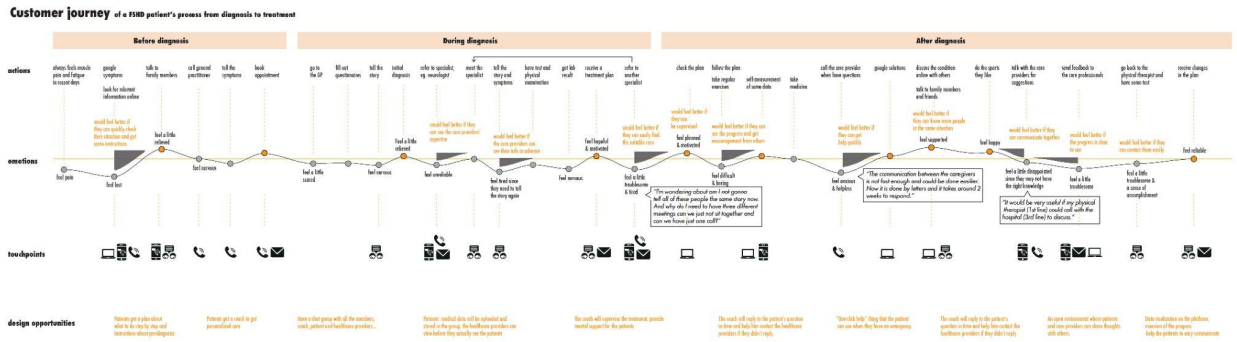



Figure 3. Overview of the customer journey map

The first stage is mainly the detection stage of the disease. At this stage, users begin to notice some symptoms of illness, but they cannot confirm what they are suffering from. So they began to search for relevant content on the Internet and discuss it with their family members. Since this disease is a genetic disease, some of their family members have a high probability of being a patient of this disease, so the patient's search at this time will not be aimless. The psychology of patients at this stage is often worried and confused because their body begins to have problems but they don't know the specific cause. The miscellaneous information on the Internet sometimes has a certain misleading effect, which makes the patients feel more anxious. This stage is a relatively intensive stage of user interaction with the Internet, so in this stage, we need to consider how to make our website visible and attract users' attention.

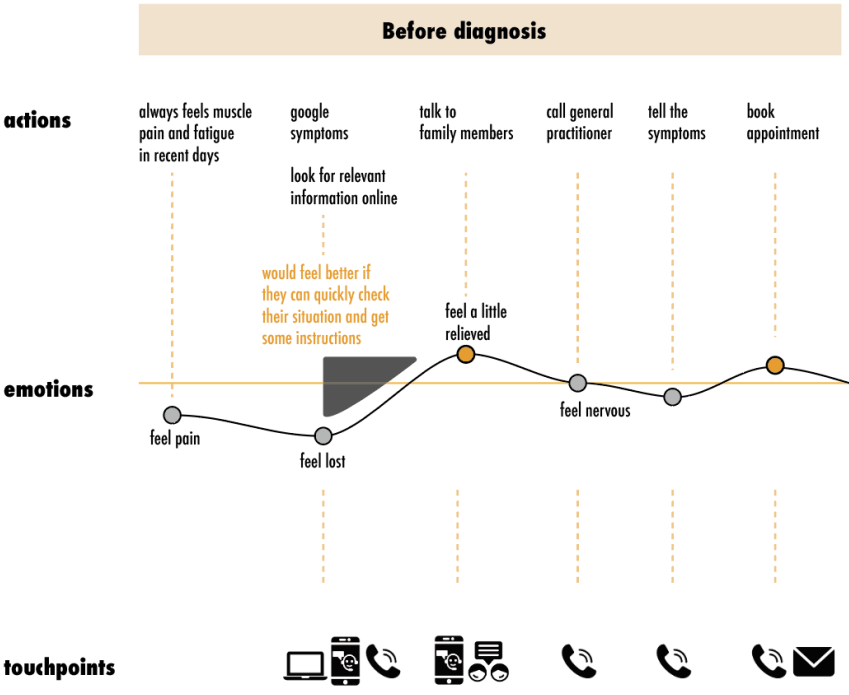



Figure 4. Before diagnosis

The second stage is the diagnosis stage of the disease. Due to the rarity of this disease, some doctors do not have much experience or professional knowledge about this disease. Therefore, users will interact with many different medical roles at this stage until the final diagnosis. However, in this process, many user actions are repeated. For example, every time they meet a new doctor, they need to repeat their story. This is a great compromise in the efficiency of the entire process. Also, if all the healthcare professionals work separately, there will be conflicts in the formulation of the final treatment plan.

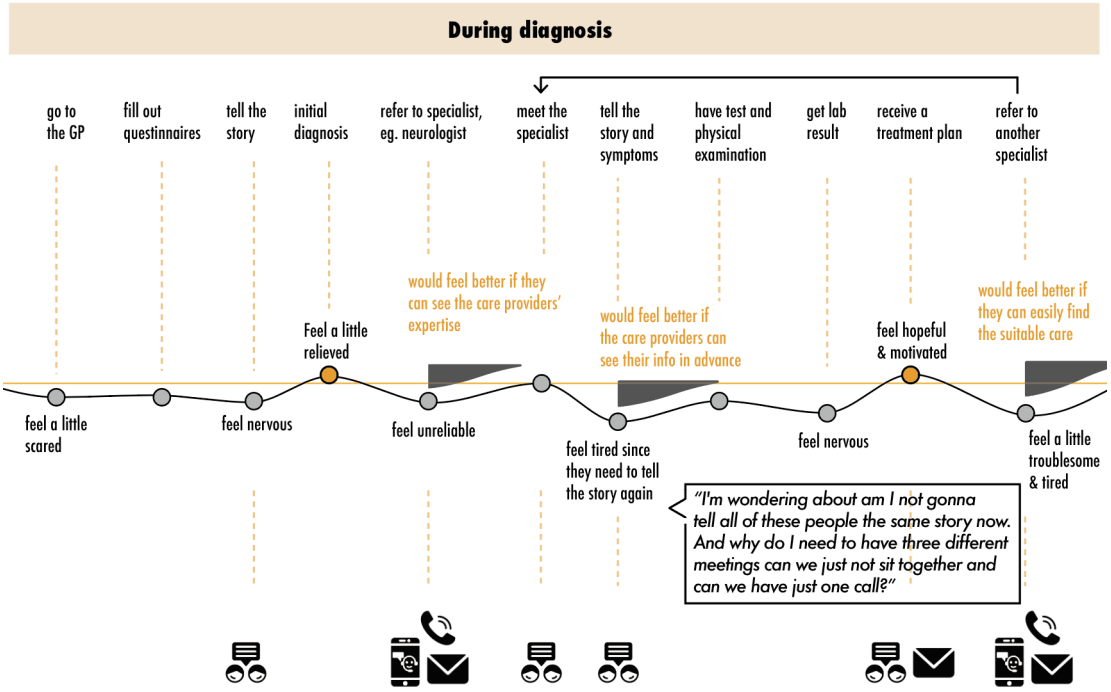



Figure 5. During diagnosis

The third stage is the treatment stage of the disease, which is also the part that this project is focusing on. According to previous research, FSHD is a disorder that cannot be completely cured, which means that once a patient becomes affected, they may coexist with this disease for life. Communication with health care professionals does not stop at this stage but becomes even more important since patients often encounter many problems during the treatment. However, the main problem in this process is that the healthcare role they contact often does not have the right knowledge to solve the problem well. So the patient needs to turn to another person for help. This is a waste of time and energy. Also, since the treatment process of this disease is going to be very slow, users are prone to negative emotions in this process. Therefore, effective feedback and support from medical staff and communication with the outside world become indispensable.

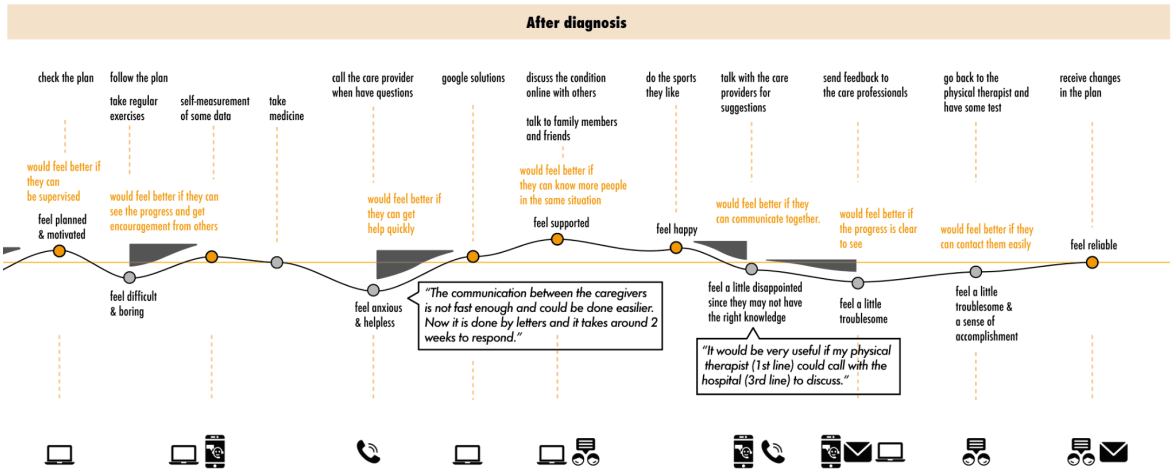



Figure 6. After diagnosis (treatment)

## 5.3 The communications between different characters

According to the result of the user research and the customer journey map, a map of communications among different characters was made and several problems have been found in the current healthcare process (see Figure below). In general, communications can be divided into three main areas: communications between the patient and the healthcare providers (mainly through emails/phone calls/face-to-face talk), communications among different healthcare providers in the healthcare network (mainly through emails/face-to-face talk/system in hospital), and communications between the patients and others (mainly through an online platform, face-to-face talk), this will include other patients and their family members. While in this project, I will mainly focus on the communication among healthcare professionals and towards patients since they are interrelated and it is a more crucial part of the improvement of patient experience and treatment quality.

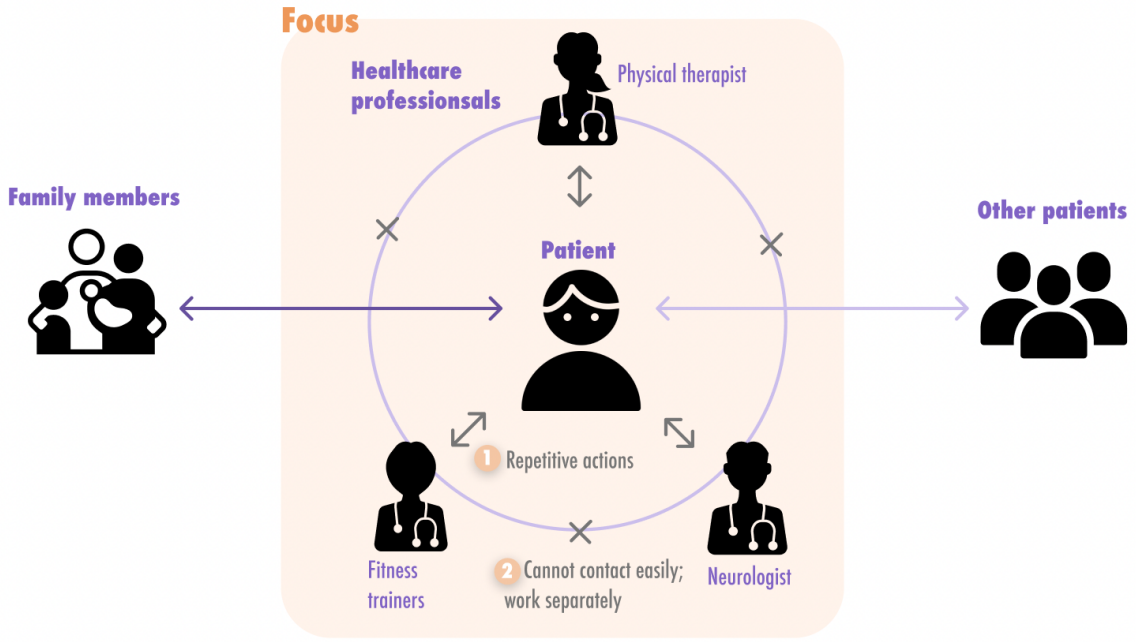



Figure 7. The map of communication

### 5.3.1 Communications between the patient and healthcare professionals

The main problem of communications between the patient and the healthcare team is that patients often need to take some repetitive actions when visiting different medical roles, such as conducting repeated checks or telling the same story to different people. One male patient said in the interview that, *"I'm wondering if I am going to tell all of these people the same story now. And why do I need to have three different meetings? Can we just not sit together, and can we have just one call?".* Some patients also mentioned that they often feel frustrated since they need to tell their stories again and again. This process will cause a waste of time and money. Therefore, it would be more effective if the patient's medical information such as test results can be stored in one place where they can take control of their data and share it easily with different care providers when needed.

Some patients also found that when they need help during their daily treatment, they often cannot get help in time. In one case, the contact person cannot solve the problem properly and needs additional help from other care providers since they don't have the right knowledge about FSHD. One patient mentioned that he normally meets his physical therapist once a week but these people don't often have the right knowledge about FSHD. So he had to turn to another healthcare professional and repeat the story. So he would like that *"my physical therapist can call the physician more easily and also me being in that conversation".* Another participant who has lived with FSHD for quite a long time mentioned in the interview that, *"I once had a physical therapist, it was a young person. This person asked me every week if my complaints were resolved. But I was like these complaints have been there for 20 years and are never gonna be resolved. I felt like I was disappointing him because he didn't know.".* This further confirms that not all related healthcare professionals will have sufficient knowledge about FSHD that can fulfill the user needs properly.

In another case, the person they contacted often cannot reply in time. Current communications with care providers are normally through phone calls and text messaging, such as email (see Figure below), which might not be very efficient in getting informed and adding additional questions. One patient said that when he has troubles, they will mostly contact the physical therapist first by email, but the reply is late, sometimes it may take a week long. Another patient also said that" *The communication with the caregivers is not fast enough and could be done easily. Now it is done by letters and it takes around 2 weeks to respond. Depending on that new questions arise and a new letter has to be written to ask the new questions.".* The delay in reply and help may worsen the problem and bring negative psychological effects to the patient, such as anxiety and worry.

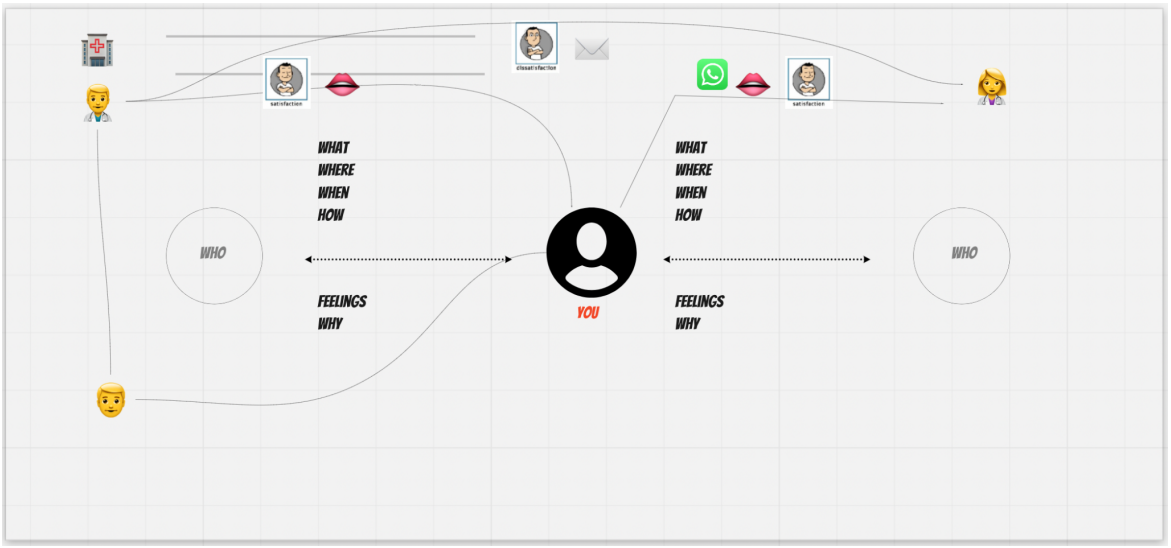



Figure 8. The communication map of one participant

Frequent daily communication with healthcare providers is important for FSHD patients. In the treatment phase, patients often need to re-check their body condition regularly with the healthcare professionals to help them understand the current situation and get feedback. Talking with those professionals can also make them feel more supported during the treatment process. Some care providers, such as the physiotherapist of the patient, will conduct regular calls with the user to monitor their activities. However, verbal communication in the format of Q&As sometimes is not efficient and helpful. Some information cannot be expressed easily from texts, but it needs more visual support. Patients may forget some details or sometimes cannot express themselves clearly to the care providers. Therefore, it would be helpful if we provide a way for patients to better record their daily treatment activities and feelings so that the care providers can intuitively see the progress and the condition of the patients and discuss it during the follow-up visit.

In short, it is beneficial for the patients to have the opportunities to talk about their needs and current situation to different healthcare professionals more effectively and can show their treatment progress to them through simple approaches. The problems of the patient need to be taken seriously and solved without delay. It needs to be clear for the patients to know when to contact them through what approach. Patient data needs to be exchanged fluently and updated in time to avoid repeating.

### 5.3.2 Communications between different care providers

To better understand the issue from the care providers' perspective, besides getting some information from the patients, I also searched for some useful information online. The problems between different healthcare professionals are mainly manifested in the difficulty of contacting and informing each other. During the diagnosis and treatment of a disease, there will often be multiple medical and nursing roles involved in the decision-making throughout the process. Especially for some complex chronic diseases such as FSHD, for example, there are neurologists, rehabilitation doctors, physiotherapists, psychologists, and dietitians etc. This is mainly due to the difference in understanding and knowhow of the disease among different medical and nursing roles,

resulting in patients often needing to check with multiple healthcare professionals in different hospitals to get a confirmed result. However, there are gaps in the exchange of user data. Different hospitals often apply different healthcare systems, which makes the patient data may not be updated in time, and the transmission of information records becomes difficult. While patient data such as test results are used to compile a comprehensive medical history which makes it possible for the healthcare team to offer appropriate medical care. Delays in getting patient records can cost a considerably higher risk of practice mistakes and consequent cost increases.

The situation during the treatment phase is similar where the healthcare professionals still need close contact and effective collaborations with each other, especially during the revision of a treatment plan or discussions about some of the patient's rare problems. But only by the patients, they cannot bring the different roles together. In the interview, some patients mentioned that the physical therapist can't contact their rehabilitation doctor easily, who knows more about FSHD but always needs him to contact in the middle. One patient said the same, *"now if my physical therapist has a question for the hospital, the physical therapist asks me to ask it in the hospital. I don't mind, but for some people, this could be hard to do.".* This kind of untimely communication leads to some patients' problems that cannot be properly solved in time, which is detrimental to their treatment. Therefore, it is important to ensure the different healthcare providers have the opportunities to easily contact each other, make decisions together if needed and determine who can best help the patient. This is also mentioned by some patients in the interview. One patient said that "*What I would like to add is that it would be very useful if my physical therapist (1st line) could call the hospital (3rd line) to discuss. That would be an important addition.".* This further indicated the patient's need of making the separate diagnosis and treatment process more integrated.

On the strength of the analysis above, some points can be summarized to answer the research question:
*What are the main factors that affect effective communication between patients and healthcare professionals?*

1. Obstacles in interhospital contact and data exchange
2. Inefficient communication tools selected
3. Insufficient skills and knowledge owned by the communication person

### 5.4 Summary & pain points of patients

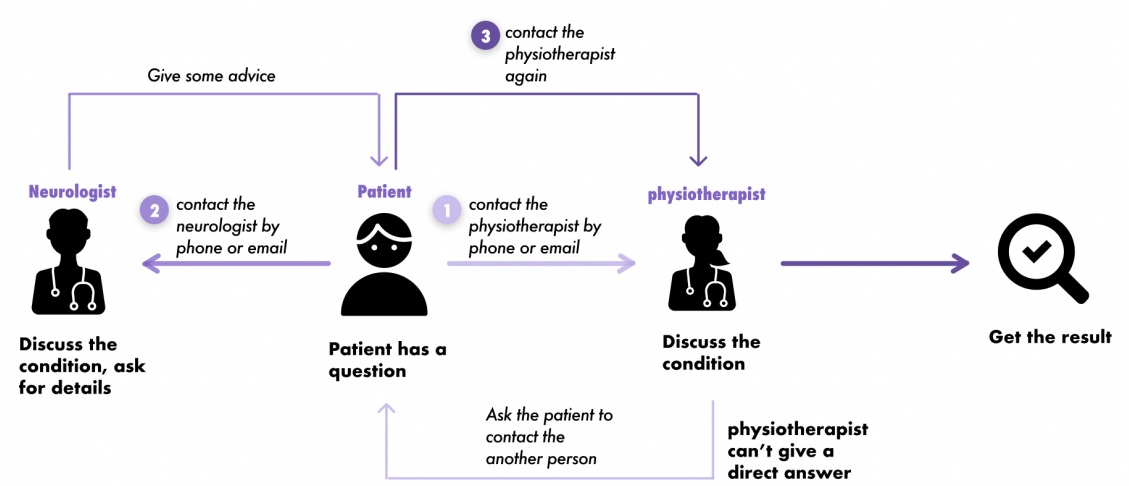



Figure 9. Task flow of the current communication

The figure demonstrates the task flow of the current communications between the patient and the healthcare professionals. In the actual scenario, there will be more characters involved such as a rehabilitation doctor, a psychologist, a euro-therapist, and a dietetic. Based on the analysis above, it can be concluded that as a patient of FSHD, the main problem for them is that they often cannot get sufficient help in time when they encounter a problem. Here are some reasons for this problem.

1. The reply time is often long due to the **busy work** of the healthcare professionals.
2. Patients have to take **repetitive actions** (eg. share data, tell the symptoms) when contacting different healthcare professionals.
3. Different healthcare professionals work and communicate separately with the patient, patients **cannot get a summarized and complete answer.** In other words, the communication towards the patient is not summarized as one diagnosis and support session, instead, the patient gets to hear partial solutions from different healthcare professionals

### 5.5 User needs

Based on the pain points and the analysis above, it can be concluded that patient needs a network to get a complete diagnosis and support. They need to be able to easily contact people in the healthcare network and get the right help in time when they encounter difficulties in the treatment phase of their disease in order to behave correctly and avoid mistakes. They also need to feel more supported in order to prevent additional pain and stress. While in order to fluently communicate their problems with the healthcare team, they also need a way to easily share data with different members of the healthcare network.

# 6. Market research of the online healthcare platforms

## 6.1 Research objective

After conducting the user research, the understanding of both patients and caregivers was bolstered and some pain points and user needs were identified. Since the goal of this project is to design an ideal online healthcare platform for FSHD patients to facilitate effective communications, before the design phase starts, it's helpful to look for current solutions in the existing platforms to get inspiration and learn from their advantages. Therefore, market research of the existing healthcare platforms was conducted. The primary goal of conducting competitive research is to understand the current market and more importantly, to forecast the potential for the market. Understanding what the competitors are offering also helps me to determine the type of service I want to deliver and how to make it better target the audience. By analyzing the advantages and disadvantages of each service and making comparisons, it can help to differentiate our business and service.

## 6.2 Setup

Generally, eight online healthcare platforms were selected as research objects (see Figure below). The selected platforms covered a wide range of current healthcare platforms in the Netherlands. They are either famous and widely used in the target population or have some typical service which makes them unique in the market. For each website, I investigated the core functions and services they offered in their platform, as well as the strengths and weaknesses of their service. Also, I paid special attention to the functions related to communications since it is what this project is focused on. The whole process was done by thoroughly browsing their websites, registering as members to use it if possible, and searching for customer reviews on the internet if there is any.


Figure 10. Selected platforms

## 6.3 Results & Analysis

### 6.3.1 Target group

Every website has its target audience. Generally, they can be divided into three categories. The first is specifically targeting patients, such as *SUMUS*. For these websites, it will often cover a wider range of patients, not just for patients with chronic neuromuscular diseases. These websites usually help the patient in completing their treatment plans and provide them with practical information about the disease management. The second group of websites is specifically designed for healthcare professionals, such as the *OpenHealthHub*. They are mainly aiming at helping care providers to better monitor their patients and manage their condition. The last group is designed for multiple roles, which will include both patients and healthcare providers, such as *IVIDO.* They focus more on data exchange and collaborations among patients and the healthcare professionals. In addition, some websites allow anyone interested in this kind of disease to join, such as *SPIERZIEKTEN NEDERLAND*. Which is more like an online community that offers opportunities to share thoughts and spread knowledge. In terms of the designed platform, having a clear view of who will be the target audience that is dominant in the usage.

### 6.3.2 Functions & features that facilitate communication

Since this project will mainly deal with issues related to communications and collaborations between different healthcare roles and the patients, it is helpful to make a deep investigation of the related functions in the current platforms. Based on the research, it is found that many platforms have common functions which aim at improving the communication experience of both patients and the healthcare team.

#### 6.3.2.1 Remote healthcare

With the development of technology and the impact of the Covid-19, virtual communication via video has gradually become the new trend. Besides normal communication via emails, platforms, such as *Hinq* and *Gezondheidsmeter* offer opportunities for healthcare professionals to have affordable and unlimited online visual contact with their patients and fellow healthcare providers through online video calling. By doing this, patients can reach the healthcare team easier, thus improving communication efficiency.

Some platforms allow healthcare professionals to remotely monitor the patients. Better home monitoring plays a very important role in facilitating communications between patients and care providers. The platform *SUMUS* provides healthcare professionals with a clearer view of the treatment progress of their patients through videos and sensors in the wearables so that they can adapt the individual exercise plans with the feedback from the patients.

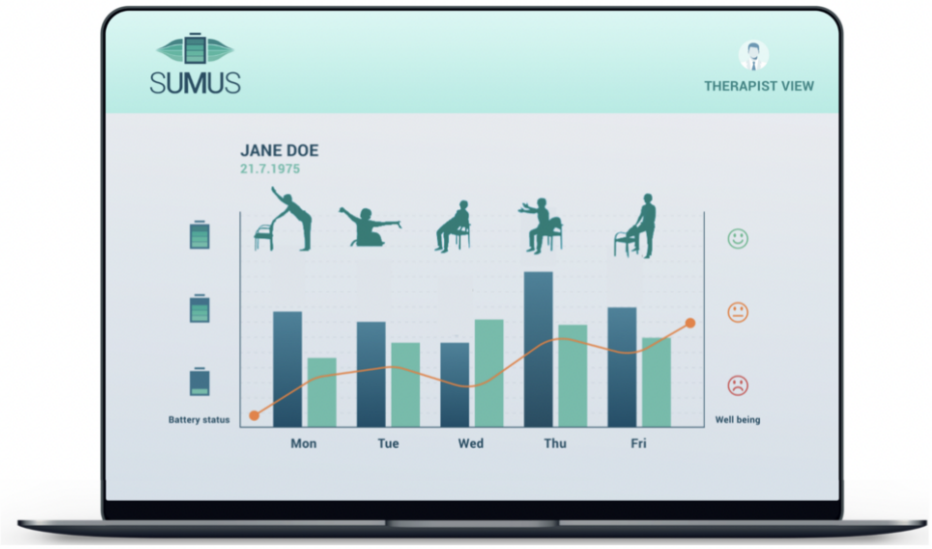



Figure 11. Video platform with exercises in *SUMUS*

Similar to *Openhealthhub,* patient data can be generated through medical devices such as a smartwatch and the healthcare team can view all the gathered information in the central dashboard. This allows the healthcare professionals to intuitively gain a clear view of the patient's condition and make changes accordingly.

Figure 12. Dashboard of daily monitoring data in *Openhealthhub*

In some websites such as *Gezondheidsmeter*, they allow healthcare professionals to create customized questionnaires and treatment plans for their patients, by providing some modular elements for treatment and self-management to efficiently communicate the changes in treatment.

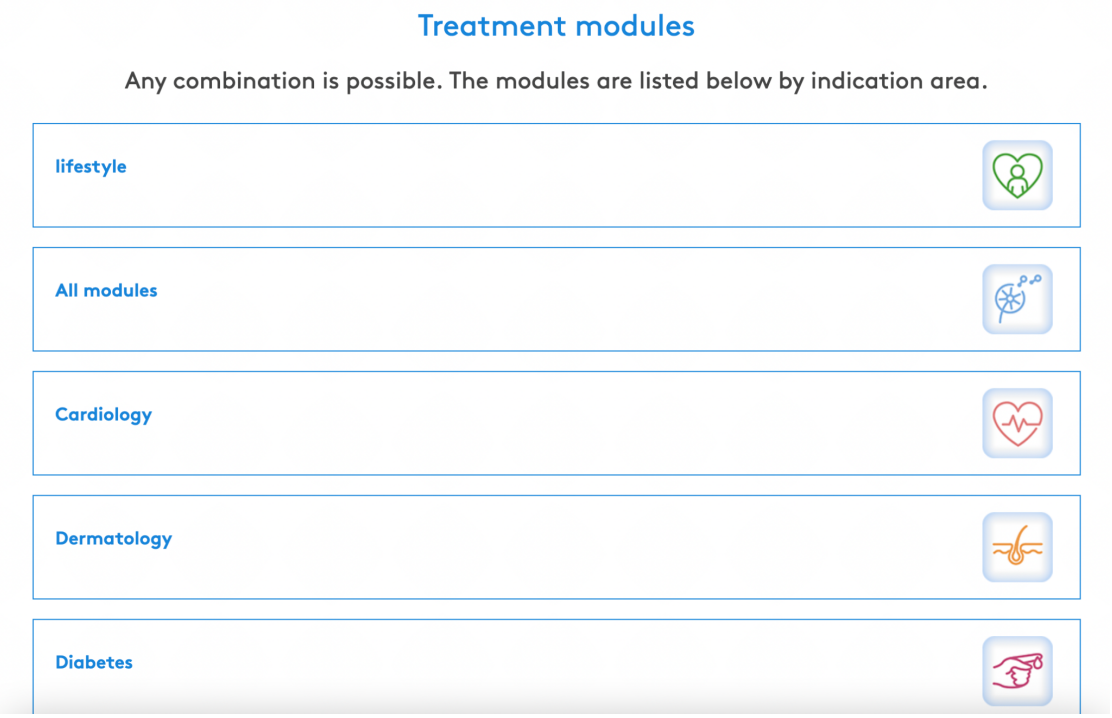



Figure 13. Modular elements in *Gezondheidsmeter*

6.3.2.2 Data exchange

Many platforms have the function aiming at facilitating data exchange among patients and care providers. The *MedMij* appointment system creates a safe environment for storing all the related patient health data, such as the medication and self-measurements (see Figure below). Users can view their records and easily share the various medical data with different specialists (see Figure below). By using this system, users can have a clear overview of their medical journey and have a feeling of being in control of their data. The sharing function helps to bridge the gap in data exchanging between different healthcare institutions.

