Integrated Product Design Master Thesis

Self-management tool for sarcoïdosis patients of the Erasmus MC using the data-driven 'Patient Journey Community Mapping' approach

Heleen Kicken

July 2023

Medisign Specialisation
Faculty of Industrial Design Engineering
Delft University of Technology

TU Delft

Erasmus MC
Universitair Medisch Centrum Rotterdam

Convergence

Master Thesis Integrated Product Design

Heleen Kicken

Student number: 4645065

Delft, July 2023

Medisign Specialisation
Faculty of Industrial Design Engineering
Delft University of Technology

Supervisory TU Delft team

Chair:	Prof. dr. ir. R.H.M. Goossens
1st mentor:	Ir. R.G.H. Bluemink
2nd mentor:	Dr. J. Jung

Integrated Product Design Master Thesis

Self-management tool for sarcoïdosis patients of the Erasmus MC using the data-driven 'Patient Journey Community Mapping' approach

Heleen Kicken

July 2023

Acknowledgement

During this thesis project, I had several people that assisted me and provided their guidance. Therefore, I would like to express my gratitude.

Starting with a big thanks to my supervisory team. At my kick-off meeting, you mentioned that we are doing together this project and that we are in the same team. These words calmed me through my whole project, I know that I could always come for advice. My chair Richard helped me a lot with my daily project management. The weekly updates kept me on track with my planning and made this a relatively smooth process. Secondly, my first mentor Bart helped me with my project management. You put everything in perspective and asked critical questions, which led to me pushing to be a critical and independent designer.
Last, but not least, my second mentor Jiwon. First of all, thank you for this project! And thank you for your active guidance and the many meetings together where you zoomed out for me. This gave me more grip on my project, and avoided me getting too lost into details. You felt often like a supportive (but critical) friend in my project.

Nick, thank you for your data science expertise. It was an interesting and needed collaboration from a designer's perspective that I am happy to have done and learned.
I also would like to thank the medical experts of the ILD department of the Erasmus MC. Prof. Dr M. Wijsenbeek-Lourens, specialist nurse Y. Gür-Demirel and Dr V. Kahlmann thank you for your time and crucial feedback. It was interesting to sit together and brainstorm together with people in the medical field.

A special thanks to my parents, without their unconditional support I wouldn't be the person I am today. Dad, thank you for always being there for me and showing constant enthusiasm about my study and ambitions. I hope, and kind of know, that you would have been proud of me. Mom, thank you for your support during my study period. I am finished! I can always count on you, even in crisis moments, I know that you are there for me. Thank you. And my brother, Mart, thank you for being my big brother's inspiration. I know that you are always there to (really) listen.

Last, besides my supervisory team and family, my close circle was closely present throughout the whole process. First, a big thanks to my boyfriend. You proofread my whole thesis three times and corrected it. I think many yawns have been there, but I appreciate it. And of course, you were there during the many meltdowns and victories. Thank you! Also, a big thanks to my roommates who were always supportive during my process and willing to listen. I can't wait to be there for you during your graduation, you are going to rock it! :) Lastly, a big thanks to my peers that helped me with testing and brainstorming. The many sits together helped me a lot.

I feel blessed to have worked with many supportive people. Their contributions and encouragement have been essential to the success of this project.

Heleen Kicken, Rotterdam, July 2023

Summary

Sarcoïdosis is a complex and rare disease, which can affect any part of the body. The disease has symptoms, side effects and treatment plans varying per patient. In the Netherlands, yearly up to 7000 to 8000 people are diagnosed with sarcoidosis, in an acute or chronic form (Sarcoïdose - UMC Utrecht, n.d.). In the Netherlands, there are three sarcoïdosis specialist centres, and Erasmus MC is one of them. The Interstitial Lung Disease department of the Erasmus MC is trying to provide the right care for sarcoïdosis patients. However, together with the Convergence Program, a collaboration between the Delft University of Technology and the Erasmus MC, they analyse how the care at the hospital can be optimised. However, for patient care at home, there is still room for improvement, as expressed by medical experts.

In this project, the methods and results lead to a patient journey map that indirectly improves the sarcoïdosis patient journey. The method of Patient Community Journey Mapping from Jung (2023) sets the base for the analysis. This is a data-driven approach to utilising online patient stories for machine learning. Together with a data scientist from Erasmus University, posts of wijhebbensarcoidose.nl are analysed and converged into a patient journey map. Topic listing is applied to the database of 7500 posts, followed by quantification of popular topics, and a sentiment analysis to show the urgency of a topic. The conducted patient journey map consists of 1) a medical journey path and 2) the topics derived from the computational analysis.

A co-creation session with pulmonologists and specialist nurses was done to validate the resulting patient journey map. Followed by an interview with a patient to validate this map. These sessions were organised to get an even more realistic patient journey map.

Sarcoïdosis is a complex disease, and often multiple topics are discussed in one post. Therefore, an analysis is done to see the co-occurrence between topics. From this resulted that the key value is formed by everything related to finding a balance in life with sarcoidosis. The patient journey map emphasised multiple needs that are mentioned negatively, according to the sentiment analysis. This led to three important patient needs to take into account for this project. Together with the key value, the main four patient needs are the following:

1. Help patients with finding a balance in life after their diagnosis.
2. Give patients a clear overview of their medication intake.
3. Monitor the patients’ quality of life sarcoidosis aspects.
4. Provide patients with information about sarcoidosis-related topics.

These formed the base of the designed system in the form of an application: Sarcoïdosis voor jou. This application has four main pages where the focus on each page is a different need. The self-management tool can be created with the internal company Digitaal Verbonden. Together with the ILD department, the application can be created with some additional research steps. This project can argue why certain functions should be implemented in the general Digitaal Verbonden application for Erasmus MC patients.

Table of contents

1. Project introduction

This graduation project focuses on the improvement of the patient experience of sarcoidosis patients at the Erasmus Medical Centre. In this chapter, an introduction of the disease and stakeholders Erasmus MC and Convergence Program is given. Then the scope is confined, following an overview of the project approach with the chosen method and ending with the thesis structure.

1. Introduction

Yearly, 7000 to 8000 patients in the Netherlands are diagnosed with saroïdosis, making sarcoïdosis a rare disease (Sarcoïdose - UMC Utrecht, n.d.). This is a disease characterized by the growth of tiny collections of inflammatory cells (granulomas) in any part of the body. In this project, the special focus is on patients with lung sarcoïdosis.

Sarcoïdosis can be a one-time-only disease, re-occur more often or it can be a chronic disease. Patient experiences could provide valuable information to improve the quality of care and reduce healthcare costs. Therefore, the patient, care provider, healthcare institution, health insurer, and various authorities would benefit from insight into the patient’s perspective. However, the patient perspective is often only limitedly included in the current remote patient monitoring development. Conventional methodologies (e.g. the Likert scale or interviews) are limited in harnessing the value of patient experiences to develop remote patient monitoring systems, due to the labouring consuming time, according to the PhD thesis of Jiwon Jung (2023). Therefore Jung created the ‘Community Journey Mapping’ method in which a digital social media platform (e.g., sarcoïdosis patients website: wijhebbensarcoidose.nl) is used as a data source for mapping a patient journey. This method is a collaboration between a designer and a data scientist. The latter uses necessary data to frame invaluable data for the patient journey map. This method is used in this thesis to emphasize the patient’s needs in a patient journey map. For the most critical moments, that are visualised, a design intervention is made.

This project is done in collaboration with the Erasmus Medical Centre, specifically for the Centre for Interstitial Lung Diseases and Sarcoidosis. Moreover, the Convergence program for Health & Technology is a stakeholder, this is a collaboration between the Erasmus MC and the Delft University of Technology. They have the vision to shape the digital transition with human-centred technologies in a responsible way (Mission & Vision - Convergence, 2022). This is very broad, but within this project, the focus is on the transition from hospital to home care. There is an increase in development for these transition technologies to monitor at home for the patient (Van Velsen et al., 2013), however, this is not yet the case for sarcoïdosis patients.

1.1 Project scope

The project starts with improving the journey of sarcoïdosis patients in the context of Erasmus MC, using the conducted patient journey map. This project scope soon develops, after the analysis, into: supporting sarcoïdosis patients at home in finding a balance in life. This project takes place in 20 weeks and the feedback comes from the Erasmus MC resources (e.g., patients and medical experts). The target group is patients that are diagnosed with sarcoidosis, especially lung sarcoidosis. It does not matter if they already have the disease for years, or are just diagnosed with it. The goal is to include everyone, it doesn’t matter how ‘experienced’ the patient is.

To design this project intervention, the patient journey map for sarcoïdosis is visualised. Therefore, a social media platform is analysed and interpreted to use as input for a visualisation of the patient journey map. This map quantifies the patients’ needs and visualises the corresponding sentiments.The medical experts (e.g. specialist nurses and doctors) give their input to keep this patient journey map truthful. Also, the patient’s perspective shows the urgency of these needs and provides a good validation as a basis to design an intervention. Furthermore, a company’s perspective shows the feasibility of the design intervention. Eventually, the design intervention illustrates how achievable this is and what the future steps are.

Figure 1.1: *Lead stakeholders of this project.*

1.2 Project approach

This project is divided into four parts: 1) Analysis, 2) Synthesis, 3) Ideation and Prototyping, 4) Final Design and Evaluation. The project approach is visualised in Figure 1.2 with a step-by-step visualisation. There are also iteration loops visualised to show when interviews are conducted, resulting in an iteration step on the design.

1.3 Project structure

The project is divided into the parts as discussed in the previous section. The Analysis chapter gives an overview of an elaborated analysis for this project, including a literature study where the sarcoïdosis medical overview is discussed together with the transition to home care. Furthermore, a contextual sarcoïdosis study is done, to show what Erasmus MC provides to patients to use as resources when they are diagnosed. The third part of the analysis chapter is the online community study, where the patient journey map data preparation with a data scientist from the Erasmus University is discussed. The last part is a conclusion of the full analysis. The data and the other two studies together form a patient journey map with the patients' needs visualised.

The second chapter is Synthesis, where the conclusion of the Analysis chapter is discussed and concluded. The goal is to find a project direction as well as criteria for the design intervention.

The Ideation and Prototyping chapter shows what kind of design intervention can be generated based on the synthesis' direction and criteria. The final goal is to have a working prototype that can be tested. The test feedback from the ideation and prototyping phase is analysed and implemented in the Final Design of Sarcoïdosis Intervention chapter. Here a summary is presented together with what needs to be done to create this prototype in the future. The last chapter shows the evaluation of the graduation process and evaluation of the final design. This final chapter ends with a personal reflection.

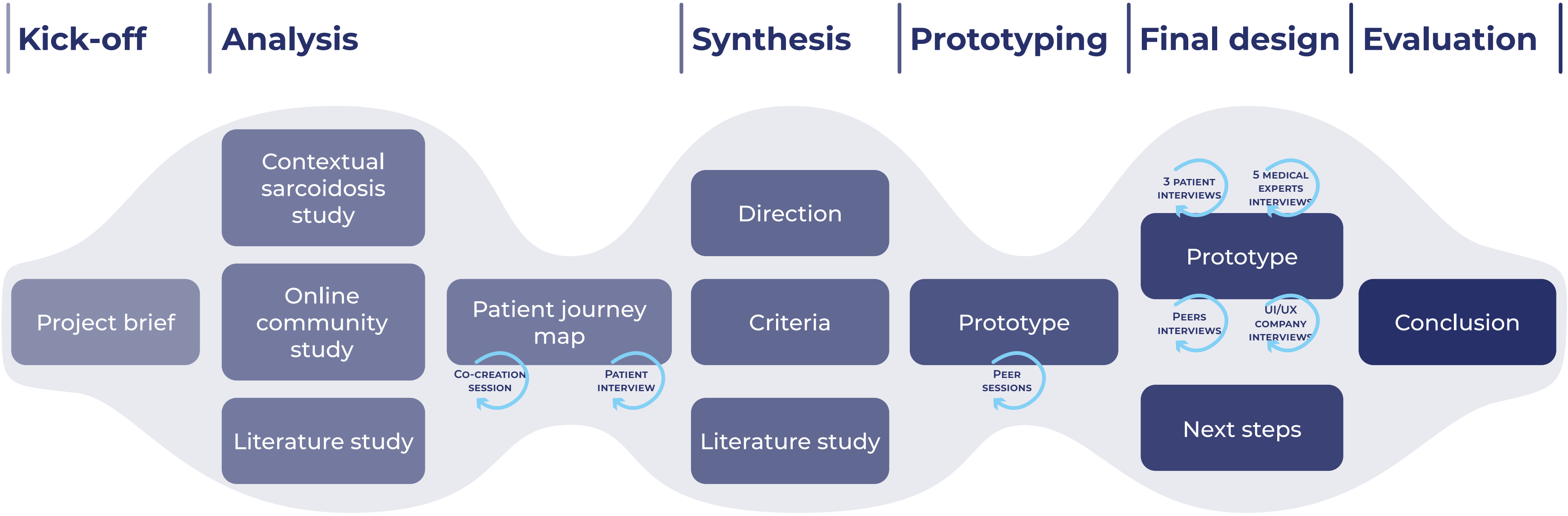


***Figure 1.2:** Project approach step by step.*

2. Analysis

The basis of this project consists of a three parts analysis:

1. A literature study about the medical image and the developments.
2. A contextual study of sarcoidosis patients in the Netherlands and with regard to Erasmus MC
3. A computational method to analyse the patient’s needs from wijhebbensarcoidose.nl

These parts together form the input for a sarcoidosis patient journey map.

2. Introduction

This chapter analyses the project from different perspectives and uses different sources to form a coherent and comprehensive patient journey map. These different perspectives and sources are a scientific literature study, the contextual sarcoïdosis image in the Netherlands and the online community study for this project. The goal is to visualise how patients with sarcoïdosis perceive their life with sarcoïdosis.

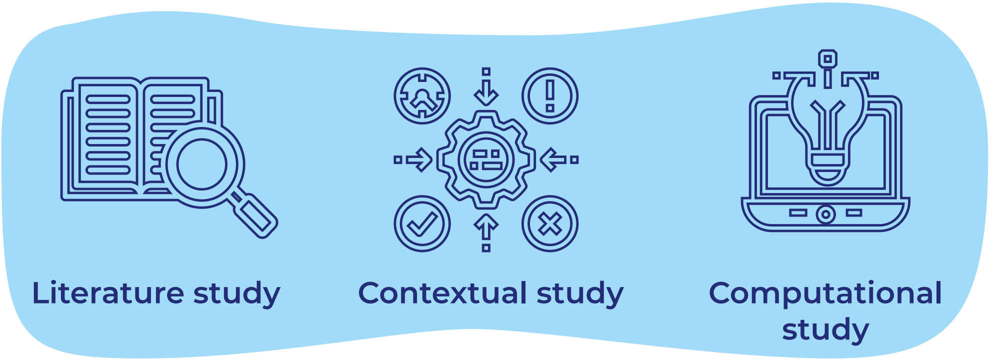


***Figure 2.1:** Three part analysis*

2.1 Literature study

2.1.1 Introduction

A literature study is done to provide more information about sarcoïdosis in general, but also more specific medical aspects. The goal is to show the medical side of sarcoïdosis, with its most common and varied symptoms, medication and side effects. Another goal is to show with literature that the transition to home monitoring is becoming more and more important for patients and hospitals. Therefore, in this part, the following questions are answered:

Research question 1: What entails sarcoïdosis from the medical side, with regards to epidemiological features, causes, treatment, and diagnosis?
Research question 2: What kind of influence has the medication had on sarcoïdosis patients and how can this be solved?
Research question 3: What is the trend for the transition from hospital to home self-monitoring?
Research question 4: What is Patient Community Journey Mapping and why does it function for this assignment?

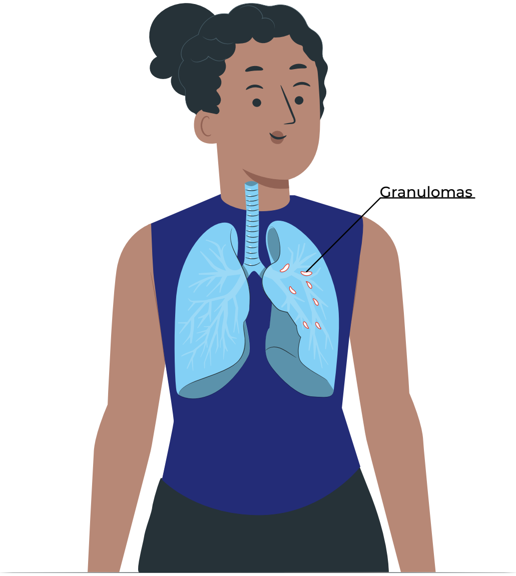


***Figure 2.2:** Sarcoïdosis medical image*

2.1.2 Sarcoïdosis medical overview

Sarcoïdosis is a rare and inflammatory disease with granulomas. It can have an effect on any organ in the body, predominantly the lungs, skin and eyes. In the Netherlands, there are 7000 to 8000 people living with sarcoïdosis yearly (Sarcoïdose - UMC Utrecht, n.d.). The symptoms, tests and side effects of sarcoïdosis vary among patients. They often include cough, shortness of breath, chest pain, exercise limitations and pronounced fatigue. Because of the variety, it makes it harder to give an effective personalized treatment plan right from the beginning. Furthermore, since the symptoms are broad and not very specific, and sarcoïdosis is a rare disease, general practitioners can’t diagnose sarcoïdosis right away (Sarcoidose.nl, 2023). According to the research of Drent et al. (2021), less than 10% of patients die from sarcoïdosis. Most fatal cases are due to lung sarcoïdosis, followed by cardiac complications.

Sarcoïdosis occurs in patients due to a triggering antigen that reacts to certain varying factors. For example, race or ethnicity is a factor, but also the patient’s genetic background and the geographic location of the patient’s living and working environments are factors. The prognosis varies a lot for each patient. Sarcoïdosis can be a one-time acute case that gets noticed by the patient and the doctors, but it can also resolve without getting noticed. Besides the one-time cases, sarcoïdosis can be chronic inflammation. This would mean that after two years of having sarcoïdosis, the disease becomes chronic and can lead to complicated fibrosis and/ or irreversible organ failure. Approximately one-third of the patients get chronic sarcoïdosis (Obi et al., 2021). Granulomas, a type of inflammation, often resolve spontaneously, however with sarcoïdosis, this isn’t the case. Sometimes it evolutes even toward pulmonary fibrosis (Ziegenhagen et al., 2003). Many characteristics of sarcoïdosis are known, however, to this day, doctors and experts keep on researching sarcoïdosis to get to know more about this disease and its causes.

Influencing factors

Many variables influence the chance of getting sarcoïdosis. For example, sex and heredity, and genetic and environmental factors affect the probability of getting the disease.

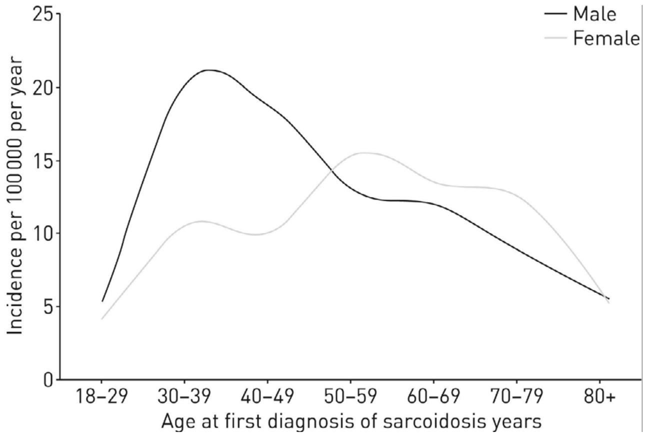


Figure 2.3: *Distribution of sarcoïdosis patients by age at diagnosis and sex (Arkema et al., 2016).*

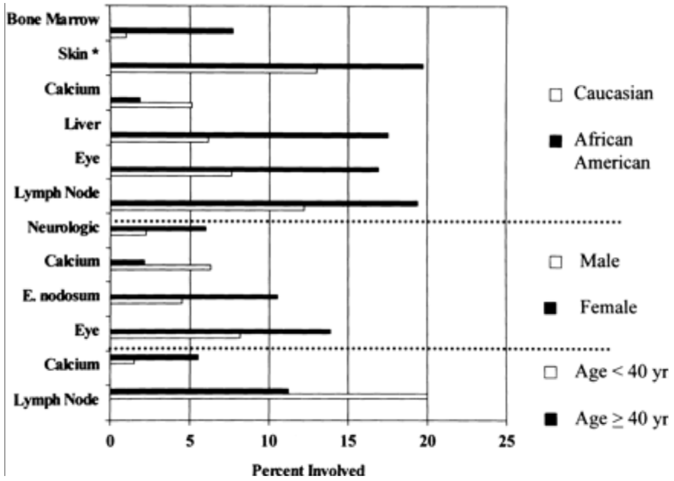


Figure 2.4: *Significant differences between groups on the basis of race, sex and age (Baughman et al., 2001).*

Sexes

Sarcoïdosis affects all sexes, but women have a slight predominance compared to men (Drent et al., 2021). The disease occurs mostly for men at the age of 30 to 50 years, and for women, this peak moment would be between 50 to 60 years. See Figures 2.3 and 2.4 for a diagnosis visualisation of the sexes and ages.

For women, sarcoïdosis influences their pregnancy period. There are higher risks of adverse events, therefore doctors need to be prepared and informed when a pregnancy is planned. When women want to get pregnant, some medication should not be prescribed. Nevertheless, a lot of research indicates that women with sarcoïdosis can have successful pregnancies. The symptoms of the disease of pregnant women even improve within the majority of the research, for example, fatigue becomes less (Hadid et al., 2014) (Kobak, 2020).

Heredity

It is shown that a family history of sarcoïdosis increases the risk for a first-degree relative by a factor of 3.7 (Arkema & Cozier, 2020). However, due to a lack of diagnostic sensitivity, variations in diagnostic techniques, and seasonal variations, it is difficult to make an accurate assessment of this.

Genetics and environment

The antigen that triggers sarcoïdosis is genetically influenced, but environmental characteristics also influence the process. Sometimes even occupations influence the process. According to Hena et al. (2019), multiple occupations and environmental exposures are associated with sarcoïdosis, for example, mouldy environments, insecticides, agricultural employment, metalworking, firefighting, and exposure to inorganic dust and silica dust. These exposures came from a conclusion from analysing an unlikely amount of sarcoïdosis cases among rescue workers at the World Trade Center in 2001 (Hena et al., 2019).

Diagnosis

The diagnosis of sarcoïdosis can take a long time, because of the clinical diversity. The diagnosis is made using a variety of clinical indicators, the detection of granulomas with one or even more tissue samples, and the exclusion of other possible causes of granulomatous illness. A lot of testing needs to take place for example a CT scan, X-ray photo and a biopsy of a certain specimen from the lungs. Often multiple tests need to be done to be able to diagnose the disease. The most effective testing way is endobronchial ultrasound guide transbronchial needle aspiration (TBNA) or bronchoscopy with TBNA (Drent et al., 2021). However, this differs also per type of sarcoïdosis, for example, neurosarcoïdosis can be difficult to diagnose. An MRI of the head is needed, with a cerebrospinal fluid analysis and detection of sarcoïdosis outside the nervous system. This shows the complexity of diagnosing sarcoïdosis.

Treatment

The causes for sarcoïdosis are variable per patient, which leads to a difficult diagnosis phase, leading to a complex treatment plan. The treatment plan depends on the risk of organ failure and the extent to which the patient’s quality of life is impaired (Drent et al., 2021). Therefore, the efficacy of treatments for sarcoïdosis and the side-effect profile related to them vary substantially from patient to patient. A straightforward treatment protocol that is effective for every patient is therefore not practical. When the disease occurs spontaneously and vanishes after a while, a treatment plan is not needed. On the other hand, treatment for chronic sarcoïdosis can lessen illness symptoms and avoid long-term consequences (Gerke, 2020).

According to the trial research of Kahlmann et al. (2022) patients with sarcoidosis benefit from online cognitive behavioural therapy based on mindfulness. This research shows that not only medicated treatment plan can improve the well-being of the patient, but also non-medicated treatment plans.

2.1.3 Sarcoïdosis symptoms and medication

At this point, it is clear that sarcoïdosis is a complex disease and is dependent on the patient's symptoms. In other words, sarcoïdosis needs a treatment that is dependent on nonspecific suppression of the immune response, which differs per patient (Lazar & Culver, 2010). The general clinical treatment plan does not (yet) exist.

The treatment plan for sarcoïdosis focuses primarily on the suppression of the immune system, thereby preventing organ damage or even death (James & Baughman, 2018). For sarcoïdosis there were long-time guidelines for a (pulmonary) treatment plan (since 1999), however, these have changed lately due to developments. According to Belperio et al. (2022), the guidelines still consist of three degrees in therapy:

1. Primary therapy contains oral glucocorticoids, which are anti-inflammatories (for example prednisone).
2. The second-line therapies contain azathioprine and methotrexate (MTX), which are focused on suppressing inflammatory responses. It is often combined with the primary therapy.
3. The third-line therapies contain mycophenolate mofetil, leflunomide and anti-tumour necrosis factor agents. These are also inflammatory suppressors.

Often these therapies are followed by each other when the others did not respond that well. This shows that multiple medicines are possible but also that this depends on the patient.

Sarcoïdosis patients can have multiple diverse symptoms, both physical and mental. The most common physical symptom for sarcoïdosis patients is fatigue. According to Millward et al. (2021), it can be present in up to 80% of sarcoïdosis patients. It is a tricky symptom because the cause is difficult to identify. It can be related to sarcoid activity, drug side effects, anaemia, hypercalcaemia, thyroid disturbance or a sleep disorder (Millward et al., 2021). Besides fatigue, dyspnea is also a common physical symptom. At the same time, this is an important indication for treatment (Nunes et al., 2019). Also, half of the sarcoïdosis patients cough a lot. It is part of the disease, however, other causes, such as reflux or post-nasal drip have to be excluded (Moor et al., 2020).

Besides the physical symptoms, there are also mental symptoms as a result of the disease. According to the research of Tavee and Culver (2019), anxiety is reported in up to 33% of patients and depressive symptoms in up to 66% of patients. It is even investigated that patients with depression or anxiety tend to have a higher symptom burden and different perceptions of disease severity (Ireland & Wilsher, 2010).

According to Bodenheimer et al. (2002), there are many aspects of chronic disease care that can only be managed by patients themselves. For sarcoïdosis management is symptom relief a major aspect, which can be relieved by patients themselves by for example physical training or cognitive therapy. According to research from Strookappe et al. (2016), patients consider physical training in sarcoïdosis valuable and they would implement it as the standard of care. With physical training could pulmonary involvement, fatigue and reduced exercise tolerance be improved. According to Strookappe et al. (2015), people with various stages of sarcoïdosis can benefit from an organized, supervised exercise program by experiencing reductions in their symptoms, quality of life, ability to exercise and muscle strength. Lastly, cognitive behavioural therapy has the potential to improve stress, anxiety and depression in sarcoïdosis (Saketkoo et al., 2018).

This said, sarcoïdosis patients considered the quality of life and functionality as the most important treatment outcome (Baughman et al., 2018). Besides this, self-management support is an important tool for chronic disease care models (Kingod et al., 2017).

2.1.4 Influence of side effects on Quality of Life

It appears to be that psychological symptoms are associated with worse clinical outcomes for sarcoïdosis (Sharp et al., 2019).

The sarcoïdosis treatment plan often varies. According to Saketkoo et al. (2021), it depends on whether the symptoms are brought by:

- mild sarcoïdosis activity (reversible),
- severe activity (irreversible organ damage),
- a combination of mild and severe symptoms,
- side effects activity,
- comorbidity activity,
- and lastly non-sarcoïdosis-related activity.

These distinctions show that symptom distress can result clearly from a sarcoïdosis manifestation, but may also be non-specific, such as pain or fatigue, which are often present in sarcoïdosis patients' physical appearance (Voortman et al., 2019). Due to sarcoïdosis's wide range of illness phenotypes, symptomatology, and behavior, treatment options that might mitigate Health-Related Quality of Life (HRQoL) concerns are possible (Saketkoo et al., 2021). These treatment options are currently pharmacological, but this can also concern non-pharmacological options (e.g., exercise or cognitive therapy).

This multi-dimensional concept of HRQoL measures how well a person's health affects their ability to interact with activities essential to their well-being, such as earning a living, spending time with family, and following their interests (Verschakelen et al., 2015).

According to a research of Cox et al. (2004), 66% of their study patients are dealing with depression, and this is associated with a reduced HRQoL. This makes that HRQoL in sarcoïdosis important because for initiating treatment it is important to improve the HRQoL (Obi, 2020).

HRQoL

The Health-Related Quality of Life is based on the Bio-Phsycho-Social Model of Health (Borrell-Carrio, 2004), which is based on biological health treatment effects, psychological health and social and financial factors. According to Saketkoo et al. (2021), to capture the HRQoL the following factors are important:

- Impact of symptom burden;
- Patient perceived disease severity;
- Treatment side effects;
- Healthcare interactions (physical, psychological and social well-being).

The HRQoL can be favourably or negatively influenced by personal factors, environmental factors and symptom burden (Saketkoo et al., 2012). For sarcoïdosis, there is a need to focus on these factors because of the complexity of sarcoïdosis (Van Helmondt et al., 2019). The basis of a clinician-initiated strategy to improve HRQoL is a setting where a patient feels respected, heard, and believed. This is followed by open-minded investigations based on the patient's medical history. The Picker Institute (Picker, 2023) defined this patient-centred care and integrated it into the NHS Patient Experience Framework, shown in Figure 2.5.

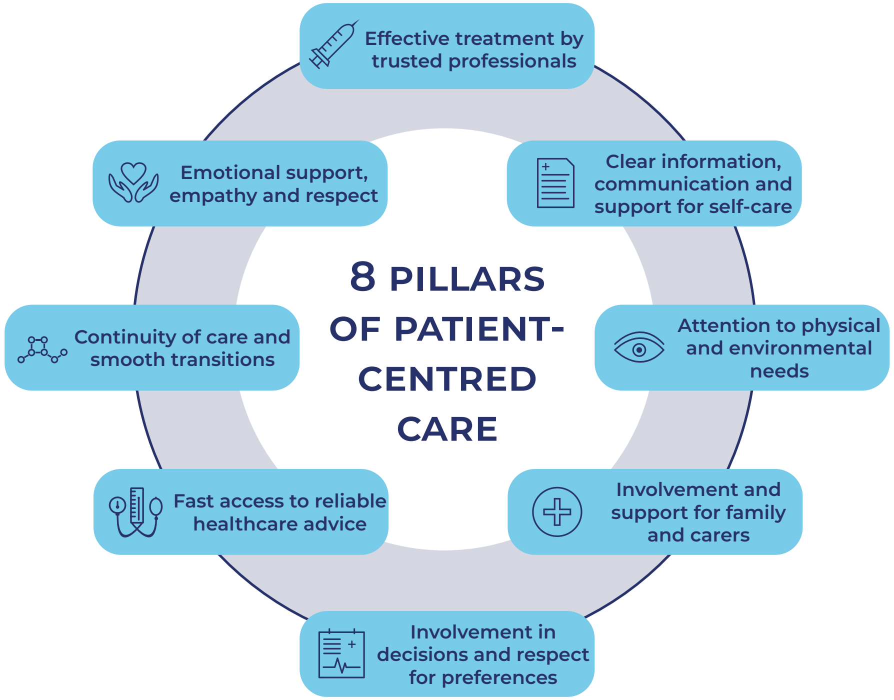


Figure 2.5: *Inter-related principles of patient-centeredness (Saketkoo et al., 2021).*

2.1.5 Transition from hospital to home monitoring

These days in healthcare, there is a transition happening from hospital remote monitoring to at-home remote monitoring. Remote monitoring in general has many advantages for patients with health complications. With simple applications, their health can be easily monitored, thinking of essential vital signs like heart rate, temperature and blood pressure. This is already monitored in the hospital, however, there is an increase in development for these technologies to monitor at home for the patient (Van Velsen et al., 2013). To reduce the patient flow to hospitals, patients get help at home and use digital accessibility to improve the patient's health conditions.

Benefits per stakeholder

Patients who have chronic conditions must take responsibility for their own daily care. They are in the best position to assess the intensity of their symptoms and the effectiveness of any treatments from home. They have the biggest influence on their care path and should actively participate in their treatment to have a positive effect (Celler et al., 2003).

For hospitals, the digital transition reduces major hospital costs. At present, hospital care is expensive for patients themselves and for insurance. In the Netherlands the healthcare allowance is a safe way for patients to limit their costs, however, it can still be relatively expensive due to deductible excess. In other countries, like the United States, patients need to pay their hospital expenses if they don't have insurance. Therefore, the digital transition improves the patient's medical condition and reduces the costs for hospitals. Because patients monitor their condition from home, they need to go to the hospital for consults, treatment or interventions less often, because they prevented their worsening on time. According to a study of Cryer et al. (2012), they saved up to 19 per cent per patient over costs for their healthcare paths, by implementing a digital application in their system for patients. In this study, they used the 'Hospital at Home' model to provide hospital-level care within patients' homes. Besides the reduced healthcare costs, they also showed comparable or better clinical outcomes and a higher satisfaction level.

The medical experts benefit from this because their patients need to come to the hospital less often for a consult, treatment or intervention. Even for smaller questions they can easier answer their patients' questions if needed. Sometimes medical experts are overloaded with questions from patients, resulting in a delay in the rest of their work. The conflict consists of wanting to be there for the patients, but also in the time that suits the best for them. However, this is not always possible, because patients call whenever they feel like it according to a specialist nurse of the Erasmus MC.