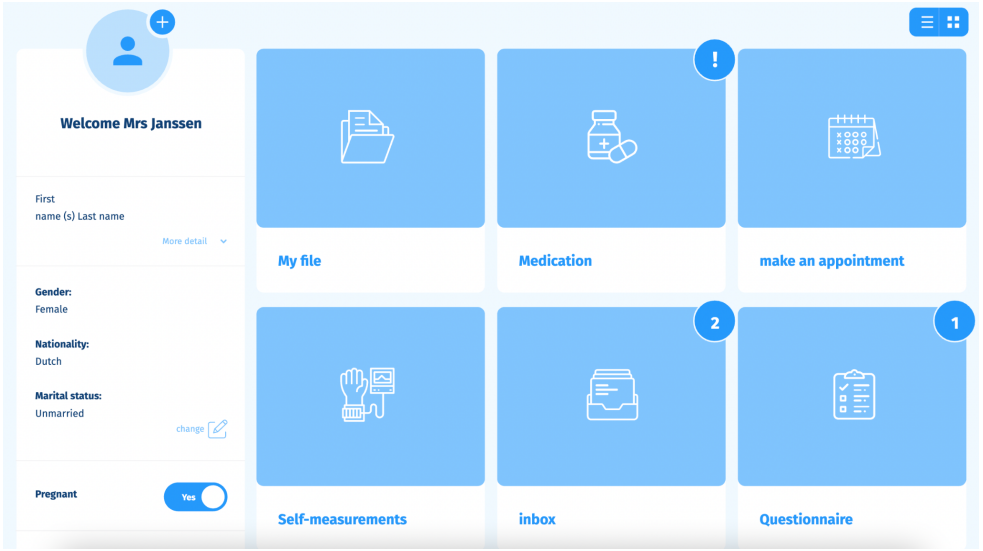



Figure 14. PGO in *Medmij*

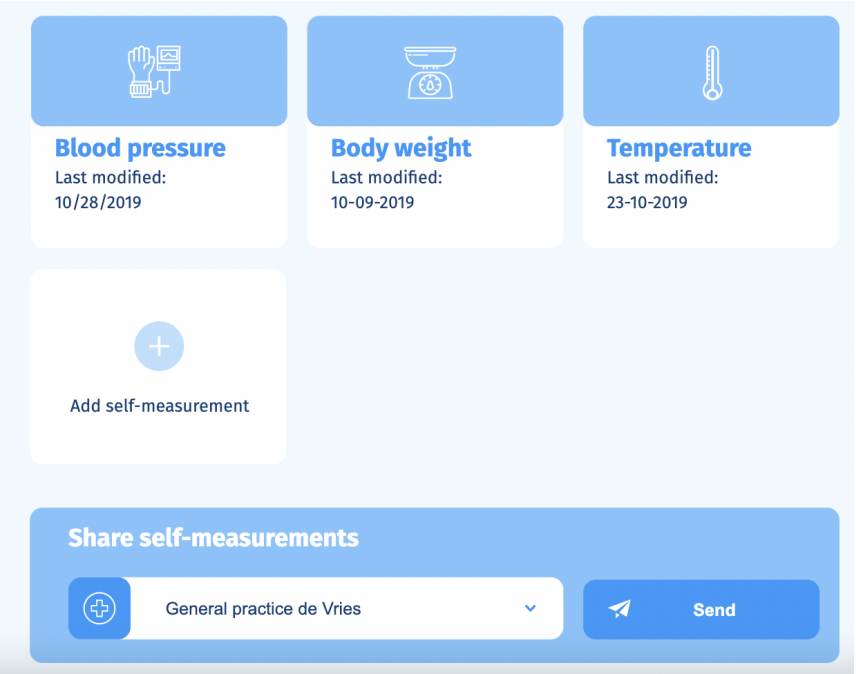



Figure 15. Share data in *Medmij*

In another online healthcare platform *IVIDO,* it also offers the possibility for users to request health data from different practitioners and share it with other care providers (see Figure below). While it also allows data sharing between different healthcare professionals. But to ensure data safety, the patient's permission is required before each operation. After a patient file is modified, it can then be sent back to the previous doctor, so that the information is always up-to-date among different healthcare professionals.

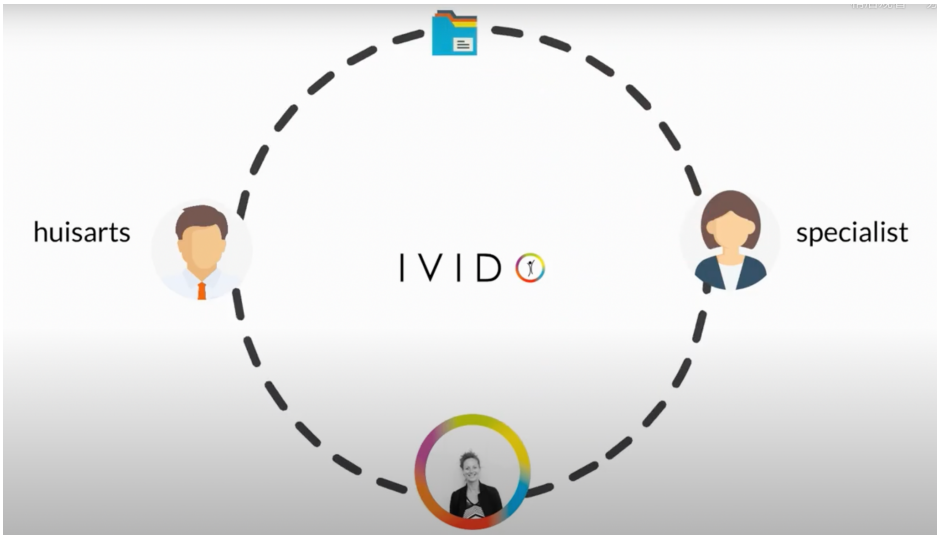



Figure 16. Illustration of the data exchange mechanism in *IVIDO*

6.3.2.3 Online activities

Some platforms, such as *SPIERZIEKTEN NEDERLAND* provide users with online courses and meetings (see the figure below). This offers opportunities for patients to get in touch with more healthcare professionals and improves the engagement of different patients and provides a positive atmosphere in the online environment.

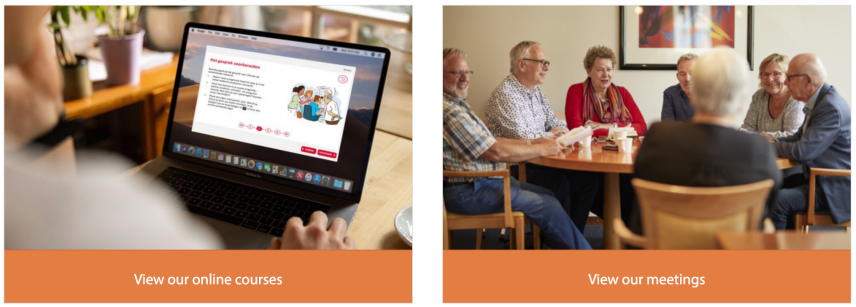



Figure 17. Online courses and meetings in *SPIERZIEKTEN NEDERLAND*

## 6.4 Insights

Some insights related to the user experience and interaction design of the platform can be summarized. Firstly, the interaction with the website needs to be simple and intuitive due to the features of our target audience. Secondly, privacy and data security is an important aspect, it's important to make people feel safe about the designed platform. Because the user's medical information is relatively private, we need to design to increase the user's sense of security and trust in the platform. This will mainly be reflected in the security of the internal database and the user's feeling of the information on the user interface. Thirdly, the display of the data needs to be direct and clear, since the patient data can be complex and large. For example, the display of the patient dashboard in *Medmij* platform (see Figure below) is clear and has a unified design language. However, the content of different elements in the dashboard are not in the same hierarchy. Some are types of data such as "medication", and some are actions such as "make an appointment". This will potentially bring some misunderstanding when searching specific functions. Finally, guidance and clear instructions are important, especially for websites which have multiple functions. The information structure should be clear.

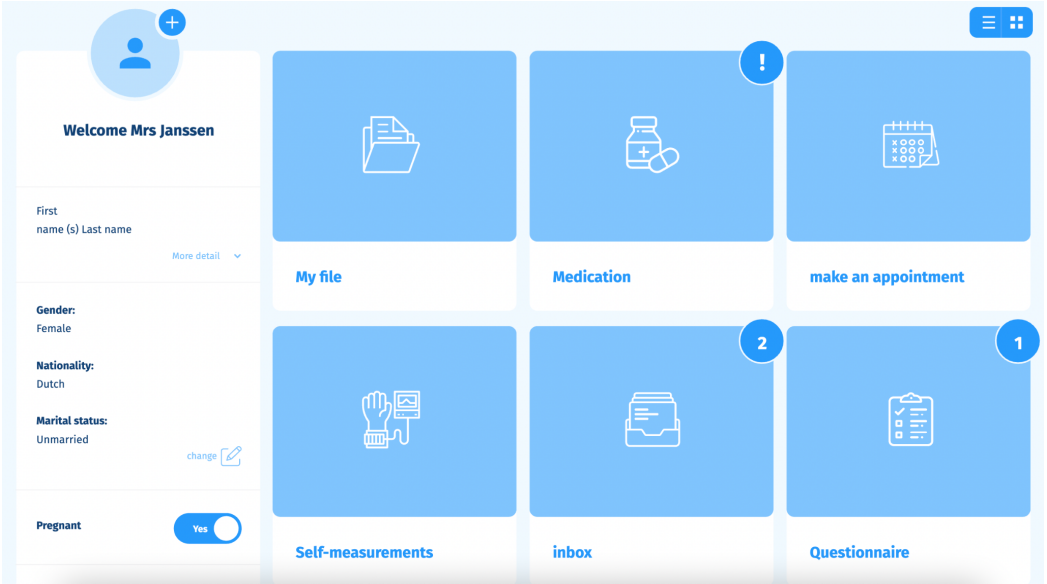



Figure 18. The patient dashboard in Medmij

# 7. Design brief

### 7.1 Design goal

Based on the analysis of the user research and insights from the market research, the main goal of my design is to help FSHD patients get the right help in time during the treatment of the disease. The achievement of this goal is closely related to the way and process the patients and the healthcare professionals communicate with each other.

### 7.2 Design vision

I want the FSHD patients, as the target audience of the design, to feel more supported and guided during their treatment of FSHD. While using the design, users will still get a feeling of being in control of their data. The interactions in the designed platform will be simple and intuitive to make it easy to use for users of different ages.

### 7.3 Project scope & focus

Based on the customer journey, it is common that users will suffer from different problems at different stages during their diagnosis and treatment process. While after diagnosis with FSHD, patients need to spend a lot of time and energy on the treatment of the disease during the rest of their life, for example, they have to revisit their physiotherapist regularly, they need to talk about their treatment plan with the healthcare professionals to make it more applicable. They need help from multiple care providers during their treatment, thus more effective communications during this phase become even more important. Therefore, the design will mainly focus on improving the user experience in the stage after diagnosis.

In addition, from the previous research, it can be concluded that users have a worse experience of communicating with healthcare professionals. Compared with communication with others who are in the same situation, having an effective communication experience with the healthcare team is more important in ensuring the treatment quality. Therefore, in the design, I will pay more attention to the communications between the healthcare professionals and the patients.

### 7.4 Design requirements

Based on the analysis above, some design requirements for the online platformcan be generated.

1. Convenience: Users should be able to ask immediate questions easily on this platform at any time when they encounter difficulties.
2. Connected: The platform should enable real-time chat for people who use the platform, including FSHD patients and the related healthcare professionals.
3. Complete: The platform should enable users to receive a complete diagnosis and support based on their needs.
4. Comfort: The interactions on the platform should be easy and intuitive, and make users feel pleasant when using.

# 8. Ideation & concept development

This chapter mainly discusses the process of transferring the user needs into design solutions.

## 8.1 Brainstorming session

### 8.1.1 Setup

The brainstorming session helps to generate more ideas from diverse perspectives targeting the pain points and user needs. A brainstorming session was conducted with the participation of four fellow students from the industrial design engineering department. Since the activity will be conducted fully online, the online conference platform "Zoom" will be used as a communication tool. A Miro board was made for this session (see figure below). Generally, it consists of two parts, a brief introduction of the project background and the research result, and then there are some tasks for the participants to complete. The participants will brainstorm on four questions. For each question, they have 7 minutes to brainstorm, which is followed by a short discussion session for 5 minutes. The content of this task was mainly based on the pain points and user needs generated before. The whole session will take about 1 hour.

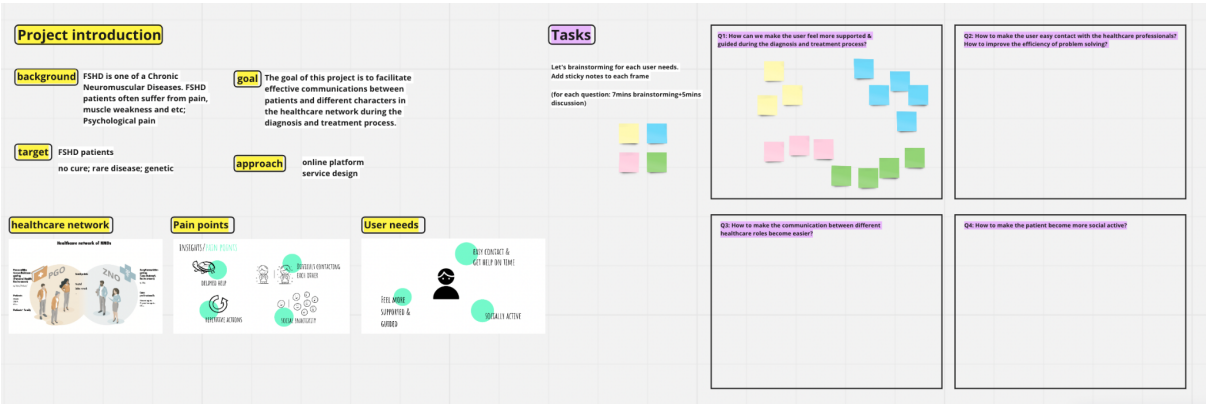



Figure 19. Miro board of the brainstorming sessions

### 8.1.2 Results & analysis

After the session, I classified everyone's answers into different collages (see the four figures below) and summarized some key points for each question. In terms of the first question, "*How can we make the user feel more supported & guided during the diagnosis and treatment process?*", people's answers can be summarized as follows: provide users with a user manual to inform them of some precautions and common problems; arrange for a person to visit users regularly; establish a mutual assistance group where people can communicate freely.

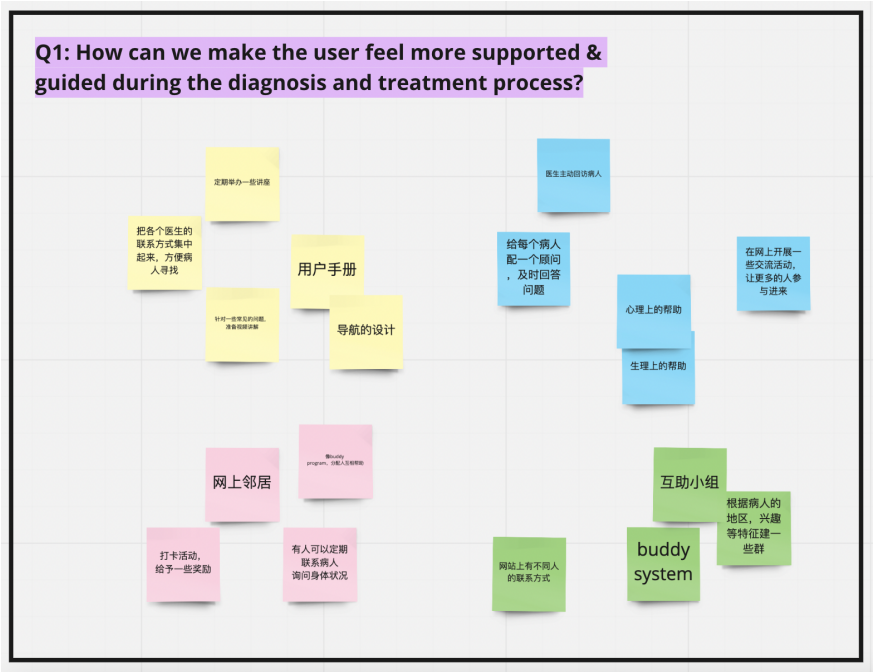



Figure 20. answers for question 1

In terms of the second question, *"How to make the user easy contact with the healthcare professionals? How to improve the efficiency of problem-solving? "*, the ideas that everyone put forward mainly focused on: summarizing the contact information of various doctors and placing them in a more obvious position; encouraging people to post questions in the forum and solving the problems raised by others; providing a consultant for each user that they can answer the user's questions at any time; a buddy system, so the users can ask their buddy when they need help.

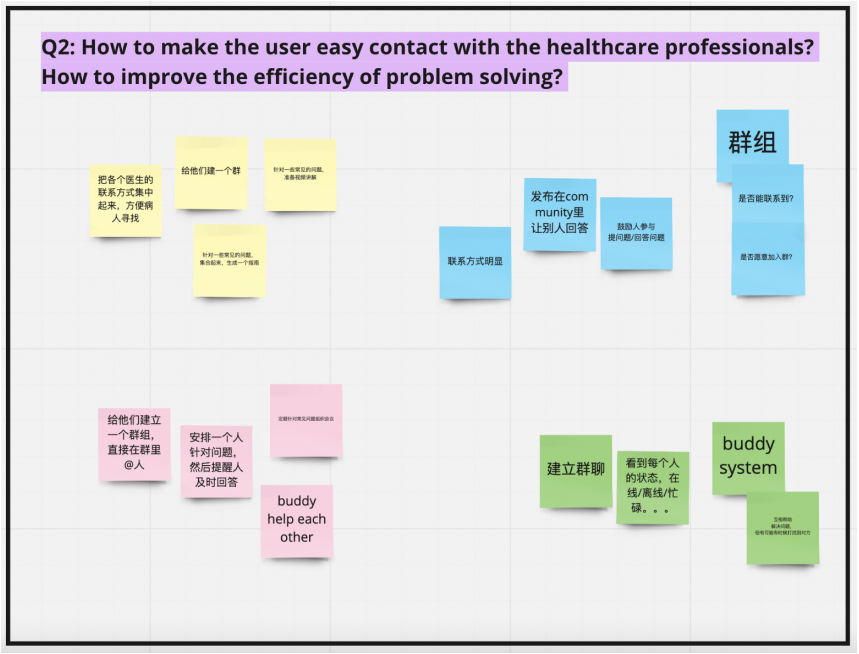



Figure 21. answers for question 2

In terms of the third question, "*How to make the patient more socially active?*", people's

answers are mainly summarized as providing users with more interaction opportunities in the online community. Carrying out more simple and easy-to-participate activities, such as sign-in every day, mini-games, etc., to increase user participation. Providing people with more opportunities to share and exchange thoughts, regularly holding lectures or sharing sessions, so that people can have more exchanges. The other is the combination of online and offline. Different groups can regularly organize some offline activities, such as doing yoga together, to enhance people's communication and get a certain amount of exercise.

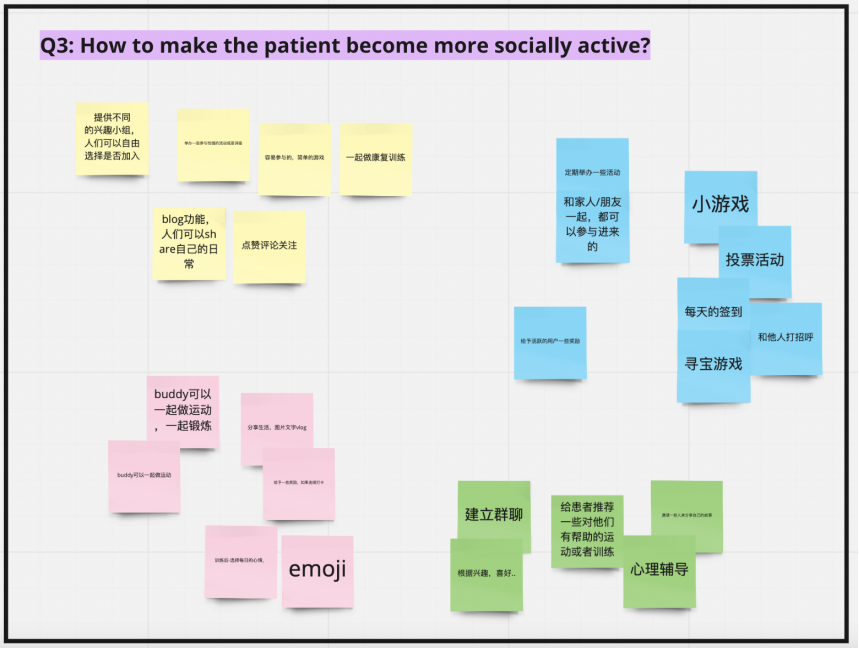



Figure 22. answers for question 3

In terms of the additional question, "*How to make the communications between different healthcare roles easier?".* Everyone's answers can be summarized as focusing more on improving mobile collaboration and taking advantage of the fast internet for communication. This not only saves time but also improves the accuracy of the information. Adding different healthcare roles into one environment or one group and discussing together can significantly improve communication efficiency. Online conferencing tools can also be promoted.

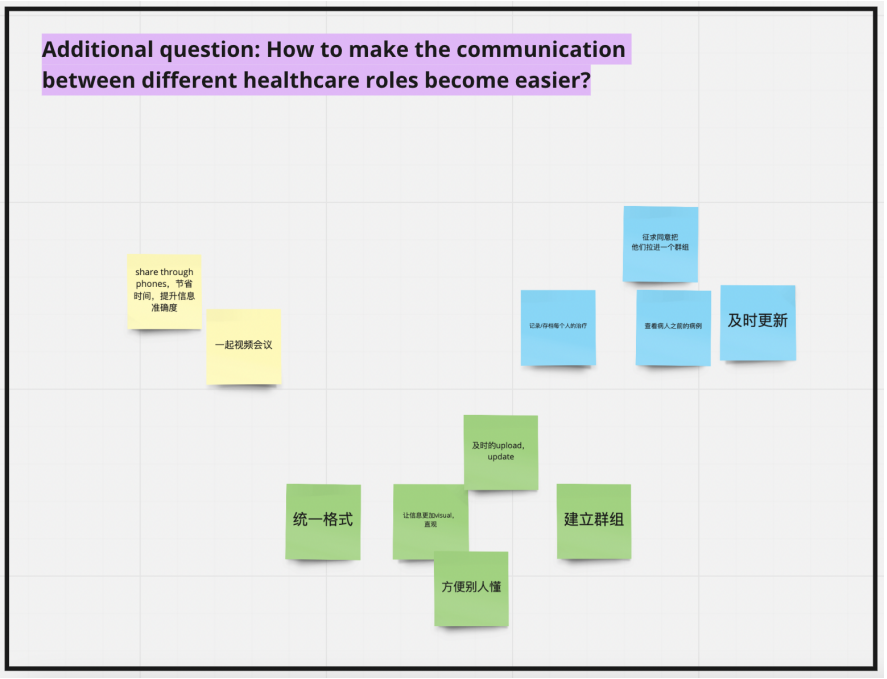



Figure 23. answers for question 4

### 8.1.3 Design opportunities

According to the analysis of the customer journey and the results of the brainstorming session, some design opportunities can be generated (see Figure below).

**Design opportunies**

1. Uploading the patient's information to the cloud uniformly, and every medical staff can view the previous diagnosis information after obtaining permission.
2. When making some key decisions, such as the update of treatment plans, or discuss solutions to rare problems, providing medical staff with opportunities for intensive discussion, such as by online video conferences.
3. Helping find the right medical staff, such as the map showing the expertise of the medical staff.
4. Letting different medical staff know who is involved in which stage and what they have done. This will also help them become more responsible.
5. Providing them with a convenient communication platform and let them join the same chat group.
6. Informing someone to remind and urge relevant personnel to respond in time.
7. Providing patients with tools to record the progress of their treatment more easily, which is convenient for medical staff to follow up and monitor.
8. Providing patients with more opportunities to get in touch and interact with others.

Figure 24. design opportunities

## 8.2 Evaluation Matrix

### 8.2.1 Objectives

After brainstorming, lots of design opportunities and possible ideas were generated. I further came up with some concrete ideas. However, not all ideas are suitable for the user's context and can bring them the most value, so it's important to filter these ideas. The evaluation matrix makes it possible to weigh many ideas and rate them according to a set of defined criteria to find the most promising ones. The difficulty of concept execution and the value it will provide to the user and the company are two typical factors (see figure below) (https://servicedesigntools.org/tools/evaluation-matrix). By placing ideas in the matrix and making comparisons, it helps to narrow the ideas down and select the ones that are the most valuable to the target audience and the target problems.

### 8.2.2 Result & analysis

With the design goal of helping FSHD patients get the right help in time during the treatment of the disease, the value of an idea is judged by how well it fulfills the user needs of easily contacting the healthcare roles in the healthcare network and feel more supported in this process. While the complexity is mainly judged by the difficulty of technical implementation and the number of stakeholders involved. After discussion, the generated evaluation matrix can be seen below.

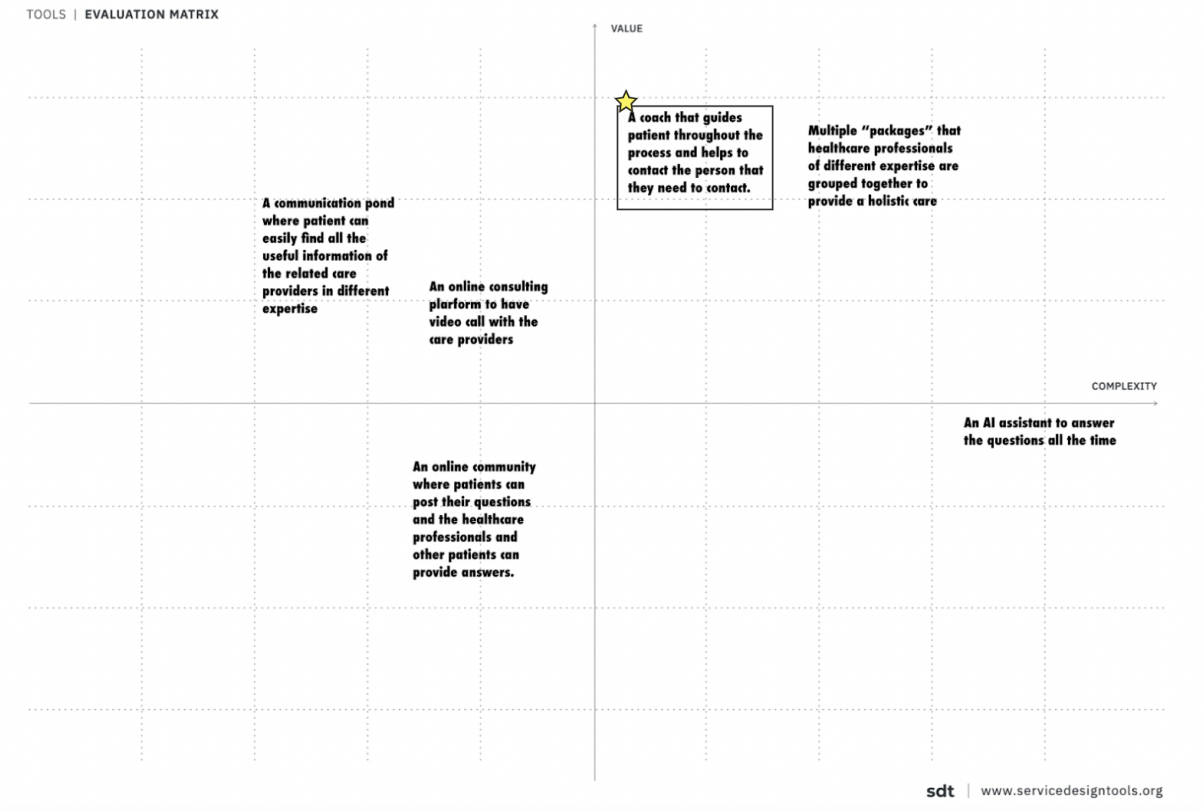



Figure. 25 The evaluation matrix

According to the figure, bringing the healthcare professionals into groups and having a coach guide the user throughout the process can add more value to the user since it may make them feel more guided as well as improve the efficiency of problem-solving.

So I will choose to include this in my design. However, this will be more complex than just having an online community or online consulting platform since there will be new roles involved. In terms of the AI assistant, it can add some value but it will need more technology investment to train the system. The AI assistant also cannot deal with some unique problems of the user. Gathering the contact information of various healthcare professionals together can be helpful while it is simple in techniques so I would also consider this in the design.

### 8.3 The initial idea

According to the result of the brainstorming session and the evaluation matrix, an initial idea of the service is generated. The core of this idea is to provide personalized care coordinated by one contact person in the healthcare network (see figure below). There will be a **coach** that guides the users throughout the process and helps them contact the people that they need to contact in the healthcare network. This will be the basis of the service, the concrete functions in the service will be further discovered.

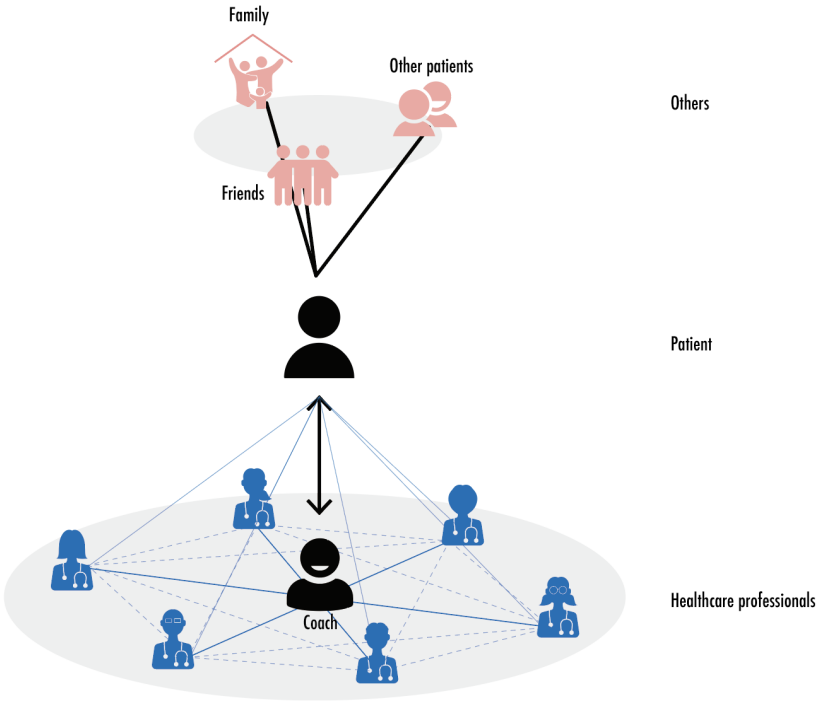



Figure 26. the initial idea

Then I sketched out some possible functions in the platform with the basis of the "coach" idea and made some low-fidelity prototypes. When designing the platform, I considered the following aspects. First, we need to open up the communication channels. This means we need to bring together the various healthcare roles so that we have a clear idea of the roles involved in the whole healthcare network, thus facilitating that we can easily contact them afterward. So I wanted to display the names and basic information of the different healthcare professionals on the user interface.

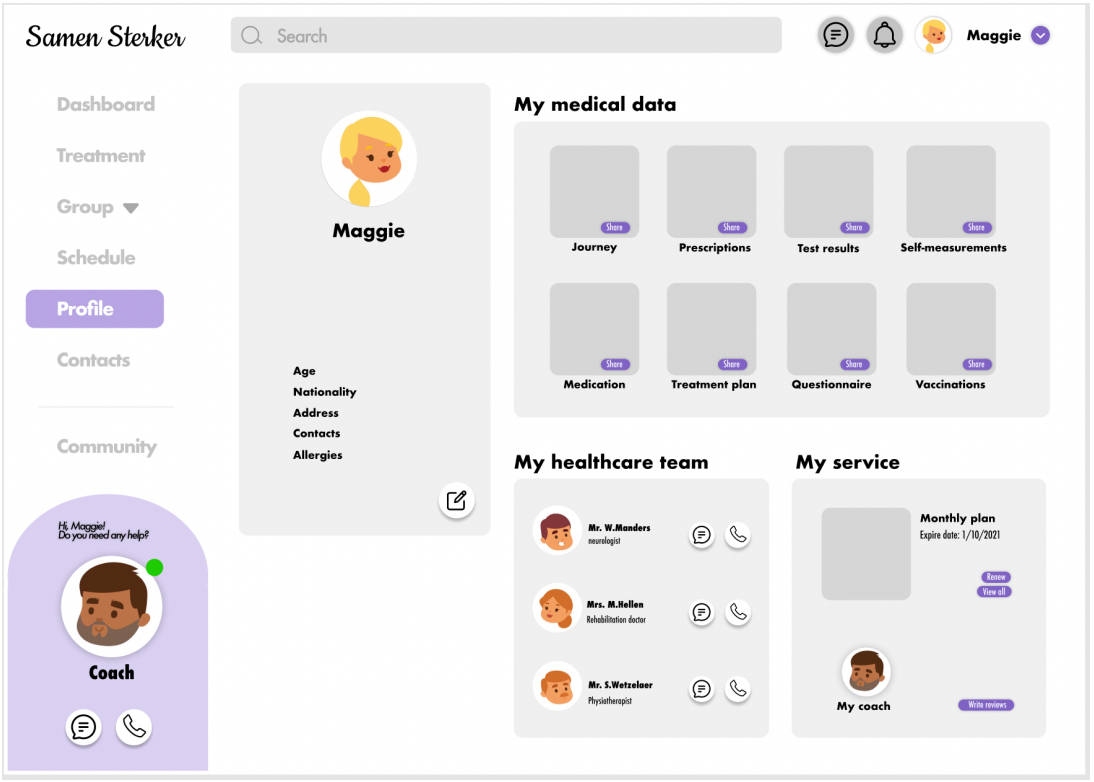



Figure 27. Patients can clearly see their healthcare team

Then, we had to consider how to make it easier for these people to communicate with each other. So I thought I could create a discussion group and add all the healthcare professionals to it. This group will mainly be managed and maintained by the coach. When patients have a question, they can quickly inform the healthcare team by sending a message in the chat group. When a patient's message is not responded to in time, the coach is responsible for reminding the medical staff to respond. Patient-related data are displayed in this group so that group members can easily view them when needed.

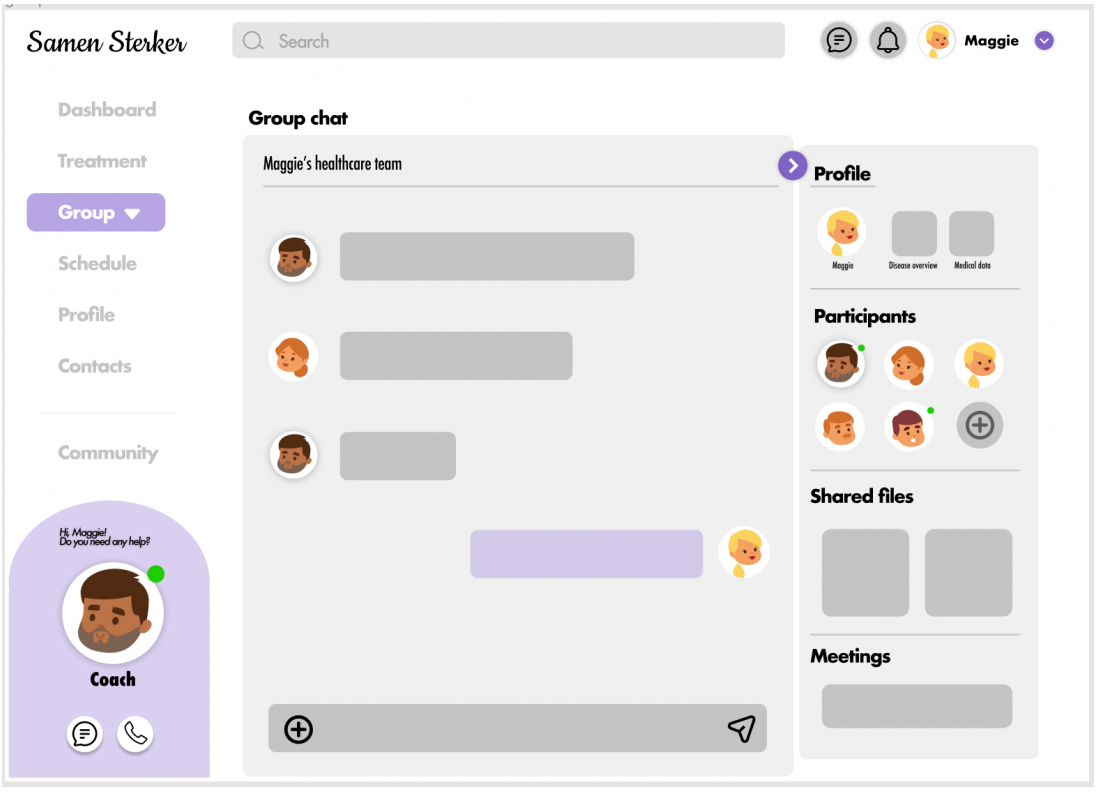



Figure 28. The chat group with all healthcare professionals

Finally, healthcare professionals need to closely monitor and give advice to the patients. Considering that the communication between them is mainly about the patients' condition and the progress of their treatment. So it is important to make the data more clearly visualized and easily accessible to healthcare professionals. Only in this way can their communication be more meaningful, rather than an empty dialogue. So I thought we should make it easier for users to record their daily training on this platform and to allow medical professionals to evaluate or give advice on their training so that they can quickly identify problems in their training and then improve.

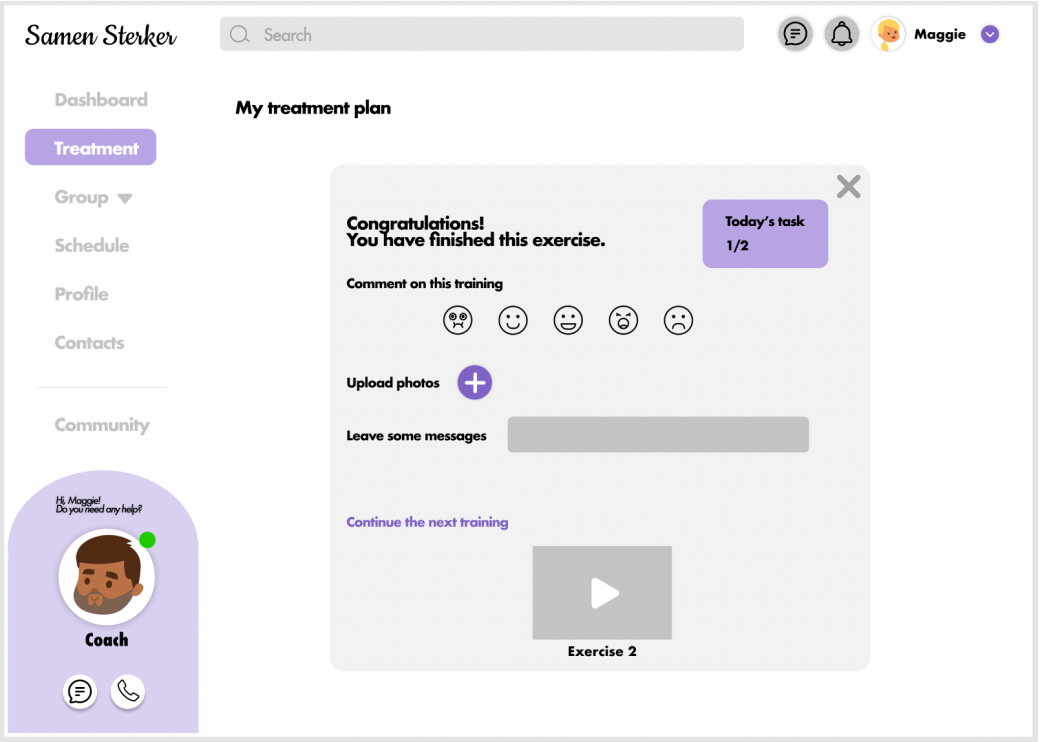



Figure 29. Patients can conduct a self-evaluation after each training

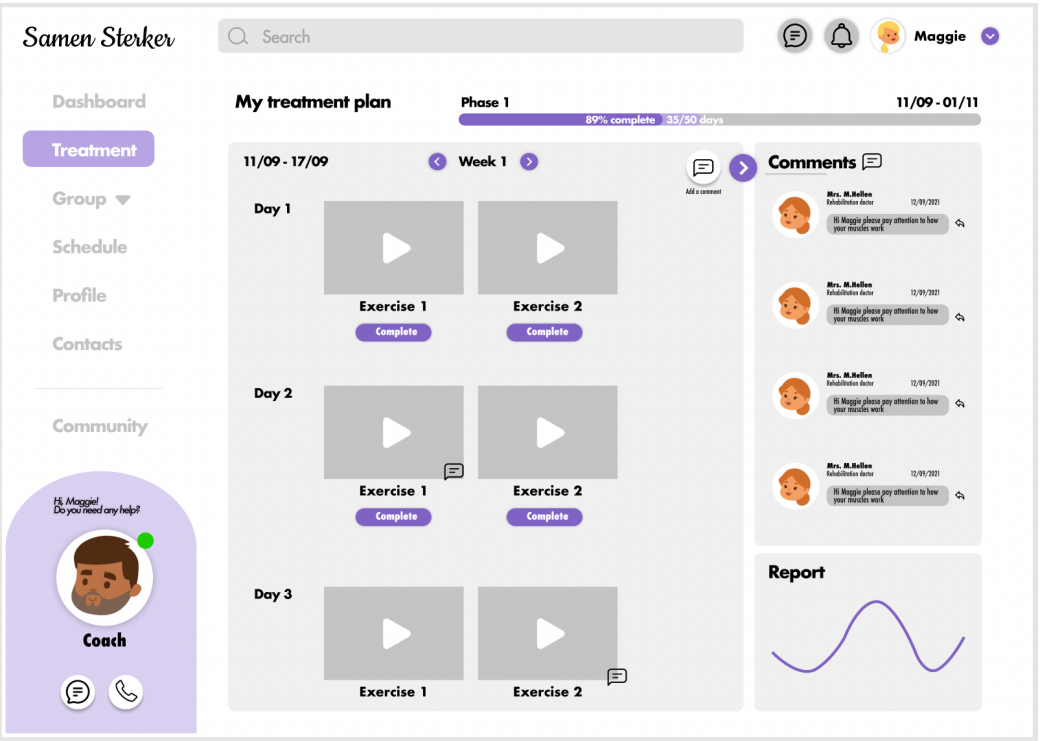



Figure 30. patients can read the comments on their exercise

## 8.4 Role-playing & iteration 1

### 8.4.1 Objectives

After defining the suitable ideas, a role-playing session was conducted. Role-playing allows the participants to act out a usage scenario to demonstrate the service concept. By personally simulating what might happen to the service in a real scenario, I can further validate the feasibility of the design concept. At the same time, this co-design session can also help me to find some problems in the design, especially in terms of the relationships between different stakeholders, so that I can make subsequent improvements based on the insights and ensure the value can be proposed to all stakeholders in the service infrastructure.

### 8.4.2 Set-up

The whole session will be conducted online using the online conferencing software *Zoom.* I invited three of my friends to act as actors. I created some low-fidelity experience prototypes using the software *Figma*. Those prototypes will then be used in the role play session as props.

Before this activity starts, I will briefly introduce the background of the project and the whole process of diagnosis for the participants, so that they can be better integrated into the context. Three scenes will be acted out in this role-play session covering the key touchpoints and interactions. Participants will be assigned to different roles. For each role, there will be a simple persona introducing their basic information and features. I will also provide the participants with some simple scripts which can facilitate the development of the story. But most of the time, they will complete the story with their understanding and imagination. After acting out, there will be time for people to discuss their feelings and findings. The whole session will take about one and a half hours to complete.

<u>Scene 1: Ask for help</u>

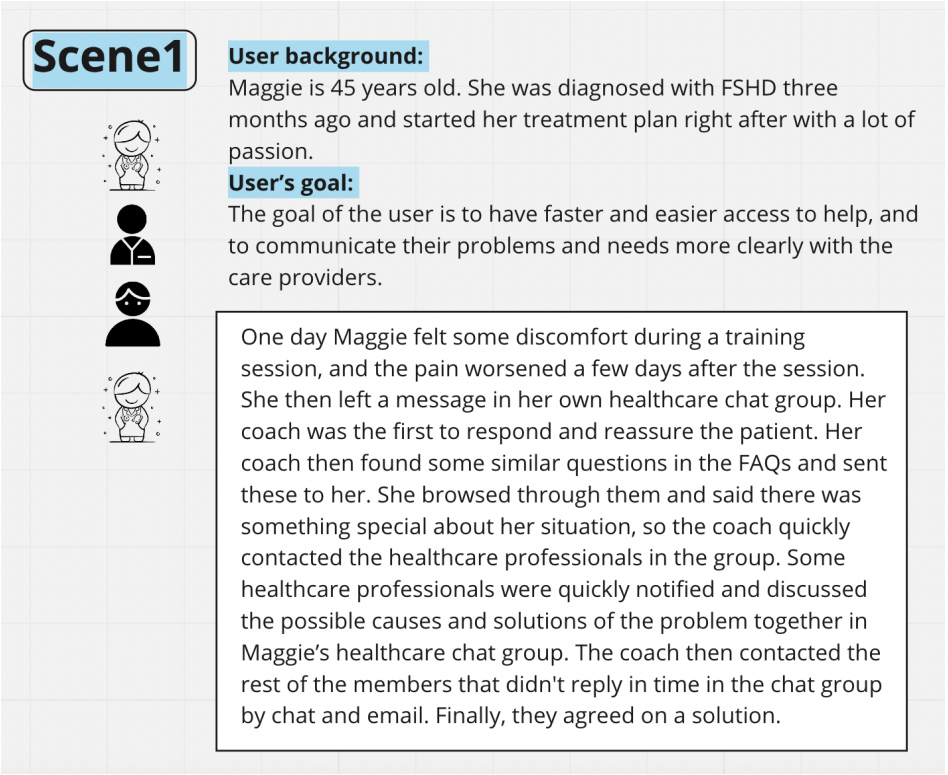



Figure 31. Scene 1

## Scene 2: Meet the care provider

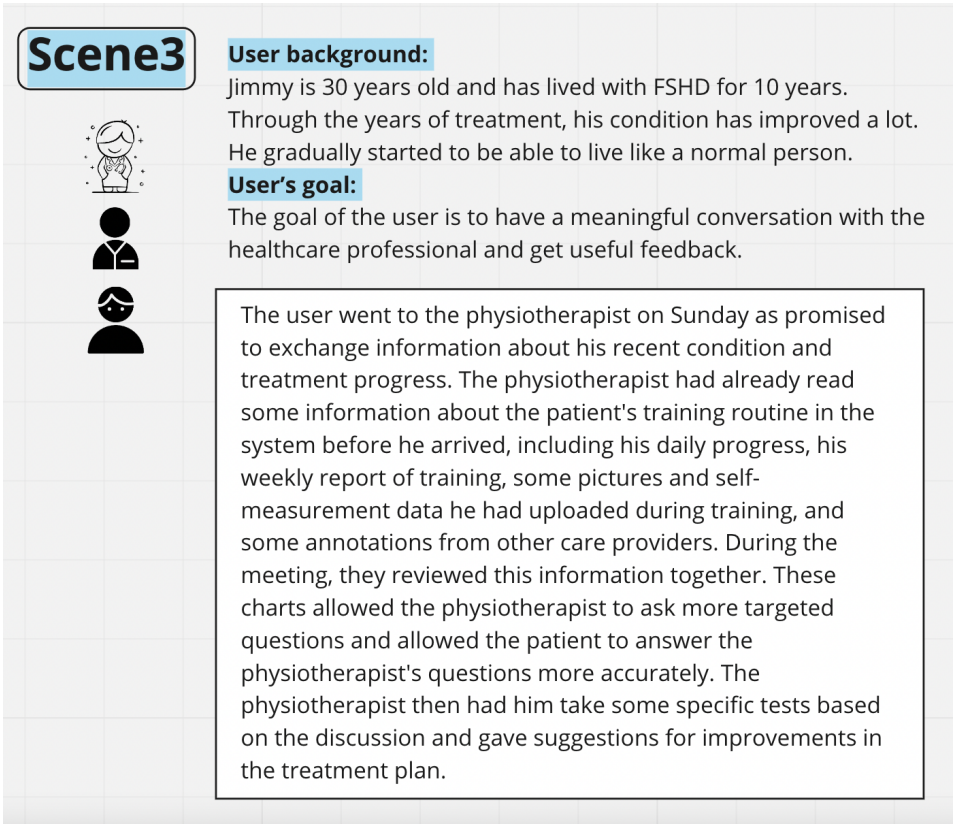



Figure 32. Scene 3

### 8.4.3 Insights & adjustments

Based on the discussions and observations of the whole session, some insights can be generated which allows making adjustments related to the concept and interactions.

Scene 1

Coach: "*Oh! It has been two hours and still, no one has replied. I think I have to contact them to remind them. Okay here I can see their contact information easily, so maybe it's good to send them an email.*"
Patient: "*What did they say before? There are too many chats and it's too hard to find the point I was looking for.*"
Care provider 1: "*I am kind of late, there is quite a lot of information here.. so hard to find the key points.*"

Insights

Care professionals tend to have busy schedules and too many message reminders can be a burden to their work. Constantly popping up messages may interfere with their normal work. Also, in the current design of the chat group (see figure below), there is no hierarchy between different messages, so when there are too many messages within a group, the inability to quickly locate key information can waste their time and the efficiency of problem-solving. From the patient's view, they need to review some messages from the chat history. However, in the current design, it is relatively hard for them to easily pinpoint the message they want if they forget the keywords or date. Therefore, it would be helpful to both stakeholders if we can categorize the importance of the messages and help the group members to notice the important messages quickly.

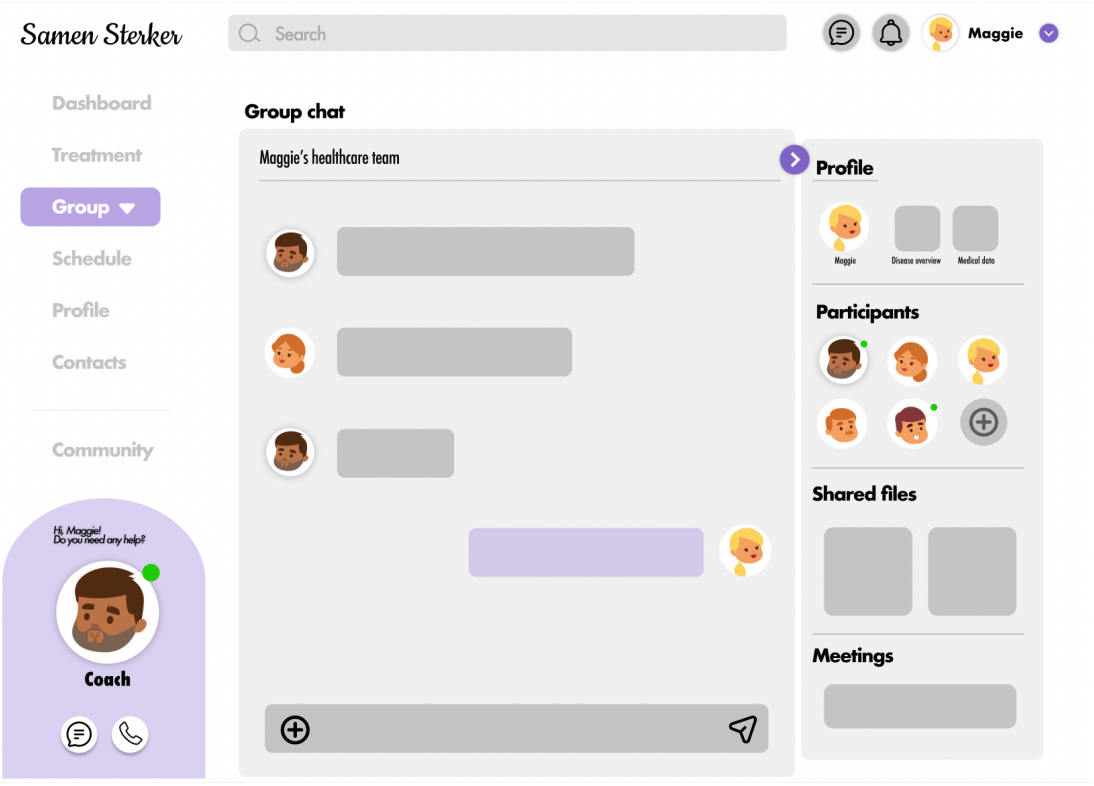



Figure 33. The chat group page (current)

Adjustments

To achieve this, during the chat, every member in the group can “highlight” the messages that they think are important and useful. This can be achieved by a long press on the particular message and then selecting the star-shaped icon. There is no restriction on the message that people can highlight. In other words, they can set not only other people's but also their own messages as highlighted messages. After a message is highlighted, the background color of that chat bubble will be changed. And the profile photo of the person who highlights the message will be shown below that chat bubble. When people review their previous chats, they can turn to the "highlight view" mode. In this mode, all the marked messages will be visually more obvious for people to read.

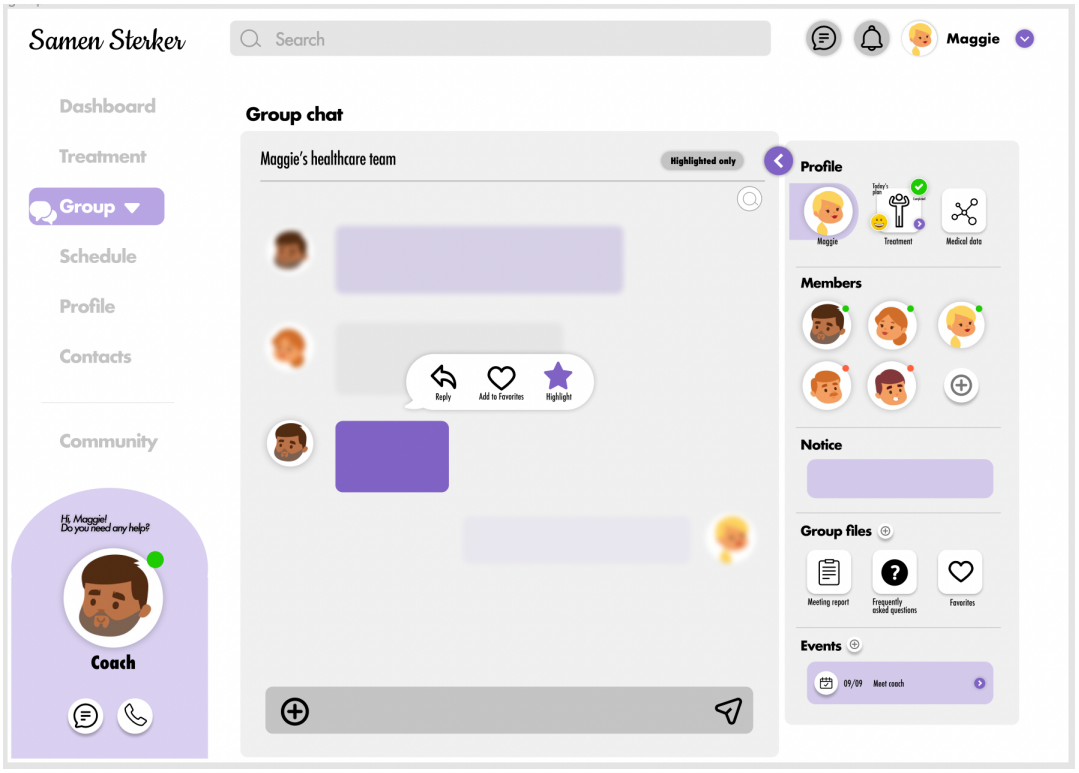



Figure 34. To highlight messages

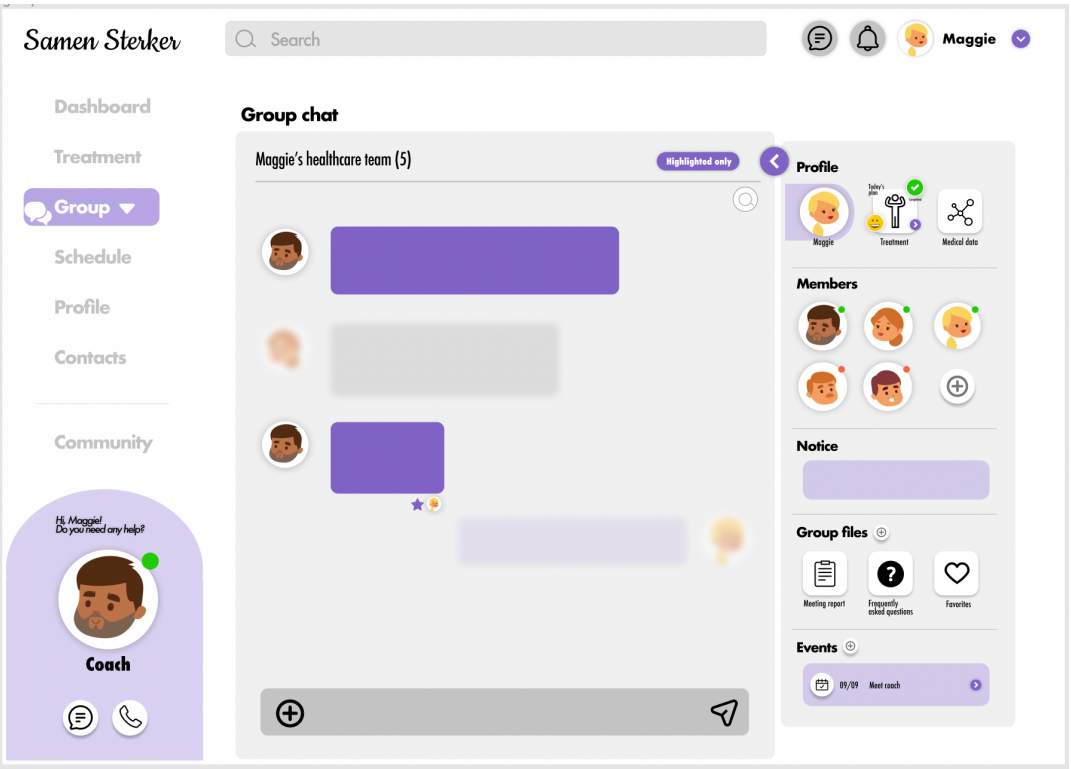



Figure 35. Only read highlighted messages

In addition, not all messages will have a message reminding the g in order not to disturb the healthcare professionals when they are at work. While it is still needed to ensure that they will be quickly informed by the important messages and moments. Therefore, besides the normal function that people can “mention” someone by long pressing on their profile photo. In a chat group, the coach has the right to mark a message as “important”. This could happen when a patient's question is not answered and resolved promptly or when there is some emergency. To set an “important” message can be done by a long press of that chat bubble and selecting the “exclamatory mark” shaped icon. Only the interface version of the coach will display this feature. When a message was marked as “important”, all the group members will not only receive web notifications but also receive an email in terms of this message. Also, when they open the group chat, that “important” message will float on the top of the whole chat frame.