Sarcoïdosis trends

Healthcare is transitioning to home care, which includes more and more apps and products for patients. They are designed for the prevention, diagnosis, monitoring and treatment of specific health conditions (Mission & Vision - Convergence, 2022). For sarcoïdosis, there are multiple platforms where patients can share their experiences and look for information. In 2019 research was conducted about sarcoïdosis monitoring at home, using SarcOnline. This is an online eHealth application developed for sarcoïdosis patients at the pulmonary department of the Erasmus MC (Moor et al., 2019). It entails a secured personal platform, which allows patients to monitor their health-related information, including pulmonary function tests, activity, quality of life surveys, and explanations about symptoms and medicines. The quality of life surveys include HRQoL surveys, namely the King's Sarcoïdosis Questionnaire, Euroqol-5D-5L questionnaire (about mobility, self-care, daily activities), Hospital Anxiety and Depression Scale and Fatigue Assessment Scale. From this application, the conclusion was that a comprehensive home monitoring program is feasible. According to this study, the use of home monitoring may enable prompt detection and response to changes in symptoms, lung function, and activity, making it appealing for use in everyday care.

Risks

For every trend, there are risks involved which need to be taken into account in the process, to prevent or reduce the damage. This is also the case for this transition. When something is designed for the patients at home in any way (digital or physical), there are groups that aren't included and cannot or won't use the design. This can be because a group has no internet, money for buying the facilitations for usage or has a physical disability. This is one of the biggest goals in designing for patients at home: reach any kind of patient. Therefore it is important to involve these groups and make adjustments and achieve blended care. This means setting up quality, accessible digital care for most patients (Luscii, n.d.). According to Luscci that can be done by making an application clear and simple for the user, but also reaching as many patients as possible by designing in an intuitive way and lastly by thinking outside the box to reach the groups that aren't accessible. Lusccii created a project where these people can lend an iPad from selected hospitals and monitor their health. It is possible because the cost is limited and can be paid from the savings healthcare organisations achieve with remote patient monitoring. This sometimes can be reduced by up to 65 per cent (Three Ways to Ensure No One Gets Left Behind in Digital Care, n.d.).

The Convergence Consultation Room is working on using the available technology in a better way from the patient's perspective, this is done with the Flagship Project (Mijnster, 2022). Maybe the doctor is happy with a monitoring application, but what does the patient think? Their perspective matters, as they are the users and main stakeholders in this case. This is important to take into account.

2.1.6 Patient Community Journey Mapping

A new data-driven approach that utilises online patient stories is designed by Jiwon Jung during her PhD at Delft University of Technology. These stories are conducted from online data with the help of supervised and unsupervised machine learning techniques.

Patient stories are often used as data for a patient journey map. A patient journey map is a visual tool that shows the patients' perspectives on their experience of their care path, including the medical care path and touchpoints with necessary stakeholders. Qualitative data is used to visualise the maps. The conventional data collection method is often to hold extensive interviews and elaborated online forms (Jung, 2023). This method includes extensive interviews and elaborated online forms. Often the number of participants is low and therefore gives a detailed view of that certain group, but misses different populations, ages, or other demographic characteristics. Interviewing, online forms and different novel methods are often labour-intensive and take a long time to analyse the qualitative data. However, online there are plenty of social media platforms where patients express their experiences with other related patients. They want to express themselves, vent, ask for help and give tips to other patients with their perspectives. These platforms have a hugely unique and rich database for certain patient experiences. Therefore Jung designed a method to use these online databases and use machine learning methods to analyse this data and let it contribute to an intuitive patient journey map.

According to Cantamessa et al. (2020), machine learning is a type of artificial intelligence that broadly automates the process of human learning. There are two methods in machine learning, namely: supervised and unsupervised machine learning. The labelled datasets created by human beings (such as designers) are used in supervised learning to anticipate patterns within the data. On the other hand, unsupervised learning discovers clusters and patterns with unlabelled datasets. Jung's approach uses supervised learning.

Jung's method involves collaboration between a designer and a data scientist. The data scientist can create a code to shorten the pile of data to the most relevant objects. The designer can analyse these outcomes and look at how to visualise this in a patient journey map. The designer shall first make a patient journey map based on the patient's healthcare path protocol according to the hospital, see a version that a research student made for patients with cancer (see Figure 2.6).

Cancer often starts with small health complaints.

The ground falls away beneath you when you hear the diagnosis, life is set to change.

The importance of information availability and transparancy in a way that is not overwhelming.

It takes time to process the information and the emotions that come with it

Difficult to deliver the news to family or others.

Stepping aboard the fast moving train of different hospital tests.

Waiting for the test results is stressfull you need to find a way to make the waiting time more bearable.

Being well informed and thinking about pro's and con's (quality vs quantity of live) helps patients to make tough decisions in which they want to have a say in.

Patient discusses treatment and talks about procedures.

Seeing cancer as a fight you need to win.

You need to find your own way to deal with the unpleasant side effects caused by the treatment.

Patients find it important but difficult to have a healthy diet and active lifestyle while dealing with less energy and fatigue.

Recovery takes time you need to find your own way of doing this and taking the time.

Patient looks for distraction in nature, hobbies or people.

Working while being in treatment can help with the mental health but it is important to be flexible to deal with challenges of treatment.

Patients tries to stay positive and hopeful, enjoys the little things and small victories.

It is important for the patient to be mentally healthy and to seek help if needed.

Figure 2.6: *Example of a first patient journey map (Jung, 2023).*

Next, the data scientist comes up with quantification of these certain moments. The designer uses this to give a view of how many times a certain subject is discussed on the social media platform. See Figure 2.7 for the visualisation of implementing this quantification.

Often these maps are co-created with doctors and experts connected to that specific patient journey. The medical experts is giving their opinion and perspective on the journey and validates whether the designer's choices are correct or need improvement.

"I am 51 and I still have hot flashes, night sweats, sleep disturbance, restless legs."

"Cough, pain in mouth, tongue & throat and extreme mucous levels are about the same."

"I have been on a number of magic mouth rinses, mucusitus mouth washes, nystatin as well as the good old salt and baking soda regime."

Figure 2.7: *Example of the patient journey map quantified with machine learning (Jung, 2023).*

2.1.7 Literature conclusion

This chapter shows the literature study of sarcoïdosis. The disease is rare, complex and varies per patient, which leads to a complex treatment plan and diverse symptoms and side effects. The medical world keeps doing research on sarcoïdosis because the factors, causes and best treatment plan still needs to be found. The treatment can be pharmacological and non-pharmacological.

It is clear that sarcoïdosis patients consider the quality of life and functionality as important, however, they have also an increased chance of depression and anxiety. Thus a clinical self-management tool that focuses on patient-centred care to improve the HRQoL of sarcoïdosis patients should be designed.

Health-Related Quality of Life questionnaires can help doctors and patients to have a better understanding of the patient's quality of life. Based on these questionnaires the patient can get a better treatment plan and understanding of how to cope with their disease. Patient-centred care can be a result of this and helps the patient.

There is also research that shows that the transition from hospital to home care can improve living with chronic disease.

Literature study | Key main takeaways

- Sarcoïdosis is a rare and complex disease, with variable symptoms, side effects and treatment plans per patient.
- Transition to home care is beneficial for hospitals, medical experts and patients.
- Patient-centred care is important to take into account and this can be tested among other things with HRQoL questionnaires.
- A self-management tool with cognitive behavioural therapy can increase the quality of life for patients with sarcoïdosis.
- Patient Community Journey Mapping is an appropriate method to emphasize the patient's needs.

2.2 Contextual sarcoïdosis study

2.2.1 Contextual introduction

In this part of the analysis, the goal is to emphasise how care is organized for sarcoïdosis patients. This gives a feeling of how it works and what kind of tools already exist for patients in this area.

The following questions are answered in this chapter:
Research question 1: What is the structure in the Netherlands concerning hospitals and expertise centres for sarcoïdosis patients?
Research question 2: What kind of patients does the Erasmus MC have and how does the hospital provide care?
Research question 3: What kind of tools already exist for sarcoïdosis patients of the Erasmus MC to help them at home with their disease?

2.2.2 Sarcoïdosis in the Netherlands

The Netherlands counts approximately 7.000 to 8.000 sarcoïdosis patients (Sarcoïdose | St. Antonius Ziekenhuis, 2023). Patients often start at the GP's with their symptoms and they get a referral to a specialist centre for sarcoïdosis. There are also treatment centres, that are closely connected to the expertise centres (Sarcoidose Belangenvereniging Nederland, 2019).

Figure 2.8: *Expertise centres in the Netherlands.*

There are three sarcoïdosis specialist centres in the Netherlands, namely Interstitial Lung Diseases Expertise centre St. Antonius Hospital, Sarcoïdose Centre Erasmus MC and centre for Neurosarcoïdosis Amsterdam UMC (Sarcoidose Belangenvereniging Nederland, 2020). See Figure 2.8 for a geographic overview of these centres. A specialist centre is accredited on a European level, based on the following criteria: quality of care, transition care, continuity of the centre, collaboration with other parties, information & communication, research and cross-border care (Sarcoidose Belangenvereniging Nederland, 2019). Each specialist centre has its own information website for sarcoïdosis, but often refers to the official online patient organisation.

The online patient organisation for sarcoïdosis is sarcoidose.nl. They provide patients with multiple informative flyers and other information sources about sarcoïdosis. They want to help the patients no matter in what stage the patients are. Patients can find tips about family, work or treatment, and can also read stories from fellow patients and join organised meetings. Besides this, they have an Advice Council, this council informs the website about sarcoïdosis developments and gives answers to patients' questions. In this council, there are all kinds of medical experts included from different specialist centres (Sarcoidose Belangenvereniging Nederland, 2023). This patient organisation is closely connected to the specialist centres.

Besides this official patient organisation website, there is a social media platform where people can share their experiences about everything that they want to share. This platform is called wijhebbensarcoidose.nl. This website started in 2007 when Joachim Dekkers was diagnosed with sarcoïdosis and he missed a platform to connect with other sarcoïdosis patients, so he created one (Joachim, 2019). It is created with the thought to help the patient but also their close circles like partners, kids or friends.

Thus, patients have access to care in three places in the Netherlands and there are two types of independent online platforms with information and care for the patients.

2.2.3 Sarcoïdosis healthcare in the Erasmus MC

This thesis is done for the Erasmus MC, they also have a special website for sarcoïdosis. Here, patients can find what this specialist centre does, a disease overview, the poli clinics, with whom they collaborate and their research (Erasmus MC, n.d.). Their centre is closely connected with other centres like cardiology, immunology, lungs and neurology. In their centre, they have six pulmonologists (doctors specialised in lungs) and one specialised nurse (Erasmus MC, n.d.).

The sarcoïdosis patients' demographics of the Erasmus MC patients are visualised in Figures 2.9 and 2.10. It can be concluded that women are the majority of the patients and that they are older than men. This resembles the earlier stated fact that women, in general, are older when they are diagnosed with sarcoïdosis than men (Drent et al., 2021).

Underrepresented patient group

Every disease has an underrepresented group, to whom medical experts have a hard time providing good healthcare to them. Sarcoïdosis has also an underrepresented group which is at the Erasmus MC even more of an issue due to the variety of ethics in Rotterdam. Specialist nurse Y. Gür-Demirel gave insights during an interview into what the underrepresented group of sarcoïdosis is according to her knowledge. She highlighted that Turkish or black young men often neglect their disease, therefore they are not consistent with their medication intake or other therapies. Also, there are a lot of black single mothers that, for example, can often not arrange a babysitter, leading to them not showing up for their appointments. Lastly, there is often a language barrier with Turkish or Arabic-speaking patients.

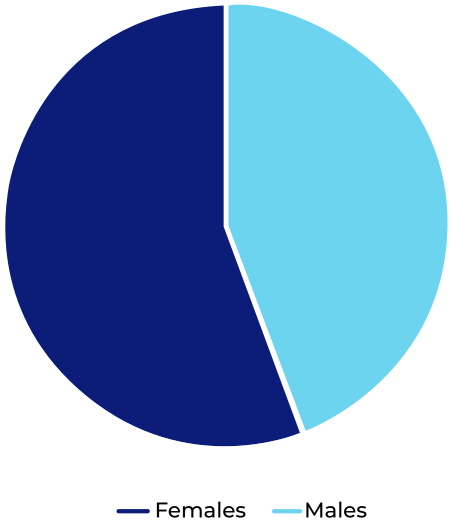


Figure 2.9: *Distribution of gender of sarcoïdosis patients at Erasmus MC.*

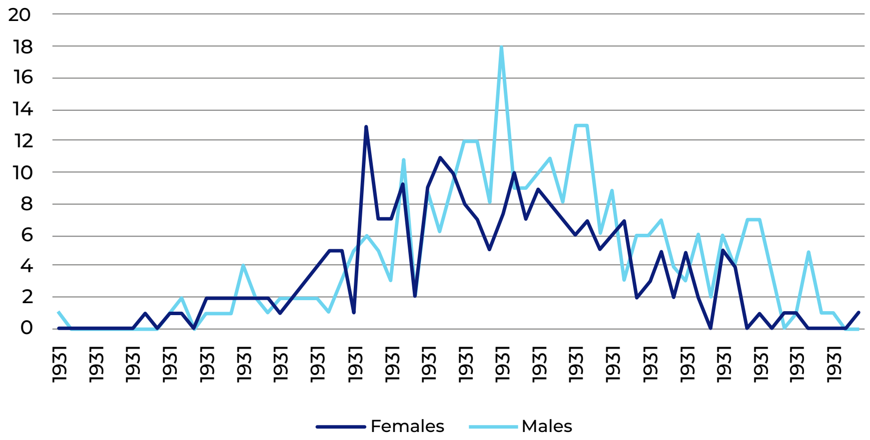


Figure 2.10: *Gender distribution versus birth year of sarcoïdosis patients at Erasmus MC.*

2.2.4 Sarcoïdosis patient home monitoring

Several studies are conducted to see how patients can monitor their disease at home, with the goal to improve their disease. For sarcoïdosis, this is also the case, and there are several studies done by the Erasmus MC in collaboration with other hospitals.

Research is conducted in 2019 about a tool for patients at home to monitor the vital condition of their lungs (Moor et al., 2019). This research is realised with the external company Curavista and their gezondheidsmeter.nl function (Figure 2.11 shows the website). Patients have a breathing device at home that is connected to their mobile phones to transfer data. The patient can test their lung capacity with the breathing device, and transfer the results to sarconline.nl. The patients and the medical experts can see these results over time and make together a decision about their treatment plan. Besides giving an overview of the lungs, they also test the quality of life of the patient. It differs per patient if they are using this platform regularly.

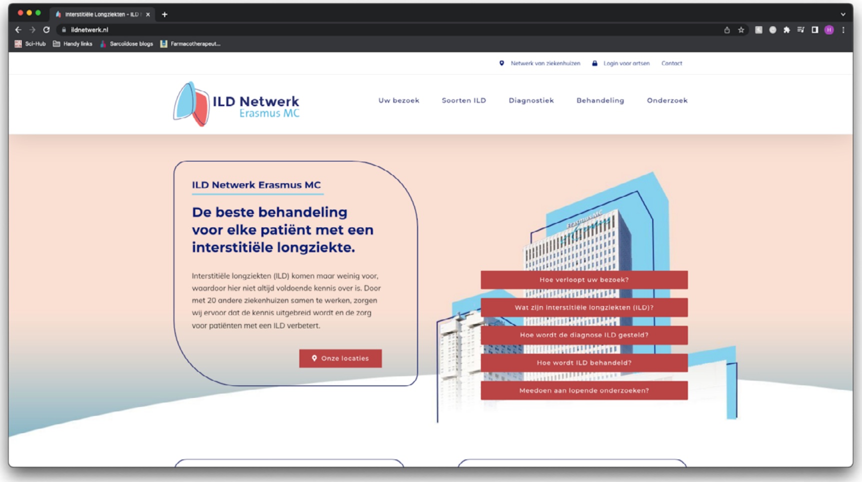
Erasmus MC collaborated together with 20 other hospitals in the Netherlands. They made a platform and wrote the information in a medically correct way to make it understandable for patients, it's called: ILDnetwerk.nl. ILD stands for Interstitial Lung Diseases, the Erasmus MC has an ILD department. Their subjects are different lung diseases treated in specialist centres they have in their hospital group. Figure 2.12 shows the website homepage. On the website, the diagnosis is discussed, together with different treatment plans and research that is happening.

Sarcoïdose online

Sarconline geeft meer inzicht in de ziekte en het ziektebeloop aan mensen met sarcoïdose en hun behandelaars. U kunt online en beveiligd uw medische gegevens bijhouden.

U vindt informatie en de mogelijkheid om online met uw zorgverleners te communiceren. Het Erasmus MC is hier als eerste ziekenhuis mee gestart. U kunt bij uw behandelaar navragen ofsarconline in uw ziekenhuis ook beschikbaar is.

***Figure 2.11:** Sarconline.nl for sarcoïdosis patients (screenshot of sarconline.nl, 2023).*



ILD Netwerk Erasmus MC

De beste behandeling voor elke patiënt met een interstitiële longziekte.

Interstitiële longziekten (ILD) komen maar weinig voor, waardoor hier niet altijd voldoende kennis over is. Door met 20 andere ziekenhuizen samen te werken, zorgen wij ervoor dat de kennis uitgebreid wordt en de zorg voor patiënten met een ILD verbetert.

***Figure 2.12:** Homepage of ILDnetwerk.nl (screenshot of ildnetwerk.nl, 2023).*

2.2.5 Contextual conclusion

The contextual side of sarcoïdosis in the Netherlands is connected with three specialist centres, and the Erasmus Medical Centre is one of them. The Erasmus MC provides a general sarcoïdosis polyclinic website, using a patient monitor tool and having an informative website with medical facts about sarcoïdosis. Besides the hospital side, patients can use the patient organisation’s website for information and can share their experiences on a social media platform. On the next page is a visualisation shown of the contextual conclusion.

Contextual study | Key main takeaways

- There are three specialist centres for sarcoïdosis patients in the Netherlands, and the Erasmus MC is one of them.
- Patients have access to two independent online platforms for sarcoïdosis.
- Patients have access to one sarcoïdosis monitor platform and an information platform, from the Erasmus MC.
- Underrepresented patients are often: young Turkish and black men, black single mothers and people that speak Turkish or Arabic.

Figure 2.13: *Overview of the context for sarcoïdosis patients at the Erasmus MC.*

2.3 Online community study

2.3.1 Introduction

The online community study gives the method that has to be done as input for visualising a patient journey map, to emphasise the patients' needs.

Research question 1: What kind of needs do patients express on the social media platform?
Research question 2: What are the most talked about needs and their sentiment?
Research question 3: How do these needs compare with the medical journey steps?
Research question 4: How are needs related to other needs?

2.3.2 Method

A patient journey map gives information about the process for a patient with a certain disease step by step. In this project, data is used from wijhebbensarcoidose.nl to determine the healthcare path for patients with sarcoïdosis. However, the data on this specific social media platform is very raw and has a too large number of posts to manually analyse it. Therefore the raw data is converted to usable data, to use the data with machine learning for quantification and for sentiment analysis. The steps are shown below in Figure 2.14.

Often a co-creation session with medical experts takes place to validate the map. This also happened in this project and Appendix B shows the setup, the session itself and the derived feedback. From this session, it is clear that there is an additional step needed in the data analysis. This begins with excluding fewer topics, clustering some topics a bit differently, changing the interpretation of the sentiment analysis and looking at co-occurrence between topics. In this chapter, the final methodology is explained, with the co-creation session's feedback included.

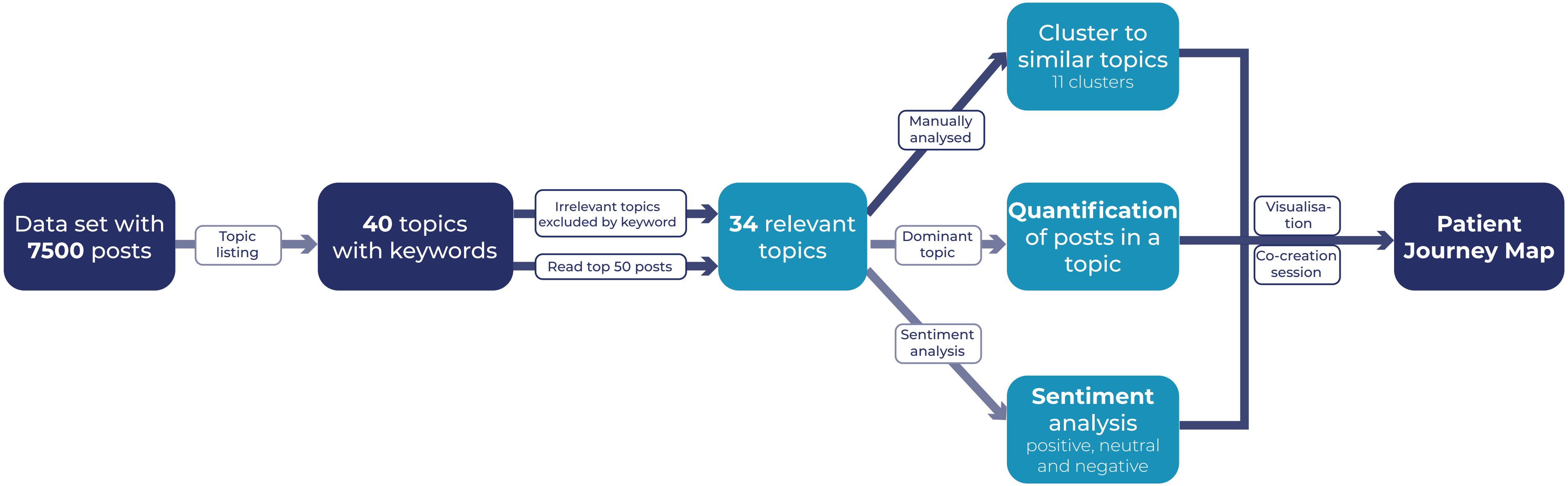
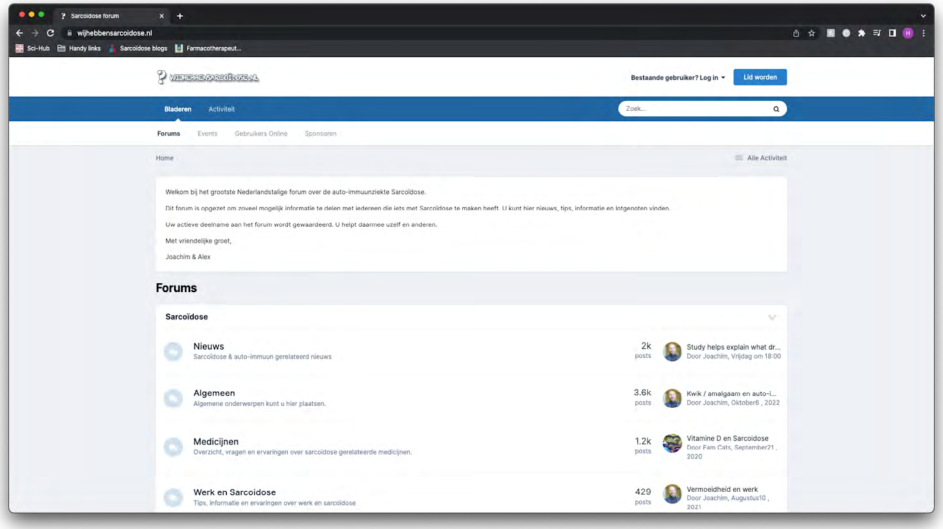


Figure 2.14: *Online community study approach step by step.*

2.3.3 From raw data to useful data

The database is from the open social media platform wijhebbensarcoidose.nl. They have an open database and a database that is only available with a user account. In this project, only the open database is used, thus without the user account availability. This results in a database of approximately 7500 posts, including 7 of the 8 categories that are feasible on the website (see Figure 2.15 for the website and the sum of its categories). The category ‘News’ is not taken into account because it doesn’t include patient experiences, only sarcoïdosis-related news development. The database with posts includes the main posts and reactions to these posts, see Figure 2.16 as a visualisation of the set-up of these posts.



Welkom bij het grootste Nederlandstalige forum over de auto-immuunziekte Sarcoidose.

Dit forum is opgezet om zoveel mogelijk informatie te delen met iedereen die iets met Sarcoidose te maken heeft. U kunt hier nieuws, tips, informatie en lotgenoten vinden.

Uw actieve deelname aan het forum wordt gewaardeerd. U helpt daarmee uzelf en anderen.

Met vriendelijke groet,

Joachim & Alex

Forums

Sarcoïdose

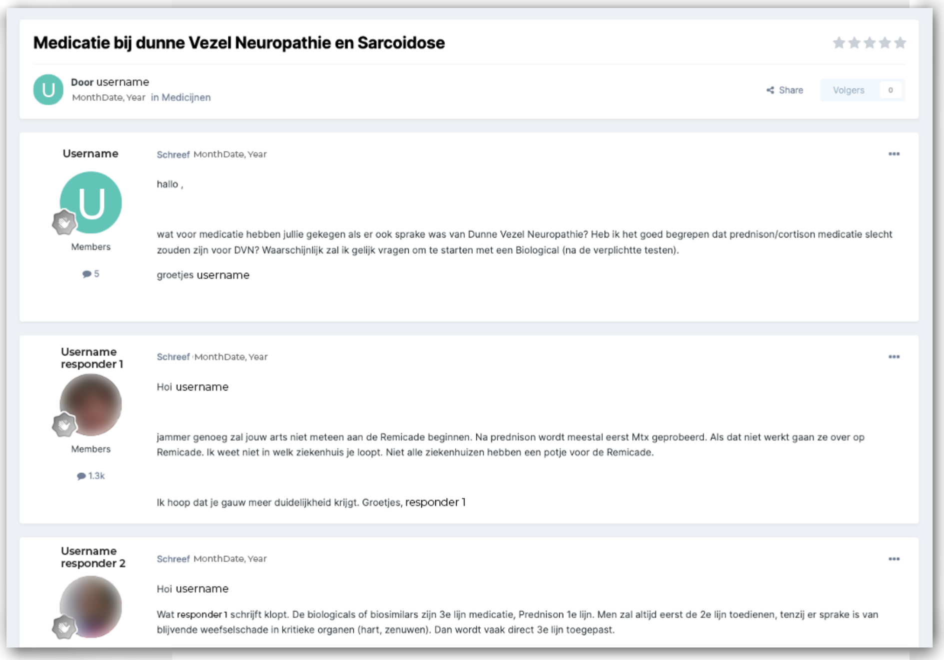
Nieuws
Sarcoïdose & auto-immuun gerelateerd nieuws
2k posts
Study helps explain what dr...
Door Joachim, Vrijdag om 18:00

Algemeen
Algemene onderwerpen kunt u hier plaatsen.
3.6k posts
Kwik / amalgaam en auto-i...
Door Joachim, Oktober6 , 2022

Medicijnen
Overzicht, vragen en ervaringen over sarcoidose gerelateerde medicijnen.
1.2k posts
Vitamine D en Sarcoidose
Door Fam Cats, September21 , 2020

Werk en Sarcoidose
Tips, informatie en ervaringen over werk en sarcoidose
429 posts
Vermoeidheid en werk
Door Joachim, Augustus10 , 2021

Figure 2.15: *A screenshot of wijhebbensarcoidose.nl with categories (in Dutch) (screenshot of wijhebbensarcoidose.nl, 2023).*



Medicatie bij dunne Vezel Neuropathie en Sarcoidose

Door username
MonthDate, Year in Medicijnen

Username
Schreef MonthDate, Year

hallo ,

wat voor medicatie hebben jullie gekegen als er ook sprake was van Dunne Vezel Neuropathie? Heb ik het goed begrepen dat prednison/cortison medicatie slecht zouden zijn voor DVN? Waarschijnlijk zal ik gelijk vragen om te starten met een Biological (na de verplichtte testen).

groetjes username

Username responder 1
Schreef MonthDate, Year

Hoi username

jammer genoeg zal jouw arts niet meteen aan de Remicade beginnen. Na prednison wordt meestal eerst Mtx geprobeerd. Als dat niet werkt gaan ze over op Remicade. Ik weet niet in welk ziekenhuis je loopt. Niet alle ziekenhuizen hebben een potje voor de Remicade.

Ik hoop dat je gauw meer duidelijkheid krijgt. Groetjes, responder 1

Username responder 2
Schreef MonthDate, Year

Hoi username

Wat responder 1 schrijft klopt. De biologicals of biosimilars zijn 3e lijn medicatie, Prednison 1e lijn. Men zal altijd eerst de 2e lijn toedienen, tenzij er sprake is van blijvende weefselschade in kritieke organen (hart, zenuwen). Dan wordt vaak direct 3e lijn toegepast.

Figure 2.16: *Post thread with information from wijhebbensarcoidose.nl (screenshot of wijhebbensaroicodse.nl, 2023).*

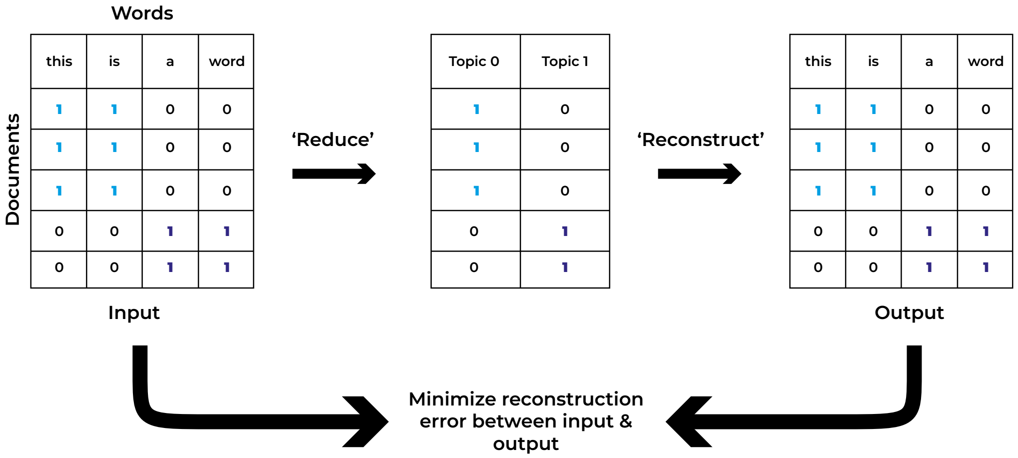
Part 1: Topic modelling

The database that is collected with 7500 posts contains only raw data. Raw data is the content as visible on the internet, this is not usable for manual analysis because of the large amount of posts. Therefore machine learning is needed to clean and filter the data. The data scientist filters this pile of raw data with a method called ‘topic modelling’. This is a statistical method to determine what pattern of words occur together in documents the most often. These words together give an indication of what kind of topics can be found in the dataset without actually reading all the 7500 posts. A Non-Negative Matrix Factorization (NMF) is used for the Topic modelling, see Figure 2.17 for the basic working of NMF. This means the raw data file with 7500 posts is reduced to topics indicated by the same words. This is reconstructed to putting the words within one topic together. This minimises the reconstruction error between input & output.

During Topic modelling, it appears to be that users use words that have no value for this analysis very often. Therefore the output of these keywords has to be finetuned because it contained some useless keywords (e.g., usernames, Dutch places and thank-you words). Therefore the following things are excluded from the topic modelling:

- Excluding 10k Dutch names, by using a Dutch name database (Nederlandse Voornamen Top 10.000 « Naamkunde, n.d.);
- Excluding Dutch places (Wikipedia-bijdragers, 2023);
- Excluding specific words, this full list is in Appendix C.1.

The result of this statistical method with the raw data is a topic list with 40 topics that include an enumeration with keywords (see Appendix C.2 for this list).



this	is	a	word
1	1	0	0
1	1	0	0
1	1	0	0
0	0	1	1
0	0	1	1

Topic 0	Topic 1
1	0
1	0
1	0
0	1
0	1

this	is	a	word
1	1	0	0
1	1	0	0
1	1	0	0
0	0	1	1
0	0	1	1

Figure 2.17: *Non-Negative Matrix Factorization.*

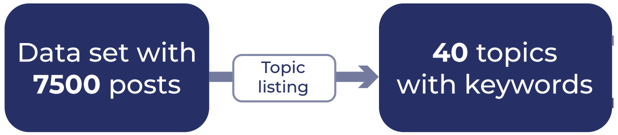


Figure 2.18: *Topic modelling step.*

Part 2: Excluding topics

The topic list is created and the topics were manually analysed. The designer interprets the keywords and derives a conclusion from them. This analysis can be seen in Appendix C.2. From this filtered topic list, some more topics can be excluded from the data analysis because they are not relevant to this analysis. The exclusion criteria for taking certain topics into account are the following:

1. Topics that are forum specific, like talking about certain features (buttons) from the website, or discussing what could work better on the website for example.
2. It shouldn't involve gender- and age-specific moments, because sarcoïdosis is a gender-neutral disease and can happen at almost any each age.

With these rules, the topic list is analysed and four topics are excluded. Then from the remaining 36 topics, each relevant topic and its top 50 posts are manually read. This is done to check if the previously conducted conclusion from only the keywords is correct. This resulted in two extra excluded topics because they are about specific forum questions and not about sarcoïdosis. See Appendix C.3 for the excluded topics and each reason to exclude. Eventually, 34 topics remained for further analysis.

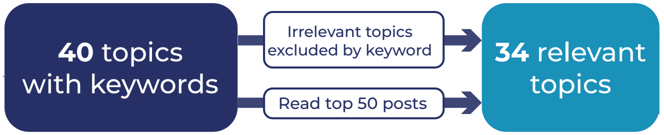


Figure 2.19: *Relevant topics step.*

Part 3: Cluster the topics

The post relating to the 'News' category is not included, therefore it is not 7500 relevant posts but 6499. The data export with 34 relevant topics, resulted in a database of 6466 posts that each was signed to a dominant topic. Manually the topics are analysed and clustered together. Table 2.1 shows the result of this clustering.

Table 2.1: *Topic cluster.*

Cluster		Topics
1	Change in daily routine	0, 1, 29, 30
2	Influence of medication	3, 34, 15, 4, 2, 21, 5, 9, 39
3	Experience of diagnosis process	8, 27, 38
4	Experience of physical complaints	11, 13, 31,35
5	Experience of sarcoidosis physical complaints	7, 12, 26, 33
6*	Pregnancy	18, 22, 36
7	Questioning about sarcoidosis	6, 23, 25
8	Alternative treatments	14, 28, 37
9	Different types of sarcoidosis	20, 24
10	Balancing between work and sarcoidosis	10, 17
11	Sharing of advice	16, 19, 32

* *These topics are excluded earlier from the analysis*.

2.3.4 Quantification input for the patient journey map

This new converged database is used for quantification and sentiment analysis for the patient journey map. From the 34 relevant topics, the data scientist generates an overview of each dominant topic per post. This indicates how many posts there are about one topic and how many are used for the quantification of the patient journey map by giving the number of posts per dominant topic (see Appendix C.4 for the clustering and Appendix C.5 for the quantification). Figure 2.21, on the next page, shows how the cluster (with their topics) and the quantification look like from the database.

2.3.5 Sentiment analysis as input for the patient journey map

The last step is sentiment analysis. This is done to give an enhanced feeling of each topic and to show how the user is feeling towards that topic. The sentiment analysis is done with the base sentiment multilingual algorithm (Cardiffnlp/Xlm-roberta-base-sentiment-multilingual · Hugging Face, 2022) which is generated from a larger webshops review Dutch database. Because of the database of 6466 posts within this project, this sentiment algorithm is based on an originally larger database and gives a better indication of our smaller database. Eventually, it shows the number of posts on one topic that is positive, neutral and negative. The formula below is used to determine a range from 0 to 1 and how positive the topic was. See Appendix C.6 for the sentiment analysis overview per topic, with its positive and negative numbers.The formula indicates the positive or negative sentiment of a topic.

positive-negative indication = positive posts / (postive posts + negative posts)

2.3.6 Designer's interpretation

Eventually, from the raw database to the quantification and sentiment analysis, a patient journey map is visualised. This is discussed later in chapter 2.4. The goal of this data analysis is to show numbers to the patient journey map in a comprehensive and clear way to show the feelings of the patients. This is used in the visualisation of the patient journey map. Figure 2.20 shows how the latest steps were independently done.

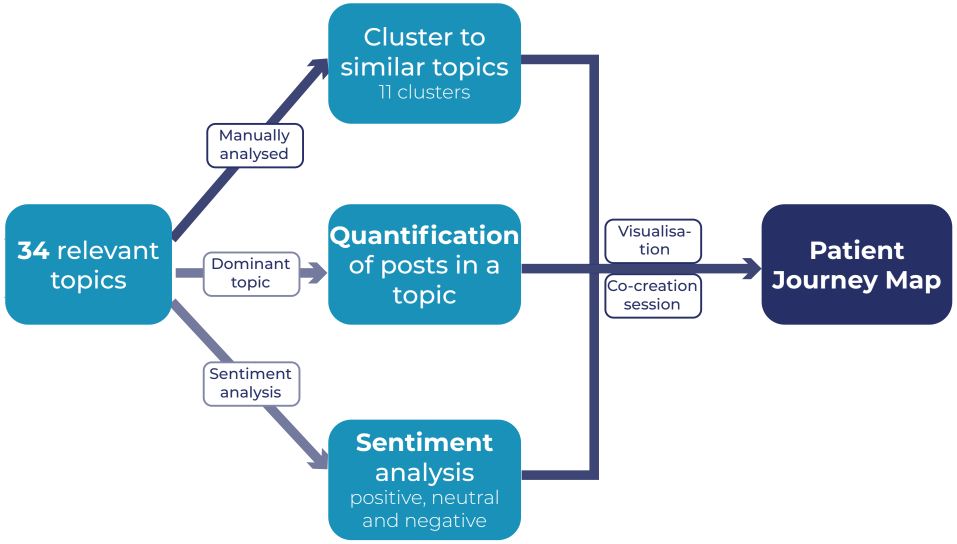


Figure 2.20: *Last steps of the online community study.*

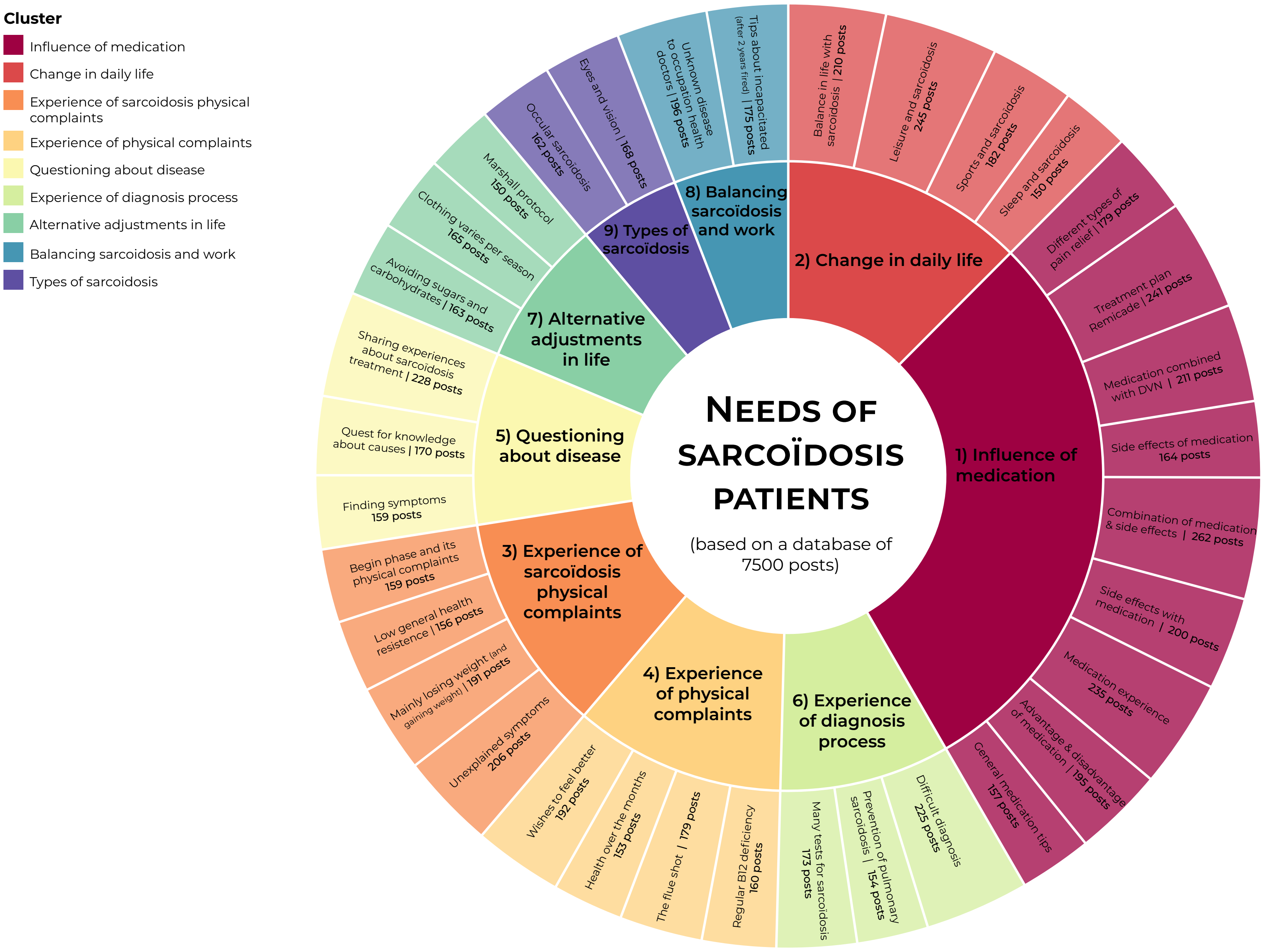


Figure 2.21: *Overview of the database with the clusters and topics (made with rawgraph.io, 2023).*

2.3.7 Co-occurrence

A post does not discuss only one topic, meaning that there is mixed data in one post. This is caused by one of the characteristics of sarcoïdosis because of the diverse mixture of symptoms. Till this moment in the methodology, only the dominant topic is taken into account. However, the occurrence within one post indicates a lot about the relationship between topics. Therefore, the relation between topics is visualised to show how topics relate to each other. Figure 2.22 shows the results of these relations in a co-occurrence matrix, showing how many posts are mentioning two topics. In Figure 2.22 it is seen that topic 0 relates the most with other topics, the highest number of posts are within the row and column of topic 0. What this means, is discussed in Chapter 3: Synthesis.

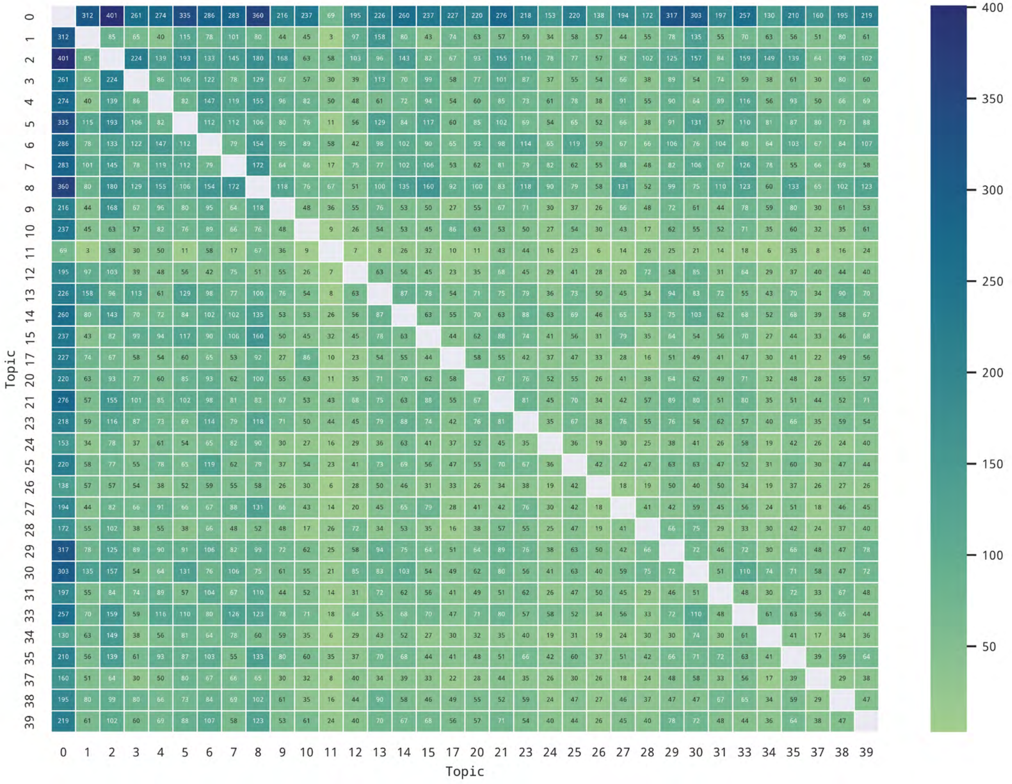


Figure 2.22: Co-occurrence between topics.

2.3.8 Online community study conclusion

The 7500 posts of wijhebbensarcoidose.nl are used in the format of 34 topics that are mentioned the most. These topics often relate to each other and that is shown by the clustering and co-occurrence between topics. The online community study gives a good start to visualise the patient journey map.

Computational study | Key main takeaways

- Data from wijhebbensarcoidose.nl can be used as data input, with 6499 posts.
- Topic modelling can be used for analysing large numbers of posts.
- 34 relevant topics have been conducted that fit into 11 clusters.
- Sentiment analysis gives a good view per topic of how people are talking about a specific topic.
- Topic 0 has the highest relation among the other topics. This means that this topic is often mentioned together with other topics.

2.4 Patient journey map concepting

2.4.1 Introduction

The patient journey map for sarcoïdosis is designed to get an enhanced feeling about the healthcare path that sarcoïdosis patients are going through and how they experience it. Therefore a distinction between the step-by-step procedure is made in this map, and the experiences derived from the earlier discussed online community study. The patient journey map is also validated by medical experts from the Erasmus MC during a co-creation session, the feedback is taken into account in making the patient journey map. See Appendix B for the setup, feedback and illustration of this session. Besides the medical experts, a patient took a look at the patient journey map and gave feedback. This is implemented in this chapter and the feedback can be read in Appendix D.

Research question 1: How can the needs of the online community study be mapped on the patient journey map?

2.4.2 Medical journey

The patient journey map starts with the medical journey step-by-step. This chronicle step-by-step procedure is generated by the ‘Zorgpad’ of sarcoïdosis for Erasmus MC, and from the sarcoïdosis patient organisation (see Appendix E for the informative flyer that they share for patients). The ‘Zorgpad’ file is the protocol that the hospital has for patients with sarcoïdosis and which the medical experts follows with a patient. The informative flyer from the patient organisation includes the same steps, however, it’s from a patient perspective. The medical journey can be divided into more generic phases: First symptoms, Referral, Diagnosis, Treatment and Follow-up. See Figure 2.23 the derived medical journey path for sarcoïdosis patients.

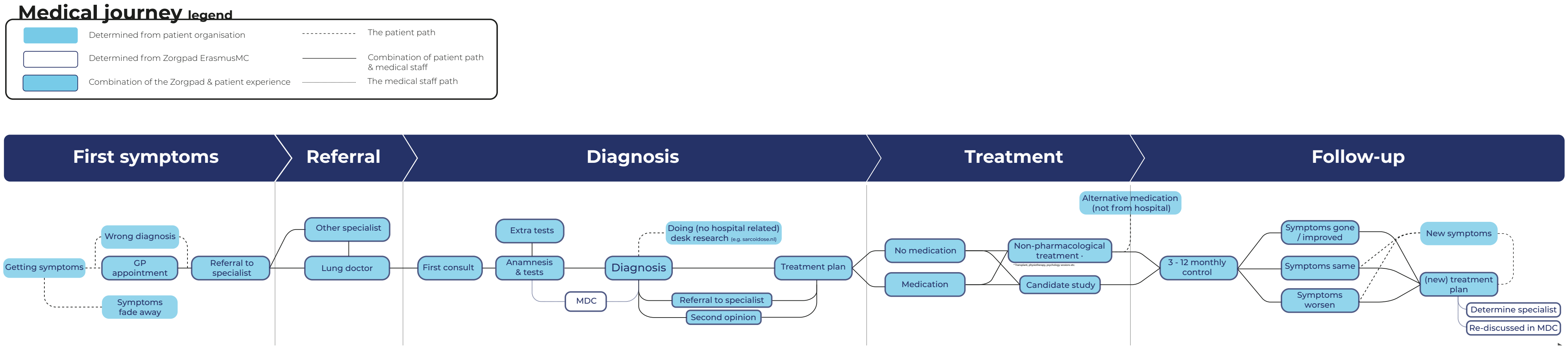


***Figure 2.23:** Medical Sarcoïdosis Patient Journey.*

2.4.3 Duration of clusters

The next step is to determine when a cluster begins and when it ends, to emphasise when a cluster is present for patients besides the medical journey steps. The Y-axis indicates where the clusters are happening, going from home to hospital (in the middle is both). The X-axis follows the chronological path of the medical journey. However, there is no data available for the time frame, only what kind of topics are present in that cluster. Therefore the starting point is guessed based on reading the top 50 posts from each topic within that certain cluster. After this educated guess, using patient validation, the starting point is updated. For the majority of the clusters, the ending is not a hard line and therefore goes till the end of 'Follow-up' and continues for the rest of the disease. See Figure 2.24 for the duration of each cluster on the medical journey chronological line.

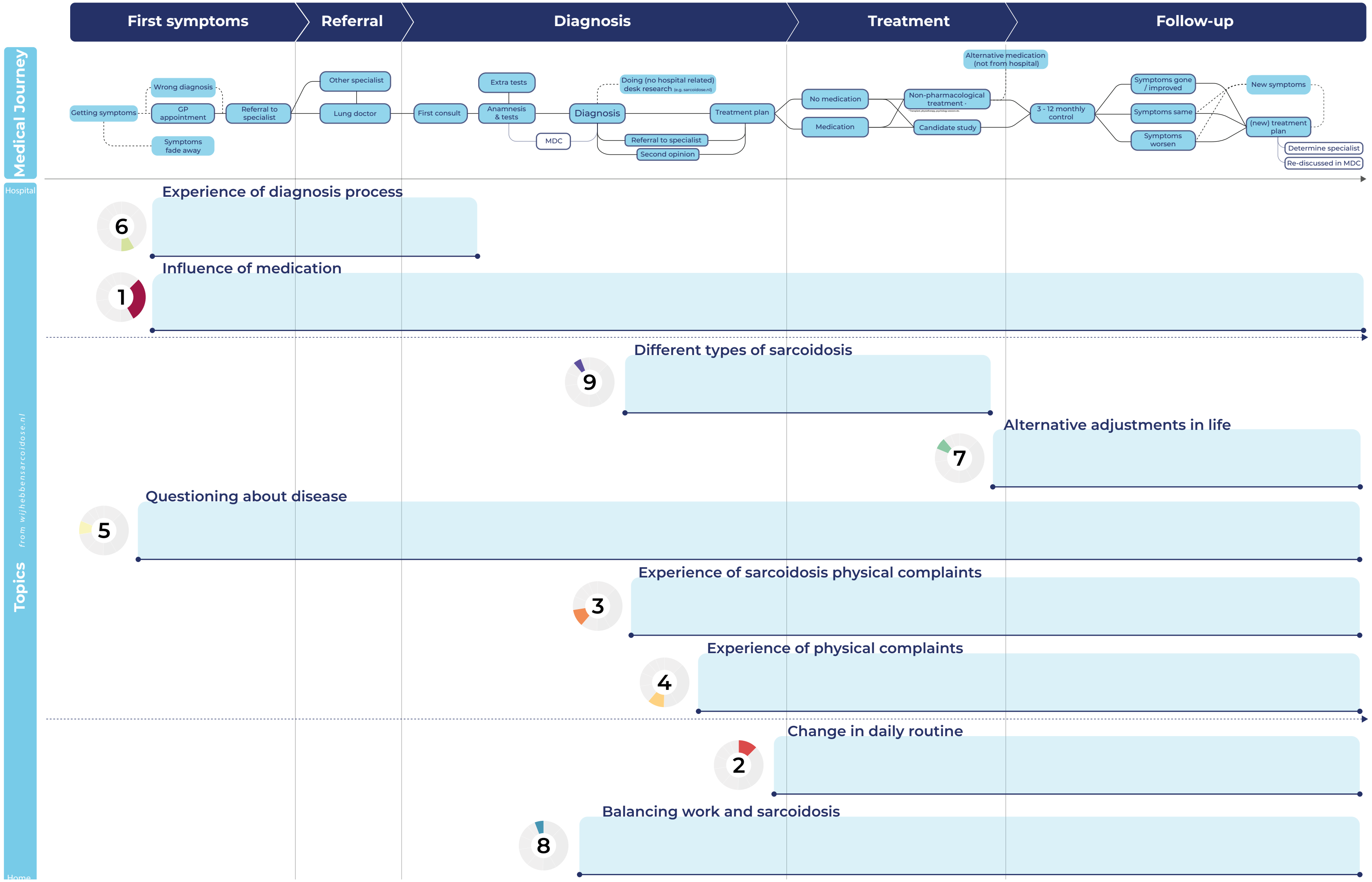


__Figure 2.24:__ Duration bars of each cluster.

2.4.4 Topic and sentiment journey

The next step entails positioning the topics in the duration clusters bars. They are separated from the timeline but they are put in (presumably) chronological order. Thus, the width of each topic doesn't say anything about the topic's duration. See Figure 2.25 for the clusters and their topics inside the duration bars.

Then the topics are visualised in a way that shows the quantification of each topic, looking at the height of the topics. Figure 2.26 shows how the quantification can be read. Figure 2.27 shows how that looks for the patient journey map.

Figure 2.26: Topic quantification per cluster showing that height indicates the quantification.

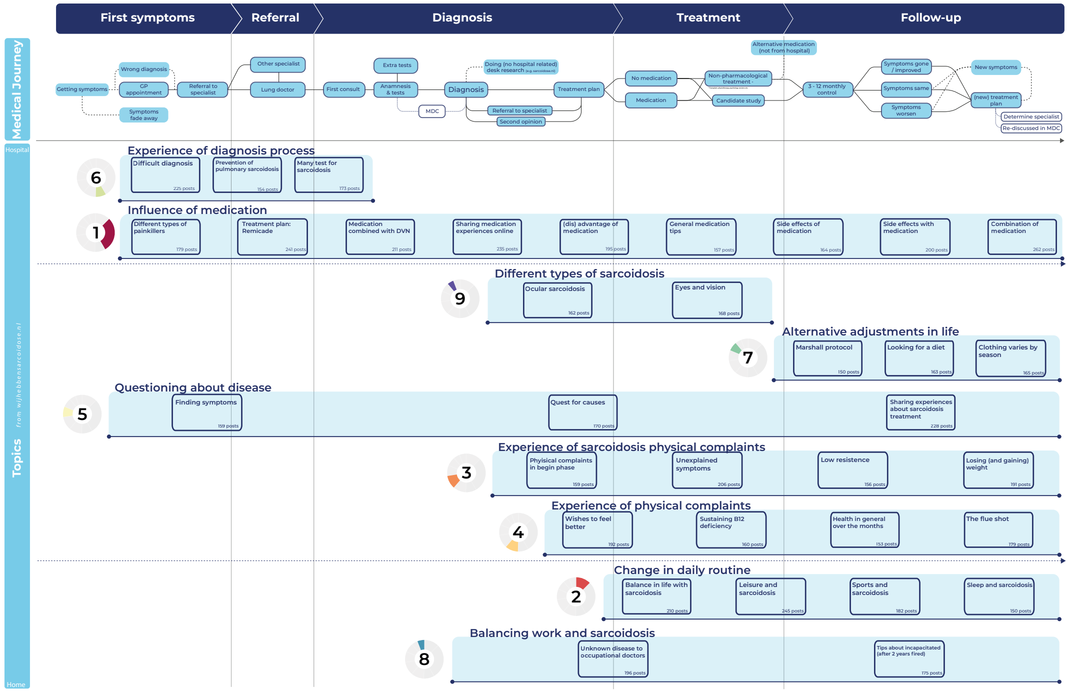


Figure 2.25: Topics are put in the cluster bars.

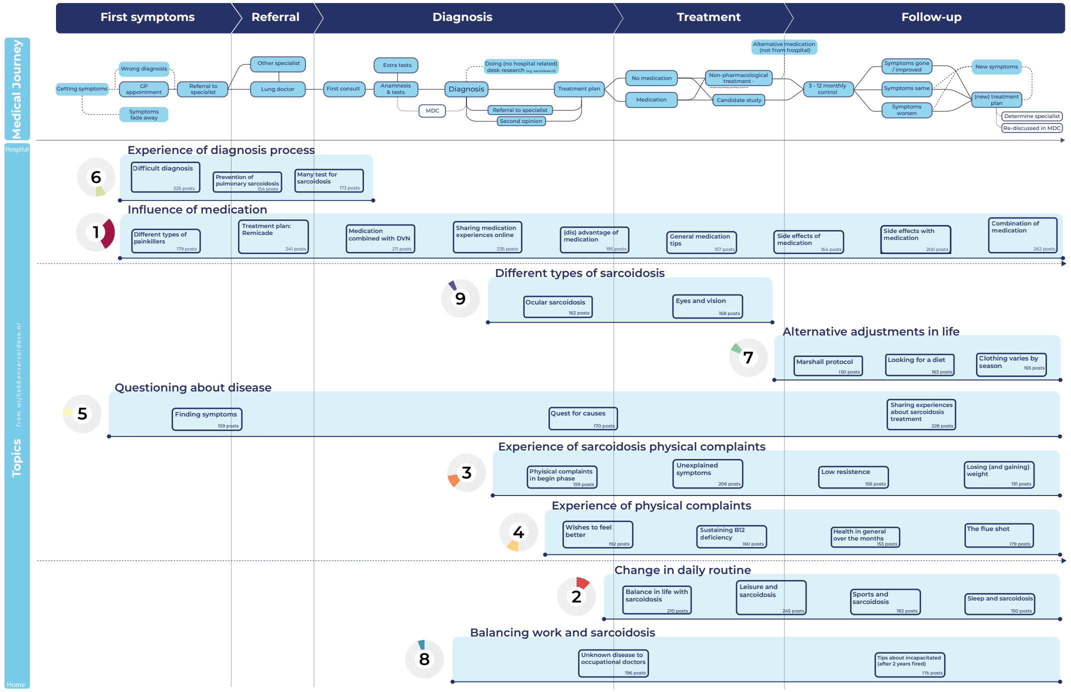


Figure 2.27: Quantification of the amount of posts per topic.

Lastly, the topics are visualised in a way that shows what the sentiment is for that topic. Figure 2.28 shows the colours that visualise the topic's sentiment.

Figure 2.28: *Legenda for topic sentiment per cluster.*

2.4.5 Final patient journey map

Figure 2.29 shows the sentiment analysis in the final version of the patient journey map. This is the version that is also delivered to the medical experts to show the needs of the patients.

Patient journey map | Key main takeaways

○ The patient journey map consists of two parts: 1) a Medical journey and 2) a topic-related patient analysis

○ The topic-related analysis consists of quantification and sentiment analysis to emphasise the needs.

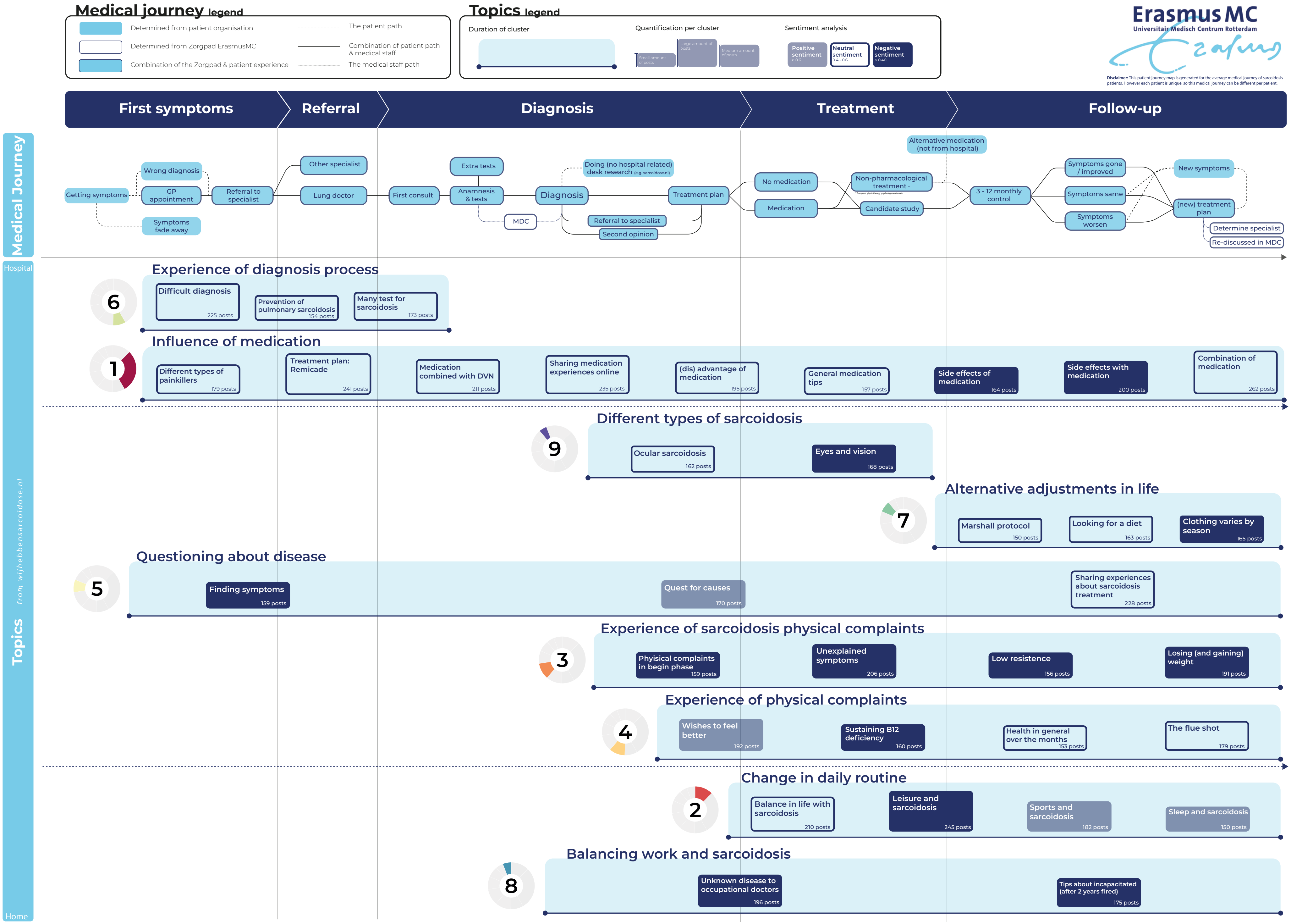


Figure 2.29: *Final patient journey map.*

3. Synthesis

In this chapter all the previous results are combined and formed to a connected whole in the form of a patient journey map and a determined direction for ideating.

3.1 Introduction

This chapter focuses on the previous analysis and the results, to come to a direction that is the base for the rest of this project for designing an intervention. By doing this, the project assignment is scoped down to the most valuable direction resulting from the analysis chapter.

Research question 1: What does the co-occurrence say about the clusters?
Research question 2: What are the most important points taken from the patient journey map?
Research question 3: What kind of criteria points are important to take into account?

3.2 Patient Journey key value

The sarcoïdosis patient journey map is made as a path to highlight the care path of sarcoïdosis patients. It gives a view of what they are going through from the moment they get symptoms, till they are diagnosed and have to live with it. Furthermore, the map sets the base for the further development of this project.

As discussed in 2.3.7, the co-occurrence visual shows how the topics relate to each other, and what topics are discussed in the same post. The correlation is visualised on the patient journey map, shown in Figure 3.1. The figure visualises how the most prominent topic of one cluster is mentioned in a post together with other topics, shown together with the number of posts where this co-occurrence is seen. There is a distinction in the colour of the text with posts in it, see Figure 3.2 for the meaning of the differences in colour and the number of posts that co-occur with another topic.

__Figure 3.2:__ Legenda of co-occurrence map.

It can be concluded that every topic relates the most to topic 0: Balance in life with sarcoïdosis. Only topic 34 has the highest amount of posts in that cluster relating to a different topic than topic 0, namely topic 2. Nevertheless, the figure shows that topic 0 forms the keystone of all the topics. Therefore the scope can be specified to helping patients with finding balance in life back after their diagnosis. Balance is also something that often re-occurred when doing the analysis. For example, multiple blogs on the patient organisation website talk about the struggle of trying to find the balance back after getting the diagnosis (Koppelman, 2020). Also, according to the patient that is interviewed for validating the patient journey map, trying to find a balance in life is important for sarcoïdosis patients. It is a key value that is continuously present in their life (see Appendix D for the full interview).

This key value forms the base of the main research question for the next phase. Finding balance in life is constricted by the way how the patient personally prefers doing this. Therefore, the patient has the biggest influence on how they find their balance in life. As discussed in the literature analysis, the quality of life has an impact on the patient journey for sarcoïdosis patients. Consequently, this has an impact on the balance of life for these patients, and this is a thing that patients can monitor themselves. Therefore, the research question to design an intervention for is:

How can sarcoïdosis patients manage and improve their quality of life?