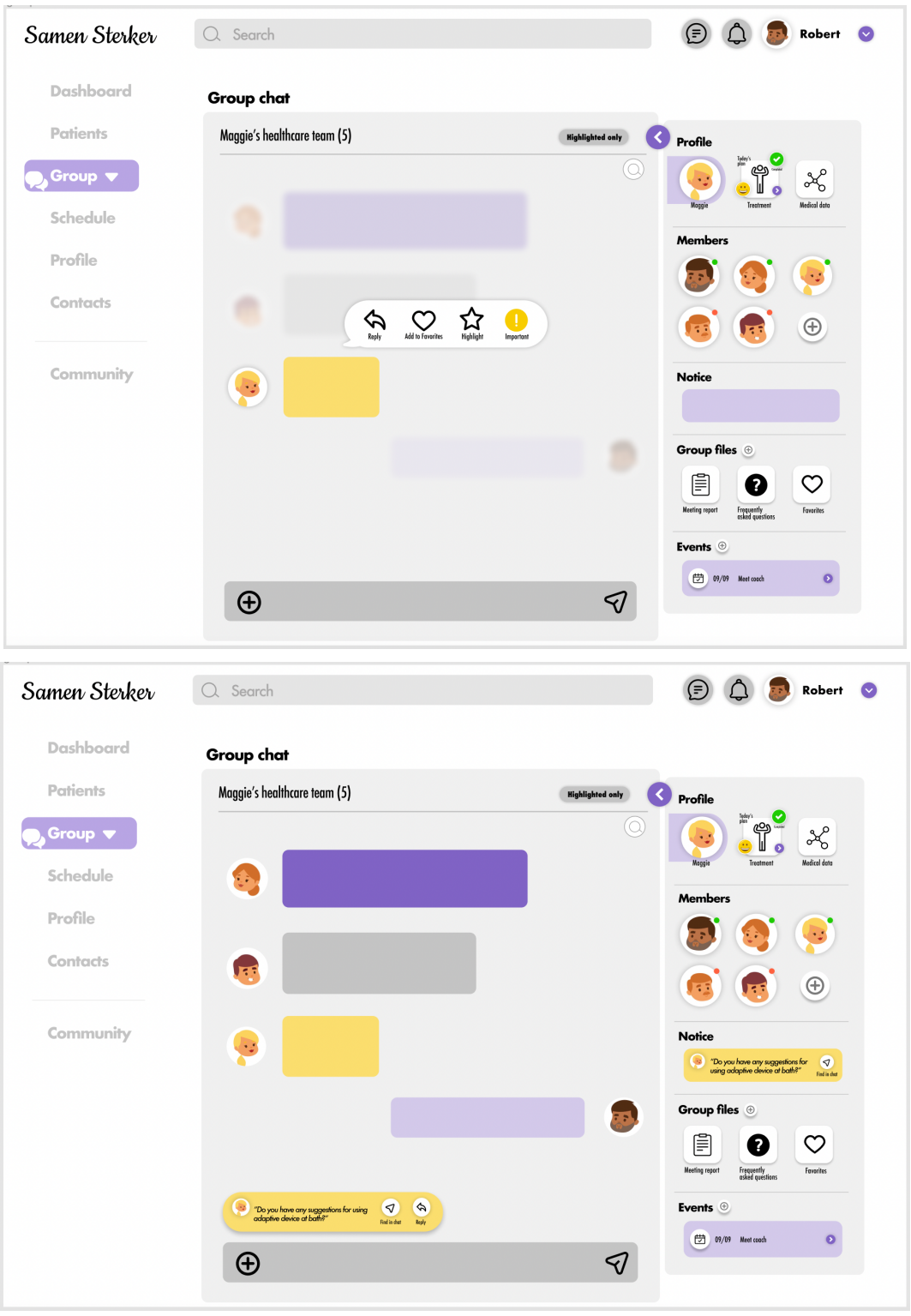



Figure 36. Mark one message as important

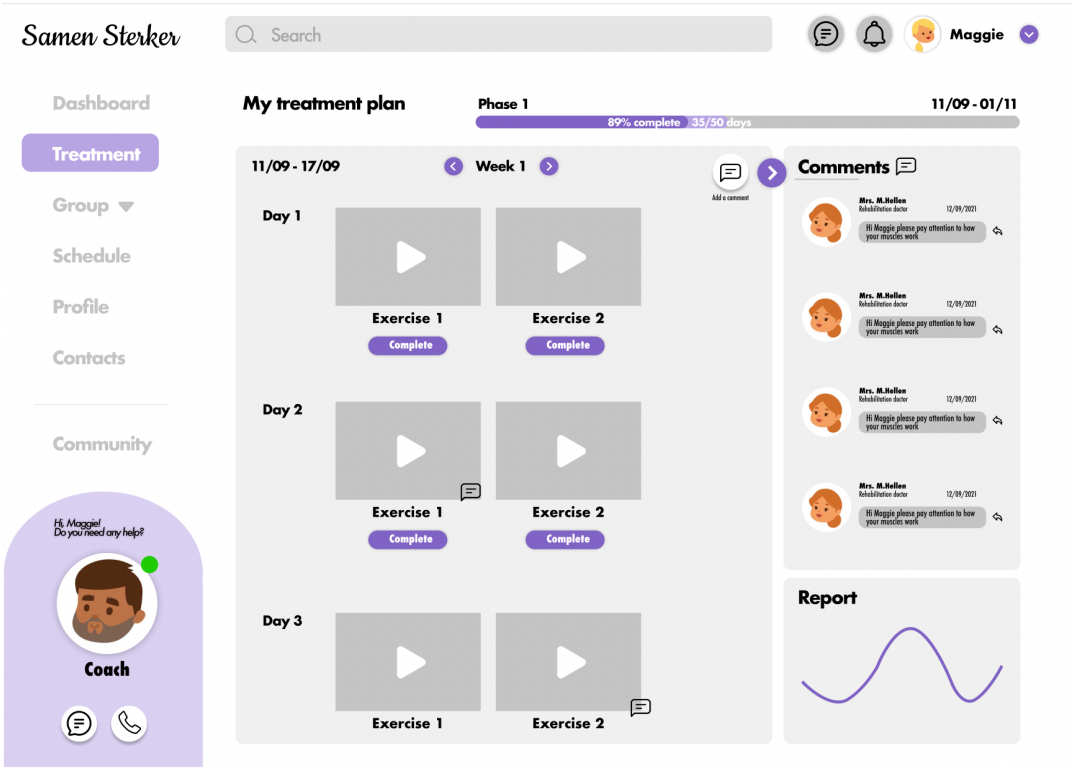
Scene 2

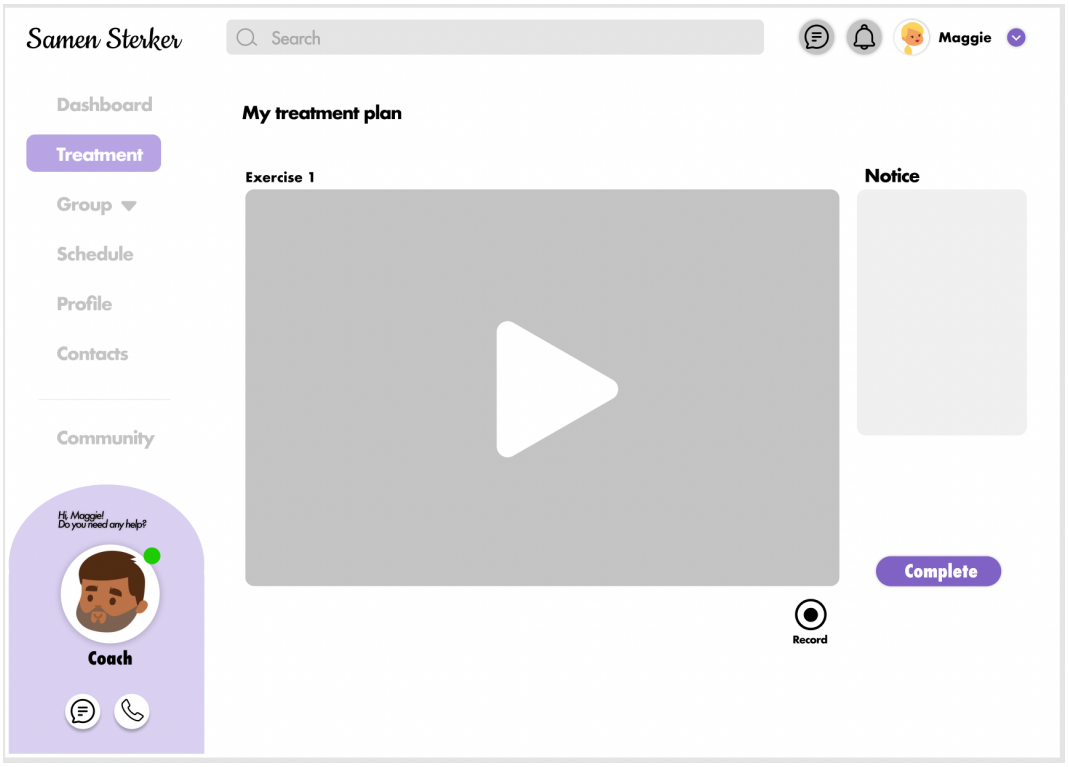
Care provider 1: *"For this exercise, I think I need to tell him some more instructions."*

Insights

According to the feedback, from the healthcare professionals' point of view, the possibility of adding comments to the patient's daily exercise videos and their treatment summary can be seen as a helpful way of communicating and monitoring (see Figures below). The patient also holds the view that that advice might be useful for the upcoming treatment activities. However, both the patient and the healthcare professionals think that the common comments shown next to the treatment videos might not be that effective for improving the training quality, since many errors are caused by some incorrect actions of the user during the exercise, and it's more meaningful to give some guidance to the user's real-time actions as much as possible. So sometimes it is not easy for the patient to quickly understand the points and realize what goes wrong just by words. Therefore it could be helpful if we make the communications around the video more interactive.

In addition, it is also important to consider whether healthcare providers can keep up with the patient's daily treatment or not. Because they may not have much time to watch each person's video carefully. Therefore, we need to at least ensure that they can quickly reply to important matters from the patients.


Samen Sterker
Search
Maggie
Dashboard
Treatment
Group
Schedule
Profile
Contacts
Community
Hi Maggie!
Do you need any help?
Coach
My treatment plan
Phase 1
11/09 - 01/11
89% complete
35/50 days
11/09 - 17/09
Week 1
Day 1
Exercise 1
Complete
Exercise 2
Complete
Day 2
Exercise 1
Complete
Exercise 2
Complete
Day 3
Exercise 1
Exercise 2
Comments
Mrs. M.Hellen
Rehabilitation doctor
12/09/2021
Hi Maggie please pay attention to how your muscles work
Report


Samen Sterker
Search
Maggie
Dashboard
Treatment
Group
Schedule
Profile
Contacts
Community
Hi Maggie!
Do you need any help?
Coach
My treatment plan
Exercise 1
Notice
Complete
Record

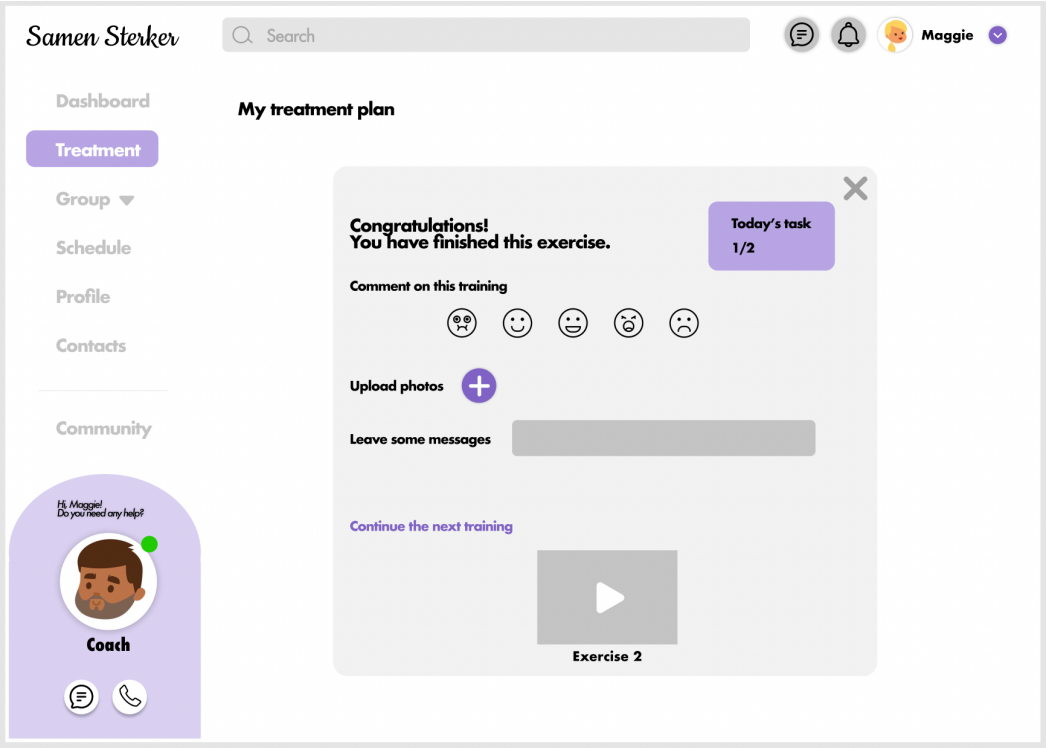



Figure 37. The treatment page (current)

Adjustments

After finishing one training, users can rate its completion and leave some comments to themselves or the healthcare team. At the end of the page,  there is a button for them to choose whether to send this training summary to the rest of the medical team. This is mainly the case if the user does not feel good about the workout or if they encounter problems. After sending, the healthcare professionals will quickly be informed by an email and also web notifications. At the same time, the system will automatically generate a training completion message for the user and send it to the group. By applying this function, the medical staff will be more quickly informed of the user's needs and can focus on those more urgent moments when they need help, thus increasing efficiency and saving time.

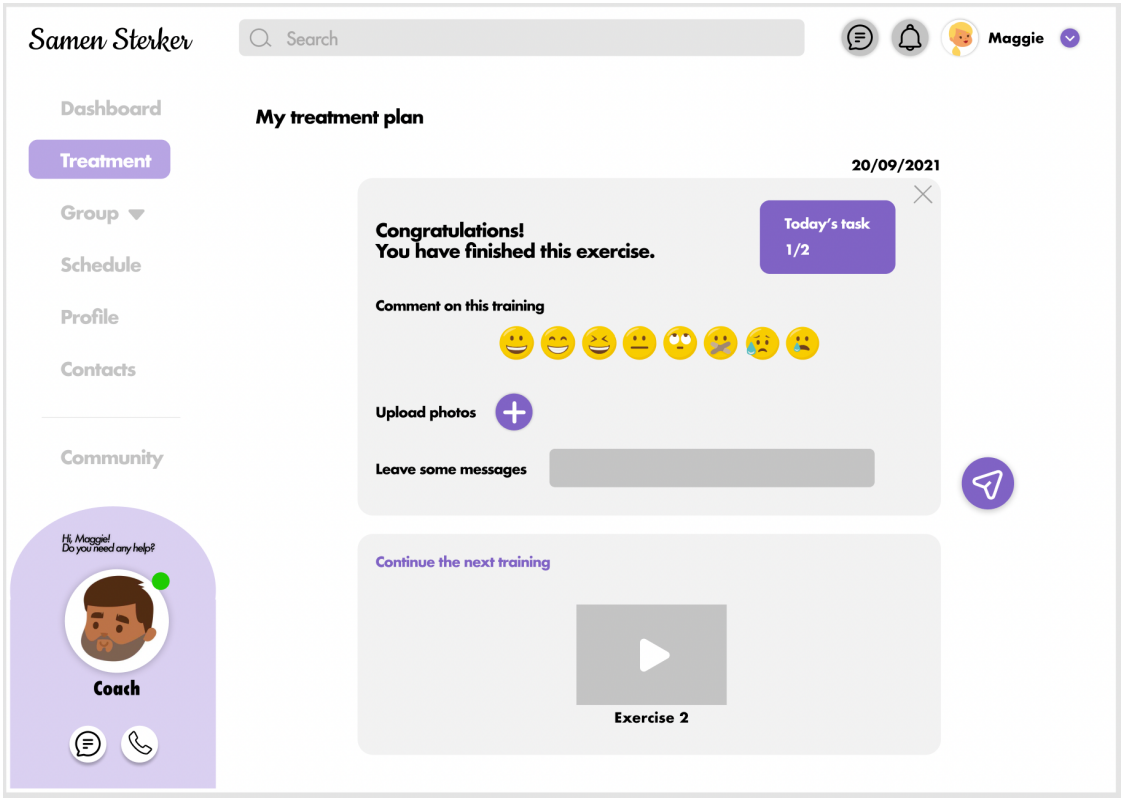



Figure 38. Quickly inform the healthcare team

Once the care providers see the message, they can add comments to the recordings at any time while reviewing the user's treatment videos. Previously they can just add common comments on the video by clicking the "message" icon. But now they can simply drag the "comment" icon to the video screen at the footage they want to comment on (see Figure below). Besides adding words, they can also draw on the screen or add images. After adding one comment, there will be markers appearing on the progress bar. By doing this, it makes it easy for the users to quickly and clearly notice when and what they did wrong and where they need to pay attention to. The user will also feel more supported by daily contact with the healthcare professionals.

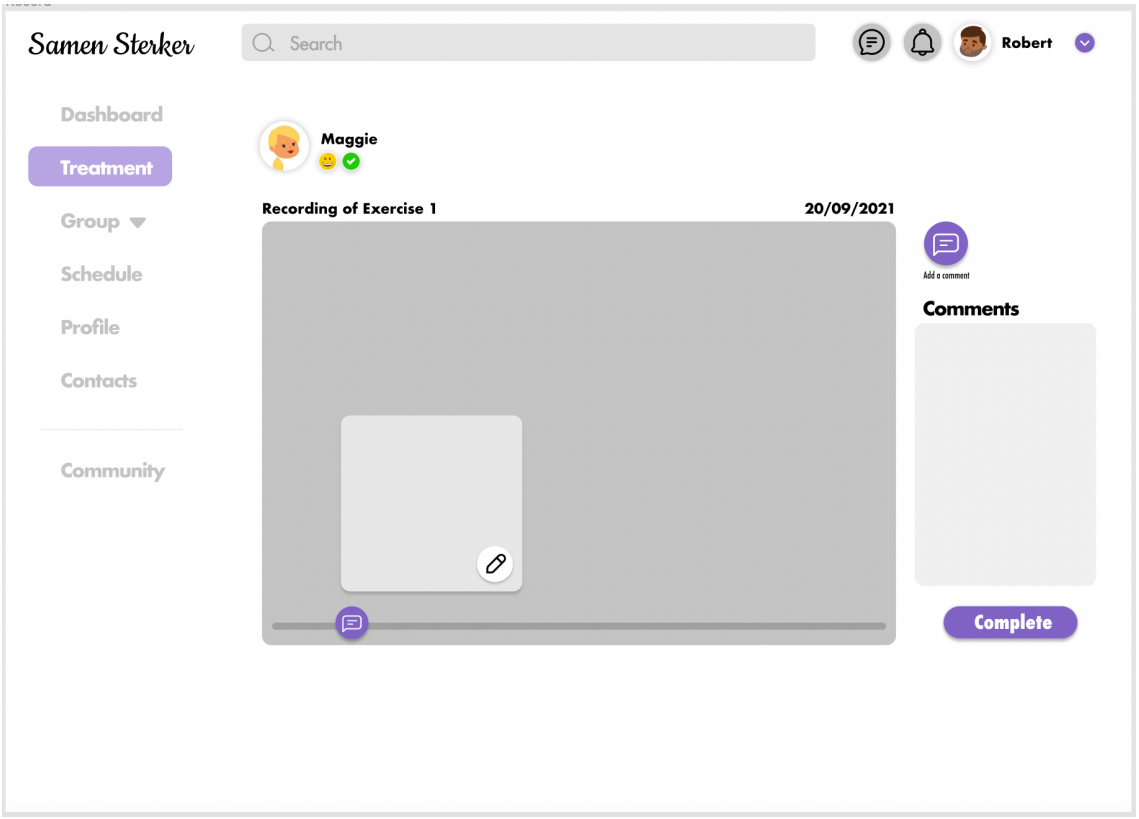



Figure 39. comment on videos - healthcare professional's version

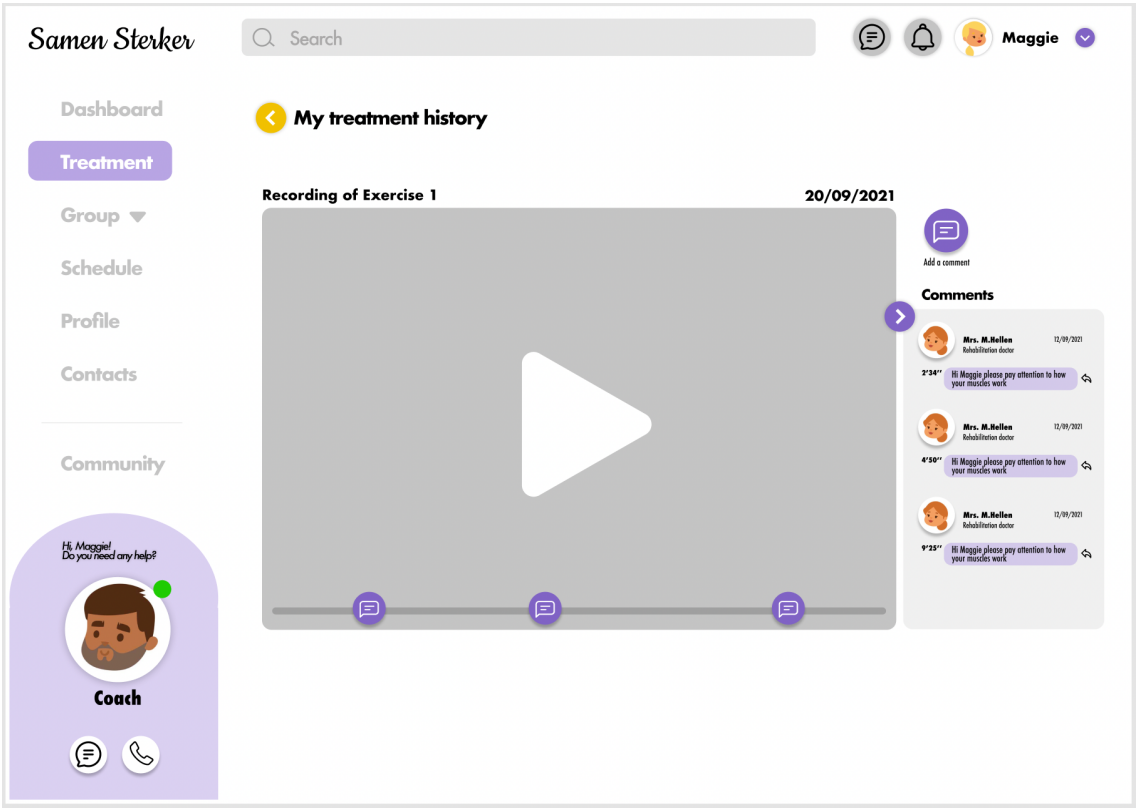



Figure 40. comment on videos - patient's version

## 8.5 Iteration 2

As the design of the chat group is the core of the whole service, after talking to Nikolas, I made a further exploration about the optimal way of communication in the chat group.

### 8.5.1 Way 1: To communicate in one chat group together

In the current design, all the healthcare professionals involved in the diagnosis and treatment process of the patient will be added to one chat group. When the patient wants to discuss something with the healthcare team, for example when he needs help, he can post the question in the chat group and wait for the reply. If people are not responding timely, the patient's coach is responsible for contacting them. This will be achieved by marking this message as an "important message". The group members will get informed by emails and web notifications. Then they can discuss the problems together in the chat group and agree on a solution.

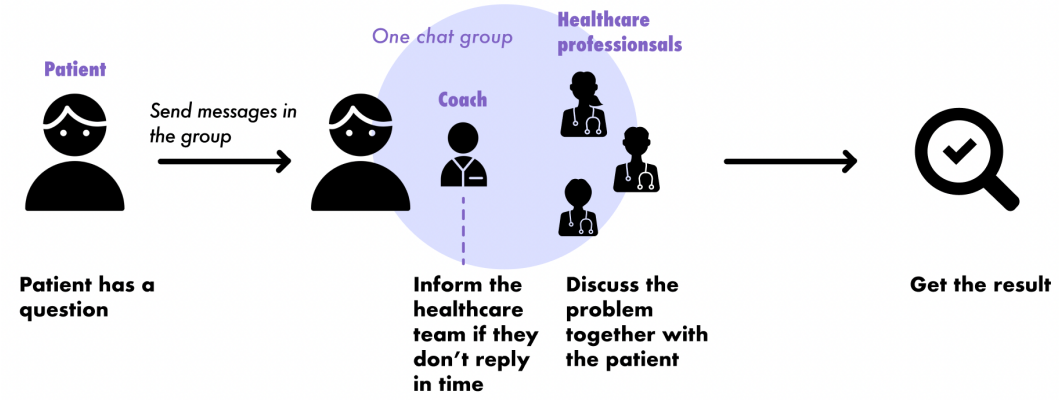



Figure 41. To communicate in one chat group together

Advantages

1. Patients can participate in the discussion process at any time, allowing them to better express their problems and needs.
2. Patients can see the entire discussion process, which means they can visually see that their problems are being addressed and valued, thus increasing their sense of security and reducing impatience.
3. Details of the discussion that are useful to the patient but may be overlooked by others are more likely to be noticed by the patient.

Disadvantages

1. The role of the coach in the whole process is weakened. He only plays the role of reminding members to reply. This is not consistent with the original intention to use the coach as a link between the various members of the healthcare network.
2. It increases the burden of understanding and decision-making for users. The user needs to spend time reading different content when everyone discusses it together, and in the end, the user may not know who to listen to.
3. Since different healthcare roles have different areas of expertise, notifying everyone about whatever issue may add unnecessary workload to some people and make information redundant.

### 8.5.2 Way 2: To communicate separately in different groups

In this model, all relevant healthcare professionals are not added to a chat group beforehand, but they can see each other's information in the user interface. When a patient has a problem, the patient will always communicate with the coach first. During this process, the coach can get a general idea of what the patient's problem is and use this as a basis to call on the care providers with the relevant knowledge and competence to discuss a solution in a chat group. After the discussion, the coach will help summarize the results and give feedback to the patient.

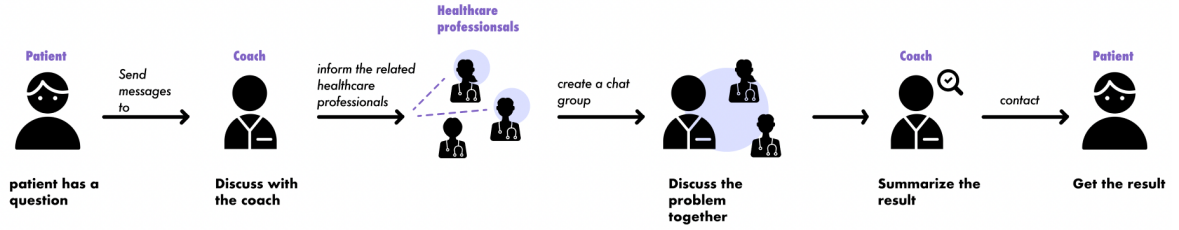



Figure 42. To communicate separately in different groups

Advantages

1. Users can get a clearer solution easily because their coach helps to summarize the discussion.
2. The user's expression will be smoother because the user only communicates with the coach they are familiar with throughout the process.
3. The timely response from the coach will be reassuring to the user, and if the coach can help solve the problem, then there is no need to bother other healthcare professionals to have a discussion.
4. Organized discussions increase the importance of the issue for each participant, and because only people with relevant expertise are selected to participate in the discussion, the efficiency of the discussion is increased and the number of people who do not participate or contribute is reduced.

Disadvantages

1. It increases the workload of the coach, and at the same time, it has a high requirement on the working ability of the coach because it has to summarize the discussion content.
2. The time spent on problem-solving may increase due to the increased number of sessions.
3. There might be some misunderstanding when retailing the information. Thus affecting its accuracy.
4. Users do not have to participate in the discussion directly, and some ideas cannot be confirmed and replied to by users in time, while some needs of users may be ignored.
5. Since the number of participants is relatively small, the discussion requires a certain degree of timeliness, and the requirement for concentrated discussion at the same time is higher due to the need of improving efficiency.

### 8.5.3 Discussion

Based on the advantages and disadvantages of each communication model, I combined some of their features and came up with some improvements to the current design.

First, different healthcare professionals will be categorized and tagged according to their areas of expertise. For example, physical therapists are better at rehabilitation, while neurologists are better at FSHD knowledge. Healthcare professionals can set their tags by themselves. So that the coach can quickly search and filter out the participants to the discussion group according to their tags. Therefore, only the care providers will participate in the discussion. By doing this, the communication will be more efficient and focused.

Second, during the discussion, both the user and the coach will stay in the chat group. This makes it easier for the healthcare team to ask follow-up questions and quickly notice the patient when some data is needed. It happens that the user doesn't have time to check all the information in the group. But whether the user joins the discussion or not, they will see updates on the progress of the discussion. This includes the formation of the discussion group, how many people have responded, the results of the discussion being compiled by the coach, etc. This gives users peace of mind by allowing them to know the overview and the progress of their issue even when they are not participating in the group chat.

The issue will be categorized according to its difficulty and urgency. A response period will be set, for example, the issue needs to be resolved within three days. All issues will have a basic deadline of three days, and if a problem is difficult to solve and requires more time or user participation, the coach will always update the user with the progress.

Finally, at the end of the discussion, in addition to getting a summary of the solution from the coach, the patient can also review the chat history. Since the highlight message feature is still available, the patient can look back at important messages if they want.

# 9. Final design & prototypes

This chapter mainly discusses the service and the finalized design by providing a thorough explanation of the whole system and the functions and features of the platform, as well as the benefits and value of the design to different stakeholders. Experience prototypes were made both from the patient's and the healthcare professional's perspectives.

## 9.1 Overview of the service

The overview of the service in the platform is shown in the figure below. In general, it is an online support system to help solve the FSHD patients' specific problems during their treatment. The service is available to all people living with FSHD, but it is more applicable to newly diagnosed or short diagnosed patients (<5 years). The main reason is that for these patients who are in the early stages after diagnosis, they are relatively new to the disease and the entire treatment process, and they are more likely to encounter more difficulties. Thus they need more guidance, support, and assistance throughout the process. This is just what this service can offer to them.