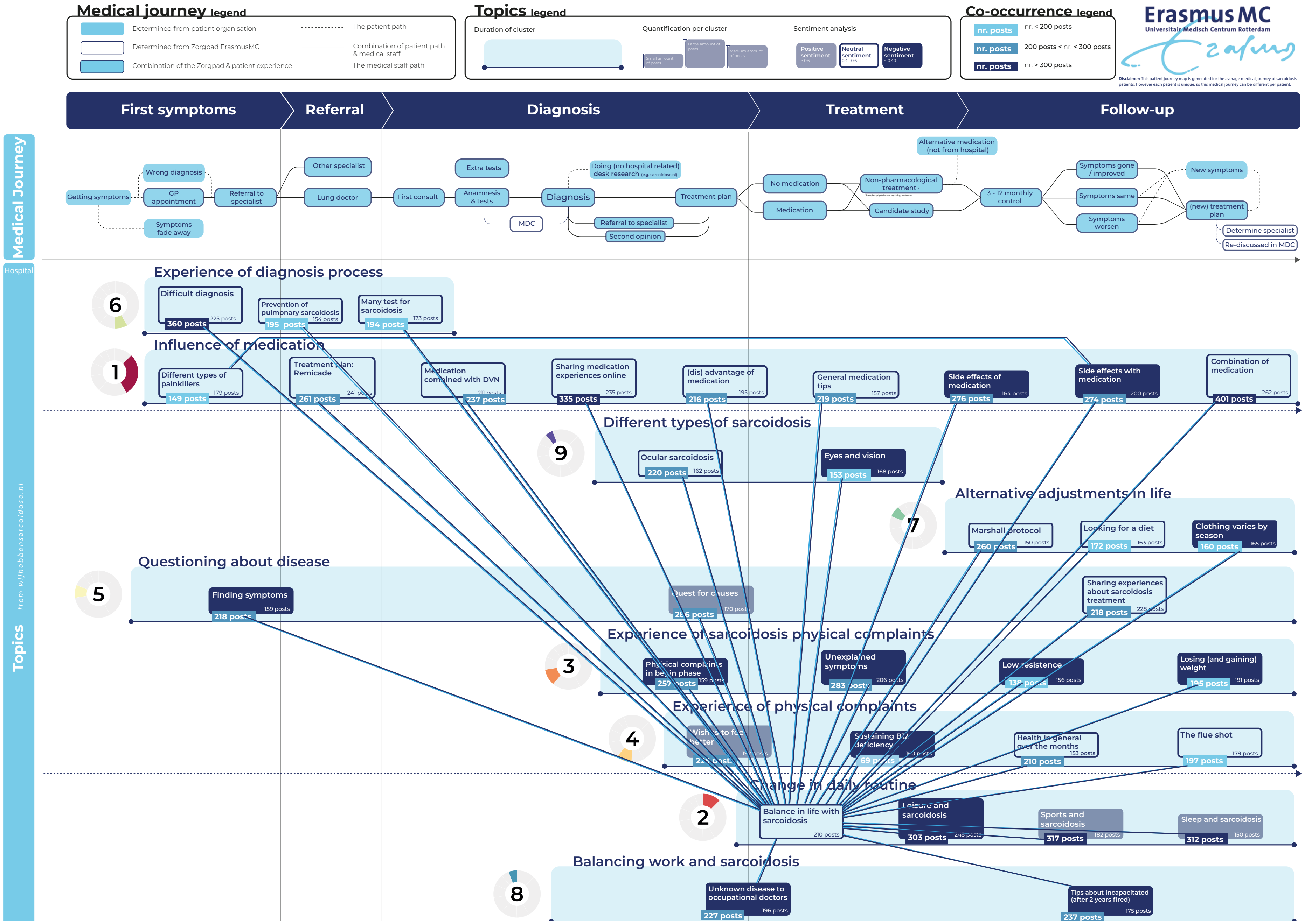


Figure 3.1: *Co-occurrence of the topics visualised as lines between parts of the patient journey map.*

3.3 Patient Journey themes

The research question is broad and needs more specification about how this is investigated. Therefore this part looks at what is important for the research question as sub-research questions. This is done by analysing the patient journey map, based on the co-occurrence visual. The co-occurrence of the patient journey map shows that almost every topic has a connection with ‘balance in life with sarcoïdosis’. So this is the key value, however, there are several themes that have the relative biggest influence on this balance. This can be concluded when looking at the highest number of posts of clusters that are connected to topic 0. The topics that have a higher amount than 300 posts that co-occur with topic 0 are taken into account for the main present themes that are relevant for possible further research in this thesis. Those topics are 1, 2, 5, 8, 29 and 30, and they are present in clusters 1, 2 and 6.

Cluster 1: Influence of medication

This cluster has the highest amount of posts on topics that also relates to topic 0. So, for example, topic 5 ‘Sharing medication experiences online’ and 2 ‘The use of combinations of medication’ have more than 300 posts that co-occur with topic 0. What is remarkable about this cluster, is the fact that it is present at the beginning of the patient’s journey and it stays in the patient’s journey for the rest of the disease. So the total cluster is constantly present in the patient journey. This could result in the large effect it has on finding balance in life.

Cluster 2: Change in daily routine

This cluster is about the change in daily routine and includes the key value topic: Balance in life with sarcoïdosis. The other three topics have a higher amount of posts than 300 posts that co-occur with topic 0. This makes these three topics, and the cluster, a highly present cluster for a patient. Of course, it makes sense that these relate to topic 0 the most because they are in the same cluster. However, it still is important to take into account these factors as separate influencers of the balance in life for sarcoïdosis.

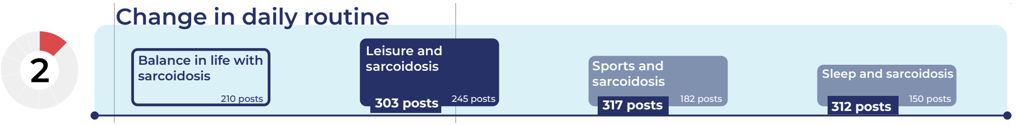


Figure 3.4: Cluster 2 with the amount of posts per topic that co-occur with topic 0.

Cluster 6: Experience of diagnosis process

This cluster is present mainly at the beginning of the patient journey. As soon as patients experience symptoms and go to the general practitioner they go through these topics. It is a difficult process with multiple loops. The difficult diagnosis topic has above the 300 posts that co-occur with that topic and topic 0.

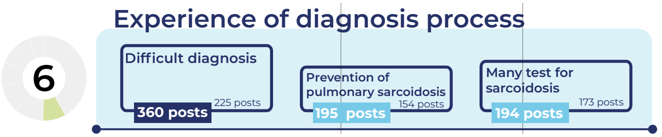


Figure 3.5: Cluster 6 with the amount of posts per topic that co-occur with topic 0.

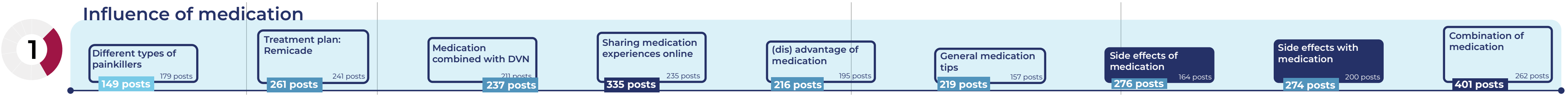


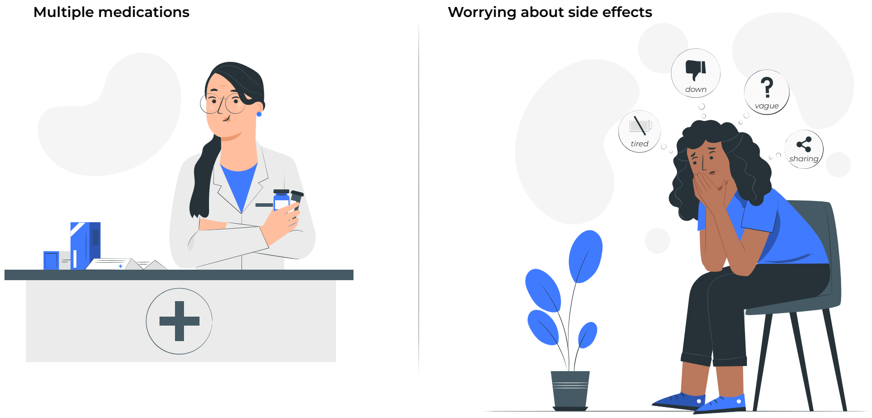
Figure 3.3: Cluster 1 with the amount of posts per topic that co-occur with topic 0.

3.4 Derived directions

The themes that are the most present in the sarcoïdosis patient journey are important to look at. They indicate the most what the most important themes are for patients with sarcoïdosis. Therefore, the clusters mentioned in Chapter 3.3 are reframed to a possible direction connected to finding balance in life. The whole cluster is evaluated based on the online community study, the relevant literature studies and feedback from the co-creation session with medical experts.

The possible derived design directions are:

- Direction 1: Supporting patients during their medication intake;
- Direction 2: Giving guidance for the patient’s new daily routine;
- Direction 3: Improving the difficult diagnosis process.


Multiple medications

Worrying about side effects

Figure 3.7: *Illustration of direction 1.*

Direction 1: Supporting patients during their medication intake

The first direction is based on cluster 1: ‘Influence of medication’. This cluster is about different types of painkillers, the Remicade treatment plan, medication combined with DVN, sharing medication experiences and the side effects of medication. In Figure 3.7 an illustration of this direction is shown. Because sarcoïdosis varies a lot between patients, the treatment plan is complex. This often leads to multiple medications (Gerke, 2020). For patients, this leads to worrying about the side effects at home. For example, fatigue is very common within this disease, but this can also be the result of inflammation or mental health, as well as from a treatment side effect. The complex symptoms lead to a complex treatment plan, which gives more symptoms in the form of side effects. It’s a very complex medical journey (Drent et. al, 2021).

In this cluster, topic 5 (sharing medication experiences) and topic 2 (the side effects of medication) are highly related to topic 0. These topics are mentioned in a neutral or negative way. The quantification of these topics shows that they are highly present in this cluster.

From the co-creation session, it became clear that doctors are present during events connected to this cluster, mostly because they are prescribing the medication. They rely on the medication explanation that nurses give to the patients. A specialist nurse highlighted during the co-creation session that she was surprised by the fact that people are discussing these worries online. She has the feeling that she gets constantly calls from patients about their worries and that she gives answers. So from this, it becomes clear that there is a gap between the hospital providing information and reaching worrying patients at home.

Direction 2: Give guidance for the patient's new daily routine

The second direction is based on cluster 2 'Change in daily routine'. This cluster is about finding balance in life with sarcoïdosis, sleep, sports and leisure combined with sarcoïdosis. In Figure 3.8 an illustration of this direction is shown. From the data analysis, it became clear that patients are struggling when they are diagnosed with sarcoïdosis. It is hard to change their daily routine and to find a new balance between living with sarcoïdosis limitations and living their 'normal' life.

In this cluster, topic 30 about sleep, topic 29 about sports and topic 1 about leisure are highly present in this cluster. Sleep combined with sarcoïdosis is often mentioned in a negative way. However, sports and leisure are mentioned in a positive way. This can be because these latter two events are themselves often experienced as positive and people love to actively look into this. It can be concluded that sleep is the biggest struggle, but sports and leisure are something that the patients love to get energy from. From the co-creation session, it was clear to the medical experts that from this cluster there are multiple opportunities to look into. They were mentioning the transition to home care, and the fact that patients are present online and doctors can help them online.

The medical experts are agreeing that the information part was lacking and improving it could help with providing more and better information to the patients.

> “*We could give them more information about sarcoïdosis.*
> Specialist ILD nurse

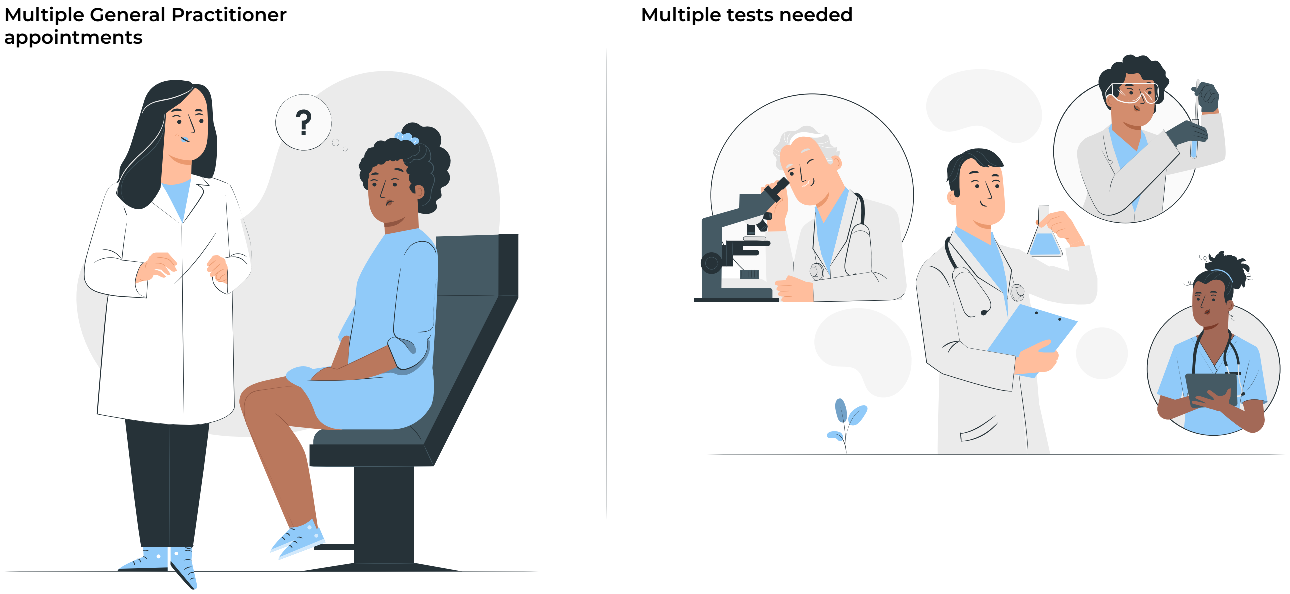
> “*This shows to professionalize the information more.*
> ILD pulmonologist

Figure 3.8: *Illustration of direction 2.*

Direction 3: Improve the difficult diagnosis process

The third and last possible direction is based on cluster 6 ‘Experience of diagnosis process’. This cluster is about the difficult diagnosis process, prevention of pulmonary sarcoïdosis and that many tests are needed for the diagnosis. In Figure 3.6 an illustration of this direction is shown. Multiple general practitioner appointments take place because they can’t diagnose sarcoïdosis right away due to highly variable sarcoïdosis symptoms (Drent et al., 2021). Also, according to the sarcoïdosis patient organisation (Sarcoidose Belangenvereniging Nederland, 2023b), there is not something like 1 blood test or scan to diagnose sarcoïdosis right away, which makes it difficult to diagnose. In this cluster, topic 8 about the difficult diagnosis process is highly related to topic 0. 360 posts are both mentioning topic 0 as topic 8. This topic is mostly mentioned in a neutral way. From the co-creation session, it became clear that doctors are present during this phase. Because they interpret the test results and determine the treatment/ management plan. The quote shows the conflict that doctors are dealing with during the first consult.

> “*Probably we should do more about explaining the disease, but we only have 15 minutes.*
> ILD pulmonologist


Multiple General Practitioner appointments

Multiple tests needed

Figure 3.6: *Illustration of direction 1.*

3.5 Resulting direction

From these three directions, one direction is chosen based on the quantification, sentiment, and expert's opinion (also from the co-creation session) and literature. The table below gives an overview of these criteria. The criteria list stretches from the most important criteria to the least important criteria. Each argumentation is valued with a double minus (--), minus (-), plus (+) or double plus (++). This gives an indication of the value of the argumentation.

From this overview, it can be concluded that direction 1 has the most potential to further dive into. It includes the biggest mentioned cluster and with that also the most mentioned topics. Moreover, the sentiment is the most negative compared to the others and according to the literature, there is an effect on the mental health of patients through the medication plan. Lastly, the pulmonologist pleads that this is the most valuable for their department. Direction 3 has the most 'negative' arguments, which means that this won't be the focus of this project. However, direction 2 shows multiple high-value arguments to take into consideration. Therefore, this direction leads to a criteria point that the chosen direction needs to consider, namely: including HRQoL questionnaires to improve patients during their patient journey.

Cluster 1 is about the influence of medication and has several topics that say something about this cluster. But the influence of medication means that it is important to regulate the medication intake. This way there is a better understanding of why a patient is experiencing a certain side effect or symptom. Therefore, it is good to take into account that a patient should have the possibility to monitor their medication intake.

Multiple topics are mentioning different medications and patients' experiences with the medication. It is interpreted as people looking for answers about their medication and trying to get answers to certain questions. It shows a lack of information sources, or at least the information isn't brought to them in a comprehensive manner such that they have no further questions. Therefore it is important to find a way to provide the patient with information about all kinds of sarcoïdosis topics.

Table 3.1: *Directions based on 4 criteria factors*

Criteria	**Direction 1** Supporting patients during their medication intake	**Direction 2** Guidance for new daily routine	**Direction 3** Improve difficult diagnosis process
Quantification	++ Biggest mentioned cluster compared to all other clusters. + Most topics in one cluster. + Two topics that co-occur with topic 0.	++ Three remaining topics of this cluster, co-occurs all of them with topic 0.	- Smallest cluster. - Only one topic highest amount of posts co-occurring with topic 0.
Sentiment	++ There is a need for improvement based on sentiment degree because it includes several negative topics and the rest is neutral. There is no positive mentioned topic.	- Only one significant topic is mentioned negatively, the other two are mentioned positively.	- Neutral sentiment for that specific topic that co-occurs the most with topic 0.
Expert's opinion	++ Pulmonologist sees the most value in taking this direction.	+ They acknowledge that something should happen to support the patient more.	+ Experts gave feedback that this could be improved.
Literature	+ Symptoms can be anything (inflammation, mental health or side effect) which is worrying and can be tackled with design intervention.	+ Research shows that the HRQoL questionnaire helps patients to monitor their disease.	- It's a complex disease, which makes it very medical to take this as a direction.

3.6 Concluding direction

From the patient journey map finding a balance in life is found to be the thread for sarcoïdosis patients. This in combination with the fact that it is important to monitor the quality of life for these patients, made the following research question:

> *How can sarcoïdosis patients manage and improve their quality of life?*

The sub-research questions are:

1. *What aspects do sarcoïdosis patients cope with regarding their quality of life?*
2. *What enables to improve patients' quality of life?*

The underlying direction, which is chosen based on analysis and co-occurrence visual, is to focus on supporting sarcoïdosis patients during their medication intake. The design intervention needs to comply with certain criteria derived from the patient journey map. The design intervention needs to include a way:

- to provide information about sarcoïdosis-related topics.
- for patients to monitor their medication intake.
- for patients to manage their quality of life.

Synthesis | Key main takeaways

- Finding a balance in life is a key value for sarcoïdosis patients, therefore the main thread for this project.
- The main research question is: How can sarcoïdosis patients manage and improve their quality of life?
- Three criteria points need to take into account for the end design:
  - Provide information
  - Monitor medication
  - Manage quality of life

4. Ideation & prototyping

In this chapter is the goal to design an intervention for the previous conducted research question that are inspired by the criteria points.

4.1 Introduction

The chosen direction needs some exploration to determine what to design. During the process thus far, it feels the most realistic to create a platform with information to help the patients at home with monitoring and understanding their disease and treatment plan. This is due to the fact that a lot of information and personal preferences need to be provided for the patients. Therefore, an online platform is the best solution. To find out if this is really the best intervention, a brainstorming session takes place to hear other people's thoughts about the possibilities.

4.2 Peer brainstorming sessions

To start the ideation phase, two peer brainstorming sessions are done, as seen in Figure 4.1. The goal of these sessions is to present the chosen direction and come up with possible interventions. This is done to create the first ideas and because the head designer should be aware of the designer's bias and tunnel vision. The sessions gave good insights into three different designers, namely from the master 1) Integrated Product Design, 2) Strategic Product Design and 3) Design for Interaction. The generated ideas go from technical aspects with sensors (master 1) to analysing the interaction between the product and the user (master 3). This variety helps to think in a different way. See Appendix F for the generated ideas and conclusion.

From the two sessions, the conclusion is that an application with a certain system is the most logical idea to start with. It becomes an online application because it needs a lot of information that is up-to-date. This idea is generated and can be read in the next section.

Figure 4.1: *Two brainstorming sessions at the IDE faculty.*

4.3 Ideation phase

From the peer sessions, an idea starts to emerge. Because of the criteria to provide the patient with information about sarcoïdosis, an online application is the most obvious starting idea. All kinds of information sources can be combined together to keep the information up-to-date and the application can be easily personalised.

The basic idea is an online application platform, connected to other existing platforms to get the information from there as input data. But determining the structure of this application starts with looking at the (sub)research questions.

First, the sub-research questions are investigated as to what the answers could be, which is shown in Figures 4.2 and 4.3. The earlier discussed criteria are taken into account and resulted in three main functions for the application. The three main functions of the application are concluded:

1. **A medication management plan.**
   To give more support and clearance during their medication intake.
2. **Quality of life information and questionnaires.**
   This would be for the patient to monitor their disease better, and to give more details to the doctors for the next steps.
3. **Information about sarcoïdosis.**
   For patients to understand the disease more and better.

As mentioned in the literature study, Patient Centred Care is important in the basis of this system. This is also a way to improve how patients can cope with the mental and physical condition of their quality of life. The main research question is about sarcoïdosis patients, so therefore patients are the subject of this project and the Patient-Centred Care method can help by providing them with the best self-management tool. The Patient Centred Care method is earlier discussed. For this part, it is applied in this project context. Each pillar of the method is analysed and applied in this system, see Table 4.1 for each pillar, the overall conclusion from the Picker Institute (Picker, 2023) and the function of the system. Appendix H shows the elaborated version of the table.

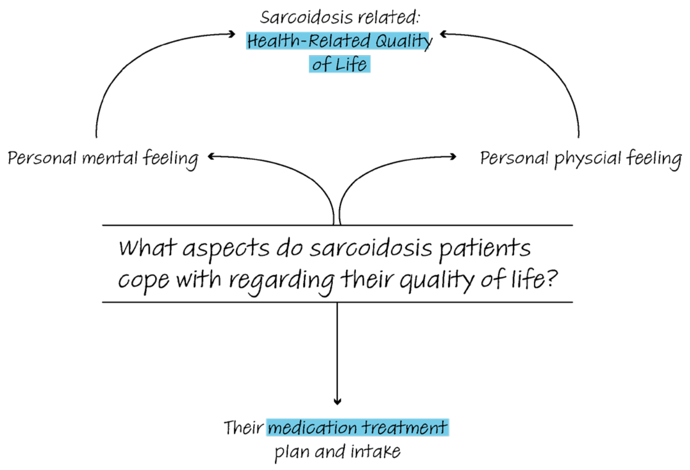


Figure 4.2: First sub-research question brainstorm.

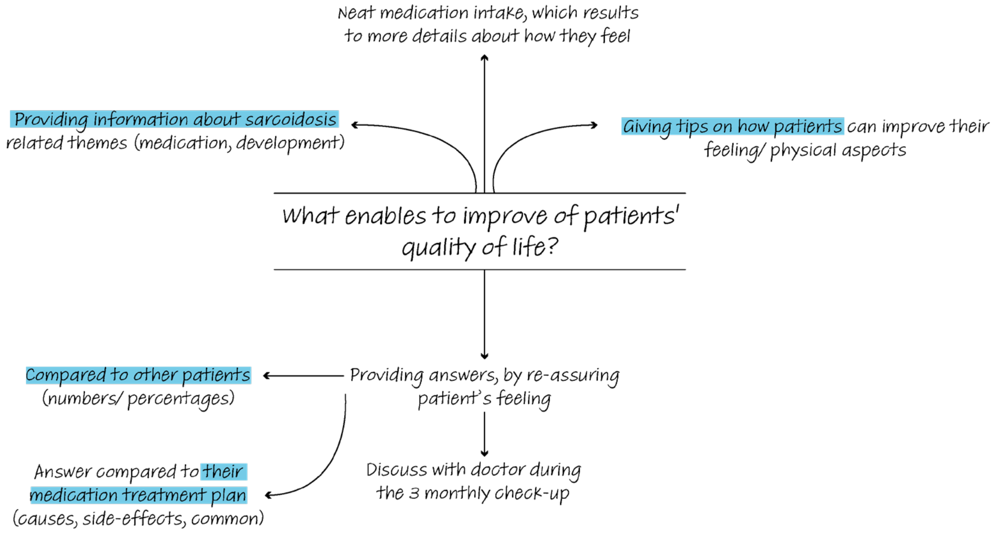


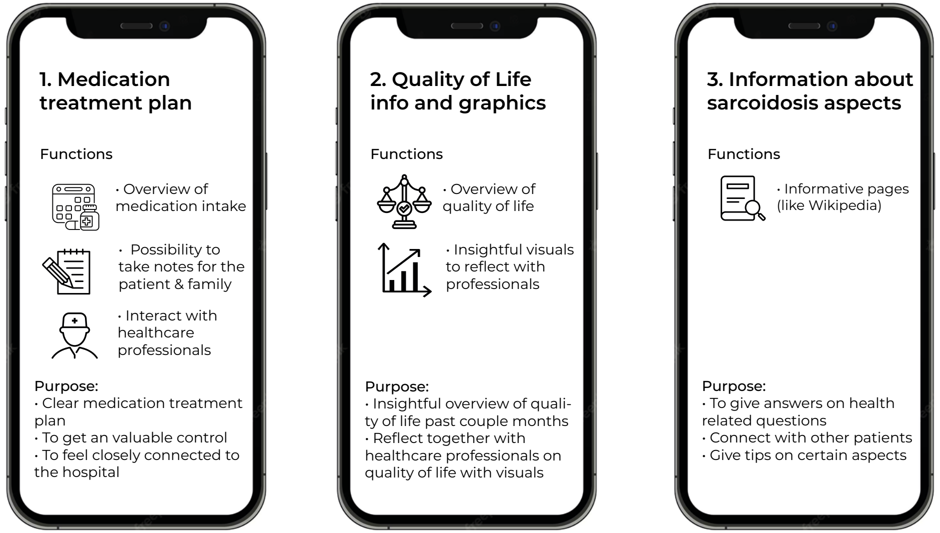
Figure 4.3: *Second sub-research question brainstorm.*

Table 4.1: *Patient-centred care and the functions for the intervention system.*

Patient-centred care pillar	Pillar conclusion	Derived system function
Coordination of care across the health and social care system	Interaction with care professionals should inspire a sense of confidence and trust	Interact with care professionals (e.g., e-consult or notes)
Emotional support alleviation of fear and anxiety	Caring and holistic approach, care should be delivered with respect, sensitivity and appreciation of the person as individual	HRQoL and general questions about the provided care (e.g., space for notes). Also, the provision of information and support in finding balance in life provides this support alleviation of fear and anxiety
Respecting patient-centred values and preferences. Awareness of HRQoL issues	Involvement in decision-making, respect for people's choices and preferences	Evaluate HRQoL questions/ answers to change treatment plan (e.g., by treatment plan)
Welcoming family & friends in decision-making	Family should be included in the decision-making of the loved one	Create space for the family to ask questions, in this case with a space for notes. The family can use the application via the patient's account
Enabling self-management and providing support to ease transitions	Seamless transitions between providers and staff. Continuity in information	Includes names and illustrations of doctors, to give a feeling about who they are
Addressing physical comfort. Including help with ADLs	Care professionals should be mindful of people's physical needs	Personal page with questions about the patient's quality of life
Access to care with attention to process, e.g. waiting times	Access to the right services at the right time is essential for high-quality care	Button for (indirectly) calling or scheduling an appointment
Information, communication, education on progress, prognosis, processes of care	Information should be provided at appropriate times, in an understandable way	Include a page with information about sarcoïdosis-related aspects

The conclusion of the three main functions is used as a start for the main pages of the app. The derived functions that are needed according to Table 4.1 are integrated in Figure 4.4. This sets the basis of the application.

The purpose and function of the main pages are determined, however, now it's important to focus on how to fulfil these functions. How should they be presented to the user? In this process, the focus is not on the form or layout of these pages, but more on what the content is of these functions. Therefore these main pages are discussed with the content that it needs.



1. Medication treatment plan

Functions

- Overview of medication intake
- Possibility to take notes for the patient & family
- Interact with healthcare professionals

Purpose:
- Clear medication treatment plan
- To get an valuable control
- To feel closely connected to the hospital

2. Quality of Life info and graphics

Functions

- Overview of quality of life
- Insightful visuals to reflect with professionals

Purpose:
- Insightful overview of quality of life past couple months
- Reflect together with healthcare professionals on quality of life with visuals

3. Information about sarcoidosis aspects

Functions

- Informative pages (like Wikipedia)

Purpose:
- To give answers on health related questions
- Connect with other patients
- Give tips on certain aspects

Figure 4.4: *Main pages with their functions and purpose.*

4.3.1 Content of medication treatment plan page

The function to give an overview of the medication intake for the patient can be in the form of a calendar. This way, it is clear to the patient what to take on a certain day. How this treatment plan is updated in the application is not clear yet.

The possibility to take notes for the patients and family is important because this is for patient-centred care important that their close circles also are included. This can be simply implemented with space where they can type something. The notes should be for the patients, family members but also for the medical experts to see that there are some questions during an appointment. So, an overview of the upcoming appointment can be included where there is space for notes. Also, a link to the hospital for the contact numbers can be included on that page.

These two functions together show a good overview of the basis of the patient's life with sarcoïdosis. Therefore, the medication treatment plan page is the home page.

According to the research of Moor et al. (2019), it is beneficial that the patient fills out an elaborate questionnaire about their well-being before they arrive at the hospital for their 3 monthly check-ups. If they fill out this questionnaire, the doctor can make a better estimation if their treatment plan needs adjustment or can stay the same. This elaborated questionnaire is based on King's Sarcoïdosis Questionnaire, the Euroqol-5D-5L, the Hospital Anxiety and Depression Scale and the Fatigue assessment scale. Therefore, when the patient's three-monthly check-ups are shown in the application at the appointment segment, it should include a link to the elaborated questionnaire.

4.3.2 Content of the quality of life page

This page has the purpose to give an insightful overview of the patient's quality of life aspects, and this can be done by showing the progress of each aspect in graphics. However, then the patient has to give data input so that they can monitor their health. Therefore, the home page can include questions that give insights into the patient's quality of life. The home page is the best place because that's the first thing the user sees when opening the application and then they are reminded of it.

The questions can be categorised into two questionnaires: 1) mental and 2) physical questionnaires. Because the patient needs to fill this in every week, it should be clear and short questionnaires. This increases hopefully the use of this function and doesn't take too much time from the patient. For the physical questionnaire, the focus is on fatigue, dyspnea, cough and general well-being. This is determined based on the most common symptoms of sarcoïdosis, according to the research of Moor et al. (2020). These symptoms are rated by the patient on a Likert scale from 1 to 5 (1 being never and 5 being constant). For the mental questionnaire, the focus is on the General Health status part of the King's Sarcoïdosis Questionnaire (KSQ) (Judson, 2017), and the physical questions are removed from this list. So Table 4.2 shows the questions that are remaining for this questionnaire.

Table 4.2: *KSQ questions picked for shorter questionnaire.*

In the last 2 weeks	Never	Seldom	About half the time	Usually	Constant
I have felt frustrated	1	2	3	4	5
I have had trouble concentrating	1	2	3	4	5
I have lacked motivation	1	2	3	4	5
I have felt tired	1	2	3	4	5
I have felt anxious	1	2	3	4	5
I have felt embarrassed	1	2	3	4	5
I have felt worried about my weight	1	2	3	4	5
I have worried about my sarcoïdosis	1	2	3	4	5
Tiredness has interfered with my normal social activities (such as going out with friends/ family)	1	2	3	4	5

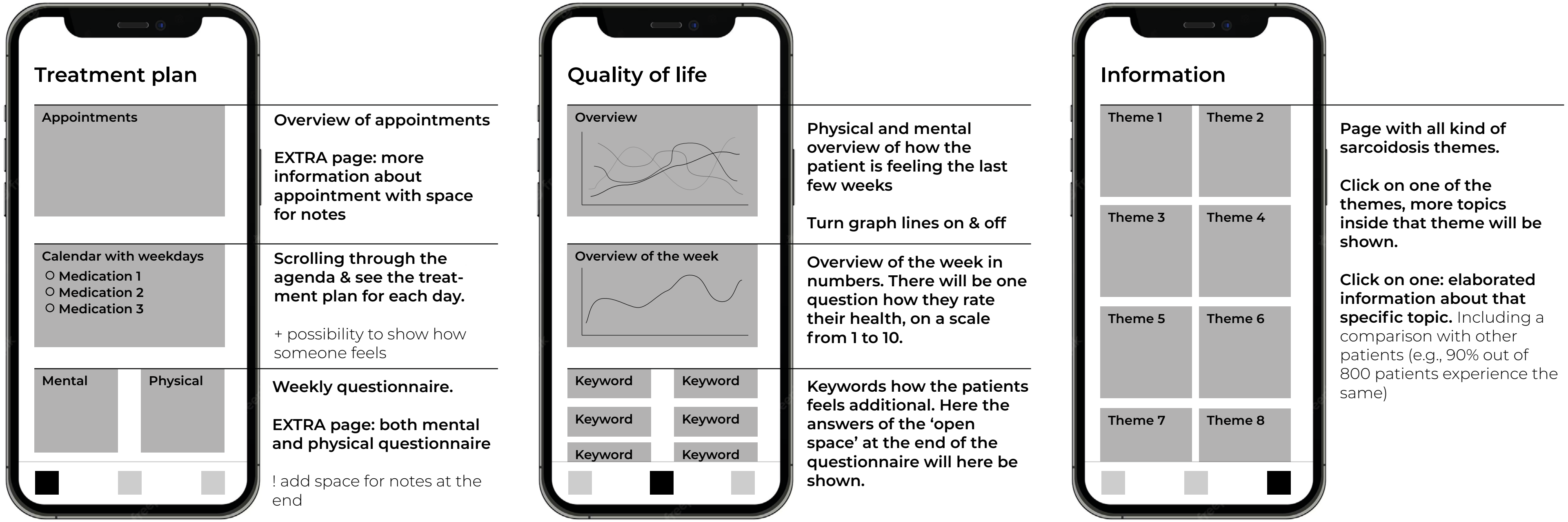
4.3.3 Content of the information page

The purpose is to give information about sarcoïdosis-related aspects. Therefore all kinds of information can be derived from the patient organization (sarcoidose.nl) and the medical website for Interstitial lung patients made by the Erasmus MC and 20 other hospitals (ILDnetwerk.nl). It is important to include on each informative page the relationship to other patients, how many patients also experience a certain symptom for example. This helps the patient to rationalize what they are feeling, or maybe it raises more specific questions but this is helpful for doctors.