Figure 43. Overview of the online support service - The process

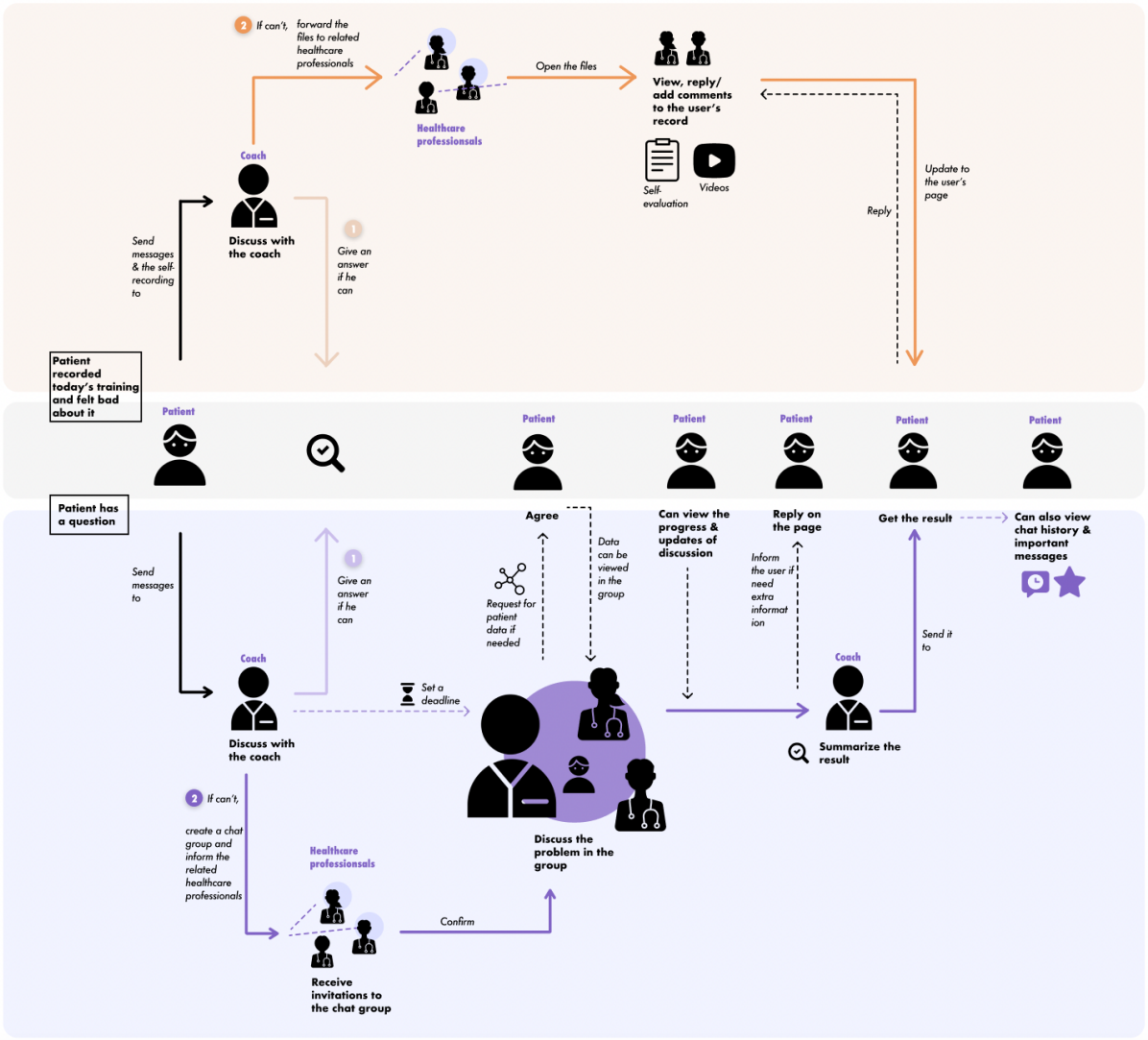



Figure 44. Task flow of the service

The system mainly covers two common situations that the patients often encounter during their treatment, one is the patient encounters some problems and needs help from the healthcare team to provide a solution, another is the patient feels bad during the daily training and wants some comments on their behaviors. The basis for coping with both situations is based on the help of the coaches in the platform. The main role of the coach is to bridge the communication gap among the different characters in the healthcare network and towards patients and facilitate their communications and collaborations.

### 9.1.1 Different roles on this platform

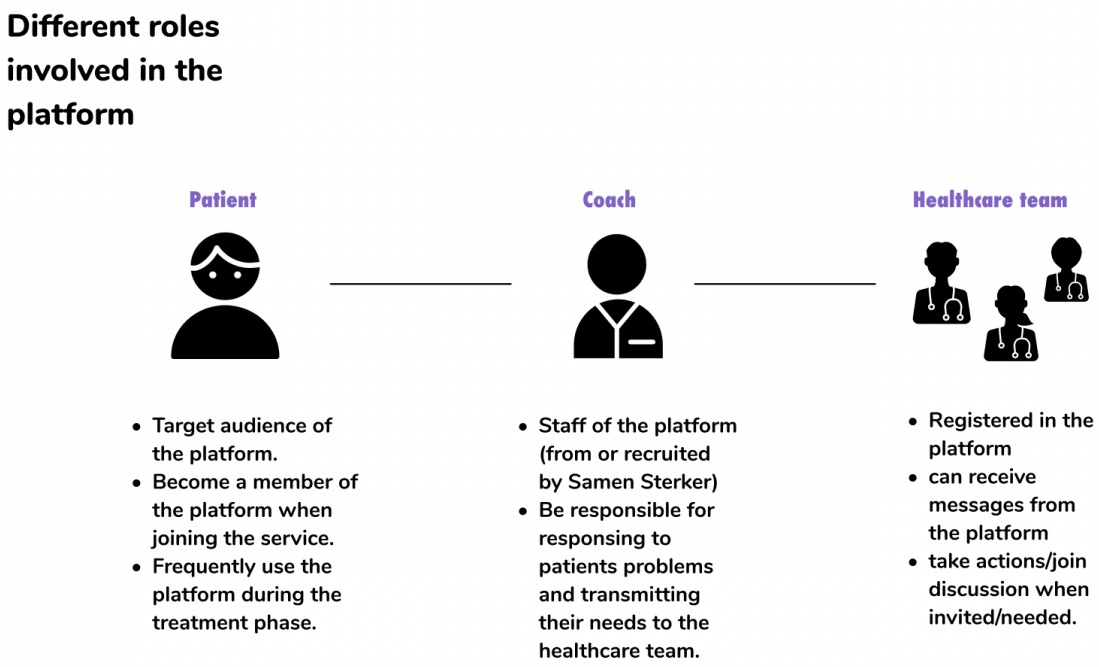



Figure 45. Different roles involved in the platform

Requirement for coach

The coach in this platform will be recruited by Samen Sterker. Here I listed some requirements for coaches.

- Doesn't need to be healthcare professionals or have professional knowledge about FSHD.
- Should have some experience/knowledge about the medical world.
- Should have enough time to work in front of the computer, can be those who work in help desks of hospitals or clinics.
- Should have sufficient communication skills to transmit the patients' needs to the healthcare team and send back the discussion summary.

### 9.1.2 The preparation stage

The service will be introduced to patients as soon as they get their treatment plan. After one user joins the service, a coach will be assigned to him/her. The coach will play a very important role in the whole treatment process, becoming the person with the closest connection to the user (see Figure below). The main responsibility of the coach is to lead and supervise the whole treatment process of the user, to eliminate the user's doubts and confusion in the process, and to help the user solve their problems by contacting the healthcare professionals. In addition, he will act as a bridge between the user and the care providers to facilitate and help each role to better connect and communicate more fluently. In the early stage of the service, the coach will first communicate with the user about the whole experience of previous visits and treatments, including the collection of some diagnostic data and the participation of various care providers. This is equivalent to creating a clearer and more systematic personal profile for the user. Based on this information, the coach will then contact the mentioned healthcare professionals and form a medical team dedicated to the user.

Their information will be entered into the system, allowing them to see the presence of each other.

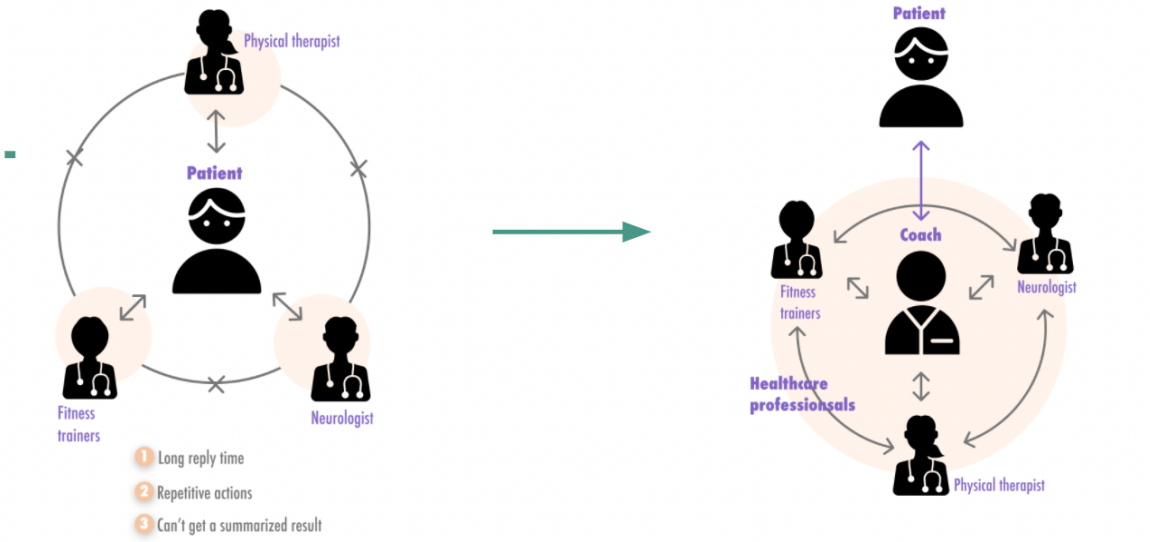



Figure 46. Previous model vs. designed model

### 9.1.3 The use stage

In the subsequent treatment process, the coach will closely follow the various movements of the user. For example, to check whether the user completed the exercise plan on time, or whether the appointment was made in time. When the user has a question or needs help, they can always contact the coach first since the coach will quickly reply to their messages and provide an initial analysis about the user's condition and their needs. Then the coach will invite the related healthcare professionals to one chat group and discuss the problem together. Not all of the care providers will be informed, but only the ones who have the related expertise based on their labels. In most cases the patient doesn't need to participate in the discussion, but they will be informed with any update in the discussion process, for example, the healthcare team requests the medical data and needs the agreement of the patient, or they need the patient to add additional information. After discussion, the coach will help to summarise the messages and send them to the user. The patient can also view the chat history and important messages during this discussion. In short, the coach will become the most reliable person to the user and facilitate the communications to become more fluent and timely.

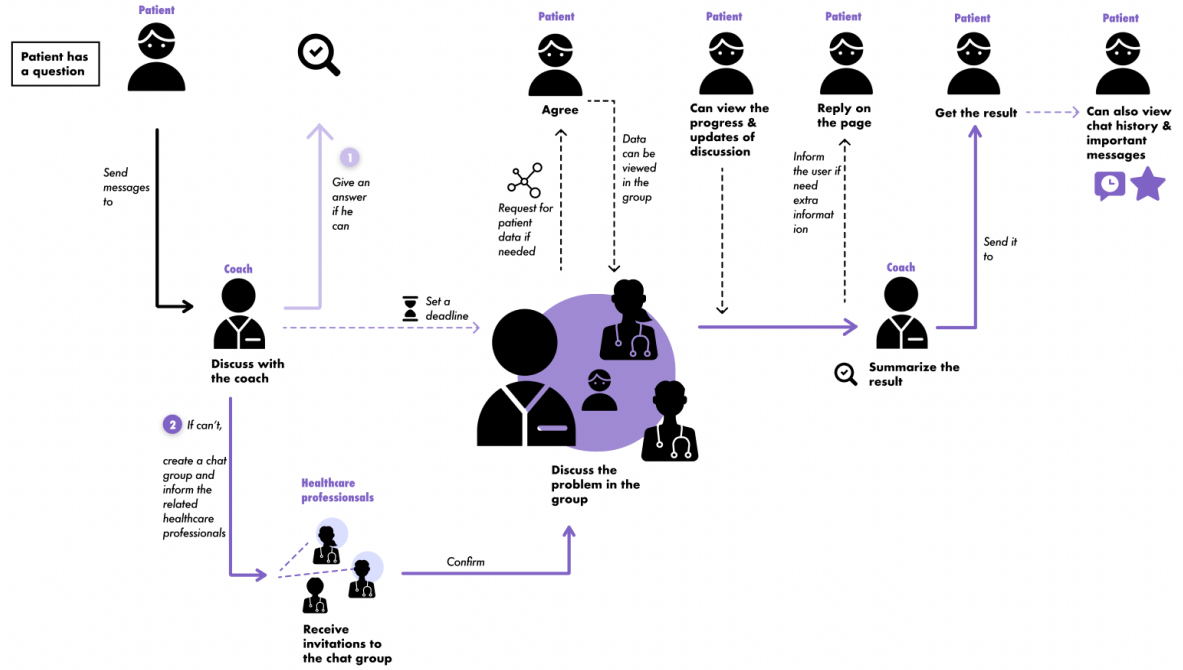



Figure 47. Communication about a question

However, not all issues need to be discussed in discussion groups, so effective communication about the patient's daily condition is also important. The coach will also help to facilitate communications between the user and the healthcare team about their daily treatment activities. Similar to the previous situation, the coach will filter the user's problems and needs before contacting the related healthcare professionals. As the patient can record their treatment progress through video recordings and self-evaluation form in the designed platform, these treatment data can be viewed and commented on by healthcare professionals. Patients can then read the comments and make some adjustments to their actions.

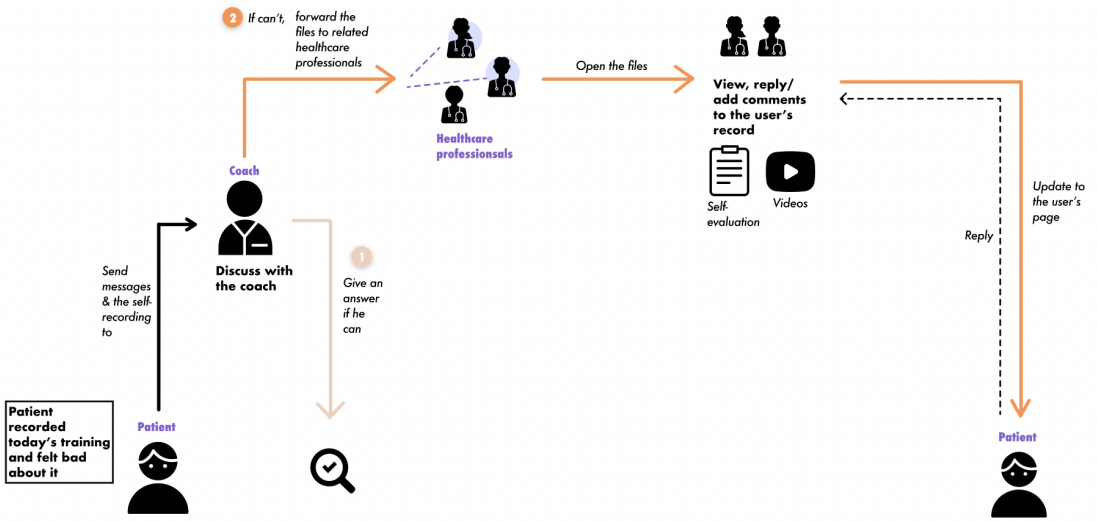



Figure 48. Communication about daily treatment

In all cases, users were asked to first contact their coach. This not only improves the reply efficiency thus placating the user, but also reduces the unnecessary workload of the healthcare professionals by filtering the questions first so that they can focus on more pressing issues.

## 9.2 Design details

### 9.2.1The patient dashboard

The information architecture and the user interface of the user homepage are shown in the figures below. It mainly consists of three parts, a menu in the upper left corner, the two quick accesses to the most important functions in the middle, and the notifications widgets in the upper right corner. There are three main parts in the menu, the treatment, where the user can see their daily tasks and their treatment plan; the chats, where the user can see all the ongoing chats and view the progress of their problem-solving; the profile, where the user can view their basic information, medical data, as well as the members in the healthcare team. In the upper right corner, users can see if they have new messages and new notifications. By clicking on their profile image, they can go to their profile page and by clicking the arrows beside their photo, they can change their login status. The two accesses in the middle can quickly navigate the user to the core functions of this platform.

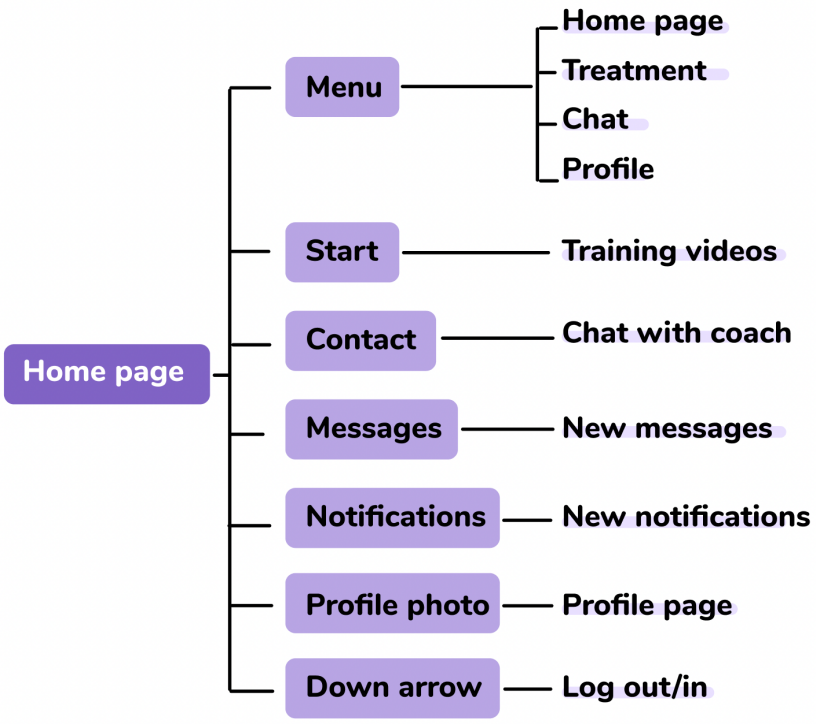



Figure 49. Information architecture - user home page

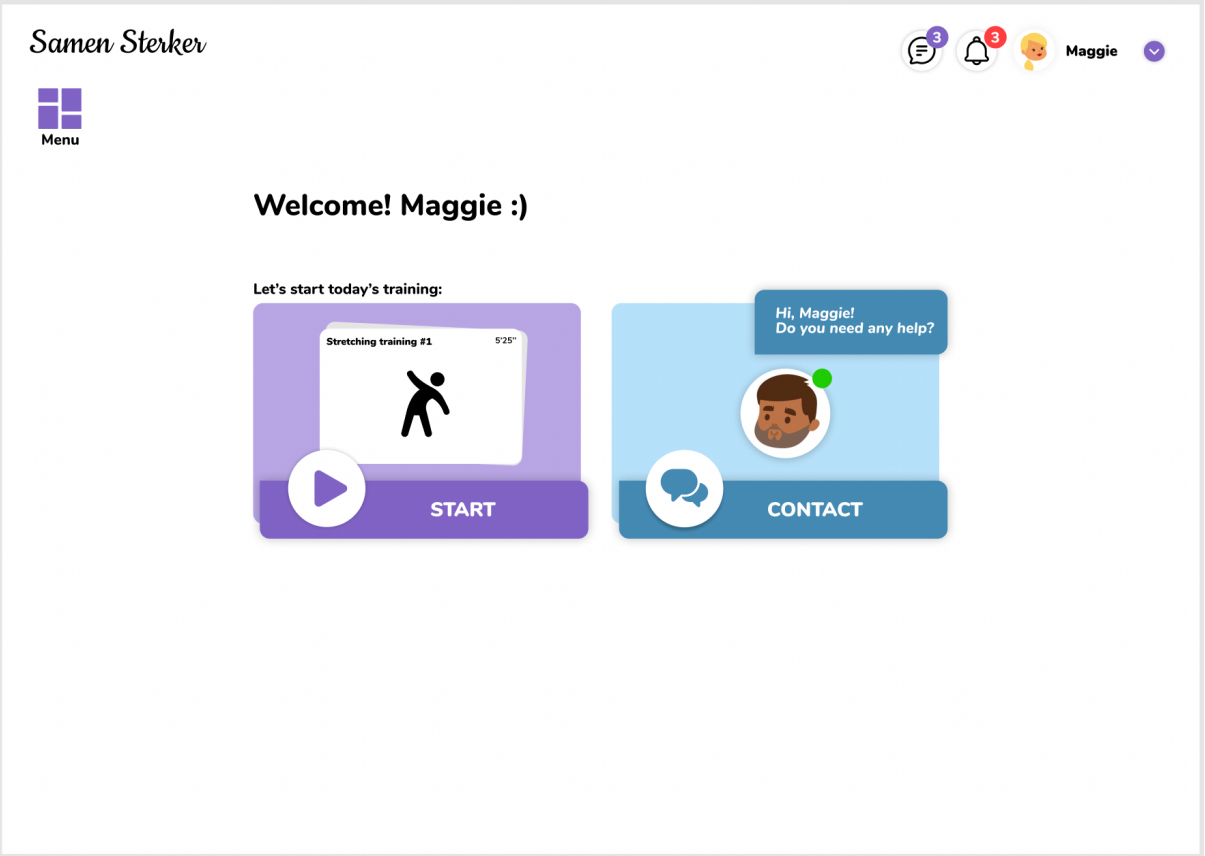



Figure 50. The home page - user's version

By clicking "start", users can begin to work on their training activities of today. By clicking "contact", users can quickly start chatting with their coach.

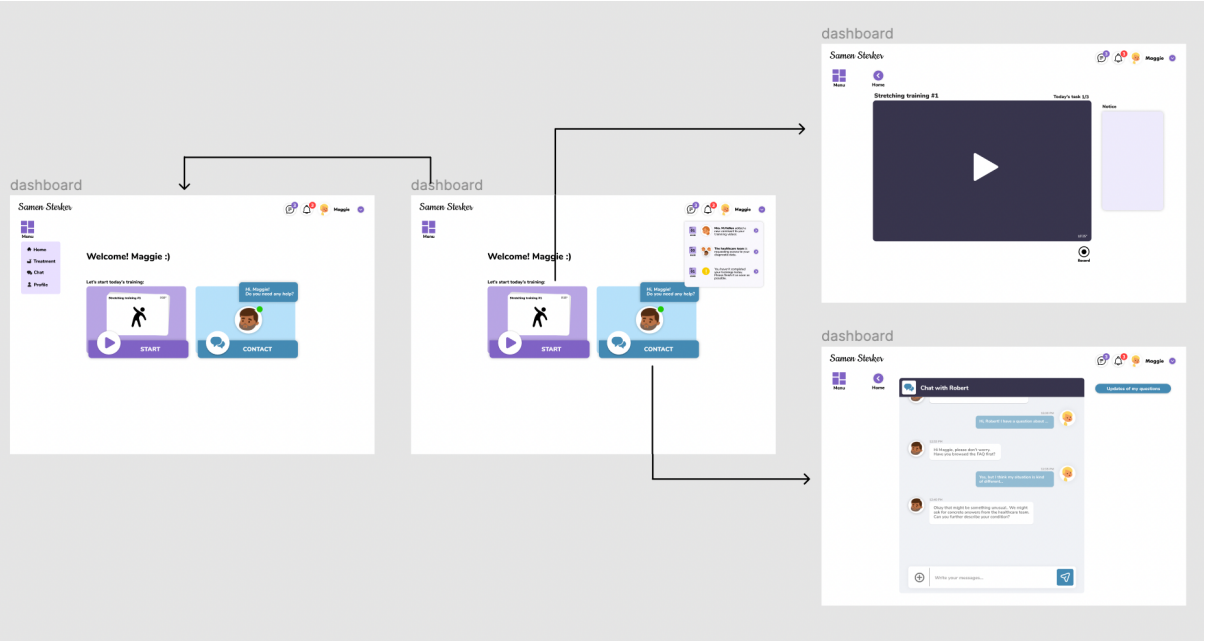



Figure 51. The task flow of home page - user's version

### 9.2.2 The treatment page

In the treatment page, users can see their daily treatment progress and the tasks for each day. The number of days and hours of training are recorded, which can improve their sense of accomplishment and promote their adherence to the program. When the user finishes today's exercises, he can take a self-evaluation about today's training. And he can quickly share the result with his coach when he feels bad about the training.

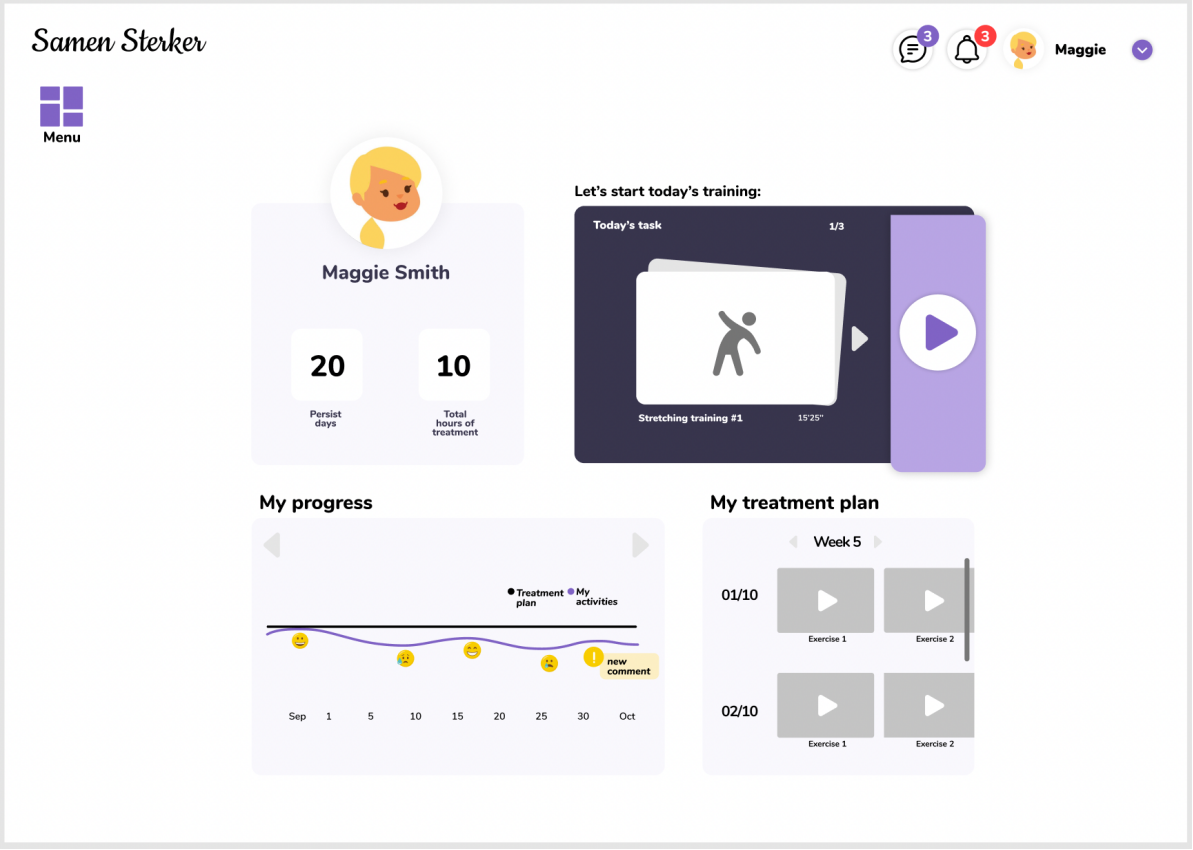



Figure 52. The treatment page - user's version

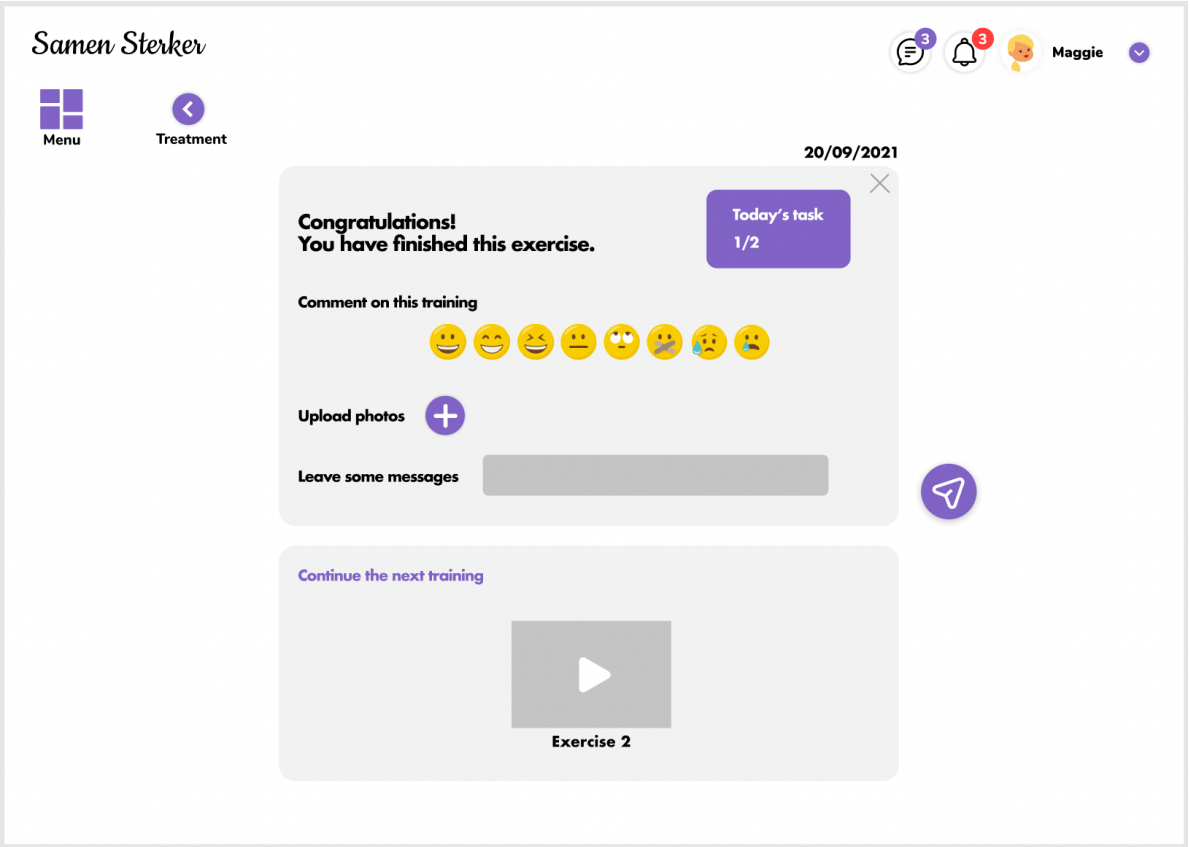



Figure 53. The treatment page - user's version

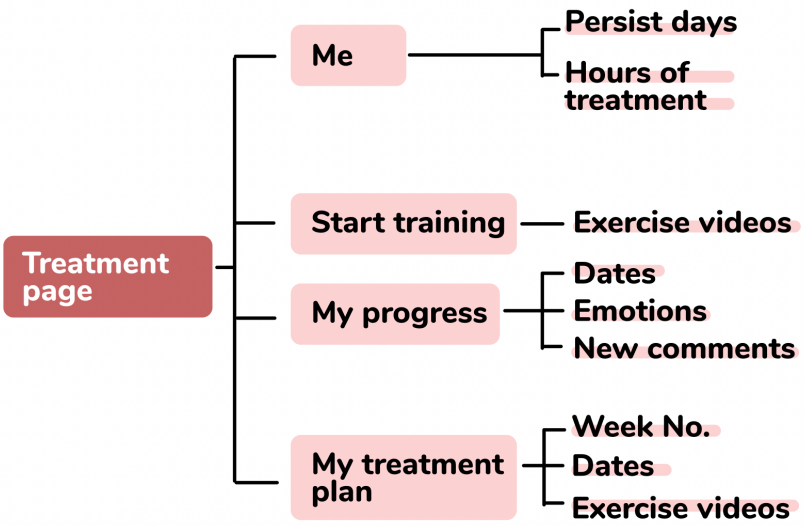



Figure 54. Information architecture of treatment page - user's version

### 9.2.3 The chat page

Every time when the user has a question or encounters any difficulties during the treatment, they can always contact their coach first for help. The coach will ask the user for some basic information and give some advice on the user's problem.
The healthcare team will not be informed only if the coach finds the problem is tricky and requires the healthcare professionals to discuss it together.