4.3.4 Extra: Content of the profile page

As each application has this, a profile page is included with personal information and preference for the app.

Thus, the three main pages for the application are discussed and in Figure 4.5 it is shown what the conclusion is for each page as a requirement. This is the starting point for the prototype. See Appendix I for the paper sketches for this ideation phase. In that appendix, every page is further explained and the personal page is included.



Overview of appointments

EXTRA page: more information about appointment with space for notes

Scrolling through the agenda & see the treatment plan for each day.

+ possibility to show how someone feels

Weekly questionnaire.

EXTRA page: both mental and physical questionnaire

! add space for notes at the end

Physical and mental overview of how the patient is feeling the last few weeks

Turn graph lines on & off

Overview of the week in numbers. There will be one question how they rate their health, on a scale from 1 to 10.

Keywords how the patients feels additional. Here the answers of the 'open space' at the end of the questionnaire will here be shown.

Page with all kind of sarcoidosis themes.

Click on one of the themes, more topics inside that theme will be shown.

Click on one: elaborated information about that specific topic. Including a comparison with other patients (e.g., 90% out of 800 patients experience the same)

__Figure 4.5:__ Overview of the main pages and their requirements.

4.4 Prototyping

The prototyping part of the application is made in Figma because this is an easily accessible program to make an application prototype. First, other medical applications are used as an inspiration for the layout of the app, see Figure 4.6 for examples.

The style is determined by the colours of the style of Erasmus MC (Figure 4.7) and the font Montserrat is chosen for the texts. Montserrat is also the font that the hospital uses for online files. Furthermore, the illustrations can be divided into icons and illustrations. Icons are used from a plugin of Figma, Icons8 to be exact, and the illustrations are used from UnDraw (Illustrations | unDraw, n.d.).

As discussed in the ideation phase chapter, there are three pages in the application. In this part, they are visualised to show how they look in the prototype. See Figure 4.8 for the toolbar at the bottom of the application with the different pages. There are many more screens, these are shown in Appendix J and are shown in the video that is put on the deliverable poster.

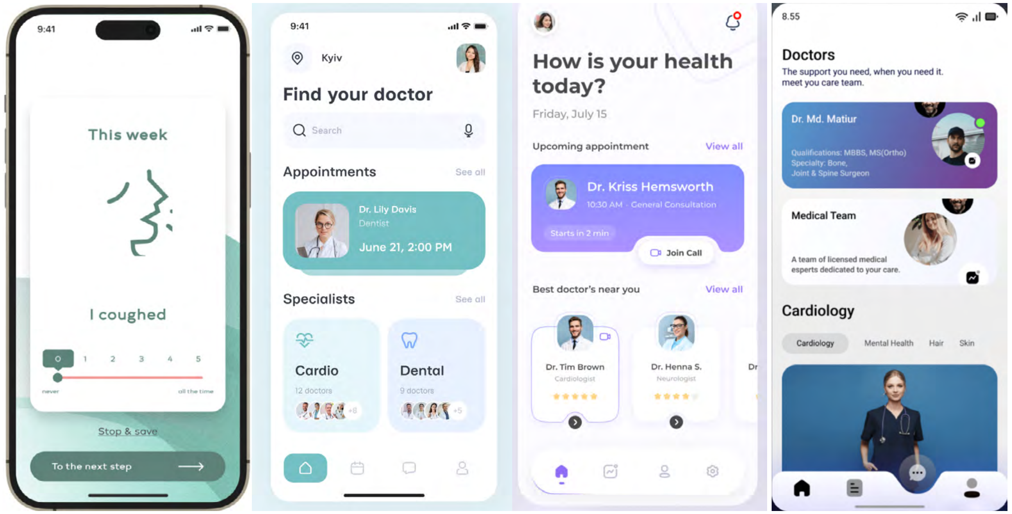
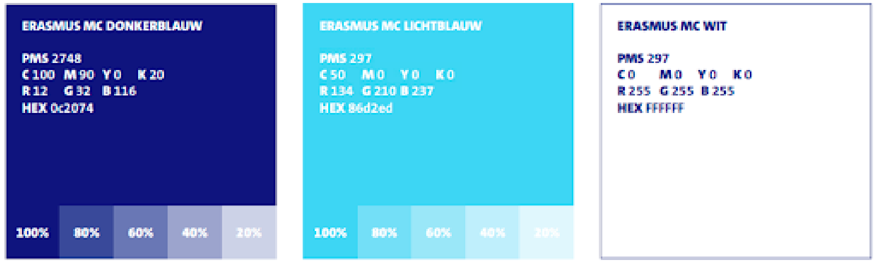


__Figure 4.6:__ Inspiration of medical healthcare applications (screenshot of behance.net, 2023).



ERASMUS MC DONKERBLAUW

PMS 2748
C 100 M 90 Y 0 K 20
R 12 G 32 B 116
HEX 0c2074

100% 80% 60% 40% 20%

ERASMUS MC LICHTBLAUW

PMS 297
C 50 M 0 Y 0 K 0
R 134 G 210 B 237
HEX 86d2ed

100% 80% 60% 40% 20%

ERASMUS MC WIT

PMS 297
C 0 M 0 Y 0 K 0
R 255 G 255 B 255
HEX FFFFFF

__Figure 4.7:__ Colour scheme from Erasmus MC (screenshot of erasmusmc.nl/huisstyle, 2023).

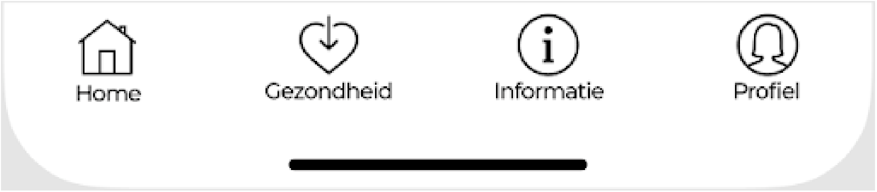
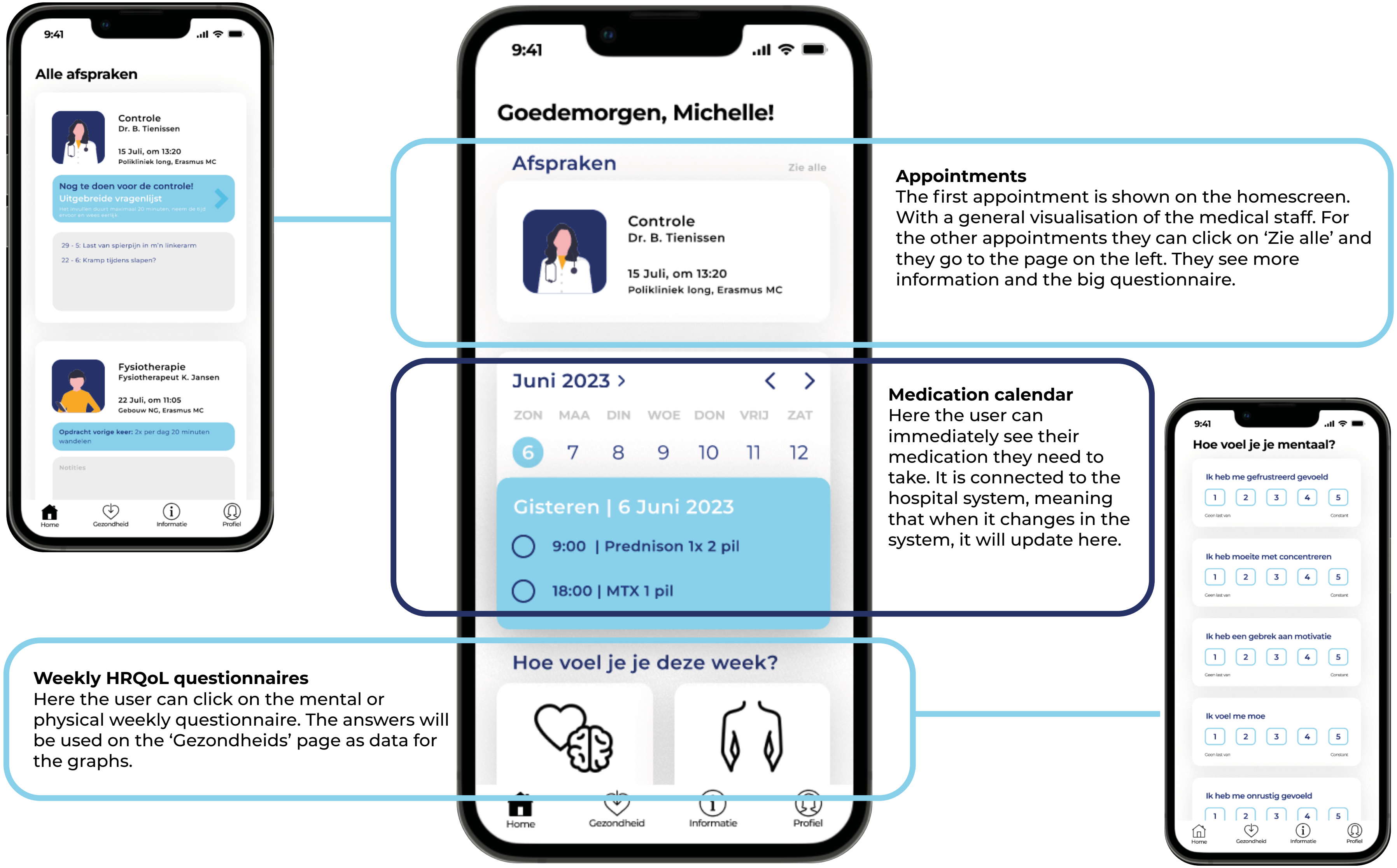


__Figure 4.8:__ Application toolbar with the different pages.

4.4.1 Home screen

The home screen is the first thing the user sees when opening the application (see Figure 4.9 for the page overview). These functions are chosen because it needs to be practical to have an overview of their contact with the hospital (appointment) and their medication plan. The weekly questionnaires are on the home page because they need to remind the patient to monitor their quality of life on a weekly basis.



Appointments
The first appointment is shown on the homescreen. With a general visualisation of the medical staff. For the other appointments they can click on 'Zie alle' and they go to the page on the left. They see more information and the big questionnaire.

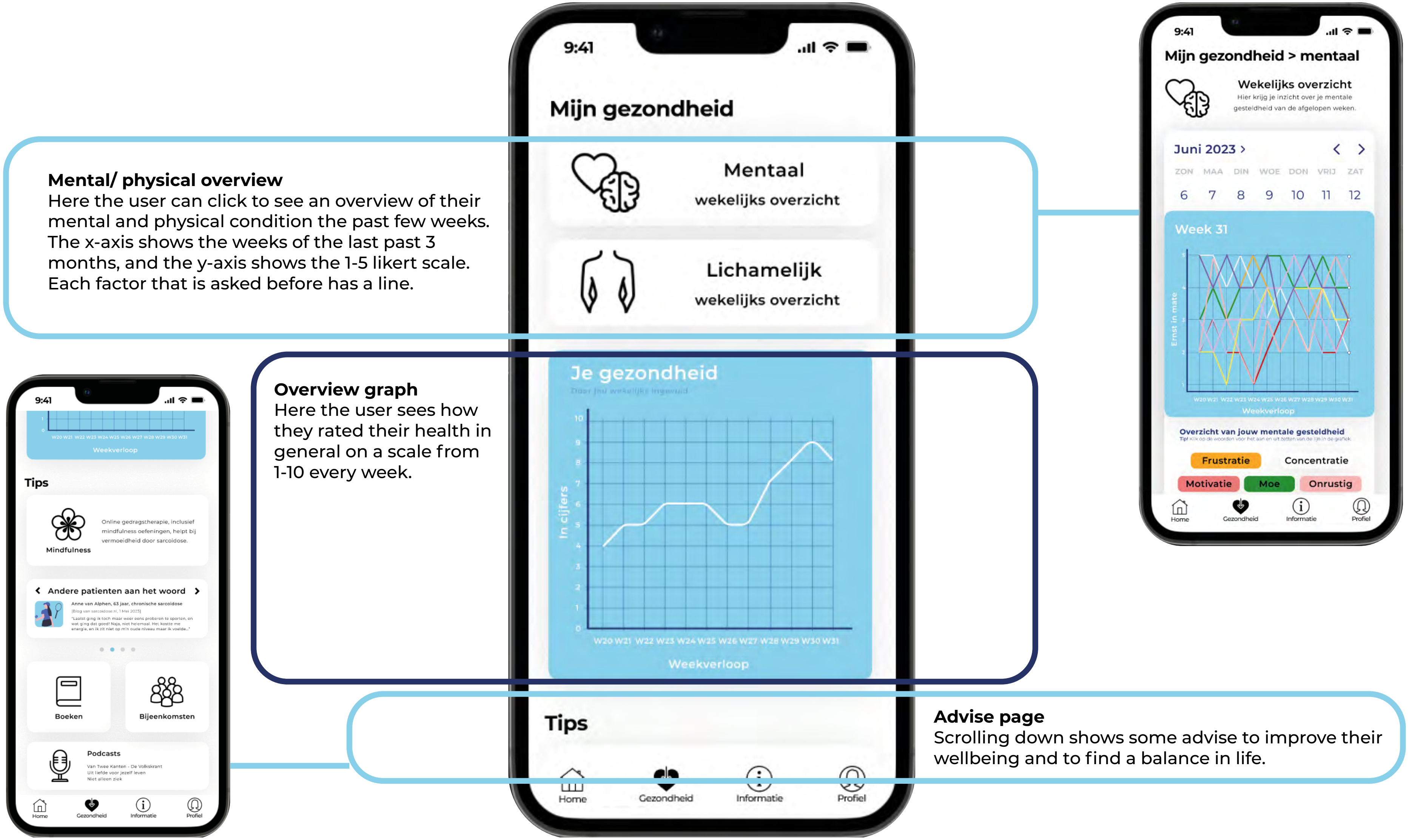
Medication calendar
Here the user can immediately see their medication they need to take. It is connected to the hospital system, meaning that when it changes in the system, it will update here.

Weekly HRQoL questionnaires
Here the user can click on the mental or physical weekly questionnaire. The answers will be used on the 'Gezondheids' page as data for the graphs.

Figure 4.9: Explanation of the home screen page.

4.4.2 Health screen

On this page the weekly questionnaires and their answers are visualised in graphs. See Figure 4.10 for the explanation of the mental and physical overview function, overview graph and advice segment. The advice segment is based on the research of Kahlmann et al. (2022), who states that mindfulness improves life with sarcoïdosis.



Hier krijg je inzicht over je mentale gesteldheid van de afgelopen weken.

Online gedragstherapie, inclusief mindfulness oefeningen, helpt bij vermoeidheid door sarcoidose.

Mental/ physical overview
Here the user can click to see an overview of their mental and physical condition the past few weeks. The x-axis shows the weeks of the last past 3 months, and the y-axis shows the 1-5 likert scale. Each factor that is asked before has a line.

Overview graph
Here the user sees how they rated their health in general on a scale from 1-10 every week.

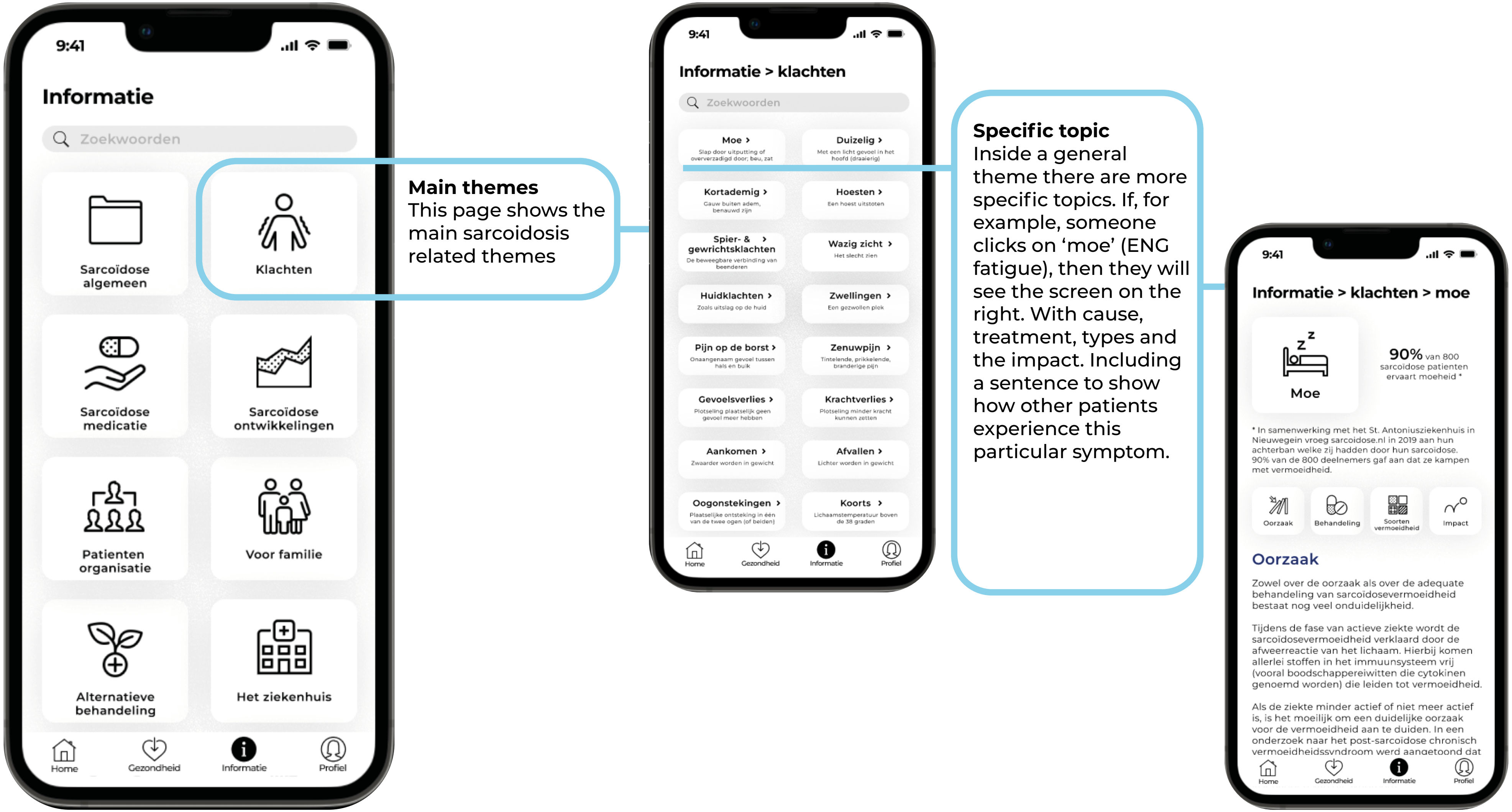
Advise page
Scrolling down shows some advise to improve their wellbeing and to find a balance in life.

Figure 4.10: Explanation of the health screen.

4.4.3 Information screen

The information screen is explained in Figure 4.11. The information data is from the patient organisation's website and from the website created by Erasmus MC and 20 other hospitals (ILDnetwerk.nl).

At this point, the main pages are discussed, and there is one page left on the bottom toolbar, this is the profile page. This can be seen in Appendix J, where every screen of the application is explained.



Main themes
This page shows the main sarcoidosis related themes

Moe > Slap door uitputting of oververzadigd door; beu, zat
Duizelig > Met een licht gevoel in het hoofd (draaierig)
Kortademig > Gauw buiten adem, benauwd zijn
Hoesten > Een hoest uitstoten
Spier- & gewrichtsklachten > De beweegbare verbinding van beenderen
Wazig zicht > Het slecht zien
Huidklachten > Zoals uitslag op de huid
Zwellingen > Een gezwollen plek
Pijn op de borst > Onaangenaam gevoel tussen hals en buik
Zenuwpijn > Tintelende, prikkelende, branderige pijn
Gevoelsverlies > Plotseling plaatselijk geen gevoel meer hebben
Krachtverlies > Plotseling minder kracht kunnen zetten
Aankomen > Zwaarder worden in gewicht
Afvallen > Lichter worden in gewicht
Oogonstekingen > Plaatselijke ontsteking in één van de twee ogen (of beiden)
Koorts > Lichaamstemperatuur boven de 38 graden

Specific topic
Inside a general theme there are more specific topics. If, for example, someone clicks on 'moe' (ENG fatigue), then they will see the screen on the right. With cause, treatment, types and the impact. Including a sentence to show how other patients experience this particular symptom.

90% van 800 sarcoïdose patienten ervaart moeheid *

* In samenwerking met het St. Antoniusziekenhuis in Nieuwegein vroeg sarcoidose.nl in 2019 aan hun achterban welke zij hadden door hun sarcoïdose. 90% van de 800 deelnemers gaf aan dat ze kampen met vermoeidheid.

Oorzaak

Zowel over de oorzaak als over de adequate behandeling van sarcoïdosevermoeidheid bestaat nog veel onduidelijkheid.

Tijdens de fase van actieve ziekte wordt de sarcoïdosevermoeidheid verklaard door de afweerreactie van het lichaam. Hierbij komen allerlei stoffen in het immuunsysteem vrij (vooral boodschappereiwitten die cytokinen genoemd worden) die leiden tot vermoeidheid.

Als de ziekte minder actief of niet meer actief is, is het moeilijk om een duidelijke oorzaak voor de vermoeidheid aan te duiden. In een onderzoek naar het post-sarcoïdose chronisch vermoeidheidssyndroom werd aangetoond dat

Figure 4.11: *Explanation of the information screen*

4.5 Prototype test

The prototype in Figma has interactions and therefore it can be tested with people. There are multiple things that need to be tested, namely:

1. Validation of the user interface, this is done with peers.
2. Validation of the purpose of the application, is done with patients.
3. Validation of the purpose of the application, is done with medical experts.
4. Determining the feasibility of the app, is done with experts from UI/UX companies.

4.5.1 Validation of the user interface with peers

This is the first test that is done after prototyping with other people. The goal is to validate whether the interface is intuitive and clear enough for the first use. The setup of this test can be found in Appendix K.1. Appendix K.2 shows the notes and answers of each session. 5 students participated in the validation test, all between the age of 23 to 25. Three students were from the Industrial Design Engineering faculty, one student from the faculty of Electrical Engineering, Mathematics & Computer Science and one student from the Hague University of Applied Sciences.

The main takeaways from these sessions were the following:
Application interaction. It appeared to be that a lot of buttons should have a larger surface to click on. People were struggling with some buttons. And some texts should be bigger because it was hardly readable on the screen.
Functional back-suggestion. This suggestion was to add a back button. Now the user has to click on the title, shown in Figure 4.12, and that should give a feeling about where they are in the app. However, if a back icon is added, going back is more intuitive.

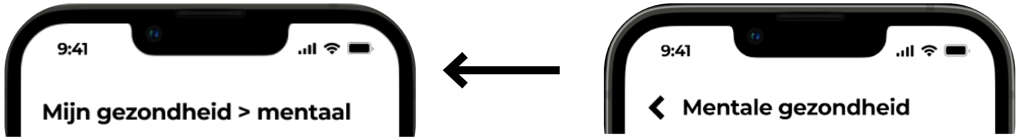


Figure 4.12: *Title of the page with function to go back.*

Health graphics. Graphics from the ‘Health screen’ are overwhelming, a lot is happening. See Figure 4.13 for a screenshot of how it is presented when the user clicks ‘mental overview’ or ‘physical overview’. Also, these graphics were not that clear because the axis titles are too small to read and give unclear descriptions. Therefore this could be improved.

Contact hospital staff. The appointments are shown with location and time, however, there should also be a link to the website of the specific hospital.

In general, the application is very intuitive according to the participants. They gave it an average of 4, on a scale from 1 to 5. Also, all five participants mentioned that the application gave them a medical feeling when they used it.

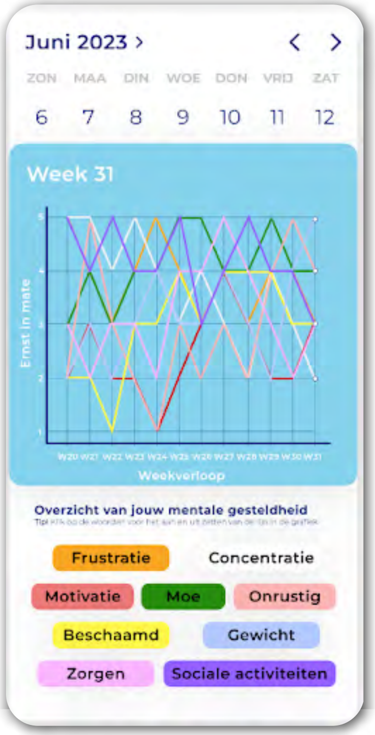


Figure 4.13: *Start of the mental overview page.*

4.5.2 Validation of the purpose of the application with patients

The main users of the application are patients, therefore their feedback is relevant. However, recruiting patients is not that easy and takes a lot of time. Eventually, three patients gave feedback. See Figure 4.14 for the online session with the first patient.

The main takeaways from this patient were the following:
Balance in life is key. From the patient journey map it is clear that the balance in life for patients is a key aspect of their life, however, this doesn't come back (enough) in the application. Therefore, this should be included or at least there should be more focus on how they can find a better balance in life.

Difficult logistics behind the application. At this point, there are several software or devices that are similar to the proposed system and application. Thus it is important to find out why this created system, is adding value to patients.

Information, appointments and medication plan. If this application exists, all three patients mentioned that they would use the application to see their medication plan. Also, they would use it to see the appointments they have with the hospital and to use the tips for finding balance in life.

Motivational notification. Multiple times it was mentioned that they would need some motivation, after using the application for a while, to keep using the app. Otherwise, they would lose interest (probably).

The patients were intrigued with the application and they would use the app. Also, it is found to be a logical result of the patient journey map (if the finding balance in life criteria is included). However, the logistics with similar devices are critical, therefore it should be highlighted how new value is added.

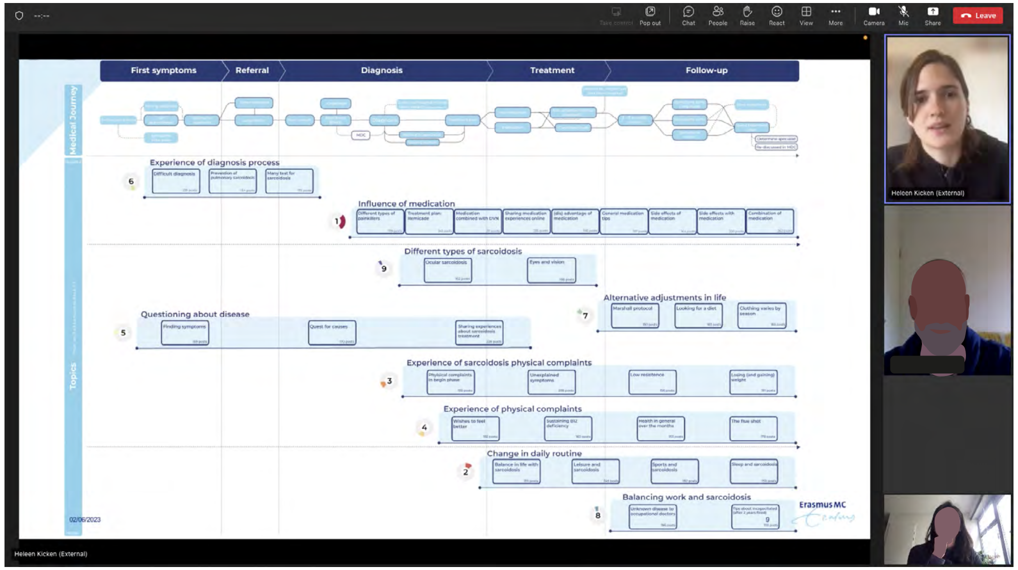


Figure 4.14: Online session with a patient.

4.5.3 Validation of the purpose of the application with medical experts

Besides the patients, the feedback of the medical experts is also important. They have knowledge of how things go for patients from the hospital perspective and they can also show what is important for the medical experts in the application. Therefore the specialist ILD nurse Y. Gür-Demirel gave her opinion about the application and also the pulmonologist Prof. Dr M. Wijsenbeek. Lastly, the pulmonologist in training V. Kahlmann gave also feedback with regard to sarconline.nl. See Appendix L for their feedback and Figure 4.15 and 4.16 shows the meeting with Prof. Dr. M. Wijsenbeek and with doctor V. Kahlmann. They bothed signed the consent form of Appendix A.2 and agreed for the photo.

The feedback of specialist nurse Y. Gür-Demirel, pulmonologist Prof. Dr. M. Wijsenbeek and doctor V. Kahlmann gave the following main takeaways:

User adds a treatment plan. Doctors often put the patient's treatment plan in the hospital's system, however, they don't always adjust it if it changes. Therefore, Y. Gür-Demirel highlighted the fact that the patient should add the treatment plan to the calendar. So this function should be included. Prof. Dr. M. Wijsenbeek added that it would be nice to connect with the pharmacists. But for now, it is a good plan to add the medication plan via both the doctor and the patient. V. Kahlmann stated the same as the other two interviewees.

Logistics compared to existing systems. Y. Gür-Demirel highlighted that it is good to take ILDnetwerk.nl into account and think of how it could be combined.

Physical advice. The health page has a segment where advice is given, however, the specialist nurse highlighted that it would be useful to include physical advice. Now there is only mental advice, with mindfulness and breathing exercises. She mentioned that for pulmonary fibrosis physical exercise improves the medical condition, however, she was not sure if this was also the case with sarcoïdosis.

Future steps. Prof. Dr. M. Wijsenbeek is convinced that this form, in an application, can work and needs concrete future steps to realise it. This should be determined. When it is realised, it can go through a randomised controlled trial (RCT).

Figure 4.15: *Meeting with Prof. Dr. M. Wijsenbeek.*

Figure 4.16: *Meeting with doctor V. Kahlmann.*

4.5.4 Feasibility of the application with UI and UX Company

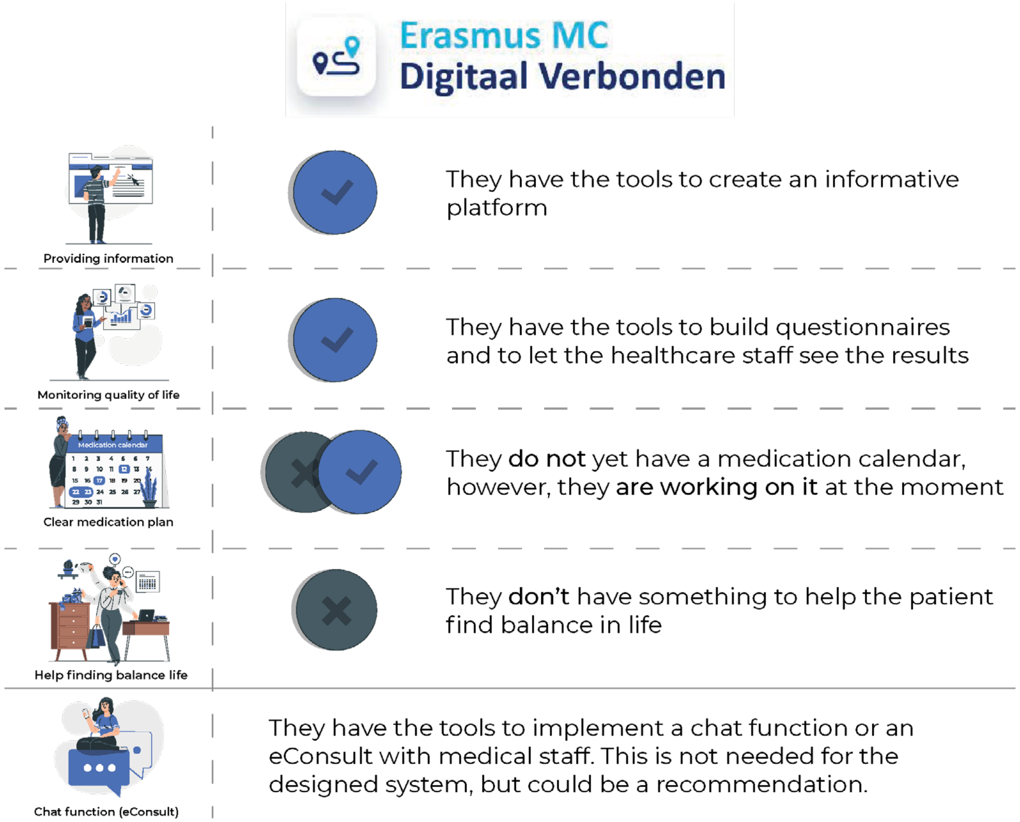
The prototype of this project is an application, and therefore feedback from a UI/UX company gives insights about how feasible this is. Therefore the goal is to go through the application and show the stakeholders that are involved in the market. Digitaal Verbonden is an intern company from the Erasmus MC that works on the launch of a patient application from the hospital. A. van der Lugt works there and gave her feedback on the application. Besides this intern company, also an ICT UX researcher of eHealth of the Utrecht MC gave her feedback on the application and its feasibility. See Appendix N for the overall feedback that is received during these two sessions.

The main takeaways from these two experts were the following:
(Un)reasonable functions. Digitaal Verbonden mentions that they have the tools to create this application. The main functions are already possible, but they are working on realising the medication calendar. However, the expert of Utrecht MC mentioned that this is very complex, because of the systems that are being used in the hospitals.

Optimistic about a balance page. Both are very enthusiastic about implementing tips and stories about how patients can improve their life with sarcoidosis. It does not exist in current applications, but Digitaal Verbonden would love to add this.

A lot of protocols. There are a lot of hospital protocols, which makes it difficult to implement something. Also, inclusivity is a sensitive aspect of an application. For example, when giving advice about exercise, someone in a wheelchair could feel insulted.

Based on the conducted interview, Figure 4.17 shows the feasibility per function within the power of the company.



Erasmus MC
Digitaal Verbonden

Providing information	✓	They have the tools to create an informative platform
Monitoring quality of life	✓	They have the tools to build questionnaires and to let the healthcare staff see the results
Clear medication plan	✗ ✓	They **do not** yet have a medication calendar, however, they **are working on it** at the moment
Help finding balance life	✗	They **don't** have something to help the patient find balance in life
Chat function (eConsult)		They have the tools to implement a chat function or an eConsult with medical staff. This is not needed for the designed system, but could be a recommendation.

__Figure 4.17:__ Digitaal Verbonden and its resources with regard to the four patients' needs.

4.6 Prototyping conclusion

The working prototype provides a view of how the application should work and should help people. The main pages of the application are valuable according to the tests that are being done. However, there are some improvements needed. The key value from the patient journey map, finding balance in life with sarcoïdosis, isn't included enough in the application. This should be more present because this is very valuable for the users, according to the patients, medical experts and UI/UX companies. Also, the logistics of making a medical application are quite difficult. Therefore, this application is a way how to visualise the system behind the application with the four values. The concept is a system where the three patients' needs (plus the new need: finding balance in life) are supported in a way. A system where multiple values need to be considered to help sarcoïdosis patients manage and improve their quality of life.

Ideation & prototyping | Key main takeaways

- Finding a balance in life with sarcoïdosis needs to be more present, so this is added to the three main values.
- The application is an example of how the underlying systems could look like.
- The underlying needs are of high value for the patients and medical experts.
- The needs are possible to turn into function, for Digitaal Verbonden. Except for the need to find balance in life with sarcoidosis, this needs a bit more research.

5. Final design of sarcoidosis intervention

In this chapter the final iteration step resulting in the final design is discussed. This final steps is based on the feedback from tests that have been done with patients, peers, medical experts and UI/UX company. The goal is to show the four patient’s needs and it requirements, next steps and limitations.

5.1 Design summary

The interstitial lung diseases department of the Erasmus MC is in charge of this project and wants to see what can be improved for sarcoïdosis patients. Therefore a patient journey map based on a social media platform for these patients formed the base for this project and emphasised the patient's needs. The patient journey map with additional analysis resulted in the following research question:

How can sarcoïdosis patients manage and improve their quality of life?

Based on the patient journey map, some patients' needs concluded that sarcoidosis patients can manage and improves indirectly their quality of life. These several patients' needs need to be tackled by Erasmus MC to improve the quality of life of their patients.

These needs are explored to understand what they are, what the current status is at the moment in the hospital and what different stakeholders think of them. After several patient interviews, medical experts interviews and even UI/UX company interviews, the eventual four patient needs are:
1. Help patients with finding their balance in life.
2. Providing information about sarcoidosis-related topics.
3. Manage quality of life mentally and physically.
4. Monitor medication clearly and provide a clear medication overview.

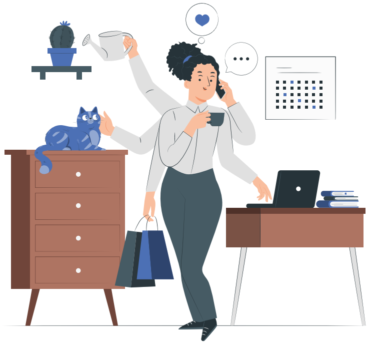
See the next page for an overview of each need and its requirements based on this thesis.

The four patients' needs are formed in an online application where these four needs are tackled. This way, the patient can manage these needs at home and improve their disease progress. This application is discussed in the functional design subchapter. First, these patients' needs are explored in a way that they are compared with existing tools for sarcoïdosis patients and how these needs would implement with the existing stakeholders.

After this system map and the functional design, the future steps and validation are discussed. Because it is important to have a feeling of how these needs can be realised in the ILD department.

5.1.1 Function summary: finding balance in life

What?



Finding balance in life with sarcoidosis

For whom?

&

&

Patient that is new with the diagnose

Patient that is familiar with the diagnose

Patient that has found their routine with the diagnose

Why?

A big key value for sarcoidosis patients is their search for a new balance in life after they are diagnosed. The disease often limits them and this is experienced negatively. Therefore this patient's need needs to be taken into account. They need some advice on how to find their balance, mentally and physically. These two ways have a big influence on finding this balance. This struggle often occurs online, on blogs and on the patient organisation website. There is a study about breathing exercises, that positively influence the disease (Kahlmann, 2022). On the other hand, is not clear how physical exercises improve the disease.

How?

Give advice on how they can find their balance:

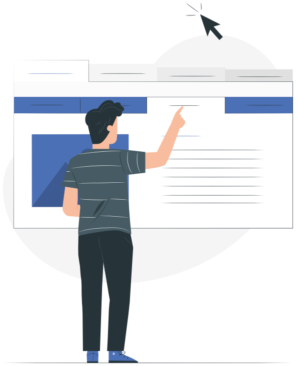
- Include the online cognitive behavior study with breathing exercises (Kahlmann, 2022)
- Include physical exercises, a study has to be done if this improves the disease and what kind of exercises this will be.
- Include a part where get informed about new events and books related to sarcoidosis.

Application performance:

- Implement these three points in the app.

5.1.2 Function summary: sarcoidosis information

What?



Providing information about sarcoidosis

For whom?

&

Patient that is new with the diagnose

Patient that is familiar with the diagnose

Why?

Because of this complex disease, patients are constantly looking for information about certain sarcoidosis aspects. From the patient journey map it became clear that patients are continuously looking for information. Also, one big pillar in patient-centred care is to focus on giving clear information to the patient. Therefore this patient need is formed. Only, it is mainly for newly diagnosed patients and for a patient that is already diagnosed for a while. But an ‘expert’ patient won’t benefit from this function, because they have found their information already or know where to find it.

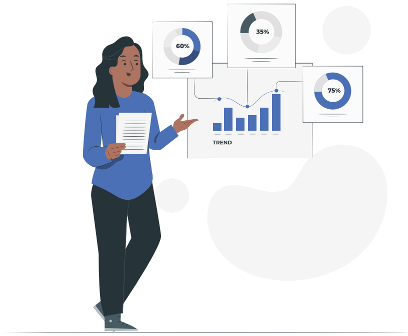
How?

Include sarcoidosis related topics:
- Explain the medical topics: what is sarcoidosis; the treatment; and diagnosis tests. Information gathering from ildnetwerk.nl
- Explain topics from a patient perspective. Information from patient organisation website (sarcoidose.nl)
- Comparison with other patients (e.g.: 80% of 800 sarcoidosis patients experience also...)

Application performance:
- Informative page with all kind of information

5.1.3 Function summary: monitoring quality of life

What?



Monitoring quality of life

For whom?

Patient that is new with the diagnose

&

Patient that is familiar with the diagnose

&

Patient that has found their routine with the diagnose

Why?

It is clear that sarcoidosis is a complex disease, it can be monitored with HRQoL questionnaires (Van Helmonndt et al., 2019). Specifically King’s Sarcoidosis Questionnaire, a questionnaire about fatigue, one about anxiety and depression and one about well-being. When patients fill these in, they can monitor and understand their disease better. Together with doctors they can look at their answers and decide together for the next plan. Therefore this need is important to include because then the patient can have a better and more effective treatment plan.

How?

Include QoL study (Mooi et al., 2019):
- King’s Sarcoidosis Questionnaire
- Euroqol-5D-5L
- Hospital Anxiety and Depression scale
- Fatigue Assessment scale

Application performance:
- Questionnaire tool as input for the big control in the hospital
- Overview in graphs for patient & healthcare staff

5.1.4 Function summary: medication overview

What?

Medication overview for sarcoidosis patients

For whom?

Patient that is new with the diagnose

&

Patient that is familiar with the diagnose

Why?

Sarcoidosis is a complex disease, which leads to multiple different medications being prescribed for patients (Drent et al., 2021). With a medication overview, in a calendar form, patients know what and when to take their medication. It provides clear information and support for self-care, which is one of the pillars of patient-centred care.

This function offers security for the patient but also for the healthcare professional. Medication is taken and the side effects are (or not) from the medication (probably).

How?

Give a clear and intuitive medication overview

Application performance:
- In a calendar form, this gives a clear overview
- Manually add to the calendar together with healthcare staff
- In the form of a dosis, so there is no doubt what kind of medication to take

5.2 System map of design

As mentioned before, there are already existing systems that the Erasmus MC uses for themselves and the patients. The Sarconline and ILDnetwerk platforms are systems that can be used at home. They both provide information for the patient, and Sarconline has an extra feature to monitor the lungs and the patient's quality of life.

Figure 5.1 shows the system map with important organisations, stakeholders and the purposes of the newly developed and existing systems. On the organisation level, the ILD department of the Erasmus MC is visualised, the internal UI/UX company of the Erasmus MC (Digitaal Verbonden), the patient organisation (sarcoidose.nl) and Curavista. The last one is included because that is the company that develops sarconline.nl. On the stakeholder level, the patient is in the centre, the medical experts is involved and the family is not yet included but is something for the new system to be included because of the patient-centred care method. The last level is the system purposes, where the four key values of this project are discussed. Furthermore, on the bottom right, the purpose of monitoring vital organs is included because this is the main purpose of sarconline.nl.

Figure 5.2, on the next page, shows how each system fits in the envisioned system map. It is shown that the newly developed system is overarching for all the project purposes and stakeholders. It can be noticed that Curavista isn't involved, this is because the internal company Digitaal Verbonden can also help in the future by realising this, therefore the stakeholder 'hospital (UI/UX internal company)' is involved. This decreases the costs of this project. For the 'Sarcoidose voor jou' system the 'hospital (ILD department)' has a bigger role. Besides the medical experts that are leading the systems, also the knowledge of this department (ILDnetwerk.nl) is actively involved.

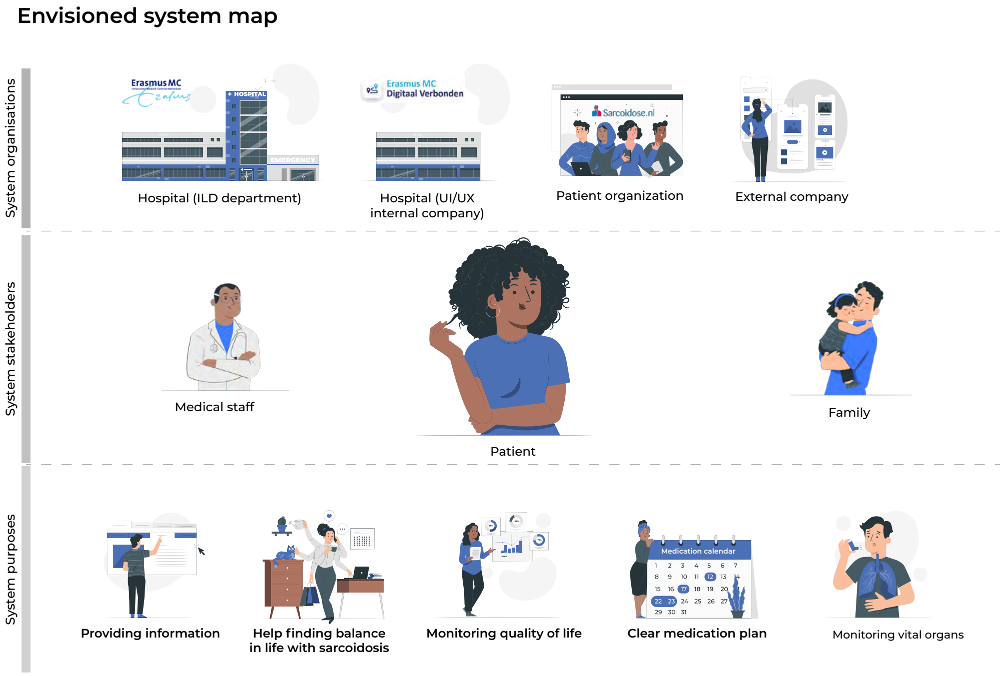


Figure 5.1: *System map with different levels and stakeholders.*

Envisioned system map

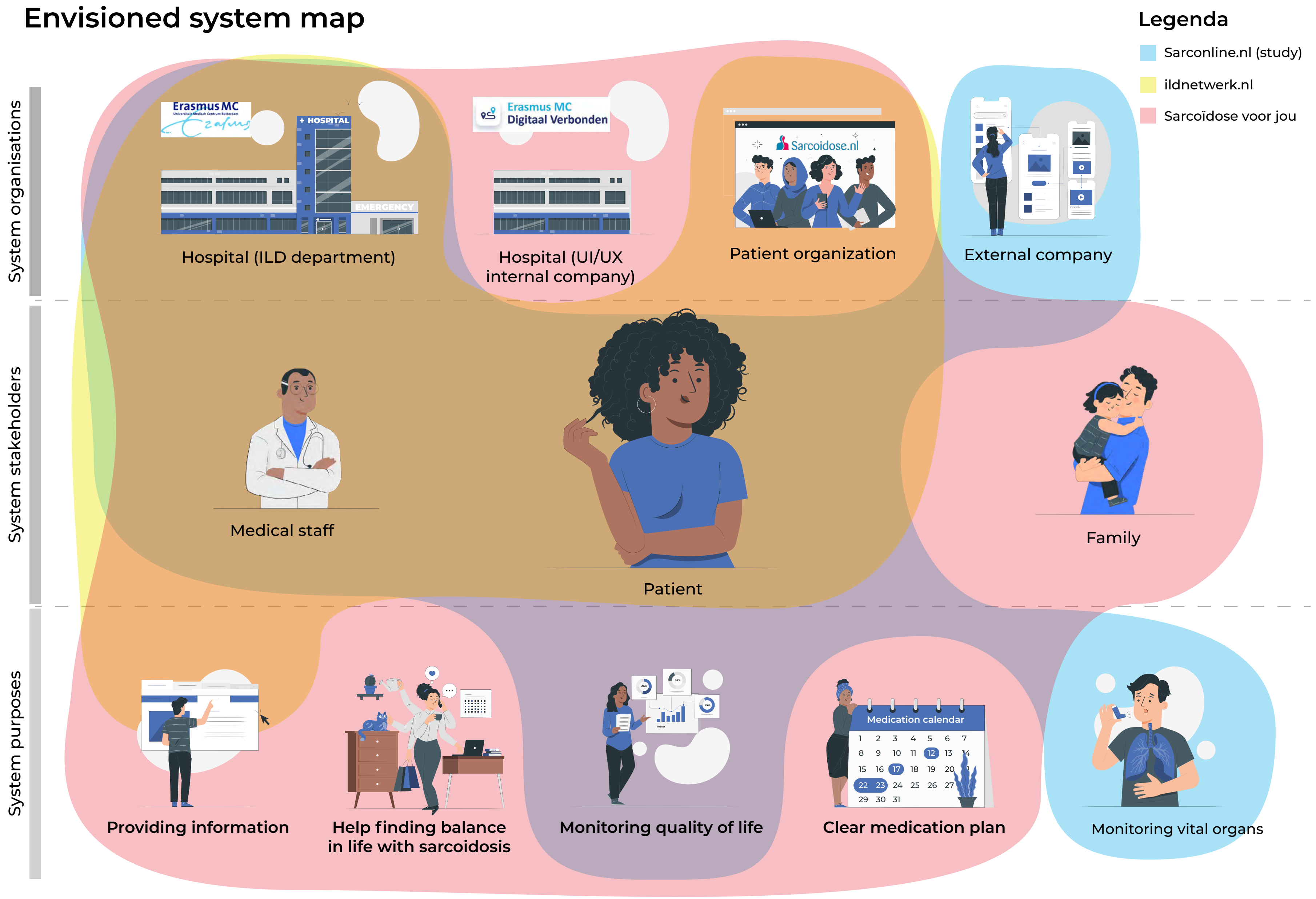


Figure 5.2: System map with a comparison.

5.3 Functional design

Eventual it is chosen to implement the system in a digital prototype. This eventual prototype is explained per each patient’s need, and therefore also per page. Scan the QR code on the poster to see a tutorial video scrolling through the application. See Figure 5.3, on the next page, for the application interaction flow. The left part shows the first-time questions, here the patient can personalise the application. This is important as it is based on the patient-centred care method. The patient can log in via DigiD, to load the basic personal information. Then they get four personal questions:

1. Since when do you have the diagnosis of sarcoidosis?
2. What do you do for sports?
3. What kind of profession do you have?
4. With who do you work?

These four questions are displayed in the account settings, and a medical expert can immediately see about these things to help the patient better.

Furthermore, each of the four important patients’ needs is explained in the next pages, after Figure 5.3.. Per the patient’ need there is an explanation about who it may concern the most: a patient that is just been diagnosed with the disease, who gets the hang of how to live with the disease, or someone who has lived with the disease for a longer amount of time. This scale is visualised with stars:

★☆☆	1 star means that this patient’ need is especially interesting for someone who is just diagnosed with sarcoidosis, and therefore ‘new’ to the disease.
★★☆	2 stars mean that this patient’ needs are interesting for someone ‘new’ and for someone who already lives some times with the disease.
★★★	3 stars mean that that particular patient’s need is interesting for a ‘new’ patient, a slightly experienced patient and someone who got the hang of it a long time now.

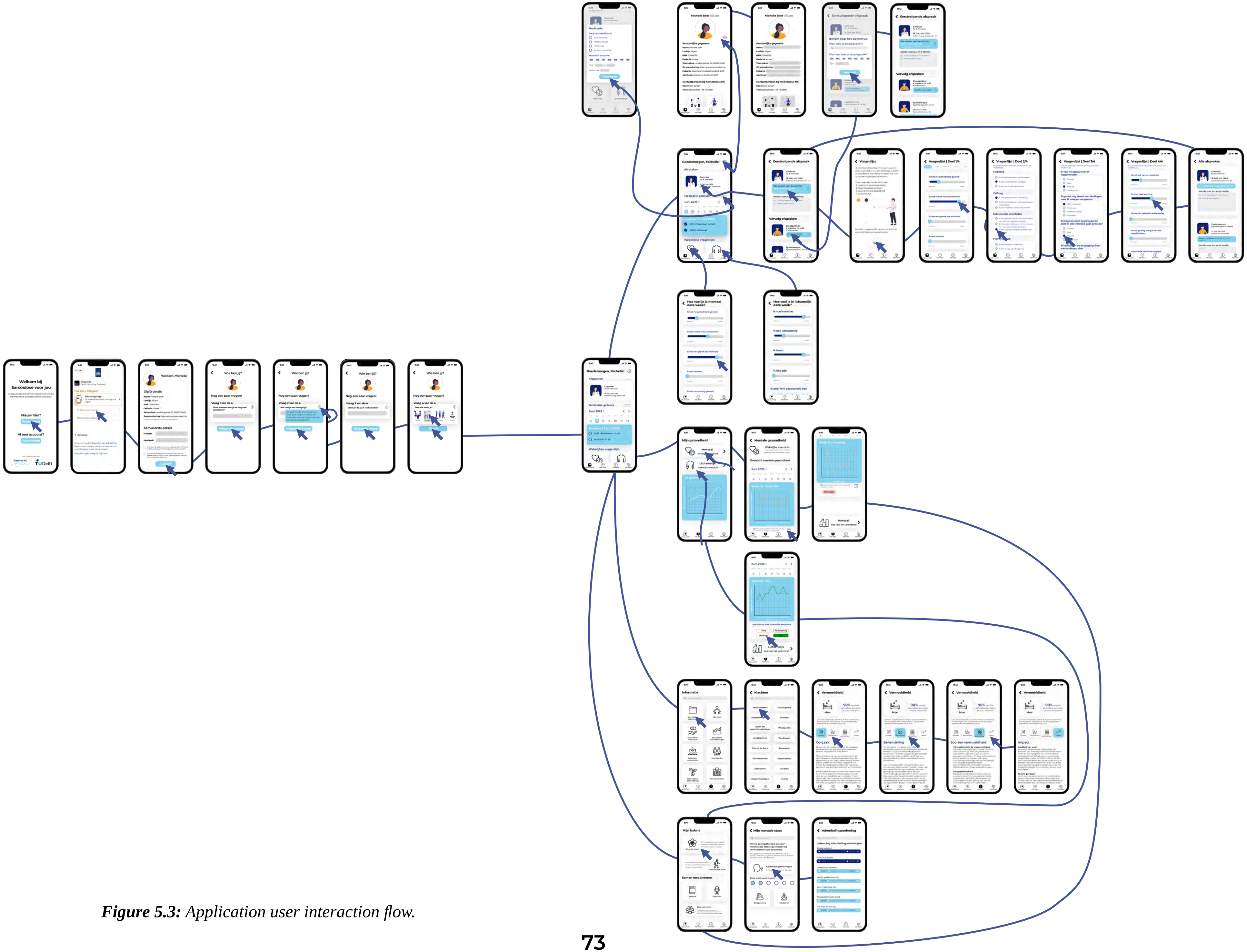


__Figure 5.3:__ Application user interaction flow.

5.3.1 Functional prototype: medication overview

Patient ★★☆

9:41

Eerstvolgende afspraak

Controle
Dr. B. Tienissen
15 Juli, om 13:20
Polikliniek long, Erasmus MC

Nog te doen voor de controle!
Uitgebreide vragenlijst
Het invullen duurt maximaal 20 minuten, neem de tijd ervoor en wees eerlijk.

Notitie voor jou en je familie
29 - 5: Last van spierpijn in m'n linkerarm
22 - 6: Kramp tijdens slapen?

Vervolg afspraken

Bloedprikken
6 Augustus, om 16:35
STAR Rotterdam
Ik ben geweest!
Geef een signaal aan het ziekenhuis

Fysiotherapie
Fysiotherapeut K. Jansen

9:41

Goedemorgen, Michelle!

Afspraken — Zie alle

Controle
Dr. B. Tienissen
15 Juli, om 13:20
Polikliniek long, Erasmus MC

Medicatie gebruik — Toevoegen of wijzigen

Juni 2023 >

ZO	MA	DI	WO	DO	VR	ZA
6	7	8	9	10	11	12

Vandaag | 7 Juni 2023

○ 9:00 | Prednison 1x 2 pil

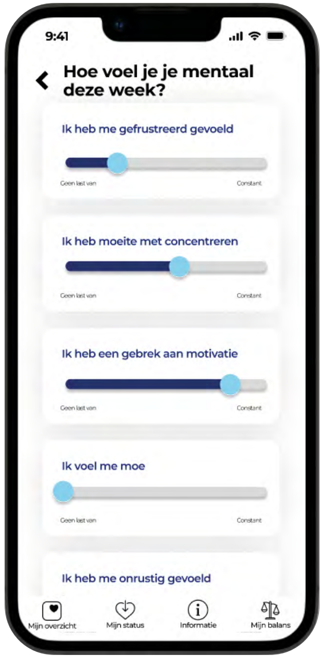
○ 18:00 | MTX 1 pil

Wekelijkse vragenlijst

Appointments
The first appointment is shown on the homescreen. With a general visualisation of the medical staff. For the other appointments they can click on 'Zie alle' and they go to the page on the left. They see more information and the big questionnaire for their quality of life.

Medication calendar
Here the user can immediately see medication they need to take. It is connected to the hospital system, meaning that when it changes in the system, it will update here.

Weekly HRQoL questionnaires
Here the user can click on the mental or physical weekly questionnaire with an answering bar (Moor, 2020). The answers will be used on the 'Gezondheids' page as data for the graphs.



9:41

Hoe voel je je mentaal deze week?

Ik heb me gefrustreerd gevoeld
Geen last van — Constant

Ik heb moeite met concentreren
Geen last van — Constant

Ik heb een gebrek aan motivatie
Geen last van — Constant

Ik voel me moe
Geen last van — Constant

Ik heb me onrustig gevoeld

5.3.2 Functional prototype: monitoring quality of life

Patient ★★☆

Mental/ physical overview
Here the user can click to see an overview of their mental and physical condition the past few weeks. The x-axis shows the weeks of the last past 3 months, and the y-axis shows the 1-5 likert scale. Each factor that is asked before has a line.

Overview graph
Here the user sees how they rated their health in general on a scale from 1-10 every week. To get a quick feeling on how they felt the last couple weeks.

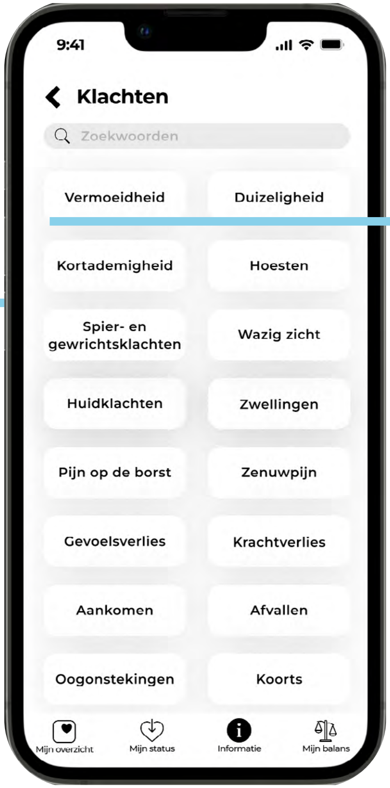
Tip! Klik op de woorden voor het aan en uit zetten van de lijn in de grafiek.

Link to balance page
Below the graph there is a button to the ‘Balance’ page. With advise on how to improve for example ‘fatigue’ (in this example).

5.3.3 Functional prototype: sarcoidosis information

Patient ★⯪☆

Main themes
This page shows the main sarcoidosis related themes.



Specific topic
Inside a general theme there are more specific topics. If, for example, someone clicks on ‘moe’ (ENG fatigue), then they will see the screen on the right. With cause, treatment, types and the impact. Including a sentence to show how other patients experience this particular symptom. This way they feel less alone in their disease journey.

90% van 800 sarcoïdose patienten ervaart moeheid *

* Uit een onderzoek van het St. Antoniusziekenhuis in Nieuwegein, het Erasmus MC en de patiënten organisatie (sarcoidose.nl) in 2019

Oorzaak

Zowel over de oorzaak als over de adequate behandeling van sarcoïdosevermoeidheid bestaat nog veel onduidelijkheid.

Tijdens de fase van actieve ziekte wordt de sarcoïdosevermoeidheid verklaard door de afweerreactie van het lichaam. Hierbij komen allerlei stoffen in het immuunsysteem vrij (vooral boodschappereiwitten die cytokinen genoemd worden) die leiden tot vermoeidheid.

Als de ziekte minder actief of niet meer actief is, is het moeilijk om een duidelijke oorzaak voor de vermoeidheid aan te duiden. In een onderzoek naar het post-sarcoïdose chronisch vermoeidheidssyndroom werd aangetoond dat het immuunsysteem van vermoeide patiënten

5.3.4 Functional prototype: finding balance in life

Patient ★★★

9:41

Ademhalingsoefening

Zoekwoorden

Iedere dag ademhalingsoefeningen

Stress loslaten 0:03:05 00:03:05

Rust in je hoofd 0:03:03 00:03:03

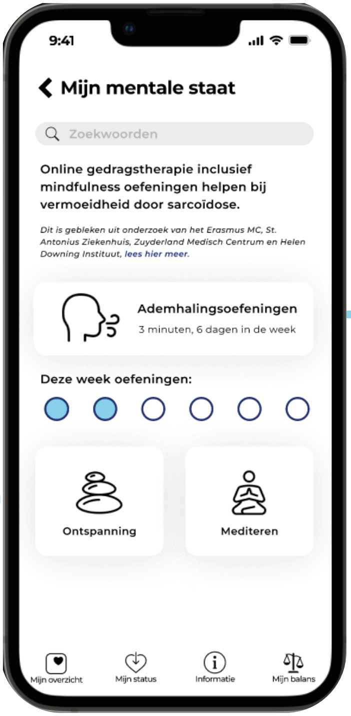
Gedachten loslaten 0:00:15 00:03:25

Met je gedachtes zijn 0:00:00 00:03:00

Even helemaal zen 0:00:00 00:03:05

Terugkeren naar jezelf 0:00:00 00:03:06

Het hier en het nu 0:00:00 00:03:03



9:41

Mijn mentale staat

Zoekwoorden

Online gedragstherapie inclusief mindfulness oefeningen helpen bij vermoeidheid door sarcoïdose.

Dit is gebleken uit onderzoek van het Erasmus MC, St. Antonius Ziekenhuis, Zuyderland Medisch Centrum en Helen Downing Instituut, lees hier meer.

Ademhalingsoefeningen
3 minuten, 6 dagen in de week

Deze week oefeningen:

● ● ○ ○ ○ ○

9:41

Mijn balans

Mentale staat
Online gedragstherapie, inclusief mindfulness oefeningen, helpt bij vermoeidheid door sarcoidose.

Beweging
Lichamelijke beweging bevordert de mentale en fysieke status van je lichaam met sarcoidose.

Samen met anderen

Bijeenkomsten
Georganiseerd vanuit de Patienten Belangenvereniging van sarcoidose.nl. Het wordt voor en door patienten georganiseerd.

Mental and physical advice
Here the user can focus on improving their mental and/or physical wellbeing. This is connected with the earlier weekly questionnaire where the focus is also on mental and physical.
The mental page includes online breathing exercises, for 6 days a week 3 minutes long. This came from a Erasmus MC study (Kahlmann, 2022) that it improves sarcoidosis patients disease.

Together with others
Here the user can see some books or podcasts related to sarcoidosis or a chronic disease in general. Also, on the bottom there is a segment where the user can see upcoming events for sarcoidosis patients. These will be organised from the patient organisation, but also from the Erasmus MC. They organise four times a year a development event for sarcoidosis patients.

5.4 Validation of the design

In general, the patients that gave feedback on the application all mentioned that they think the application is valuable for someone that is diagnosed with sarcoidosis. However, the degree of how valuable per patient is different.

Providing clear medication overview.

This is for every patient, but this only works with a notification. Otherwise, it doesn’t work for everyone to maintain attention. This isn’t affected by the disease (and therefore the sarcoïdosis patients) but by how people work.

Monitoring quality of life.

This would help every patient, but this would also need notifications. Otherwise, people do not fill it in leading to no progress to monitor.

Providing information.

This is mainly for patients that are just diagnosed with sarcoidosis. Because it is a new disease for them, they want to have access to all kinds of sarcoidosis-related topics. This is used probably less often when people get more experienced with their disease. It needs to be kept up to date, especially the part with sarcoïdosis developments. This reaches a big group of patients.

Finding balance in life.

This would be helpful for every patient! According to the interviewees, there are several moments when they still are trying to find their balance in life. This could be very helpful with that.

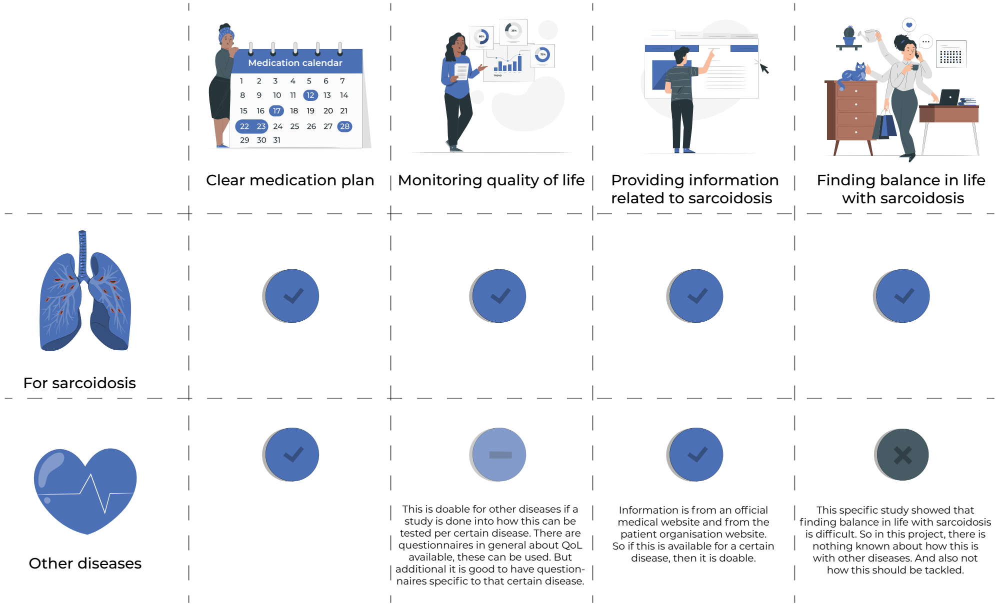
5.5 Comparison to other diseases

The final design is based on an analysis of sarcoïdosis patients. The data that is used as an input for the derived patient journey map, is from sarcoïdosis patients. Thus, the final system is designed for sarcoïdosis patients. But Figure 5.4 shows the manual comparison per patient need and if it would work for other diseases.

The first need is a clear medication plan, this is validated and designed for sarcoïdosis patients. However, this doesn't change for any other disease. The medication can change for what kind of disease it is, and this does not change the in- or output.

Monitoring the quality of life is very important for sarcoïdosis patients. However, the literature that determined it for this thesis is for interstitial lung diseases. So this is beneficial for every lung disease. Specific for sarcoïdosis there is an additional questionnaire. However, for other lung diseases, this could also work. But the need for other diseases needs to be explored, with regards to if it positively changes the healthcare for other diseases.