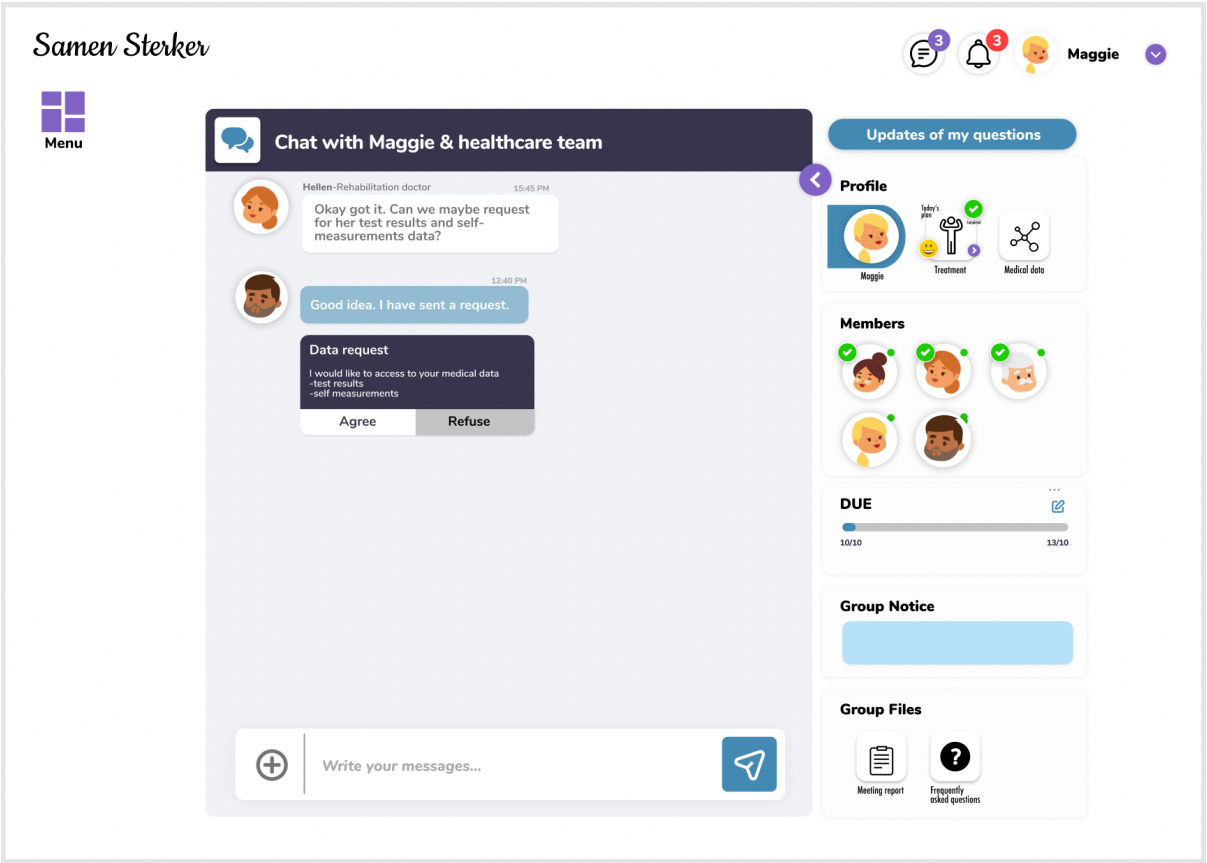



Figure 55. The chat page - user's version

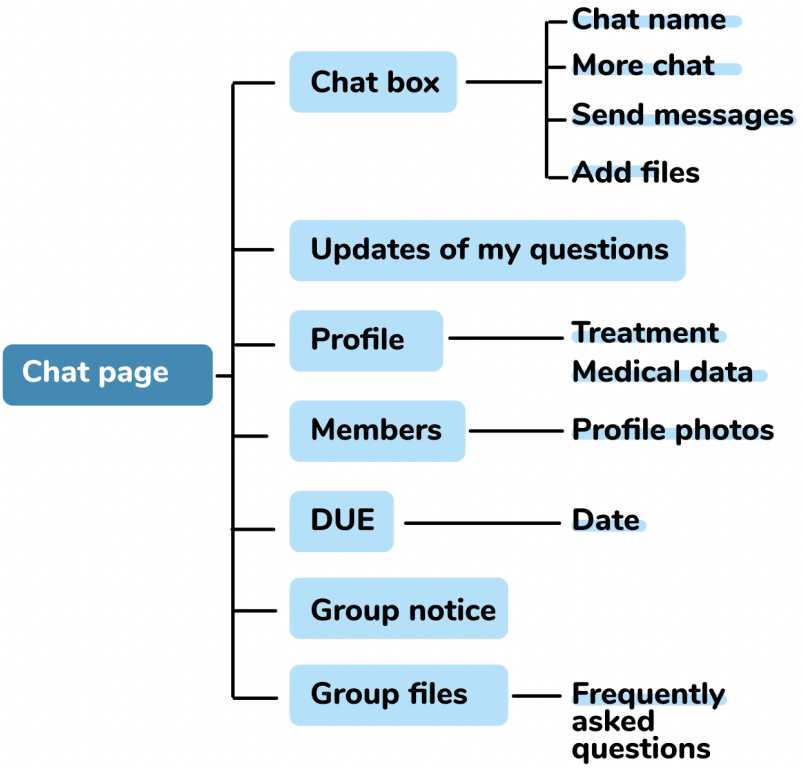



Figure 56. The information architecture of chat page - user's version

In the user interface of the coach, he can click “new group” and invite the related healthcare professionals to a chat group based on their area of expertise shown on the labels. The selected care providers will then get an email notification to join the group.

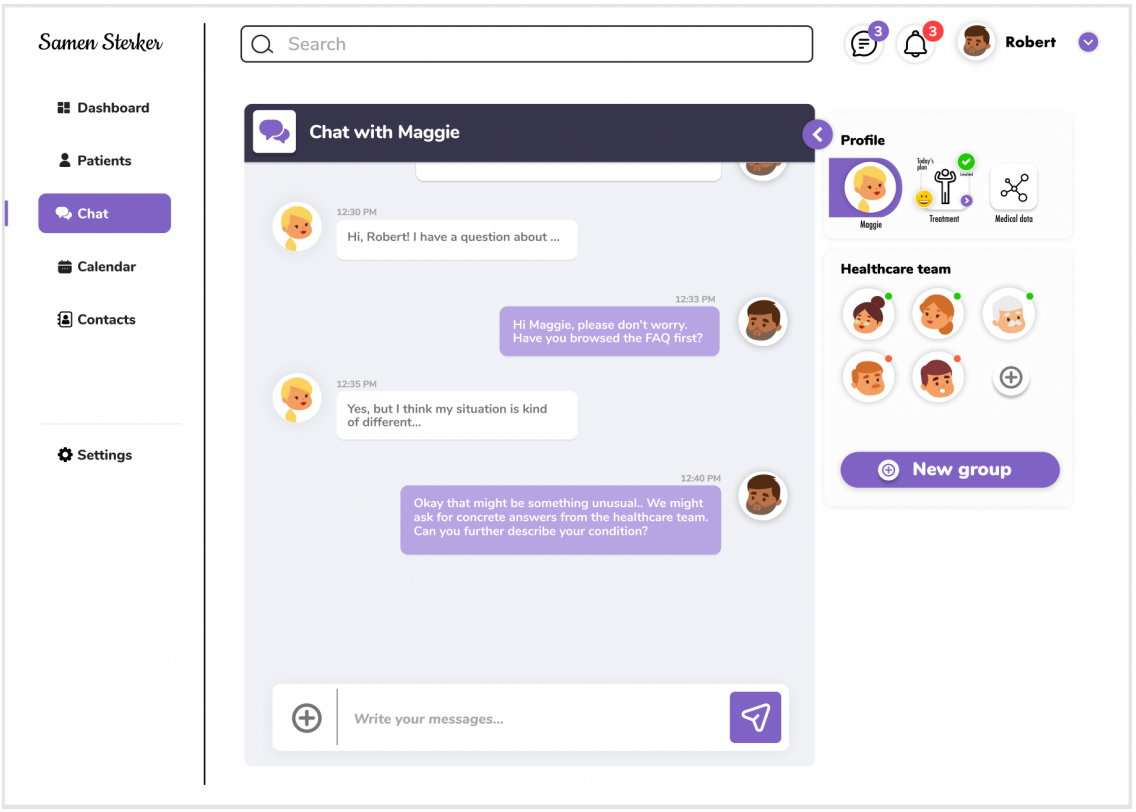



Figure 57. Create new group chat- coach's version

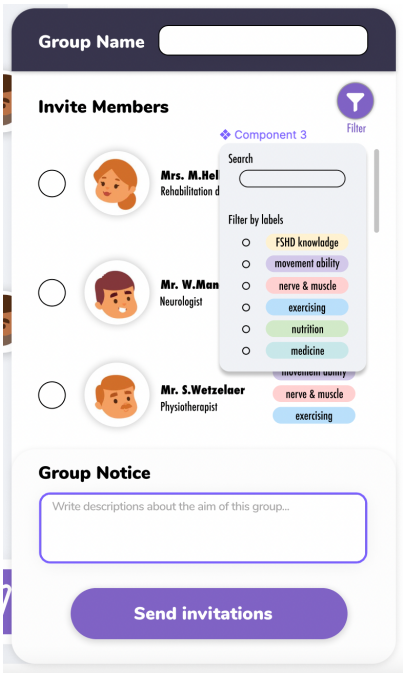



Figure 58. Quickly search by the filter - coach's version

In the chat group, the members can view the profile of the user and request access to the patient's medical data. Users will get notifications about the request both in the chat group and on the "updates" page. In order to ensure data safety, the user's medical data will only be viewed after his permission and will only be shared within the group. On the "update" page, users can also clearly see the progress of the discussion, which makes them get a feeling of being in control even if they don't have time to view all the group messages.

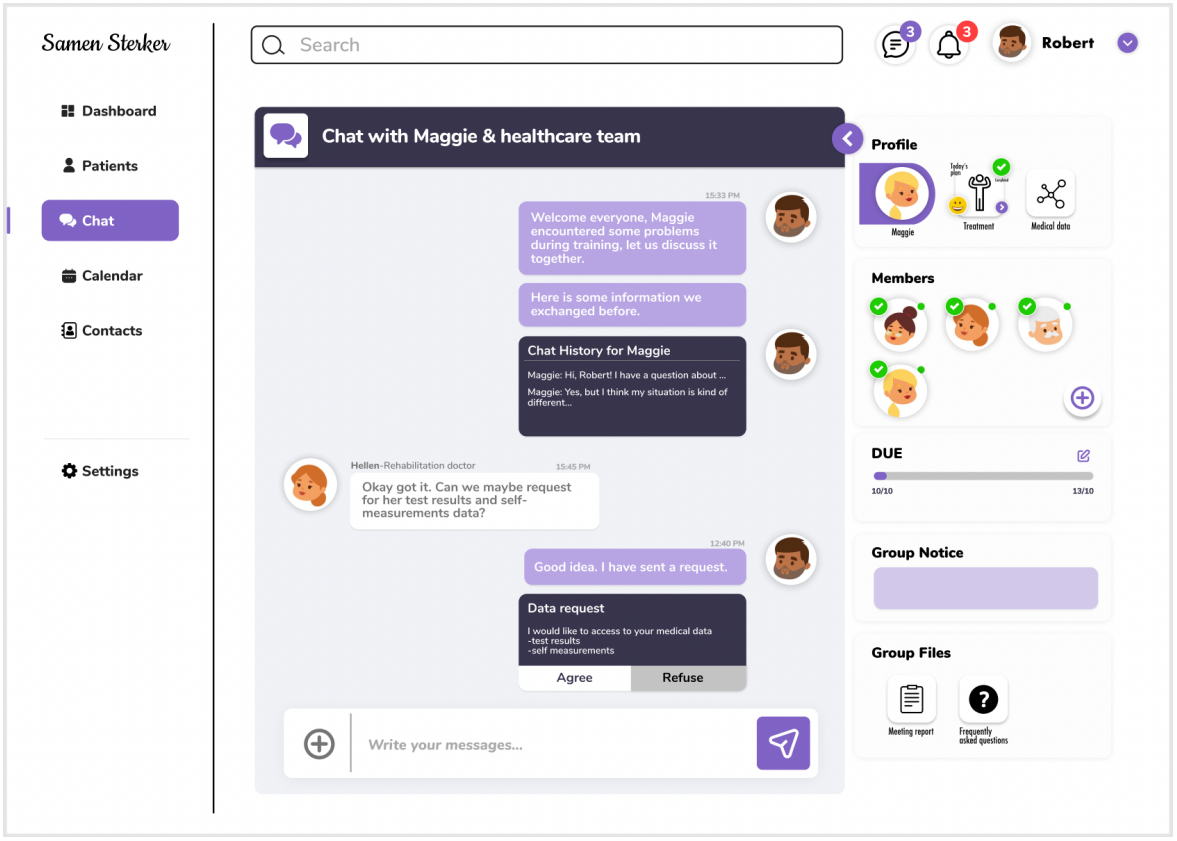



Figure 59. Data request - coach's version

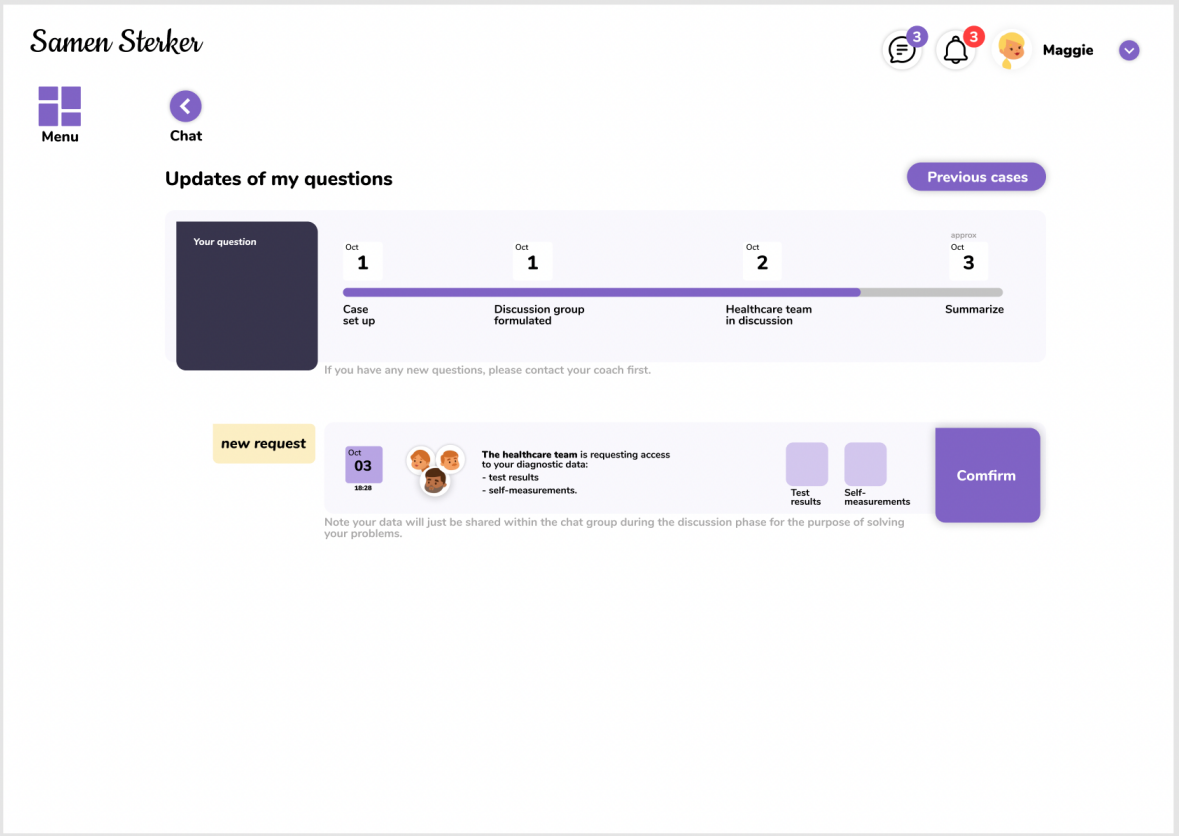



Figure 60. Updates of the progress - user's version

In order to improve the efficiency of problem-solving, each chat group will have a deadline according to the complexity of the problem. After the issue is resolved, the coach will help to summarize the result and important message during the discussion and send it to the user. Then the group will be automatically disbanded and all user data privileges will be withdrawn, but the chat history will be saved for easy review.

If a member never responds during a discussion or at a point in the process when participation is required, the coach can give him some additional reminders by clicking on the member's profile photo and then clicking on the “remind” button. Reminders are divided into three modes depending on their intensity, they are in-page reminders, email reminders, and phone reminders. By filling out the content of the reminder, the person will receive an automatic reminder sent by the system using the selected method.

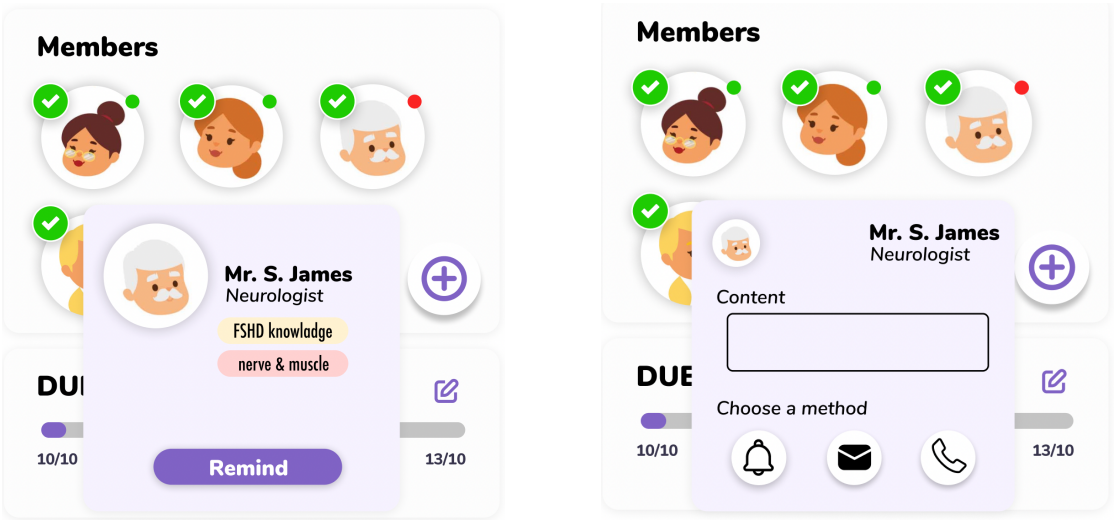



Figure 61. Remind the member - coach's version

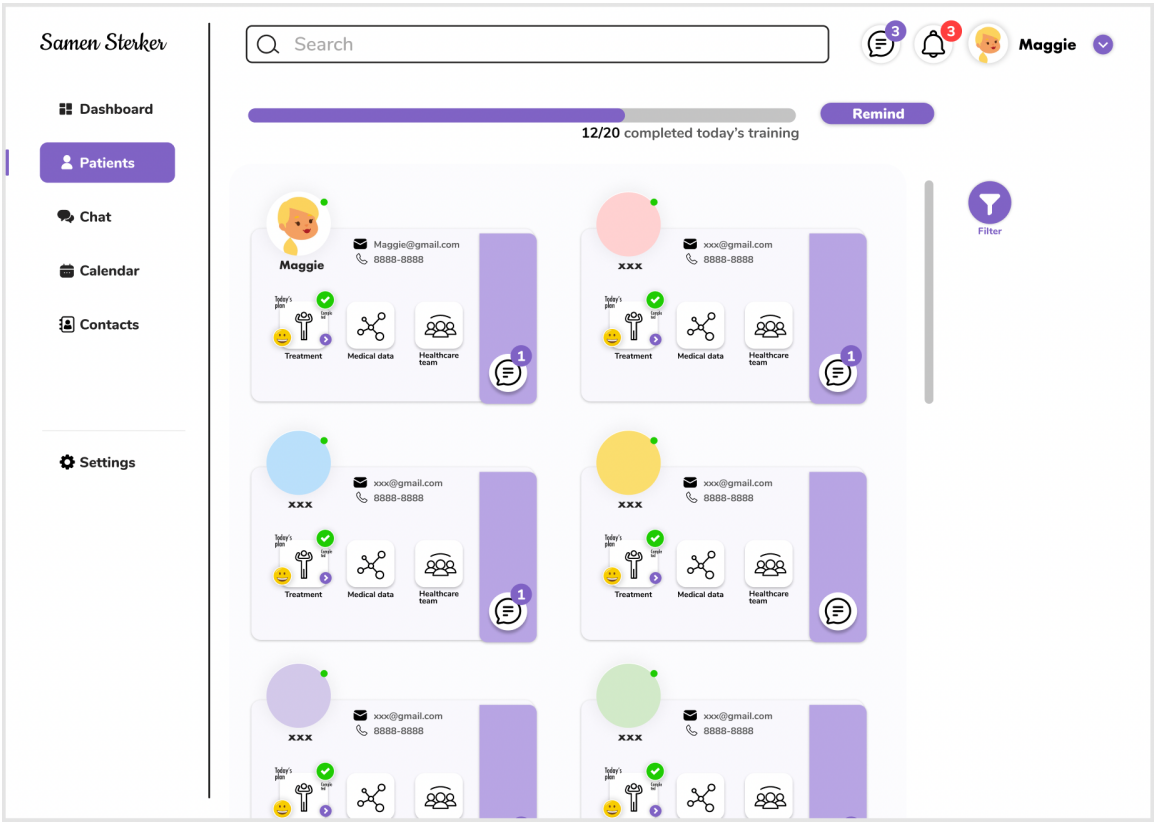



Figure 62. Patients page - coach's version

### 9.2.4 The profile page

In the profile page of the user, users can view and edit their personal information, view, upload and share their medical data. They can also see the members in their healthcare network and the service plan they chose.

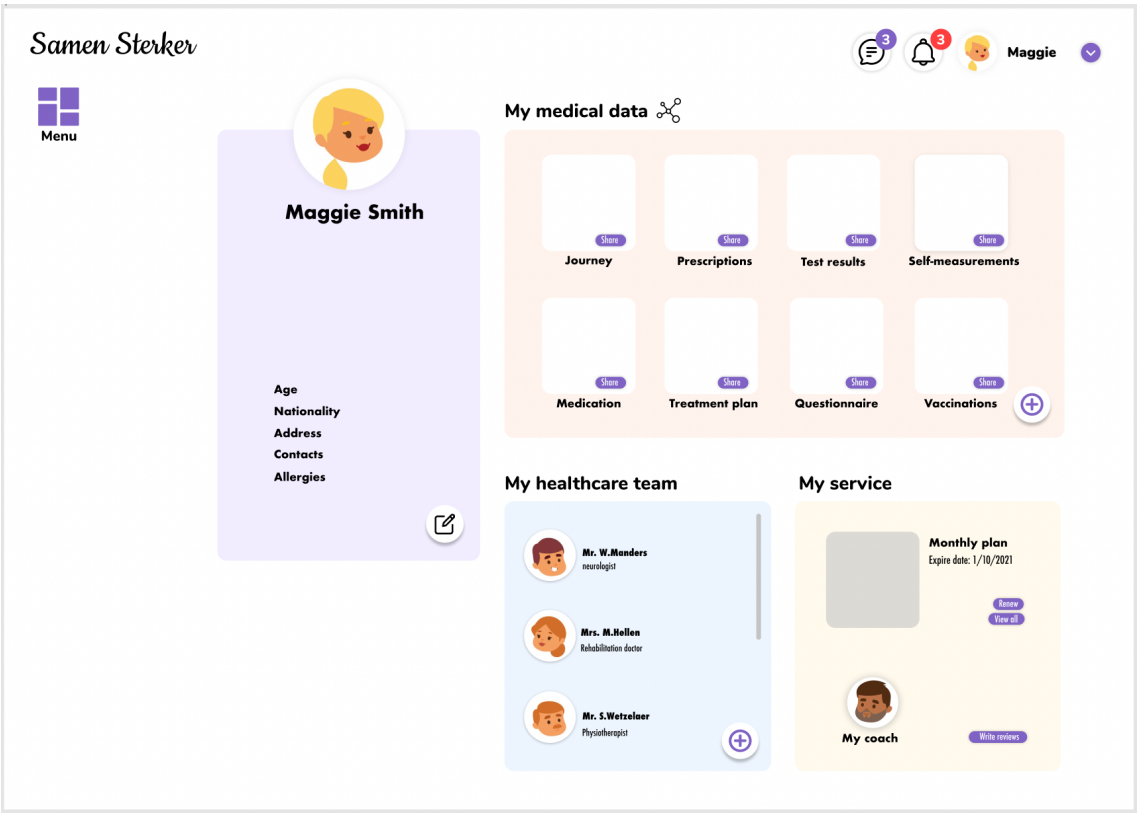



Figure 63. Profile page - user's version

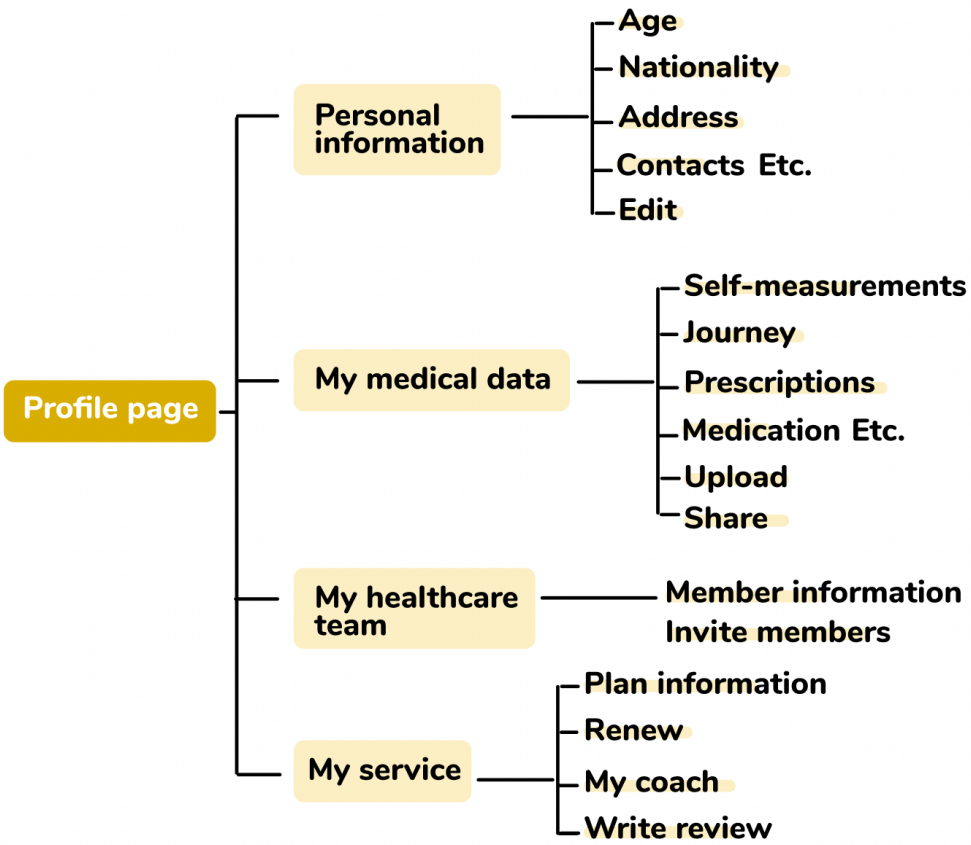



Figure 64. The information architecture of profile page - user's version

### 9.3 Benefits of the platform

The designed system optimizes the existing communication process when patients meet difficulties during treatment. First, we provide a coach to guide the user and pre-visit before contacting experts to reduce the workload of healthcare professionals and increase efficiency. At the same time, the coach will respond to the user's questions in a timely manner, thus reducing the user's waiting time and relieving anxiety. Second, with the help of a coach, patients can get in touch directly with the person who is most likely to solve the problem with the relevant expertise. And the presence of a coach makes the whole process more organized. Third, we bring these people together at the beginning so that they can focus on the problem and discuss together to agree on a solution. Fourth, we enable users to keep their personal data in one place and share it directly to the whole group when sharing information.