Providing information for sarcoïdosis patients is relevant because they are constantly looking for explanations about topics. However, this could be the case for any other disease. Patients want to know what they are diagnosed with and how to cope with it. In this sarcoïdosis topic, the medical information is coming from the official hospital website: ILDnetwerk.nl. So for other diseases, there needs to be a source with medical correct information. The information for patients on how to cope with the situation is for sarcoïdosis coming from the patient organisation website: sarcoidose.nl. For other diseases, there needs to be a formal source like sarcoidose.nl. Because on that website, there is information presented from the patient's perspective, all checked by medical experts.



	Clear medication plan	Monitoring quality of life	Providing information related to sarcoidosis	Finding balance in life with sarcoidosis
For sarcoidosis	✓	✓	✓	✓
Other diseases	✓	– This is doable for other diseases if a study is done into how this can be tested per certain disease. There are questionnaires in general about QoL available, these can be used. But additional it is good to have questionnaires specific to that certain disease.	✓ Information is from an official medical website and from the patient organisation website. So if this is available for a certain disease, then it is doable.	✗ This specific study showed that finding balance in life with sarcoidosis is difficult. So in this project, there is nothing known about how this is with other diseases. And also not how this should be tackled.

Figure 5.4: *New designed system compared to other diseases.*

The last need is finding balance in life with sarcoidosis. This is specifically related to sarcoïdosis patients. From the literature study, patient journey map and interviews, balance in life seems to be a key value for these patients to re-invent after their diagnosis. So to use this for other diseases, there needs to be a study done to see if this is valuable for these patients. Therefore, at this point, the conclusion would be that this isn't relevant (yet) for other diseases.

5.6 Further development

With this thesis, the ILD department of the Erasmus MC is advised to take action concerning the four patient's needs. They are all important for new patients and multiple needs even cover the value for patients with more experience. If the ILD department wants to continue working with these needs and wants to implement it in an application form, then certain steps should be followed. These are explained on the next pages. The steps are first focusing on creating a functional application, and then focus on steps to improve the fucntional application.

5.6.1 Next steps for clear medication overview

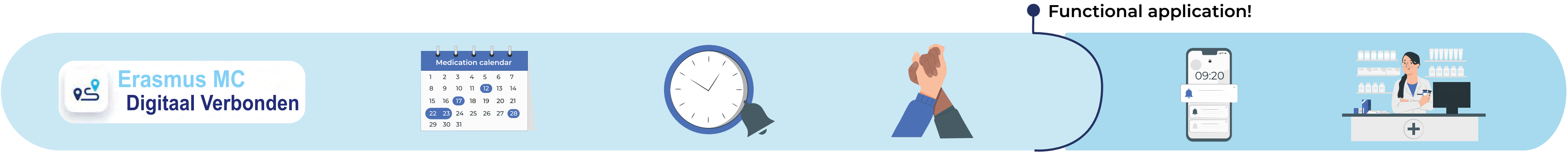
The patient's need to have a clear medication overview is doable to implement in an application. Digitaal Verbonden states that they are working on this function. The principle is minimalistic and relatively easy.

It starts with that the ILD department should sit together with Digitaal Verbonden. The ILD department has the urge to make this and Digitaal Verbonden has the tools. With their tools, the calendar function can be created with a weekly overview. Most efficient would be if it has a time function, this way the application can give notification as a reminder for the patient to take their medication. Patients stated that they would need a push notification, to be kept motivated to use this application. So it is important to implement this.

Their medication treatment plan has to be uploaded to the weekly calendar. This can be done together with the medical experts, during the patient's 3 monthly control with the pulmonologist or with the specialist nurse. It should be added manually with the medical experts because other ways are too difficult and inefficient due to the hospital's bureaucracy. For example, Hixx is the general hospital's software, but connecting with this software is a project in itself. From the medical experts' interviews, it became clear that if doctors change the medication plan, this does not come through properly in the Hixx software. This could affect the medication intake of the patient.

Following these steps, this patient's need can be used in a functional application. After creating this functional application, it is recommended to connect the medication overview to the calendar on the patient's phone. This way it has a more negligible impact on the patient's routine when they are newly using this application.

In the far future, it is preferred by pulmonologists to eventually connect this function with the pharmacist department. Because pharmacists get the prescribed recipe with the medication plan for the patient, they know what the medication intake is. It is most efficient therefore to connect the application to the pharmacist department.



Sit together with Digitaal Verbonden to discuss the steps.

Create a tool for a calendar function, with a weekly overview.

Add a time function and use notifications to remind the patient.

The patient manually adds the medication intake with the doctor.

Connect to the phone's calendar application.

Connect to the pharmacist with the prescribed medication.

***Figure 5.5:** Visualisation of the steps that need to be done for the function 'clear medication overview'.*

5.6.2 Next steps for monitoring quality of life

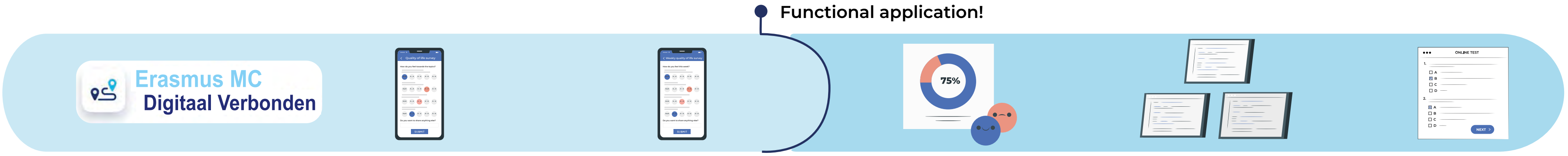
The patient’s need to have a clear medication overview is very easy to implement in an application. At this point the ILD department uses already a function for a trial, via Curavista, to send quality-of-life questionnaires to sarcoidosis patients. So, the department is familiar with this kind of questionnaire. However, if a collaboration will take place with Digitaal Verbonden, this first needs to be discussed as to how this is imagined by both sides.

The next step would be to implement the sarcoïdosis HRQoL questionnaires in an application. These questionnaires are known by the ILD department. Then together with Digitaal Verbonden they need to make shorter questionnaires and make graphics of the answers. These graphics can be visualised like in the functional prototype in this graduation project. Then the functional application with regard to monitoring the quality of life is complete.

After finishing this functional application, a study (literature or trial) can be done to see what is the most intuitive way for patients to see their progress in graphics. For example, it can be done like the output that is shown in Sarconline, however, it is possible that there is a more intuitive possibility.

Then, this is a big step, it would be beneficial for the efficiency, of the workflow of this application, to connect the application to the hospital systems. Till this point, it is an independent application with regard to this function, only the patient is involved. However, it is wanted that medical experts can see these graphics. This way they can monitor from a distance how the patient is feeling and what can be adjusted medically speaking, according to their data.

The final step is to test if this function actually improves the well-being of the patient and if it improves the workflow of the medical experts. This can be done in a qualitative study where the opinions are asked by the two groups. But also in a quantitative study if it actually improves the sarcoidosis-related aspects that are questioned in the questionnaires.



Sit together with Digitaal Verbonden to discuss the steps.

Implement the questionnaires in the already existing tool.

Make a shorter version questionnaire to fill in every week.

Determine what the **most intuitive** graphs are to show to patients.

Connect to the hospital systems. This way doctors and nurses also have insights & can help patients from a distance.

Test if this helps the healthcare, from a hospital and patient side.

Figure 5.6: *Visualisation of the steps that need to be done for the function ‘monitoring quality of life’.*

5.6.3 Next steps for providing information

Throughout the patient journey, patients are seeking for answers to a diverse set of questions. Therefore this need is highly wanted for the application. Once again, the ILD department needs to sit together with Digitaal Verbonden and set the expectations for both sides. For this function, it is important to have the right information. The advice would be to gather information from the medical side and from the human side.

The medical information should be gathered from ILDnetwerk.nl. This is supported and created by the medical experts from Erasmus MC and only entails scientific information. If something changes in development or protocol, it will be adjusted on this website.

The patient's side information should be gathered from the formal patient organisation: sarcoidose.nl. The majority of the provided information there is fact-checked by the ILD department, however, not all of it. Therefore, it is important that medical experts check what kind of information will be gathered from this website. Additionally, it is also wanted to gather advice on blogs, podcasts or books. This has a big remark that it needs to be checked by a doctor or specialist nurse. Otherwise, the application can not guarantee to have the correct information.

If these steps are completed, the functional application is complete. The next step would be to do a comparison study with other diseases. This step does not have high urgency for sarcoïdosis patients but completes this graduation project. Till this point, it is not clear if patients with other diseases have the need to have access to this completed information package. It can be assumpted that is wanted, however, this still needs to be scientifically proven.

The last step entails that if information is provided, it needs to be kept up to date. Information changes, especially for example medical developments with regard to medication or disease triggers. Therefore, once in a time (could be weeks, months or years) it should all be checked and, if needed, changed.

Sit together with Digitaal Verbonden to discuss the steps.

Gather information from a medical perspective: ildnetwerk.nl

Gather information from a patient perspective: sarcoidose.nl.
This information needs to be fact-checked with the doctors!

Additional study to numbers for comparison with other patients.

Keep updating the information!
Quickly it can become outdated, making the information general. And keep 'development' (for example) updated.

Figure 5.7: *Visualisation of the steps that need to be done for the function 'providing information'.*

5.6.4 Next steps for help finding a balance in life

For sarcoïdosis patients, this need is the most important one. It does not matter how experienced a patient is, they still come across daily struggles. Therefore, it is important that the ILD department takes this seriously. However, before they are sitting together with Digitaal Verbonden, first, some additional research has to be done. Beginning with that for patients it is important to have mental advice and also physical advice with regard to their disease.

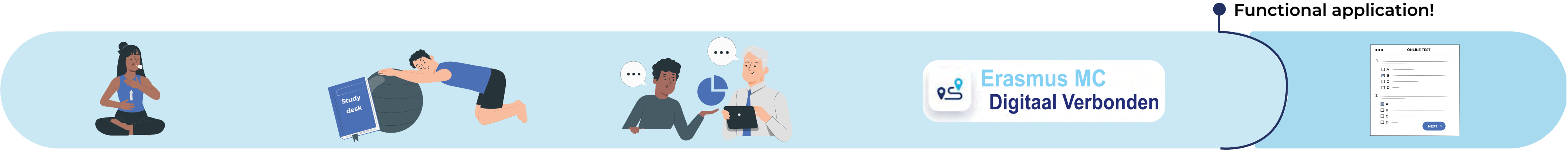
The mental advice is substantiated by the breathing exercises from V. Kahlmann's study (2022). These exercises need to be portrayed to have the resources available.

The physical advice still has to be determined. What kinds of exercises are beneficial for sarcoïdosis patients? And how should this be delivered to motivate them to do the exercises? This type of question needs to be answered for the full picture, therefore desk research has to be done. Then it can be determined what kind of exercises are important.

After these two aspects are ready to implement, additional it is wanted to include also events and books. This should be discussed within the ILD department because they need to approve this.

When all these kinds of aspects are determined, the ILD department needs to sit together with Digitaal Verbonden. With the previous needs, Digitaal Verbonden is already familiar with the function or ready to make it. However, with this need is it different. It is something completely new, and perhaps changes per disease. Therefore, they will not see the benefit of this page. For the ILD department is important to keep this in mind. They need to have the argumentation provided within this project, to show the urgency of this need to Digitaal Verbonden. If they agree to continue with this advice, a functional application can be made.

The final step then would be to test if it genuinely improves the medical journey for sarcoïdosis patients. This can be done with a trial where there are two groups: 1) that use the application and 2) that do not use the application. Resulting in monitoring their disease and physical complaints.



Determine what kind of breathing exercises need to be included.

A study desk to how physical exercises improve the disease & determine what kind of exercises this will be.

Determine together with the hospital what kind of events and books can be included.

Sit together with Digitaal Verbonden to convince them to include this. And implement the steps before in this function.

Test if this improves the medical journey of sarcoidosis patients.

Figure 5.8: *Visualisation of the steps that need to be done for the function 'help finding a balance in life'.*

5.7 Final design conclusion

In this chapter, the system map with four patients' needs was created. Furthermore, the differences between Sarconline and ILDnetwerk were visualised. The design system adds new value to sarcoïdosis patients at the Erasmus MC. The system was put into practice as a prototype to test with peers, patients and medical experts. It is shown that the needs are valuable for patients and they would use it. One function may be used more than the other, based on the experience that a patient has. Also, the application was found to be feasible. Finding balance in life needs more research regarding what it entails for the patients. Nevertheless, the need from the patient's perspective was found to be present.

The question if these functions are also for other diseases applicable is in general the case. Only finding a new balance after the sarcoïdosis diagnosis is specific for patients with sarcoidosis. To apply this to other diseases, more deep-dive research is needed.

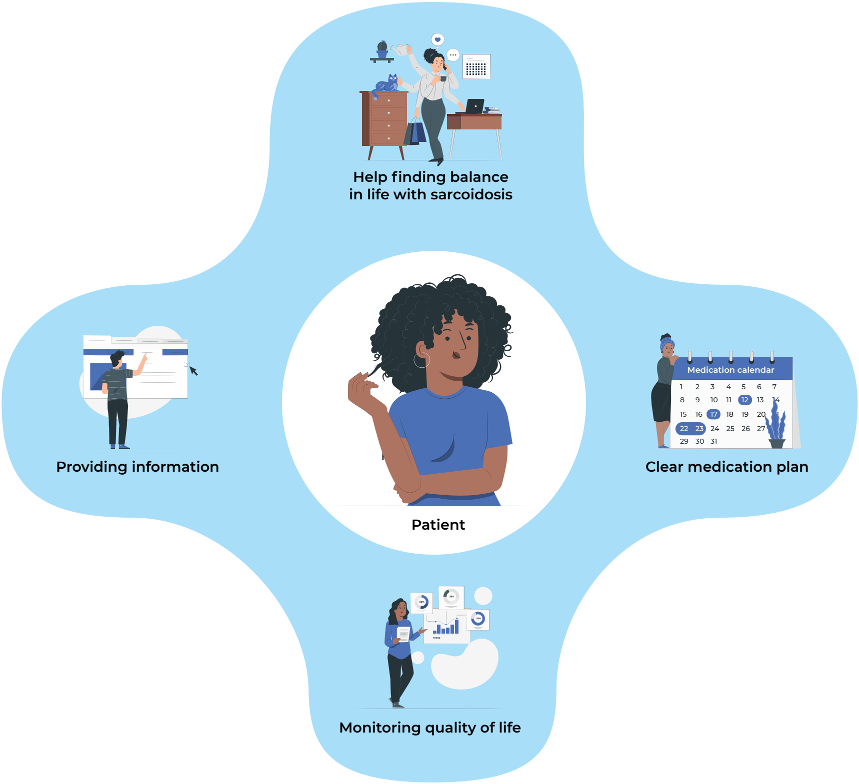


Figure 5.9: *Eventual designed system.*

Final design | Key main takeaways

- The four patient's needs are valuable for patients.
- The four patient's needs can be visualised in the form of an application, only it needs a bit more research about how to help patients with finding a new balance in their life with sarcoidosis.
- Compared to ILDnetwerk and sarconline it adds new value by overlapping these purposes and adding new values (the patient's needs).
- The system can be applied to other diseases, but more deep-dive research is needed.

6. Evaluation of the process and final design

In this chapter there is a critical discussion, based on the limitations, feasibility, desirability and viability of this project. Ending with a recommendation and a personal reflection.

6.1 Discussion & conclusion

The project started with a focus on improving the journey of sarcoïdosis patients in the context of Erasmus MC using a patient journey map. After an elaborate analysis, the scope became supporting sarcoïdosis patients at home in finding a balance in life. A literature study revealed that for finding the balance in life after being diagnosed with sarcoïdosis it is important to monitor the quality of life. The following research question was formed:

How can sarcoïdosis patients manage and improve their quality of life?

To understand what is necessary for a high quality of life with sarcoidosis, a further literature study was done. This underlined the benefits of questionnaires which patients can fill in themselves. Outside this literature study, the online computational study showed needs that also need to be tackled to improve the quality of life. This consisted of having easy access to more comprehensive information, and also having a clear medication overview. Because of the necessity of broad and up-to-date information access, an application is the best way to help patients during their disease. The patient can also easier manage, for example, their medication overview when they use an application.

6.1.1 Limitations

The project is done in a certain context and this leads to limitations. The data that is used as input is from one website and has a selected group of users. There are also both active users and users that only read or post a single post. This leads to these active users having a relatively big impact on the findings of this thesis. Since their posts are taken into account the most when analysing the data. Besides, this data does not include the experiences of patients that have no access to the internet or the time to post.

Next to the data input, there are three patients interviewed. They all fit the basic patient image: white, middle-aged and highly educated. The underrepresented groups, therefore, are not interviewed and thus not taken into account within the validation part of this project.

The medical experts' view is from the Erasmus MC directly, from the ILD department. They are all very eager to provide the best healthcare possible for their patients. However, this leads the project in a certain direction. Where they see the benefit, they express their opinion and expertise. This bias can be conscious, but also unconscious.

6.1.2 Feasibility

The feasibility of the application is shown in the section where Digitaal Verbonden is explained with their resources. The application is at the moment not yet possible. But if a connection is made with Digitaal Verbonden, then multiple aspects are already possible. They can build this kind of platform. However, they do not have the tools yet to make a page about finding balance in life. Therefore first they need to find a way to get this done. Consequently, a collaboration is needed with Digitaal Verbonden to see how they can create the software.

6.1.3 Desirability

The eventual system is based on the derived patient journey map and literature study. Thus it is based on valid input data, and patients validated in interviews that these needs would help them in the form of an application. The three patients were eager to use this app. The Erasmus MC already provides a website with information and uses HRQoL questionnaires. The addition of this new system would fulfil the need to help with finding a balance in life and have a clear medication overview. Medical experts expressed that they think that this could help the patients at home more during their disease than the care they already provide.

6.1.4 Viability

The designed system and application are created for these four patients' needs. The needs stay the same over time, but the needs become basic factors that get attention in sarcoïdosis healthcare. Therefore, it could be that after a while new critical needs develop. So some advice would be to test this in a few years again. However, as part of basic healthcare, the system helps patients to monitor their disease at home better. This is validated by the patients and medical experts. The next step would be to test in a trial if this system improves the disease for the patients.

6.2 Recommendations

After several interviews and evaluations, a list with recommendations is created. It can be split into recommendations for the system's four patients' needs, for the application, and for some additional points.

System recommendations

The system exists for four patient's needs and three of them are validated, with literature and interviews. The patient's need to find balance in life after the diagnosis is a large necessity. However, this is not clear from the literature study, only from the patient journey map.

Therefore, the first recommendation is to do a study on how severely this need is present. For analysing the urge of the need, it is recommended to do a study about finding balance in life. Analyse what this entails and how it can be tackled. The mental part is currently analysed, and mindfulness breathing exercises seem to help patients. The physical part needs more exploration, therefore a study should be conducted where the focus is on exercise and improvement of the disease. An additional questionnaire amongst the patient organisation could also give sufficient insights.
Secondly, this necessity is especially found with sarcoïdosis patients. However, a study needs to be done to be able to say if this is also applicable to other diseases.

Application recommendations

The eventual design application sets a good base, however, when the ILD department wants to continue with this format, they should focus on some details.

First of all, the application is now for Dutch-speaking patients. However, a big part of the underrepresented group is formed because of a language barrier. So, the focus should also be on making the application in English, Arabic and Turkish.
Secondly, the use of notifications should increase the usage of the app. Therefore, this needs to be implemented when the application is launched.
Lastly, to test if the system in this application format works, a test should be done to test whether the implemented patient-centred care method is used correctly in the application.

Additional recommendations

Besides the system and application recommendation, there are also some additional recommendations to take into account for the future.
First, this design is made using data from the patient's perspective, but eventually, the healthcare perspective should also be included. For example, by creating a dashboard with an overview of the patient's sarcoidosis-related symptoms. This way the medical experts can monitor the patient's disease better.
Secondly, if this design is used for patients and for medical experts, then it should be connected to the hospital software system Hixx. This is not easily done and takes some time.

These recommendations together should form an application that is ready for use!

6.3 Personal reflection

My motivation for this healthcare-related graduation project was to help people with their health. Often the patient experience can be improved, and this appeared to be the same for sarcoïdosis patients. My passion for making tangible products was less possible within this project. However, my opinion with regard to applications has changed, from being an easy way to prototype to being a way of prototyping with multiple aspects that need to be considered. At the beginning of this project some personal learning ambitions are set in the project brief (see Appendix A). Here I reflect on these ambitions at the end of this project.

Hosting co-creation sessions.

During this project I had two co-creation sessions, where one was an interactive session with medical experts and one was more of an open discussion online with a patient. These two sessions went okay but they had some hiccups. People were joining online resulting in them giving less input during the session. Also, eventually, medical experts are busy people and often are in a hurry for another meeting, so this shortened the effective time.

However, eventually, a lot of feedback was conducted from the sessions. And the interviews that were conducted after the sessions were easier to do, because of the skills that I learned during the sessions. An example of such a skill is leading a meeting in a smooth and efficient way. A lot of interviews have been done, mainly with medical experts with insightful feedback.

Prototype within the constraints of the hospital environment.

Prototyping in a hospital environment is often difficult because of the regulations. Eventually, my product stayed in the prototype phase. It was possible, with ethical approval, to test with patients and medical experts. For the prototype, there are not yet hard hospital constraints. However, now if this prototype is made, there are more constraints. To realise this, building a real app requires connections and functions that are hard to make.

Proactive attitude.

My personality resulted sometimes in a passive attitude, but a graduation project leads to me being the only one responsible for the tasks. Due to this followed in a natural way I became proactive. In the beginning, I was still listening to a lot of the ‘experts’ (read medical experts and supervisors), but after a while, the time was ticking and I needed to make some decisions. This resulted in a proactive way of working and choosing the most suitable direction for me within the project.

Overall I learned a lot from this project with regard to how I work as a designer but also regarding project management. I learned how I prefer to work, for example: with a weekly update including to-do’s. I also learned what my strengths and weaknesses as a designer are. My communication, project management, and assertiveness with prototyping and testing are my strongest skills. My weak spots can be that I quickly follow someone’s feedback or opinion, or that I am not thorough with ideation of different concepts.

All by all, I am satisfied with the end result. I got a lot of positive feedback from the medical experts and patients. I am confident that I am ready for the ‘grown-up’ jobs.

Self-management tool for sarcoïdosis patients

Heleen Kicken, July 2023

Welkom bij Sarcoïdose voor jou

De app vanuit het Erasmus Medisch Centrum die patiënten thuis ondersteund met sarcoïdose.

Nieuw hier?

Registreren

Al een account?

Aanmelden

Mede mogelijk gemaakt door

Erasmus MC Universitair Medisch Centrum Rotterdam

TU Delft

Medication overview for sarcoidosis patients

Goedemorgen, Michelle!

Afspraken — Zie alle

Controle
Dr. B. Tienissen
15 Juli, om 13:20
Polikliniek long, Erasmus MC

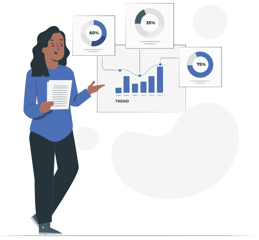
Medicatie gebruik — Toevoegen of wijzigen

Juni 2023 >

ZO	MA	DI	WO	DO	VR	ZA
6	7	8	9	10	11	12

Gisteren | 6 Juni 2023
☑ 9:00 | Prednison 1x 2 pil
☑ 15:00 | Infliximab

Wekelijkse vragenlijst



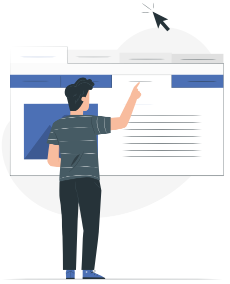
Monitoring quality of life

Mijn gezondheid

Mentaal
wekelijks overzicht >

Lichamelijk
wekelijks overzicht >

Je gezondheid



Providing information about sarcoidosis

Informatie

Finding balance in life with sarcoidosis

Mijn balans

Mentale staat
Online gedragstherapie, inclusief mindfulness oefeningen, helpt bij vermoeidheid door sarcoïdose.

Lichamelijke staat
Lichamelijke beweging bevordert de mentale en fysieke status van je lichaam met sarcoïdose.

Samen met anderen

Bijeenkomsten
Georganiseerd vanuit de Patienten Belangenvereniging van sarcoidose.nl. Het wordt voor en door patienten georganiseerd.

7. References

Arkema, E. V., & Cozier, Y. C. (2020). Sarcoidosis epidemiology: recent estimates of incidence, prevalence and risk factors. Current Opinion in Pulmonary Medicine, 26(5), 527–534. https://doi.org/10.1097/mcp.0000000000000715

Arkema, E. V., Grunewald, J., Kullberg, S., Eklund, A., & Askling, J. (2016). Sarcoidosis incidence and prevalence: a nationwide register-based assessment in Sweden. The European Respiratory Journal, 48(6), 1690–1699. https://doi.org/10.1183/13993003.00477-2016

Baughman, R. P., Barriuso, R., Beyer, K., Boyd, J., Hochreiter, J., Knoet, C., Martone, F., Quadder, B., Richardson, J., Spitzer, G., Valeyre, D., & Ziosi, G. (2018). Sarcoidosis: patient treatment priorities. ERJ Open Research, 4(4), 00141–02018. https://doi.org/10.1183/23120541.00141-2018

Baughman, R. P., Teirstein, A. S., Judson, M. A., Rossman, M. D., Yeager, H., Bresnitz, E. A., DePalo, L., Hunninghake, G. M., Iannuzzi, M. C., Johns, C. J., McLennan, G., Moller, D. E., Newman, L. S., Rabin, D. L., Rose, C. S., Rybicki, B. A., Weinberger, S. E., Terrin, M. L., Knatterud, G. L., & Cherniak, R. (2001). Clinical Characteristics of Patients in a Case Control Study of Sarcoidosis. American Journal of Respiratory and Critical Care Medicine, 164(10), 1885–1889. https://doi.org/10.1164/ajrccm.164.10.2104046

Belperio, J. A., Shaikh, F. K., Abtin, F., Fishbein, M. C., Weigt, S. S., Saggar, R., & Lynch, J. P. (2022). Diagnosis and Treatment of Pulmonary Sarcoidosis. JAMA, 327(9), 856. https://doi.org/10.1001/jama.2022.1570

Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002). Improving Primary Care for Patients With Chronic Illness. JAMA, 288(14), 1775. https://doi.org/10.1001/jama.288.14.1775

Borrell-Carrio, F. (2004). The Biopsychosocial Model 25 Years Later: Principles, Practice, and Scientific Inquiry. Annals of Family Medicine, 2(6), 576–582. https://doi.org/10.1370/afm.245

Cantamessa, M., Montagna, F., Altavilla, S., & Casagrande-Seretti, A. (2020). Data-driven design: the new challenges of digitalization on product design and development. Design Science, 6. https://doi.org/10.1017/dsj.2020.25
cardiffnlp/xlm-roberta-base-sentiment-multilingual · Hugging Face. (2022, November 30). https://huggingface.co/cardiffnlp/xlm-roberta-base-sentiment-multilingual

Celler, B. G., Lovell, N. H., & Basilakis, J. (2003). Using information technology to improve the management of chronic disease. The Medical Journal of Australia, 179(5), 242–246. https://doi.org/10.5694/j.1326-5377.2003.tb05529.x

Cox, C., Donohue, J. F., Brown, C. J., Kataria, Y. P., & Judson, M. A. (2004). Health-Related Quality of Life of Persons With Sarcoidosis. Chest, 125(3), 997–1004. https://doi.org/10.1378/chest.125.3.997

Cryer, L., Shannon, S., Van Amsterdam, M., & Leff, B. (2012). Costs For 'Hospital At Home' Patients Were 19 Percent Lower, With Equal Or Better Outcomes Compared To Similar Inpatients. Health Affairs, 31(6), 1237–1243. https://doi.org/10.1377/hlthaff.2011.1132

Drent Marjolein, Crouser, E. D., & Grunewald, J. (2021). Challenges of Sarcoidosis and Its Management. New England Journal of Medicine, 385(11), 1018–1032. https://doi.org/10.1056/nejmra2101555

Erasmus MC. (n.d.). Expertise centrum voor sarcoïdose - Erkend expertisecentrum - Erasmus MC. https://www.erasmusmc.nl/nl-nl/patientenzorg/centra/sarcoidose

Gerke, A. K. (2020). Treatment of Sarcoidosis: A Multidisciplinary Approach. Frontiers in Immunology, 11. https://doi.org/10.3389/fimmu.2020.545413

Hadid, V., Patenaude, V., Oddy, L., & Abenhaim, H. A. (2014). Sarcoidosis and pregnancy: obstetrical and neonatal outcomes in a population-based cohort of 7 million births. Journal of Perinatal Medicine, 43(2), 201–207. https://doi.org/10.1515/jpm-2014-0017

Hena, K. M., Murphy, S., Zhang, Y., Shao, Y., Kazeros, A., & Reibman, J. (2019). Clinical Evaluation of Sarcoidosis in Community Members with World Trade Center Dust Exposure. International Journal of Environmental Research and Public Health, 16(7), 1291. https://doi.org/10.3390/ijerph16071291

Illustrations | unDraw. (n.d.). https://undraw.co/illustrations

Ireland, J. J., & Wilsher, M. L. (2010). Perceptions and beliefs in sarcoidosis. PubMed, 27(1), 36–42. https://pubmed.ncbi.nlm.nih.gov/21086903

James, W. J., & Baughman, R. P. (2018). Treatment of sarcoidosis: grading the evidence. Expert Review of Clinical Pharmacology, 11(7), 677–687. https://doi.org/10.1080/17512433.2018.1486706
Joachim. (2019, September 4). Sarcoidose Centra & Organisaties [Online forum post]. Wijhebbensarcoidose.nl. https://www.wijhebbensarcoidose.nl/topic/1478-sarcoidose-centra-organisaties/

Judson, M. A. (2017). Quality of Life in Sarcoidosis. Seminars in Respiratory and Critical Care Medicine, 38(04), 546–558. https://doi.org/10.1055/s-0037-1602589

Jung, J. (2023). Developing Data-enabled Design in the Field of Digital Health. (Doctoral dissertation, Delft University of Technology, Delft, the Netherlands).

Kahlmann, V., Moor, C. K., Van Helmondt, S. J., Mostard, R. L. M., Van Der Lee, M. L., Grutters, J. C., Wijsenbeek, M. S., & Veltkamp, M. (2022). Online mindfulness-based cognitive therapy for fatigue in patients with sarcoidosis (TIRED): a randomised controlled trial. The Lancet Respiratory Medicine, 11(3), 265–272. https://doi.org/10.1016/s2213-2600(22)00387-3

Kingod, N., Cleal, B., Wahlberg, A., & Husted, G. R. (2017). Online Peer-to-Peer Communities in the Daily Lives of People With Chronic Illness. Qualitative Health Research, 27(1), 89–99. https://doi.org/10.1177/1049732316680203

Kobak, S. (2020). Regression of Sarcoidosis during Pregnancy: Case Report and Review of the Literature. Mediterranean Journal of Rheumatology, 31(4), 416. https://doi.org/10.31138/mjr.31.4.416

Koppelman, M. S. (2020). Balans… Sarcoïdose Belangenvereniging Nederland. https://sarcoidose.nl/blogs-van-marleen/balans-2/

Lazar, C. A., & Culver, D. A. (2010). Treatment of Sarcoidosis. Seminars in Respiratory and Critical Care Medicine, 31(04), 501–518. https://doi.org/10.1055/s-0030-1262218

Mijnster, B. (2022, December 22). Flagship Programs Launched - Convergence. Convergence. https://convergence.nl/flagship-programs-launched/

Millward, K., Fiddler, C. A., & Thillai, M. (2021). Update on sarcoidosis guidelines. Current Opinion in Pulmonary Medicine, 27(5), 484–489. https://doi.org/10.1097/mcp.0000000000000807

Mission & Vision - Convergence. (2022, February 9). Convergence. https://convergence.nl/convergence/mission-vision/

Moor, C. C., Gür-Demirel, Y., & Wijsenbeek, M. S. (2019). Feasibility of a Comprehensive Home Monitoring Program for Sarcoidosis. Journal of Personalized Medicine, 9(2), 23. https://doi.org/10.3390/jpm9020023

Moor, C. C., Kahlmann, V., Culver, D. A., & Wijsenbeek, M. S. (2020). Comprehensive Care for Patients with Sarcoidosis. Journal of Clinical Medicine, 9(2), 390. https://doi.org/10.3390/jcm9020390

Nederlandse Voornamen Top 10.000 « Naamkunde. (n.d.). https://www.naamkunde.net/?page_id=293&vt_list_all=true

Nunes, H., Jeny, F., Bouvry, D., Uzunhan, Y., & Valeyre, D. (2019). Indications for treatment of sarcoidosis. Current Opinion in Pulmonary Medicine, 25(5), 505–518. https://doi.org/10.1097/mcp.0000000000000604

Obi, O. N. (2020). Health-Related Quality of Life in Sarcoidosis. Seminars in Respiratory and Critical Care Medicine, 41(05), 716–732. https://doi.org/10.1055/s-0040-1710080

Obi, O. N., Lower, E. E., & Baughman, R. P. (2021). Biologic and advanced immunomodulating therapeutic options for sarcoidosis: a clinical update. Expert Review of Clinical Pharmacology, 14(2), 179–210. https://doi.org/10.1080/17512433.2021.1878024

Over Luscii. (n.d.). https://luscii.com/nl/about-us

Picker. (2023, March 14). The Picker Principles of Person Centred care - Picker. https://picker.org/who-we-are/the-picker-principles-of-person-centred-care/

Saketkoo, L. A., Escorpizo, R., Keen, K. J., Fligelstone, K., & Distler, O. (2012). International Classification of Functioning, Disability and Health Core Set construction in systemic sclerosis and other rheumatic diseases: a EUSTAR initiative. Rheumatology, 51(12), 2170–2176. https://doi.org/10.1093/rheumatology/kes185

Saketkoo, L. A., Karpinski, A. C., Young, J. E., Adell, R., Walker, M., Hennebury, T., Wickremasinghe, M., & Russell, A. (2018). Feasibility, utility and symptom impact of modified mindfulness training in sarcoidosis. ERJ Open Research, 4(2), 00085–02017. https://doi.org/10.1183/23120541.00085-2017

Saketkoo, L. A., Russell, A., Jensen, K., Mandizha, J., Tavee, J., Newton, J., Rivera, F. J., Howie, M., Reese, R. K., Goodman, M., Hart, P. L., Strookappe, B., De Vries, J., Rosenbach, M., Scholand, M. B., Lammi, M. R., Elfferich, M., Lower, E. E., Baughman, R. P., . . . Verschakelen, J. (2021). Health-Related Quality of Life (HRQoL) in Sarcoidosis: Diagnosis, Management, and Health Outcomes. Diagnostics, 11(6), 1089. https://doi.org/10.3390/diagnostics11061089

Sarcoïdose | St. Antonius Ziekenhuis. (2023, January 16). https://www.antoniusziekenhuis.nl/aandoeningen/sarcoidose#:~:text=Het%20voorkomen%20wordt%20geschat%20op,7.000%20tot%208.000%20sarco%C3%AFdosepati%C3%ABnten%20telt.