#### 9.3.1 From separate to integral

In the original situation, different healthcare professionals who serve the same patient will work separately. When they are not able to settle a question from the patient, they will ask the patient to contact another healthcare professional who might have the right knowledge. In this process, different care providers can't inform each other easily, which will lead to some misunderstandings and conflicts on the outcome.

The designed platform brings the different characters in the healthcare network together in one place and facilitates their collaborations. The problems of the patient will be solved faster and in a more focused way by bringing together healthcare professionals with relevant knowledge and experience together in a chat group. The chat group breakthroughs the communication barriers among different healthcare roles. With this chat group, they are able to work and make decisions together to agree on a solution. Thus the final solution will be more comprehensive and uniform and the patient will receive a summarized result by the coach. The patient's data will be shared in the group and can be viewed by all the members in the group at once after getting the permission of the patient. The online group chat also breaks through the time and geographical restrictions of communications, which enables the healthcare team to communicate at any time and any place to improve efficiency.

#### 9.3.2 From delayed to timely

In the previous situation, the response to the patient's problem is often not timely. It usually takes quite a long time until the patients get a helpful answer due to the delayed reply of the healthcare professionals and the unsuitable person they contacted.

In the designed platform, patients may have a higher possibility to get real-time help and reply from multiple roles in the healthcare network. With the management of the coach, the problem-solving process will become more organized and fluent. The coach will always reply quickly to the patient's issues and help them contact the people who can solve the problem based on their area of expertise. Then they will be quickly informed to join the chat group and discuss the solution by email notifications. Setting time limits for problem-solving promotes the efficiency of discussion. Any changes in the progress of the problem-solving process will be updated and synchronized with the

user. In addition, the data exchange between the patient and the healthcare professionals also becomes easier and more efficient. User data can be viewed by everyone in the group simultaneously, thus reducing the need to send it to different people multiple times.

### 9.4 User scenarios

To more clearly demonstrate the benefits of this design to the user, I created some user scenarios that occur frequently in the user's daily life and during their treatment. By comparing the scenarios and users' actions before using this service and after using this service, we can more visually see how users will use and interact with our service and verify whether my design helps users achieve their goals more easily or not.

**User background:**
Maggie is 45 years old. She was diagnosed with FSHD three months ago and started her treatment plan right after with a lot of passion.
**User's goal:**
The goal of the user is to have faster and easier access to help, and to communicate their problems and needs more clearly with the care providers.

**The story (before):**
One day Maggie felt some discomfort during a training session, and the pain worsened a few days after the session. So he contacted his physical therapist by phone, but the call was not answered. So she sent him an email. Two days later she got a reply from the physiotherapist, who gave the user some advice, but he did not know the exact cause of the discomfort, so he asked the patient to contact a more specialized neurologist for help. The neurologist explained the possible conditions to the patient, and the patient referred these to the physiotherapist, but there were some discrepancies in the content. The physiotherapist eventually gave some treatment improvements based on this.

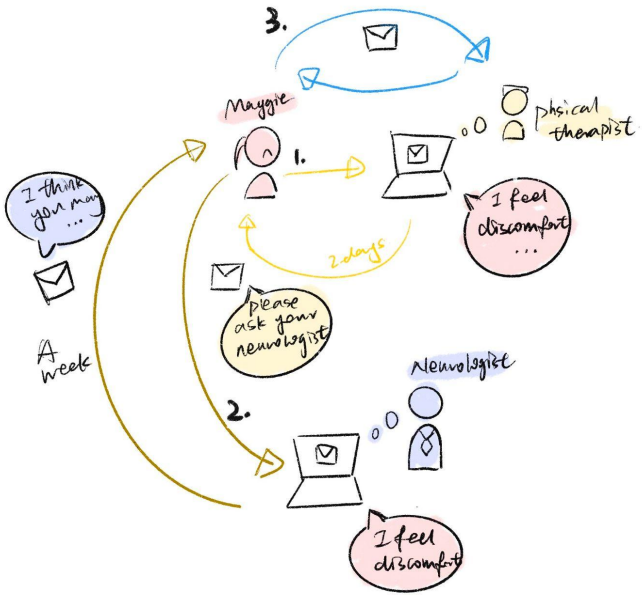



Figure 65. Previous scenario

**The story (after):**
One day Maggie felt some discomfort during a training session, and the pain worsened a few days after the session. She then contacted her coach. Her coach replied quickly and found some similar questions in the FAQs and sent these to her. She browsed through them and said there was something special about her situation, so the coach decided to invite some healthcare professionals to have a discussion. The coach then informed some care providers who have the related expertise to form a group to discuss the question. Maggie can stay in the group and join discussions when needed. And she will be informed of any updates in the group on her treatment dashboard. After discussion, Maggie received a summarized answer to her problem from the coach. And the problem and the solution were included in her problem collection for easy viewing if the problem happens again.

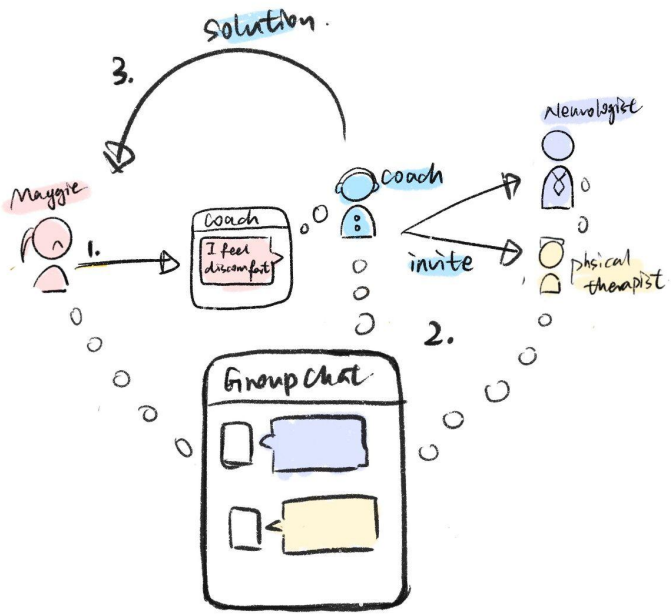



Figure 66. Designed scenario

### 9.5 Comparisons with the existing platforms

More direct communications

In the healthcare platform *IVIDO* (https://ivido.nl/), there are functions where the user can share medical data with another practitioner, and the changes in the user's file can then be sent back to the previous doctor. This offers the possibility to connect the different care providers and make the user feel more in control of their data. However, during this process, the system only supports the exchange of user data. There is still no direct communication between the two healthcare roles, thus the effectiveness will be reduced.

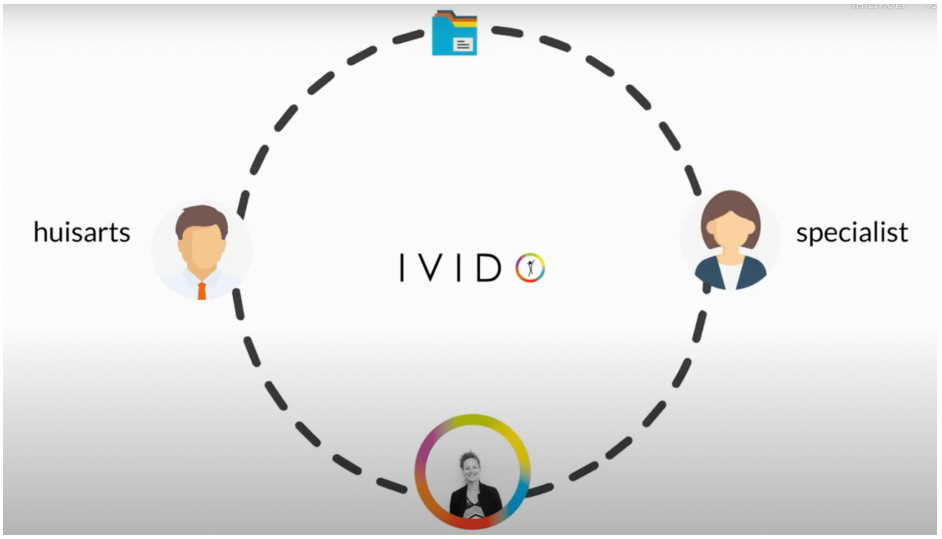



Figure 67. Data exchange in *IVIDO*

In the designed platform, the barrier in communications is eliminated. There are times

when a difficult problem requires more people to be involved in the decision. So in this design, multiple roles can be invited to the chat group at once, which facilitates joint decision making in a treatment team. During the discussion, when they request medical data from some users, they only have to request it once and that data will be shared with the members of the group.

More guidance, more support

In the *IVIDO* platform (https://ivido.nl/), users can create their healthcare network by themselves and choose whom they want to share data with. This is a critical but tedious step in the entire process. So it can be burdensome for the user to do it alone, as the user may have questions about who needs to be in the team or what data can be shared. When users have doubts or meet difficulties, they can contact customer service for help. But due to their workload and the restriction to the user data, they can just deal with some common questions or provide some general answers to the user, which cannot solve the problem fundamentally.

In the designed platform, each user will be assigned a coach to facilitate personalized holistic care after they join the service. The coach will take the responsibility of guiding and supporting the user throughout the whole treatment process and take control of the user's overall condition. When the user meets difficulties, they can always contact their coach first. Through the help of someone who is familiar with the user's condition, the problem-solving process will be more fluent. The coach of the user will also, thus makes the user feel more supported and guided throughout the treatment process.

# 10. Usability test

## 10.1 Objective & methods

In order to validate whether the final design can meet the design goal and the user needs, a usability test will be conducted with the target audience. The goal of the usability test was to ascertain if the problems improved with the designed interface. To conduct the test, several tasks will be provided for users, followed by some questions asking their opinions about their experience of the design. The tasks were designed to test the usability regarding main functions  of the online platform including the chat function and the treatment function. The subsequent questions mainly cover three aspects, functional, aesthetic and psychological effects.

## 10.2 Participants

The participants were recruited with the help of the client. In general, six people have been tested. Among the testers, three are FSHD patients (one is client) and two are physiotherapists (one is client), and one is a project manager. Although the platform is mainly designed for patients, two tests were also done with the healthcare professionals since they are also important roles that will actively use this platform. By doing this, we can gain insights from both healthcare professionals and patients' view, so that it will make the validation more comprehensive and effective.

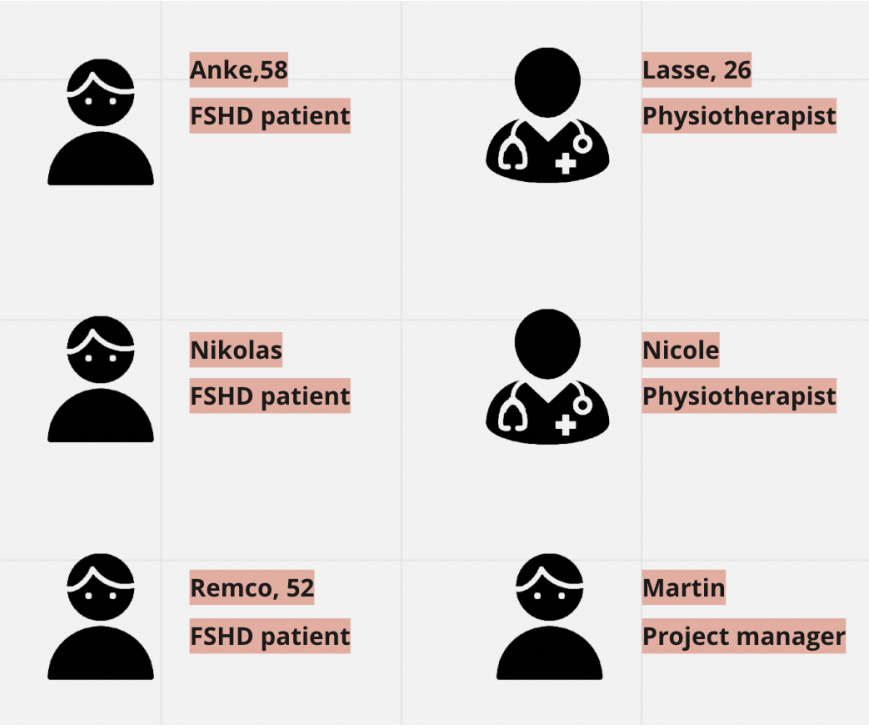



Figure 68. Participants

## 10.3 Practical setup

The tests were conducted fully online using the online conferencing platform *Zoom*. The prototypes were created using the software named *Figma*. It is a convenient and effective tool for making interactive user interface prototypes. The whole test was conducted following the test protocol (see the appendix). During the test, participants

were asked to share their screen during the test which allowed me to clearly capture their body gestures and facial emotions of how they complete each task and how they interact with the prototype. This is very helpful for subsequent analysis.

### 10.4 Result & Analysis

In this test, each subject needs to complete three tasks. During the analysis, I broke down the steps of each task and recorded the time spent on each task to help me analyze which part of the interaction was a problem or caused the user's confusion.

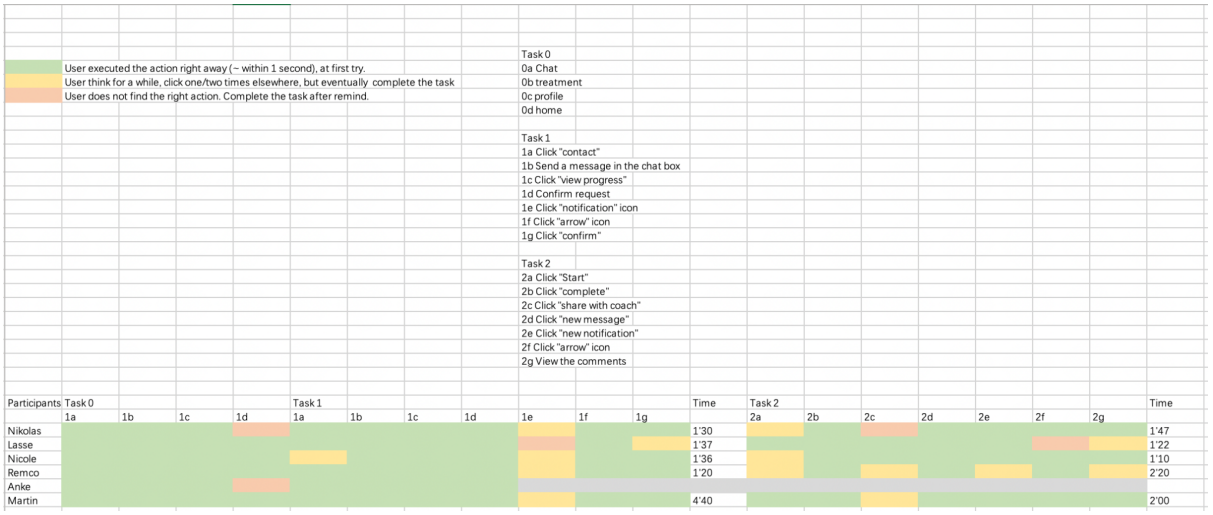



Figure 69. Test result for three tasks

#### Task 0

The first task is to let the participants freely explore the interactive prototypes, which can be seen as a preparation task for the following tasks, thus I named it “task 0”. Since there are four categories under the navigation bar (see Figure below), the first task was divided into four micro-tasks. The objective of this task was to validate whether users will be able to experience different pages during their first exploration easily. Based on the figure above, it can be seen that all the participants were able to execute the first three micro tasks successfully. However, two people did not explore the last category “profile”. But during the test it was found through observation that they should have seen this entry in the catalog, but they did not choose to click on it, probably because they thought that this feature was not the main function of this web platform and thus ignored it.

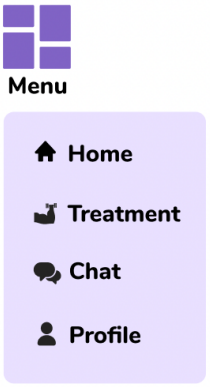



Figure 70. Four categories under navigation

**Task 1**
**Task description:** One day in the morning you feel pain on your right shoulder but you don't know why, what would you do?

The first task focused on testing how the design helped users solve problems they encountered during training, and involved mainly online chat features and problem progress track. This task was divided into 7 small steps (see Figure below). The color data showed that most of the test subjects were able to complete the first four steps smoothly, with only one user taking some time in the first step. This shows that the users understood the basic logic of the platform, which is to seek help from their own coach when they encounter difficulties. During the test most people encountered problems at step 5 (1e), where the user did not notice a new alert notification. Firstly, this could be caused by the inconspicuous reminder flag, and secondly, it could also be due to the fact that this step appears automatically five seconds after the user completes the previous step, a short interval between this step and the previous one, and the user may not have finished reading the feedback generated in the previous step and thus ignore the appearance of the new reminder.

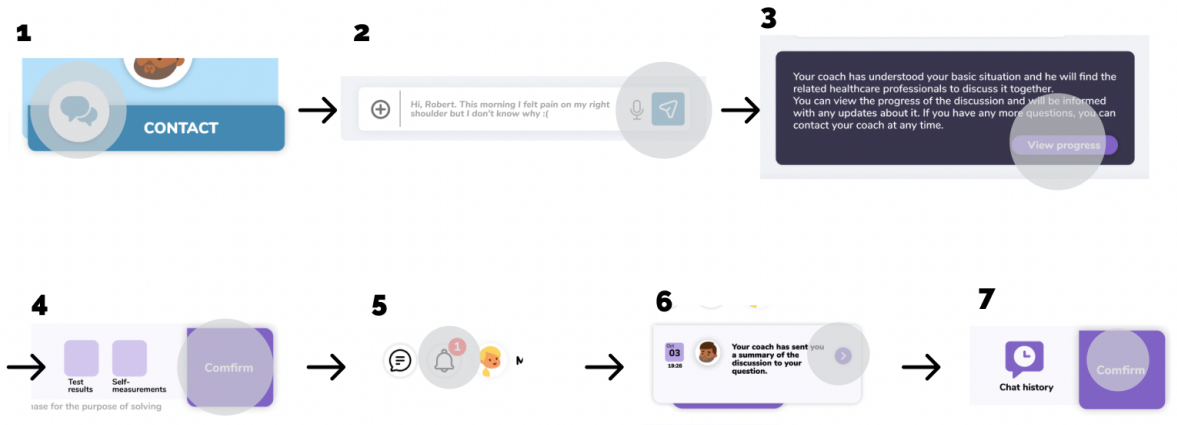



Figure 71. Micro tasks for task 1

**Task 2**

**Task description:** One day you begin your training at the platform as usual, you completed your training activities but you feel negative about the training, so you want some advice from the healthcare team, what would you do?

The second task mainly simulates the process of getting feedback from the medical staff after the user has completed the training for the day, mainly involving the training function, the self-evaluation function and the communication function. This task also has seven steps (see Figure below). The diagram shows that many people were troubled at the first step, probably because the task description was vague and the user's understanding was biased. One tester encountered difficulties in step 3 (2c), probably because the presence of the "share with coach" function was not obvious. Some text should be added to tell users that they can share when they first use it. Secondly, the self-evaluation page lacks a confirmation button, so users may feel confused when proceeding to the next step. However, in this task, users basically noticed the new message alert (2e), which proves that the learning cost for this feature is low and people can use it well after getting used to it. One user did not complete (2f), probably due to the small size of the button, which was not easily noticeable to the user.

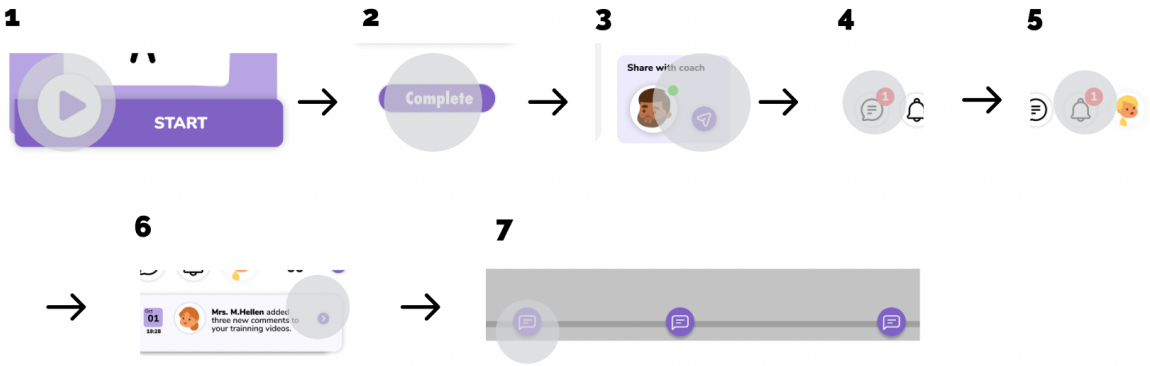



Figure 72. Micro tasks for task 2

## 10.5 Insights

Based on the test result and analysis, a problem map was created to show the problems participants encountered during the test and their advice about the design features.

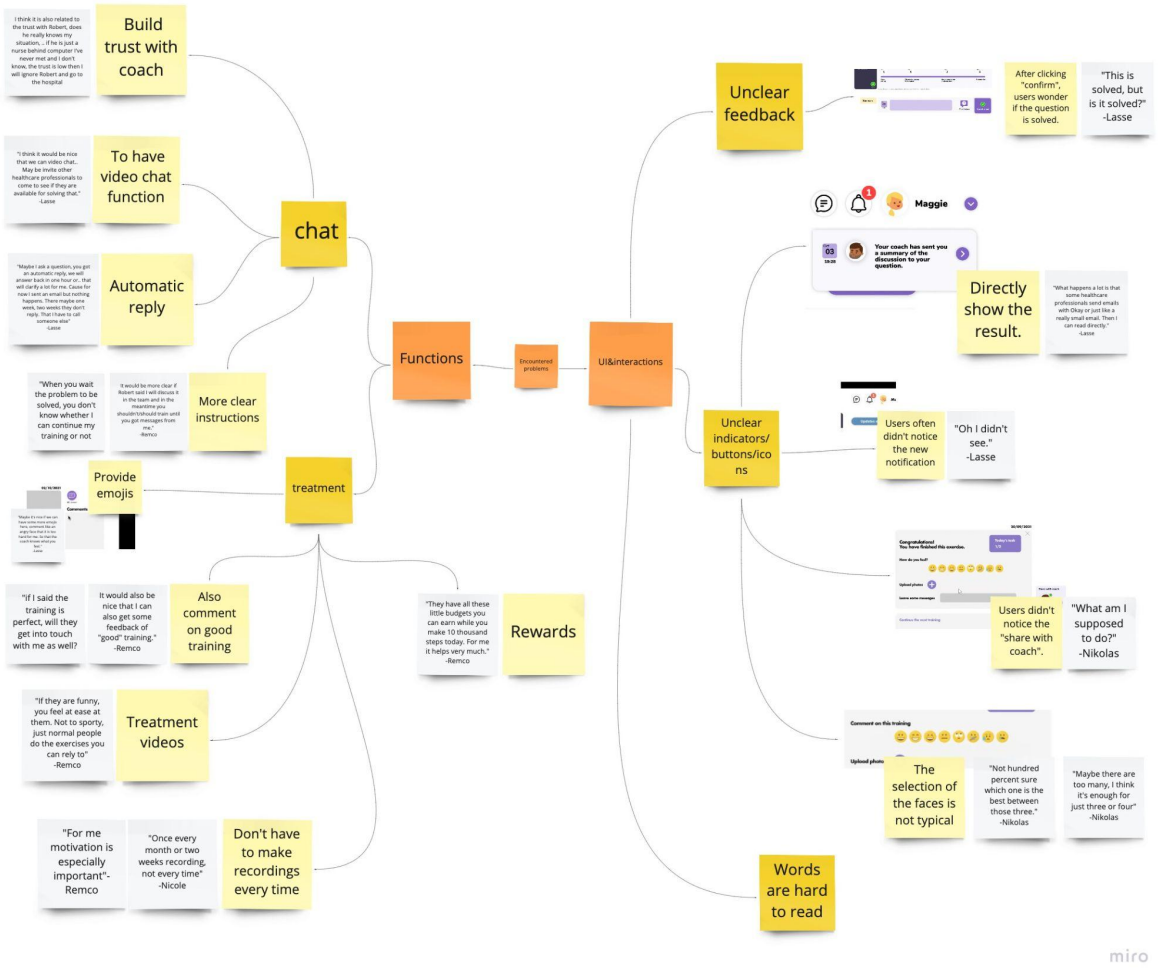



Figure 73. The problem map

**Functional aspects**

In general, the test subjects found the two main features (chat & treatment) of the web platform to be useful, and they expressed a willingness to use the platform if it was actually developed. They thought it is valuable to have a coach involved in the treatment process since it seems that there is someone always available for helping the users. And the online chat saves time for going to the physiotherapist every week. The other good comments on this design are shown in the figure below. However, one respondent indicated that she might not use the platform very much. The main reason could be that she said her physiotherapist was in her neighborhood, so when she had a problem, she could just go ahead and ask him for help. Secondly, she said that the font on the webpage was small for her, which affected the overall experience of using it. This respondent was relatively old and based on her performance during the interview I found that she did not seem to be very good at using the computer, so her answers also provoked some thought. Even though I have tried to simplify the interface as much as possible and enlarge the buttons to make it easier for older users to understand and use, I found that people still seem to have problems at some points. Therefore, I think it is important to include an initial tutorial for the platform when users first use it.


Figure 74. Good comments from participants

Some people also provided some useful advice for improving the current design. For example, some people suggested adding a video chat feature to the chat to improve communication efficiency. It was also suggested that for treatment feedback, we should not only provide users with the ability to get advice from medical staff when they feel bad but also give positive feedback and encouragement from medical staff or the platform when users feel they are doing well, which would increase user motivation.

One user mentioned the importance of building trust with the coach and whether the coach knows his situation. He said that if there is no trust, then he may not choose to contact the coach first when he has a problem but contact the hospital directly. Again, this is a point we can think about subsequently, how to build trust and increase users' reliance on the platform. I think we can increase the introduction of the coach and make more communication between the coach and the user through training.

**Interaction & Aesthetic aspects**

The design of the interactions of this platform has received positive feedback from different participants. People thought it was very direct and easy to use, which is in line with my expectations of the design. Also, users found the interface is user-friendly. The home page is simple but participants thought it is enough since the two main functions are included, patients can quickly notice who to contact when they have problems and start their treatment quickly. But there are still some elements that can be improved.

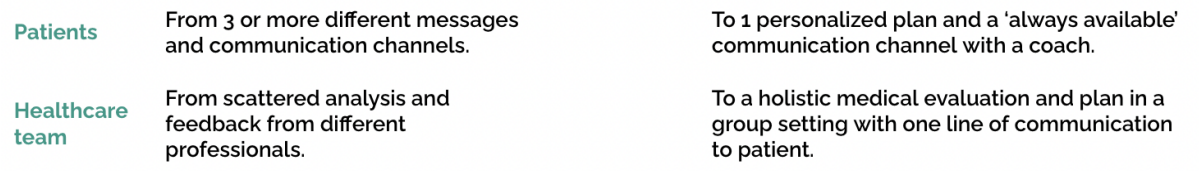
We can find that users' problems are mainly due to inconspicuous feedback and unclear icons and indicators. For example, as mentioned above, message alerts are not obvious enough so that users can easily ignore their presence. Another point is that when evaluating the training, users said that some emojis were not easy to distinguish, which made it difficult for them to make a decision. These are the things that can be improved in the subsequent design.

**Emotional effect**

In terms of the user's feeling about the design, generally, users feel pleasant when using the platform. This is probably due to the design style of the platform and the intuitive interaction with the platform. In terms of the feeling towards functions in this platform, getting timely feedback after reporting a situation to the coach makes users feel that their problems are valued. Keeping the user updated on the progress of the issue makes the user feel at ease. Getting a summary from the coach is a relief to the user. One participant mentioned that the opportunities for commenting on their training and receiving feedback from the healthcare team make him feel motivated.

## 10.6 Value of the service

Based on the test, the overall value of the design can be summarized in the figure below.




### 10.6.1 Value to FSHD patients

Feel more guided and supported

By using the designed service, users will feel more supported in the whole treatment process. They will get a feeling that there is someone who is always ready to solve their problems.

Easy approach, more convenient

Previously, it was common for users to contact their physiotherapist directly when they had a problem, but the problem was often not in the physiotherapist's area of expertise, so the user would have to spend time contacting someone else. This is a waste of time for both parties. Instead of consulting different roles multiple times with repetitive actions, the service in the platform makes the process much more fluent and effective. Now when patients have troubles, they can just contact their coach and explain the situation to him. Then it will be the coach's responsibility to assign different healthcare professionals to help solve the problem.

A more complete picture

Patients are able to get a complete and summarized answer from the healthcare team.

### 10.6.2 Value to healthcare professionals

Help improve workflow

Different healthcare professionals can discuss together in the chat group for a solution

instead of working separately,
Reduce workload
The user's question will be initially determined by the coach, and then be assigned to different specialists according to the areas that the problem may involve, thus reducing the unnecessary workload of some medical roles. For example, previously, the physiotherapist is the person users contact most often when they encounter whatever problems. But by applying the designed service, the workload of the physiotherapist will be reduced since some cases will be distributed to different members in the healthcare network. Thus, this will also enable all the care providers to focus on more pressing issues in their area of expertise.

## 10.7 Limitations of the tests

**Separate tasks for patients and healthcare professionals**

In the current test, I designed the task and test from the user's (patient's) perspective because I designed the patient-specific version of the web page. However, among my testers are patients as well as medical staff, who are all conducting the same tasks in their tests. While the healthcare professionals can still provide their useful insights in this case, perhaps I can design some different tasks for them to verify the usability of the design from their perspective. If possible, I should invite both patients as well as healthcare professionals to participate in one test, to simulate a more realistic scenario.

**Design of the scenarios**

In the current test, I only verbally described the user scenarios, including the introduction of the project before the interview and the task introduction afterward, which may not be conducive to better understanding and vicarious representation of the user's role. So in subsequent tests, it will be better to add pictures or some animations to help the user integrate into the scene.

**Test with more subject**

Due to the time and location constraints of the project and the impact of the Covid-19, I have only tested with six users. However, to more accurately verify the usability and validity of the design, I believe that the sample should be expanded.

**Test the long-term effect**

Now for the test, we can only test the user's experience and perception of the features in this platform at the moment, so the conclusion we draw now is only based on the user's first experience. However, it is not enough to test once to see if our design will be successful and whether users will stick with it and benefit from it, which requires continuous user testing and observations for some time. Also, since the design is more of a process and there will be many characters involved when it comes to a real scenario, to validate the efficiency of problem-solving and the collaboration between different healthcare professionals requires time and context. So for the long-term impact, we still need to design a plan to test or collect user feedback after the product is released.

### 10.7 Future recommendations for design improvements

In the future, I think the designed platform may consider the following points to enhance and expand the service and business and further improve the patient experience and quality of care.

**Corporate with hospitals and clinics**

To better promote our platform and benefit more patients, we can look for opportunities to partner with hospitals and with clinics. Although some hospitals have their systems for communicating with patients, I think they would be happy to use our services if our design is more convenient and effective.

**Help users build the healthcare team**

The current platform is relatively simple in that it focuses on the training phase of the user's disease to help the user communicate more easily with his or her healthcare providers. But in the interview, some users said they do not have a professional medical team, so to give users a better experience, our service can also do a little extension. For example, we can provide patients who do not have their health care network with services to help them find the right health care provider to help them diagnose their disease more effectively in the early stage. We can also hire or work with medical professionals to make them integral to the platform, and users can choose to add these people to their medical network.

**Expand the user groups**

Right now our platform is focused on FSHD patients, but there are many similarities between various chronic neurological diseases, such as the need for daily exercise and daily monitoring by healthcare professionals. So this platform can be applied to more users. We can pilot the platform with FSHD patients and if the feedback is positive and users think the mechanism in this platform is sufficient, then we may consider involving more patients who have similar diseases.

**Initial training**

I want to make the platform accessible and adaptable to users of all ages. For some elderly users and people who are not very web-savvy, I think we can provide them with some video tutorials when they start using the platform to help them understand how to use the platform faster or hold regular training events for new users to help them get used to the platform faster and answer their questions. These events can be held by coaches on this platform.

**Reward system**

To encourage both patients and healthcare professionals to actively participate in using this platform, I think a reward system can be helpful. For example, users can be rewarded with points for adherence to training. For healthcare professionals, they are also rewarded with points when they solve a problem successfully. After accumulating a certain number of points, they can redeem the corresponding gifts. By doing this, we can make users more motivated in using the platform.

# 11. Conclusions

In conclusion, this project mainly solves the problem that patients cannot get timely feedback and help from healthcare professionals during their daily training. The design provides a new model of communication. By introducing a coach, we bridged the gap between the patient and the healthcare team, making the original inefficient and disorganized communication and problem solving more organized and effective. Through testing, we can conclude that this design can meet the needs of users and enhance their experience.

However, the current design is just a starting point of a wide service system, there are great possibilities for its future. I think there are two main trends in the future of communication between doctors and patients, more intelligent and more connected. In the future, communication between doctors and patients will be easier and faster. All medical data and records of users will be securely stored in the cloud and can be controlled by the patients themselves instead of being controlled by hospitals. When healthcare professionals need to view them, users can easily find and share them with the corresponding medical staff. Hospitals will also be interoperable; they will no longer use different systems but will stay in one big interconnected network where they all work to contribute to a more complete patient medical profile. When the healthcare network becomes bigger and the data becomes more complex, the importance of having a coach becomes more obvious. With the help of coaches, the collaborations among different healthcare professionals in the healthcare network will be even more organized. The user's coach will also be smarter and more efficient. The use of artificial intelligence technology can help the coach reduce the burden of work.

# 12. Acknowledgments

This project cannot be achieved without the help of many people. In this session, I would like to express my gratitude to them.

First of all, I am grateful to my supervisory team, Henk, Silje, and Nikolas, for their help and support along the way. They gave me patient guidance and help, and gave me valuable suggestions to revise my design and thesis. Although we could not have a face-to-face meeting due to the Covid-19, I think we overcome this difficulty and worked well together. I want to thank Henk for helping me keep track of the project and sharing with me many useful documents that are helpful to my thinking. I also want to thank Silje for giving me psychological guidance when I was stressed. And I appreciate Nikolas for trusting me and allowing me to do this project, and during the project, he was very responsive and provided me with lots of useful insights.

Secondly, I want to thank all the people who participated in the interviews and tests of my project. Thank you to all of them for taking the time to participate in my project and giving me a lot of valuable feedback. This feedback has helped me a lot in my final design.

Lastly, I would like to thank my family and friends for giving me psychological encouragement and support while I'm working on the project.

# 13. References


Allen, M., et al.  (2008). Improving patient-clinician communication about chronic conditions: description of an internet-based nurse E-coach intervention. *Nursing research*, *57*(2), 107-112.

Alders, I., et al, (2017). Does patient coaching make a difference in patient-physician communication during specialist consultations? A systematic review. *Patient education and counseling*, *100*(5), 882-896.

Alders, I., et al, (2019). Patient coaching in specialist consultations. Which patients are interested in a coach and what communication barriers do they perceive?. *Patient education and counseling*, *102*(8), 1520-1527.

Darkins, A., et al. (2008). Care Coordination/Home Telehealth: the systematic implementation of health informatics, home telehealth, and disease management to support the care of veteran patients with chronic conditions. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association* , *14*(10), 1118–1126. https://doi.org/10.1089/tmj.2008.0021

Elliott, T. R., et al. (2008). Problem-solving training via videoconferencing for family caregivers of persons with spinal cord injuries: a randomized controlled trial. *Behaviour research and therapy*, *46*(11), 1220–1229. https://doi.org/10.1016/j.brat.2008.08.004

Finkelstein, S. M., et al. (2006). Home telehealth improves clinical outcomes at lower cost for home healthcare. *Telemedicine Journal and e-Health*, *12*(2), 128-136. https://doi.org/10.1089/tmj.2006.12.128

Gupta, A., et al. (2018). Towards developing an e-coach to support arthritis patients in maintaining a physically active lifestyle. In *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare* (pp. 392-395).

Harrington, J., et al, (2004). Improving patients' communication with doctors: a systematic review of intervention studies. *Patient education and counseling*, *52*(1), 7-16.

Henselmans, I. et al, (2015). Participation of chronic patients in medical consultations: patients' perceived efficacy, barriers and interest in support. *Health expectations*, *18*(6), 2375-2388.

Lindberg, B., et al. (2013). Using Information and Communication Technology in Home Care for Communication between Patients, Family Members, and Healthcare
Mul, K., et al, (2016). What's in a name? The clinical features of facioscapulohumeral muscular dystrophy. *Practical neurology*, *16*(3), 201-207.

Muscular Dystrophy Association, (2009). Facts About Facioscapulohumeral

Muscular Dystrophy.
https://www.mda.org/disease/facioscapulohumeral-muscular-dystrophy

Professionals: A Systematic Review. *International journal of telemedicine and applications*, *2013*, 461829. https://doi.org/10.1155/2013/461829

Schmidt, E., et al, (2017). What is competent communication behaviour of patients in physician consultations?–Chronically-ill patients answer in focus groups. *Psychology, health & medicine*, *22*(8), 987-1000.

Statland, J. M., & Tawil, R. (2016). Facioscapulohumeral muscular dystrophy. *Continuum: Lifelong Learning in Neurology*, *22*(6), 1916.

Tawil, R. (2008). Facioscapulohumeral muscular dystrophy. *Neurotherapeutics*, *5*(4), 601-606.

Voet, N., et al, (2014). Both aerobic exercise and cognitive-behavioral therapy reduce chronic fatigue in FSHD: an RCT. *Neurology*, *83*(21), 1914–1922. https://doi.org/10.1212/WNL.0000000000001008

# 14. Appendix

## 14.1 Project brief

Develop an online healthcare platform for NMD patients and care professionals.

project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 17 - 05 - 2021

01 - 10 - 2021 end date

## INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

In the medical world, there are over 500 rare chronic Neuro Muscular Diseases (NMD:s) millions of people are suffering from it. Due to the characteristics of chronic diseases, patients often cannot fully recover even through medical treatment, which means the treatment can only alleviate the patient's condition, but the disease will never be healed completely. Therefore, people with these diseases often not only suffer from physical disabilities, such as pain, muscle weakness and sleep disturbance, but also they may experience some mental distress.

During the process of consultation and treatment, there are multiple roles involved, such as the general practitioners, the neurologists, the physiotherapists, etc. A good user experience is inseparable from the effective communication and cooperation of these people. This is so called a healthcare network (see the figure on next page).

"Samen Sterker", known as a network for quality care and quality of life for people with chronic Neuro Muscular Diseases (NMD:s), is now focusing on improve the current situation of these groups of people. They believe that 'together we can be stronger' and aim to improve the quality of life for millions of people with any of the 500+ rare NMDs, especially for people and patients with Spinal muscular atrophy (SMA) and Facioscapulohumeral muscular dystrophy (FSHD). To be specific, Samen sterker will act as a network enabler to improve the services from 1-2-3 line medical care professionals towards the groups of people (patients) with SMA & FSHD.

Currently, there are many online SaaS (Software as a service) platforms (a way of delivering applications over the Internet–as a service), such as "Hinq" and "Mighty networks", which provide service for the patients and care professionals to improve their life quality and the whole medical experience. Each of these platforms has its own focuses and features, for example, "Hinq" pays more attention to the entire personal health environment (PGO) and Care network environment (ZNO) experience, while the "Mighty networks" is more focused on collaborations. The audience served by these websites is often very broad. In my view, the digital networks exist, but none of them are primarily directed at our target audience. However, due to the particularities of this disease, it is very necessary to find a system suitable for them. And because the concept of this healthcare network is still in the early stages of development, many problems have yet to be resolved, such as how to integrate different patient data and how to effectively communicate between different medical roles. Therefore, studying how to improve these people's user experience and design a medical network suitable for them is very valuable.

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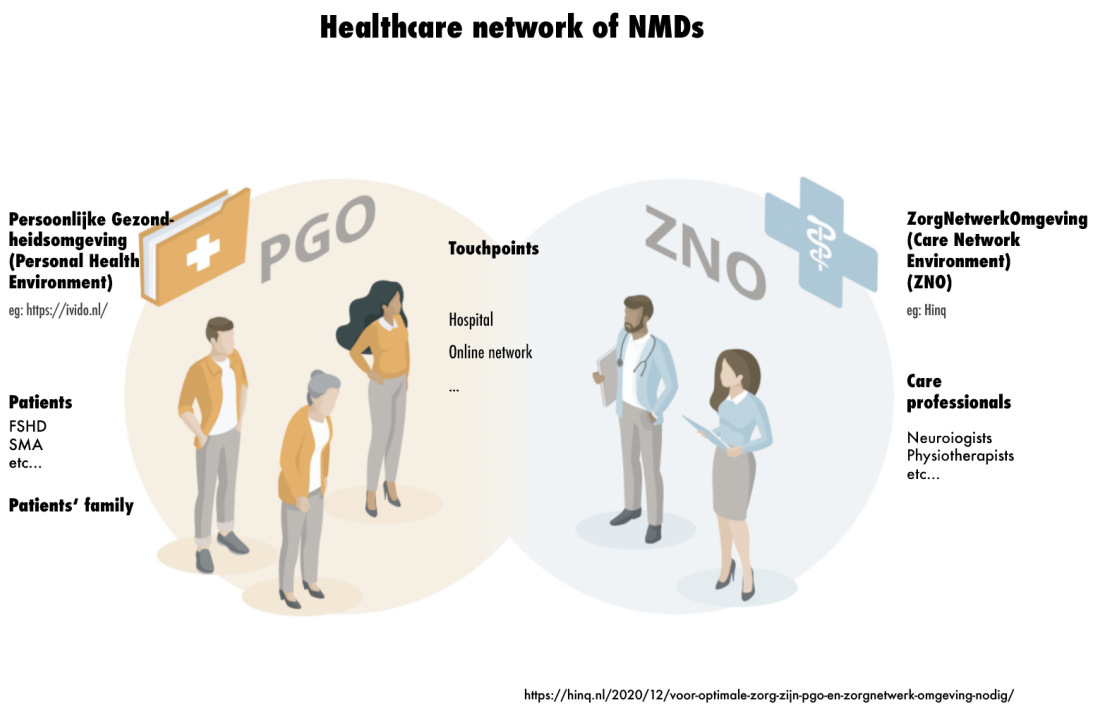



image / figure 1: The healthcare network of patients with NMDs

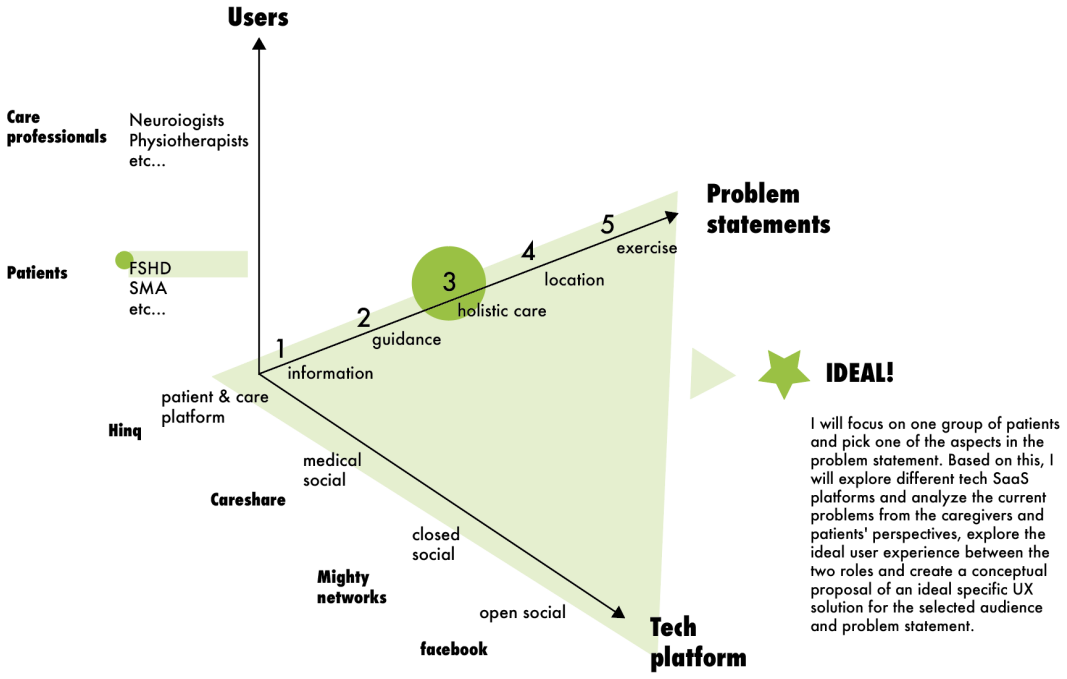



image / figure 2: The scope and focus of this project

## PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

According to the previous research by Samen Sterker, there are five high-level problem statements defined within the whole process of disease diagnosis and treatment, which include:

1. Information – know-how is often lacking at the right time and place for best possible care.
2. Guidance – Advice is not always as positive as it could/should be for patients to develop.
3. Holistic care – a complex care system is challenged to give holistic personalized care.
4. Location –the best care for NMD's is often far away and requires traveling.
5. Exercise – The proven positive impact of the right form of exercise - is far from fully applied

In my project, I will focus on one of these five directions. As a network, it is always good to think from a system perspective. Therefore, my focus will be on problem statement 3, which is holistic care. This statement is more related to effective communication among different stakeholders and the personalized care of different individuals. As a network, there are lots of different roles involved around one patient. Currently, many people visit the hospital or the doctor for a consultation, and they might ask if it is really important. Different roles of care professionals usually have no idea what the other is doing, which increases the likelihood of a mistake. As a result, the patient requires a single atmosphere in which he can interact with all his healthcare providers and has control of his data. To deal with these problems, there are lots of online healthcare platforms now. However, without good guidance on customer-centric design, there is a risk that these platforms are utilized in a suboptimal manner towards the end-user. Therefore, better understand the needs and desires of the patients with NMDs and design an online care platform for them is very valuable.

## ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... . In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

Develop an online healthcare service platform for NMD patients and care professionals.
I will focus on one group of patients and pick one of the aspects in the problem statement (statement 3). Based on this, I will explore different tech SAAS platforms and analyze the current problems from the caregivers' and patients' perspectives, explore the ideal user experience between the two roles and create a conceptual proposal of an ideal specific UX solution for the selected audience and problem statement. In other words, this project is to design the best possible UX for selected key users within the capabilities of the selected SaaS platform.

The key to this project is to explore the needs and desires of both the caregivers and patients with NMDs within the process of disease diagnosis and treatment. I will be more focused on effective communication among different stakeholders and the personalized care of different individuals. For example, how are we going to enable them to talk with each other? By researching this, we can have a better view of the reason for providing the service and define the content and functions of the service platform.

The final design solution is supposed to be an online service platform that provides service for both care professionals and patients with NMDs. It will work as a network facilitator to enable both roles to have an ideal user experience that can fulfill their needs and desires. The possible function of that platform will include an online forum where they can communicate with each other or online consultation in which the patients can get some initial diagnosis of their disease.



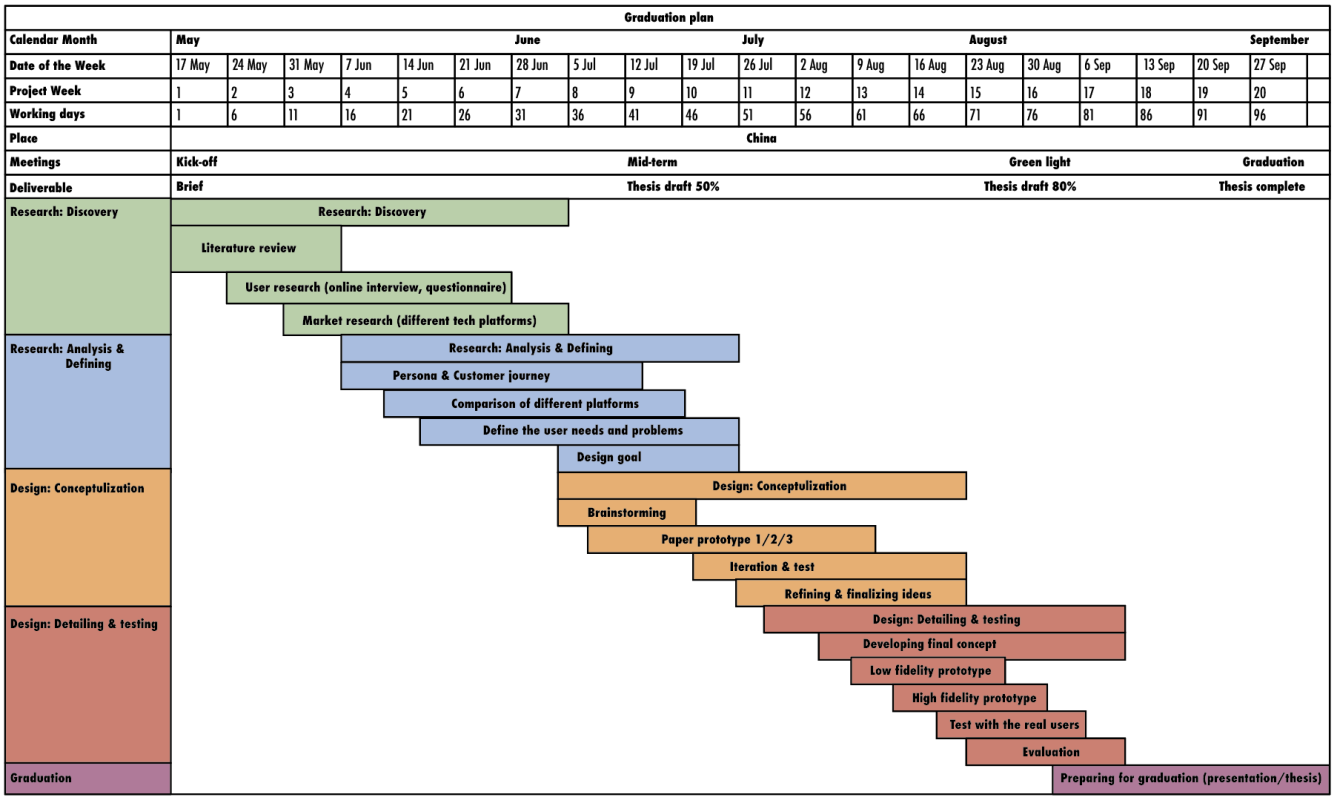
Initials & Name Qiyu Fan Student number 5053439

Title of Project Develop an online healthcare platform for NMD patients and care professionals.

## PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 17 - 05 - 2021 01 - 10 - 2021 end date




In general, this project has four different phases and will be finished in 20 weeks. It will basically follow the double diamond design model. Phase one and phase three will be the divergence phases, while phase two and four will be the convergence phases.

In the "Research: Discovery" phase, I will first do some literature review to gain an initial view of the background knowledge of the disease and the current context of healthcare in the Netherlands. Then I will do some user and market research which aims to help me find the user needs, pain points and oppoturnities.

In the "Research: analysis & defining" phase, I will focus on analysing the research result from the last phase. I will use some design techniques such as data visulization, persona and customer journey map to help me gain insights and define the problems.

In the "Design: Conceptualization" phase, I will do some brainstorming about the potential design solutions and make some easy prototypes and test them out among students and tutors. I will also do iterations based on the feedback of the tests.

In the last phase, "Design: detailing & testing", I will make a desicion on the final design soluation according to the test results before. I will then make the high-fidelity prototypes and do some tests among the real users to evalute my design. I will finally come up with some design recommandations and future improvements of the current design.



Initials & Name Qiyu Fan Student number 5053439

Title of Project Develop an online healthcare platform for NMD patients and care professionals.

## MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... . Stick to no more than five ambitions.

-I like service design, since it is more focused on a system view of a problem and it allows us to really think of the needs for multiple stakeholders, which means to benefit more people, and what we designed will not limited to one specific product, but can be more free.

-I am very interested in the topic that related to medical care and muscular disease, since now not only elderly but also many young people suffer from it, it is very practical and essential to improve this situation. I also did one course which the project is related to wrist rehabilitation, so I think I'm more experienced in this theme, so I really want to dive deep into this topic.

-By doing this project, I can also improve my expertise in the UI and UX design. This is consistent with my career plan, which is to become a UX designer in the future. So this will benefit me a lot. I will also improve my research skills through this project.

## FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.



Initials & Name Qiyu Fan Student number 5053439

Title of Project Develop an online healthcare platform for NMD patients and care professionals.

## 14.2 Interview guide

## Opening

1. Hello and introducing

   *Thank you for participating in this interview. I am a student from TU Delft following the Master Design for Interaction program and I am now doing my graduation project which is related to improving the quality of life of people with NMDs.*

   *In this interview, I would like to explore YOUR thoughts around some specific topics related to your current situation. There are no right or wrong answers. Feel free to ask questions if you have any doubts. Your input will provide me with helpful insights to my work!*

2. About privacy

- This test poses no risk to your health. We will be using Zoom to conduct this test, which is a third-party service we cannot take liability for. For the analysis, we need to record our session, which includes your computer screen, your camera and voice during the test.

  *Are we allowed to record this meeting?*

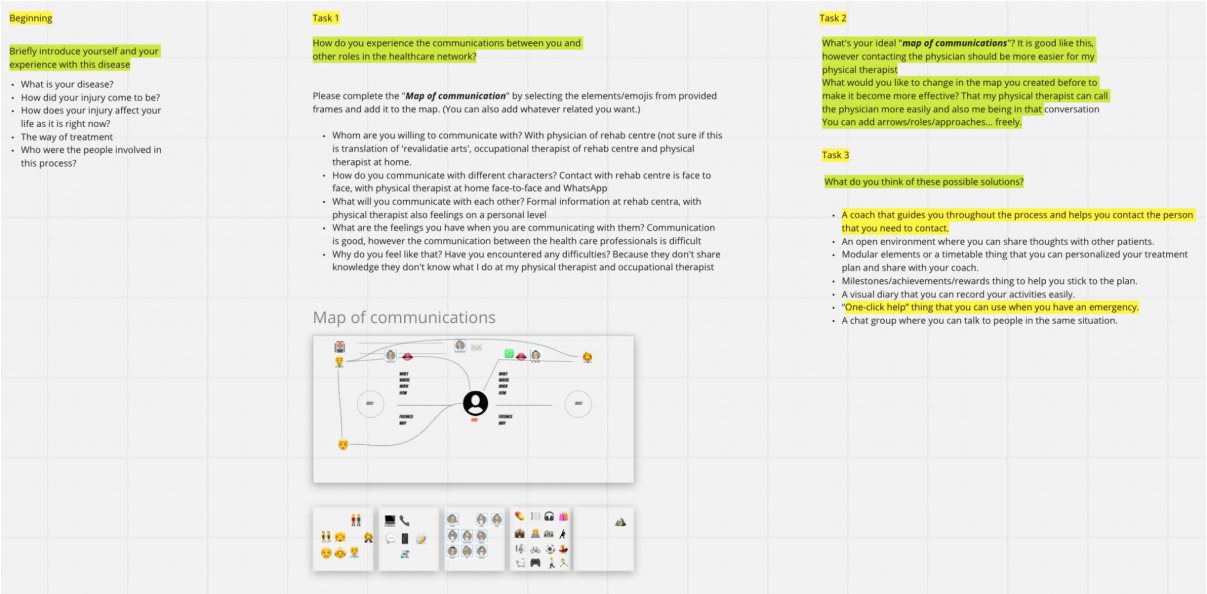
- The collected material will only be shared online within my graduation team, which includes my chair (Henk) and two mentors (Silje and Nikolas). The material will be stored on my personal computer, without anyone else having access to it (outside the group). All materials will be stored for up to 6 months. After this period, all material, except evaluation results will be destroyed.
- Personal information (such as name/phone number) will be handled separately and only be collected for the purpose of making arrangements and to initiate contact for this test. Sensitive information will not be shared with anyone else outside this group. Results of this project will be presented in an academic setting (to peers and coaches) and to our stakeholders, where photos and videos made during this activity might be showcased.

  *Do you agree? Any questions?*

3. Briefly introduce yourself and your experience with this disease.

   *What is your disease?*
   *How did your injury come to be?*
   *How does your injury affect your life as it is right now?*
   *The way of treatment*
   *Who were the people involved in this process?*

Now I would like you to complete some simple tasks. I'll give you some instructions and feel free to ask questions if you have any doubts. There are no right or wrong answers. I will not interfere with you in the process, so just enjoy it and think out loud.
Link: https://miro.com/app/board/o9J_lBgvN8c=/




## First task
Please complete the "Map of communication" by selecting the elements/emojis from provided frames and add it to the map. (You can also add whatever you want that is related.)

*Whom are you willing to communicate with?*
*How do you communicate with different characters?*
*What will you communicate with each other?*
*What are the feelings you have when you are communicating with them?*
*Why do you feel like that? Have you encountered any difficulties?*

## Second task
*What's your ideal "**map of communications**"?*
*What would you like to change in the map you created before to make it become more effective? You can add arrows/roles/approaches... freely.*

*Why?*

## Third task
Now I'll provide you with some ideas of the possible solutions that might improve the current situation.

- A **coach** that guides you throughout the process and helps you contact the person that you need to contact.
- An open environment where you can **share thoughts with other patients**.
- **Modular elements or a timetable thing** that you can personalized your treatment plan and share with your coach.
- **Milestones/achievements/rewards** thing to help you stick to the plan.

- A **visual diary that** you can record your activities easily.
- **“One-click help” thing** that you can use when you have an emergency.
- A **chat group** where you can talk to people in the same situation.

*For each, what do you think about it?*
Thanks! That’s all for the interview.

### 14.3 Test plan

**1.Introduction**

Introduce myself.
Ask if I can record the session.
Thank you very much for joining the test. Today I am going to test an online support platform to help FSHD patients solve their problems during treatment. (In case they are healthcare professionals, please now imagine that you are a FSHD patient when you use the platform.)

If they are patients:
Before we start, I would like to know some of your general information, which could help for later analysis.

1. Could you please make a short introduction of yourself?
2. Could you tell me something about your disease? eg. What is the type of the disease you have? How long have you got this disease?
3. Could you tell me something about your treatment activities? eg. What type of exercises are you now taking?

**2.Test**

I would like you to open some links and there will be some tasks for you to complete. During the test, I would like you to share your screen. I will mostly keep quiet throughout the test, but I will be here to guide you through the steps. Please think out loud while you carry out the tasks. Tell me what you do and why (or what you would do, in case a function does not work). And since the prototype is not fully functional, don’t worry if something doesn’t work, it’s not your fault. There are no wrong moves. You will help us to understand how we can improve the product.

Let’s start.

Please open the link.
Prototype link:
https://www.figma.com/proto/GjTXSk1ghTiSVojhGt5oeS/patient-4?page-id=0%3A1&node-id=33%3A1822&viewport=241%2C48%2C0.26&scaling=scale-down&starting-point-node-id=33%3A1822

https://www.figma.com/proto/W4X3Cz5CMuPLJLC9kzYnCf/test?page-id=0%3A1&node-id=2%3A74&viewport=241%2C48%2C0.58&scaling=scale-down&starting-point-node-id=2%3A74

https://www.figma.com/proto/XjwNiPieWzwPJU6uuHil2N/test-2?page-id=0%3A1&node-id=2%3A2&viewport=241%2C48%2C0.43&scaling=scale-down&starting-point-node-id=2%3A2

So in general this is an online support platform and when you join the service you will be introduced with a coach who will help you solve your problems and facilitate communications with your healthcare team. You were recommended by your physiotherapist to use this platform and after you browse it, you decided to join our service. Following the instruction you have completed the preparatory work and you begin to use it every day.

First, I will give some time to freely explore the platform. Please think out loud while you use it. Since the prototype is not fully functional, don't worry if something doesn't work, it's not your fault.

Here are some tasks for you:
**Task 1:** One day in the morning you feel pain on your right shoulder but you don't know why, what would you do?

*After they finish the task (or if they cannot finish it in five minutes), go to the next task.*

**Task 2:** One day you begin your training at the platform as usual, you completed your training activities but you feel negative about the training, so you want some advice from the healthcare team, what would you do?

This is the end of the tasks, if you want you can stop sharing your screen. Now I would like to ask you some questions about your experience.

**3. Q&A**
<u>About the function:</u>
Do you think the current problem-solving process is more efficient than before?
Do you think the functions (real chat/coach) in this platform are helpful?

<u>About the design:</u>
Do youl think the interactions in the platform (eg, click the buttons, jump between different pages) are simple and intuitive?
What do you think about the aesthetic style of the platform? Do you like it?

<u>About the emotions:</u>
Do you think you will feel positive/pleasant when using it?
Do you think you would like to use this platform for a long time?
Do you think you would like to recommend the platform to other FSHD patients in the future?
Do you have any suggestions for improvements?