Sarcoïdose - UMC Utrecht. (n.d.). https://www.umcutrecht.nl/nl/ziekte/sarcoidose/folder#:~:text=Sarco%C3%AFdose%20heet%20ook%20wel%20de,bij%20mannen%20als%20bij%20vrouwen

Sarcoidose Belangenvereniging Nederland. (2019). Behandelcentra. Sarcoïdose Belangenvereniging Nederland. https://sarcoidose.nl/leven-met-sarcoidose/waar-kan-ik-behandeld-worden/behandelcentra/

Sarcoidose Belangenvereniging Nederland. (2023a). Sarcoidose.nl AdviesRaad. Sarcoïdose

Belangenvereniging Nederland. https://sarcoidose.nl/voor-jou/belangenbehartiging/sarcoidose-adviesraad/

Sarcoidose Belangenvereniging Nederland. (2023b). Home. Sarcoïdose Belangenvereniging Nederland. https://sarcoidose.nl/

Sarcoidose.nl. (2023). Diagnose. Sarcoïdose Belangenvereniging Nederland. https://sarcoidose.nl/over-sarcoidose/diagnose/#1554208006849-5f870880-e954

Sharp, M., Brown, T. N., Chen, E. P., Rand, C. S., Moller, D. E., & Eakin, M. N. (2019). Psychological burden associated with worse clinical outcomes in sarcoidosis. BMJ Open Respiratory Research, 6(1), e000467. https://doi.org/10.1136/bmjresp-2019-000467

Strookappe, B., Saketkoo, L. A., Elfferich, M., Holland, A. E., De Vries, J., Knevel, T., & Verschakelen, J. (2016). Physical activity and training in sarcoidosis: review and experience-based recommendations. Expert Review of Respiratory Medicine, 10(10), 1057–1068. https://doi.org/10.1080/17476348.2016.1227244

Strookappe, B., Swigris, J. J., De Vries, J., Elfferich, M., Knevel, T., & Verschakelen, J. (2015). Benefits of Physical Training in Sarcoidosis. Lung, 193(5), 701–708. https://doi.org/10.1007/s00408-015-9784-9

Tavee, J., & Culver, D. A. (2019). Nonorgan manifestations of sarcoidosis. Current Opinion in Pulmonary Medicine, 25(5), 533–538. https://doi.org/10.1097/mcp.0000000000000597

Three ways to ensure no one gets left behind in digital care. (n.d.). Business Reporter. https://www.business-reporter.co.uk/management/three-ways-to-ensure-no-one-gets-left-behind-in-digital-care

Van Helmondt, S. J., Polish, L. B., Judson, M. A., & Grutters, J. C. (2019). Patient perspectives in sarcoidosis. Current Opinion in Pulmonary Medicine, 25(5), 478–483. https://doi.org/10.1097/mcp.0000000000000602

Van Velsen, L., Nijhof, N., & Kulyk, O. (2013). Health 2.0 Emerging Technologies. ResearchGate. https://www.researchgate.net/publication/259357405_Health_20_Emerging_Technologies

Verschakelen, J., Strookappe, B., Hoitsma, E., & De Vries, J. (2015). Consequences of Sarcoidosis. Clinics in Chest Medicine, 36(4), 727–737. https://doi.org/10.1016/j.ccm.2015.08.013

Voortman, M., Hendriks, C., Elfferich, M., Bonella, F., Møller, J. K., De Vries, J. A., Costabel, U., & Verschakelen, J. (2019). The Burden of Sarcoidosis Symptoms from a Patient Perspective. Lung, 197(2), 155–161. https://doi.org/10.1007/s00408-019-00206-7

Wikipedia-bijdragers. (2023). Lijst van Nederlandse plaatsen. Wikipedia. https://nl.wikipedia.org/wiki/Lijst_van_Nederlandse_plaatsen

Ziegenhagen, M. W., Rothe, M., Schlaak, M., & Müller-Quernheim, J. (2003). Bronchoalveolar and serological parameters reflecting the severity of sarcoidosis. The European Respiratory Journal, 21(3), 407–413. https://doi.org/10.1183/09031936.03.00010403

8. Appendices

Appendix A.1 - Project brief

DESIGN FOR our future

TU Delft

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT

Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME

Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy". Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name: Kicken
initials: H.J. given name: Heleen
student number: 4645065
street & no.: --
zipcode & city: --
country: Netherlands
phone: --
email: --

Your master programme (only select the options that apply to you):
IDE master(s): ● IPD ○ DfI ○ SPD
2nd non-IDE master:
individual programme: - - (give date of approval)
honours programme: ○ Honours Programme Master
specialisation / annotation: ● Medisign
○ Tech. in Sustainable Design
○ Entrepeneurship

SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair: Richard Goossens dept. / section: HCD-AED
** mentor: Bart Bluemink dept. / section: DOS-MCR
2nd mentor: Jiwon Jung
organisation: ErasmusMC
city: Rotterdam country: Netherlands

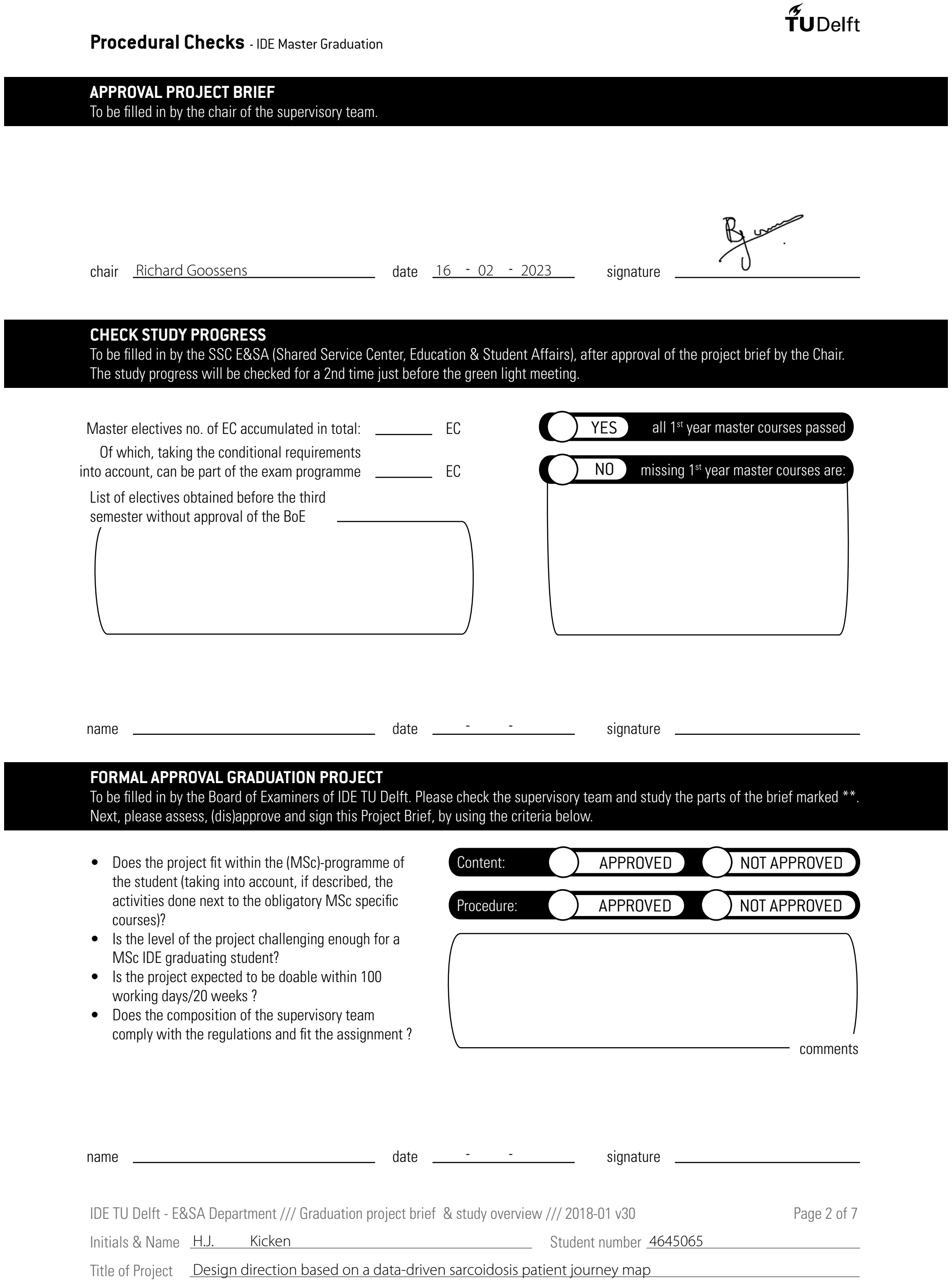
comments (optional):

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

Second mentor only applies in case the assignment is hosted by an external organisation.

Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30 Page 1 of 7



TU Delft

Procedural Checks - IDE Master Graduation

APPROVAL PROJECT BRIEF

To be filled in by the chair of the supervisory team.

chair: Richard Goossens date: 16 - 02 - 2023 signature:

CHECK STUDY PROGRESS

To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair. The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: ______ EC
Of which, taking the conditional requirements into account, can be part of the exam programme ______ EC
List of electives obtained before the third semester without approval of the BoE

○ YES all 1st year master courses passed
○ NO missing 1st year master courses are:

name: date: - - signature:

FORMAL APPROVAL GRADUATION PROJECT

To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **. Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: ○ APPROVED ○ NOT APPROVED
Procedure: ○ APPROVED ○ NOT APPROVED

comments

name: date: - - signature:

IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30 Page 2 of 7

Initials & Name: H.J. Kicken Student number: 4645065
Title of Project: Design direction based on a data-driven sarcoidosis patient journey map

Design direction based on a data-driven sarcoidosis patient journey map — 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 16 - 03 - 2023

14 - 06 - 2023 end date

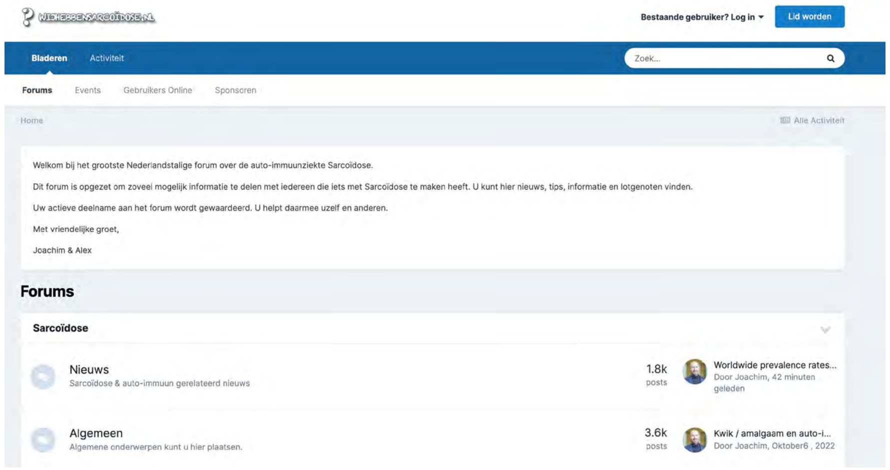
INTRODUCTION **

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, ...).

The context of this graduation project focuses on a patient with sarcoidosis, with a special focus on the lung. This is a disease characterized by the growth of tiny collections of inflammatory cells (granulomas) in any part of the body. Around 5000 to 8000 patients get diagnosed with it yearly in the Netherlands, which makes it a rare disease. It can be a one-time-only disease, re-occur more often or it can be a chronic disease. Patient experiences provide valuable information to improve the quality of care and reduce healthcare costs. Therefore, the patient, care provider, healthcare institution, health insurer, and various authorities benefit from insight into the patient's perspective. Nevertheless, the patient perspective is often only limitedly included in the current remote patient monitoring development. Conventional methodologies (like a Likert scale or interviews) to harness the value of patient experiences to develop remote patient monitoring systems are limited according to the PHD thesis of Jiwon Jung. Therefore she created the 'Community Journey Mapping' method to use digital platforms (e.g., wijhebbensarcoidose.nl) as a source of data for mapping a patient journey. This method is in collaboration with a data scientist who exports the necessary data to frame this patient journey map. A design student of the IDE faculty developed with this certain method, for a research elective, a patient journey map for sarcoidosis patients. Instead of showing the linear journey according to the Zorgpad, the complexity is shown with loops and different urgent areas. From these areas, a design intervention direction can be chosen, improve that phase for the patient. In short, this will be my graduation project.

space available for images / figures on next page

introduction (continued): space for images



Welkom bij het grootste Nederlandstalige forum over de auto-immuunziekte Sarcoïdose.

Dit forum is opgezet om zoveel mogelijk informatie te delen met iedereen die iets met Sarcoïdose te maken heeft. U kunt hier nieuws, tips, informatie en lotgenoten vinden.

Uw actieve deelname aan het forum wordt gewaardeerd. U helpt daarmee uzelf en anderen.

Met vriendelijke groet,

Joachim & Alex

Forums

Sarcoïdose

Nieuws	Sarcoïdose & auto-immuun gerelateerd nieuws	1.8k posts	Worldwide prevalence rates... Door Joachim, 42 minuten geleden
Algemeen	Algemene onderwerpen kunt u hier plaatsen.	3.6k posts	Kwik / amalgaam en auto-i... Door Joachim, Oktober6 , 2022

image / figure 1: wijhebbensarcoidose.nl

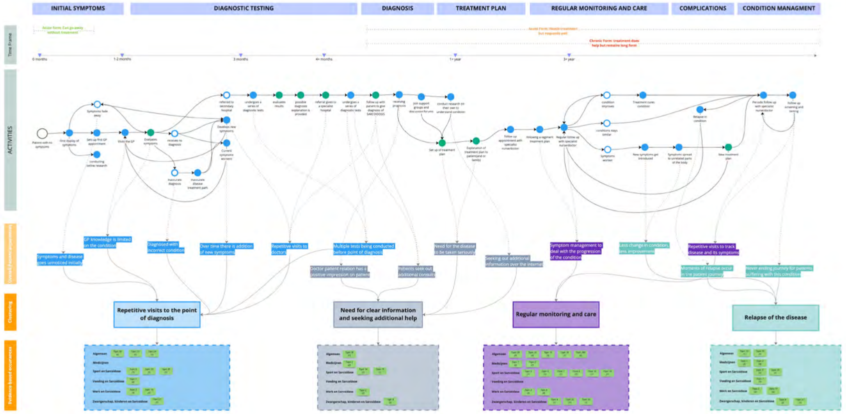


image / figure 2: Bhavika's patient journey map (student from IDE research elective)

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.

This project aims to finalise the data-based patient journey map. At this moment the map misses numbers to show the essence of certain topics and experiences. Maybe one topic is only discussed once, while others are repetitively shown on the website. Furthermore, it misses the iteration part where experts and patients state if they think this is representable and accurate, at least if it is applicable in the way they experienced it.
When these things are implemented there will be an overview of what kind of moments are urgent and need to get a closer look. Probably, there is an urge to improve a certain moment, but how? That will be analysed and looked into to what kind of design intervention is possible.

Step by step:
First, improve the patient journey map that is made by the IDE student. Increase this with more analysis of the data scientist and with a co-creation with a doctor and patient. Then the patient journey map can be finalized. Within the research elective there was already suggested to look into certain directions, this will be analysed more.

Then a certain direction will be chosen and explored more, resulting in a design intervention. This design will involve ideation with additional user studies (like interviews and co-create sessions). From there a prototype will be created for a most satisfying idea.

Lastly the feasibility testing phase. Here the 'product' will be implemented in a small number of users. This can be a mix of involving patients and the general population, depending on the completeness and aspects of exploring the prototype. But this group should fit within the Ethical criteria, thus it can be ex-patients or maybe non-patients. Then end this phase with a more iterative improvement of the intervention again based on experience feedback of using the prototype.

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.

Design an intervention to improve the journey of sarcoidosis patients in the context of Erasmus Medical Center, using the redesigned patient journey map.

I will deliver a detailed redesign of the patient journey map that gives valuable insights for doctors, patients and health insurance.
And I will design an intervention to improve the patient journey, to help patients with sarcoidosis. This design intervention will be a product/ product service that has a low - average TRLevel (because time is limited and this product will be made from scratch).

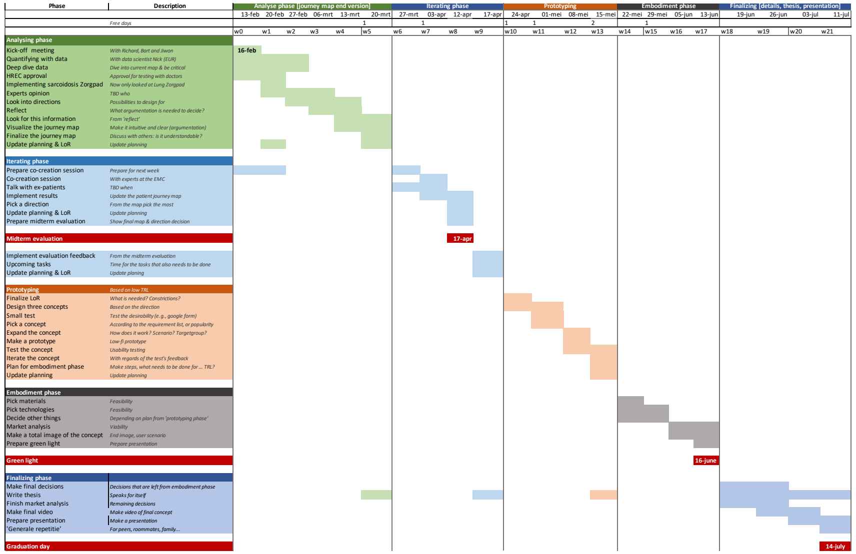
With regards to Medisign, I expect to reflect with patients and doctors on the patient journey map. Besides, I want to validate prototypes within a certain topic, with ex-patients or what is possible with regards to the HREC and METC.

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 16 - 3 - 2023

14 - 6 - 2023 end date



Phase	Description
Analysing phase	
Kick-off meeting	*With Richard, Bart and Jiwon*
Quantifying with data	*With data scientist Nick (EUR)*
Deep dive data	*Dive into current map & be critical*
HREC approval	*Approval for testing with doctors*
Implementing sarcoidosis Zorgpad	*Now only looked at Lung Zorgpad*
Experts opinion	*TBD who*
Look into directions	*Possibilities to design for*
Reflect	*What argumentation is needed to decide?*
Look for this information	*From 'reflect'*
Visualize the journey map	*Make it intuitive and clear (argumentation)*
Finalize the journey map	*Discuss with others: is it understandable?*
Update planning & LoR	*Update planning*
Iterating phase	
Prepare co-creation session	*Prepare for next week*
Co-creation session	*With experts at the EMC*
Talk with ex-patients	*TBD when*
Implement results	*Update the patient journey map*
Pick a direction	*From the map pick the most*
Update planning & LoR	*Update planning*
Prepare midterm evaluation	*Show final map & direction decision*
Midterm evaluation	
Implement evaluation feedback	*From the midterm evaluation*
Upcoming tasks	*Time for the tasks that also needs to be done*
Update planning & LoR	*Update planing*
Prototyping	*Based on low TRL*
Finalize LoR	*What is needed? Constrictions?*
Design three concepts	*Based on the direction*
Small test	*Test the desirability (e.g., google form)*
Pick a concept	*According to the requirement list, or popularity*
Expand the concept	*How does it work? Scenario? Targetgroup?*
Make a prototype	*Low-fi prototype*
Test the concept	*Usability testing*
Iterate the concept	*With regards of the test's feedback*
Plan for embodiment phase	*Make steps, what needs to be done for ... TRL?*
Update planning	*Update planning*
Embodiment phase	
Pick materials	*Feasibility*
Pick technologies	*Feasibility*
Decide other things	*Depending on plan from 'prototyping phase'*
Market analysis	*Viability*
Make a total image of the concept	*End image, user scenario*
Prepare green light	*Prepare presentation*
Green light	
Finalizing phase	
Make final decisions	*Decisions that are left from embodiment phase*
Write thesis	*Speaks for itself*
Finish market analysis	*Remaining decisions*
Make final video	*Make video of final concept*
Prepare presentation	*Make a presentation*
'Generale repetitie'	*For peers, roommates, family...*
Graduation day	

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.

My motivation for this project starts with my interest in the Medisign specialisation. I would like to improve the patient experience in a specific area. It doesn't matter to me what kind of disease or location, I just want to improve a bit.

Concerning IPD, I would like to dive into the details of the eventual prototype/ product. The embodiment phase will be limited, but with the time I have, I would like to know as much as possible about the making process, materials and details that need to be taken into account within this project.

Personal learning ambitions:
1. I would like to improve my skill in hosting co-creation sessions, to get more valuable results from these sessions. This skill can be elaborated from Contextmapping, where a brainstorming session with our client was arranged which was very valuable for the next steps.
2. I would like to learn how to test my prototype within the constraints of the hospital environment (think of Ethical and practical limitations).
3. I want to be proactive during my graduation project. I once got feedback (within ACD) that I can be passive, and let other people control a situation which limits my result therefore I aim to improve this.

FINAL COMMENTS

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

At the beginning this project brief is still very general, however this will be more specified during the project because more and more gets clear.

Appendix A.2 - Project TU Delft ethic forms and documents

Date 10-Mar-2023
Contact person Dr. Cath Cotton, Policy Advisor Academic

Human Research Ethics Committee
TU Delft
(http://hrec.tudelft.nl/)
Visiting address
Jaffalaan 5 (building 31)
2628 BX Delft
Postal address
P.O. Box 5015 2600 GA Delft
The Netherlands

Ethics Approval Application: Co-creation sessions to validate patient journey map
Applicant: Kicken, Heleen

Dear Heleen Kicken,

It is a pleasure to inform you that your application mentioned above has been approved.

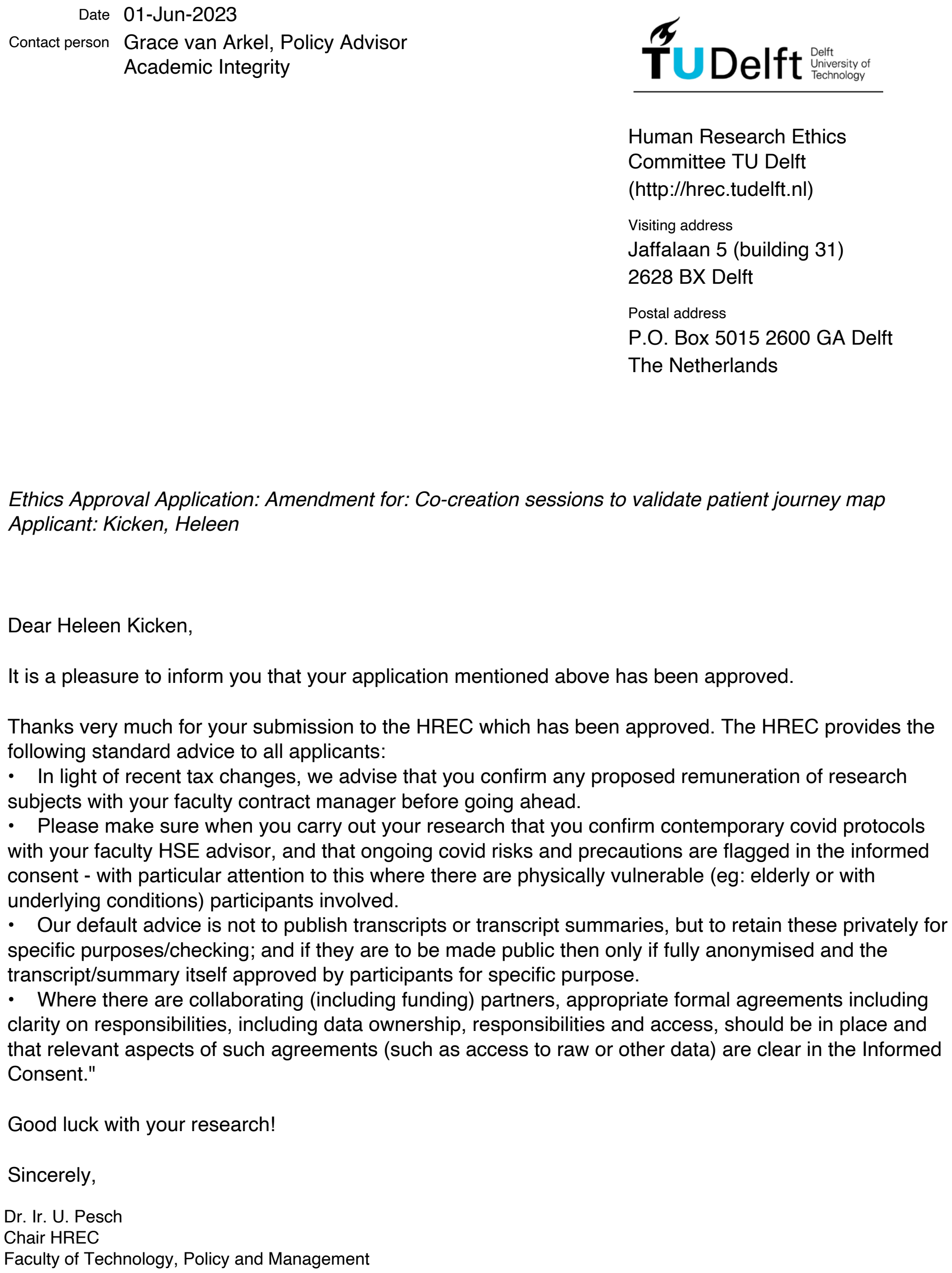
In addition to any specific conditions or notes, the HREC provides the following standard advice to all applicants:

- In light of recent tax changes, we advise that you confirm any proposed remuneration of research subjects with your faculty contract manager before going ahead.
- Please make sure when you carry out your research that you confirm contemporary covid protocols with your faculty HSE advisor, and that ongoing covid risks and precautions are flagged in the informed consent with particular attention to this where there are physically vulnerable (eg: elderly or with underlying conditions) participants involved.
- Our default advice is not to publish transcripts or transcript summaries, but to retain these privately for specific purposes/checking; and if they are to be made public then only if fully anonymised and the transcript/summary itself approved by participants for specific purpose.
- Where there are collaborating (including funding) partners, appropriate formal agreements including clarity on responsibilities, including data ownership, responsibilities and access, should be in place and that relevant aspects of such agreements (such as access to raw or other data) are clear in the Informed Consent.

Good luck with your research!

Sincerely,

Dr. Ir. U. Pesch
Chair HREC
Faculty of Technology, Policy and Management



Date 01-Jun-2023
Contact person Grace van Arkel, Policy Advisor
Academic Integrity

Human Research Ethics
Committee TU Delft
(http://hrec.tudelft.nl)
Visiting address
Jaffalaan 5 (building 31)
2628 BX Delft
Postal address
P.O. Box 5015 2600 GA Delft
The Netherlands

Ethics Approval Application: Amendment for: Co-creation sessions to validate patient journey map
Applicant: Kicken, Heleen

Dear Heleen Kicken,

It is a pleasure to inform you that your application mentioned above has been approved.

Thanks very much for your submission to the HREC which has been approved. The HREC provides the following standard advice to all applicants:
- In light of recent tax changes, we advise that you confirm any proposed remuneration of research subjects with your faculty contract manager before going ahead.
- Please make sure when you carry out your research that you confirm contemporary covid protocols with your faculty HSE advisor, and that ongoing covid risks and precautions are flagged in the informed consent - with particular attention to this where there are physically vulnerable (eg: elderly or with underlying conditions) participants involved.
- Our default advice is not to publish transcripts or transcript summaries, but to retain these privately for specific purposes/checking; and if they are to be made public then only if fully anonymised and the transcript/summary itself approved by participants for specific purpose.
- Where there are collaborating (including funding) partners, appropriate formal agreements including clarity on responsibilities, including data ownership, responsibilities and access, should be in place and that relevant aspects of such agreements (such as access to raw or other data) are clear in the Informed Consent."

Good luck with your research!

Sincerely,

Dr. Ir. U. Pesch
Chair HREC
Faculty of Technology, Policy and Management

Co-creation session for the sarcoidosis patient journey map

Thank you for participating in this research study titled Validating the sarcoidosis patient journey map with doctors and experts, from the TU Delft and the Erasmus MC.

The purpose of this research study is to validate the patient journey map that builds on anonymized online patients experiences. The co creation session will take you approximately/ maximally 90 minutes to participate. The feedback and discussion resulting from this co creation session will be used to implement it in the existing patient journey map. This way the patient journey map exists from patient experiences but also shows the medical side. Eventual the result of the patient journey map will be published in the graduation thesis. During the co creation session, we will ask you to take part of the discussion after the presentation, to get your insights and expertise on this case.

As with any online activity the risk of a breach is always possible. To the best of our ability your answers in this study will remain confidential. We will minimize any risks by implementing the results anonymous in the patient journey map.

Your participation in this study is entirely voluntary and **you can withdraw at any time.** You are free to omit any questions.

If you have some questions, you can send an email to:

the responsible researcher of this study Jiwon Jung

Or the corresponding researcher of this study Heleen Kicken

PLEASE TICK THE APPROPRIATE BOXES	**Yes**	**No**
1. I have read and understood the study information dated [27/03/2023]. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☐	☐
2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.	☐	☐
3. I understand that taking part in the study involves: - video-recorded discussion, through the Teams meeting - the recording will be used as taking notes afterwards - the recording will be destroyed at the end of this study (end of July 2023)	☐	☐
4. I understand that the following steps will be taken to minimise the threat of a data breach and protect my identity in the event of such a breach by anonymizing the implemented data: - anonymizing the discussion - saving the video recording on the SURFdrive	☐	☐
5. I understand that the (identifiable) personal data I provide will be destroyed at the end of July 2023.	☐	☐
6. I understand that after the research study the de-identified information I provide will be used for a master thesis and considering for a medical journal publication where the process will be documented.	☐	☐
7. I agree that my responses, views or other input can be quoted anonymously in research outputs	☐	☐
8. I give permission for my real name to be used for quotes in research outputs	☐	☐
9. I give permission for the de-identified completed journey map that I helped finalizing to be archived in TU Delft repository so it can be used for future research and learning.	☐	☐

Signatures

____________________________ ___________________________ _________

Name of participant Signature Date

I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

__________________________ ____________________ _________

Researcher name Signature Date

Study contact details for further information:

Heleen Kicken

Appendix B.1 - Co-creation session set-up

!All participants have signed the consent form and names can be used!

Setup

Before the session was a schedule made to time how much certain parts of the session could be (see Appendix B.2 Schedule Co-Creation Session). This schedule helped to make an estimation of the time and determine the research questions, but also what kind of materials are needed for this session. The research questions were:

1. Does the patient journey map based on open online data of patient experiences match the perspective of sarcoidosis specialists? (validation)
2. How are medical experts involved in the patient journey map at this moment? (Read: doctors, specialists, nurses)
3. How and when can medical experts be more involved in the patient journey map in the future?

The materials that are needed were:

- Patient Journey Map on an A1, with
    - Medical Journey, step by step the medical process for a patient.
    - Quantification about certain topics that are online discussed.
    - Sentiment analysis about these topics.
- Printed stickers, in this case, a doctor and nurse illustration printed that can stand on the patient journey map.
- Online Miro board, with the patient journey map, doctor stickers and instructions on what to do.
- Printed consent forms for the physical present doctors, and sent this to the online participants to sign.
- Multiple pens to write down on the patient journey map.

The presentation included the purpose of the project and co-creation session, an explanation of the derived medical journey and an explanation of the methodology behind the data analysis that is used for the patient journey map. It ended with two assignments:

1. The first one was about medical experts sticking a printed doctor or nurse on the map where they are involved now.
2. Secondly, sticking a printed doctor or nurse on the map where they think that they can mean more to the patients in the future.

During the presentation, the participants were free to ask questions and take an active role in the discussion.

Session itself

On Monday, the 27th of March the co-creation session with medical experts of Erasmus Medical Center took place. The purpose of this session was to validate the patient journey map, especially the medical journey. Besides validating also discuss and brainstorm together how the medical experts are already involved at certain moments on the map. But also how medical experts can be more involved in the future for the patient, this last point helps to scope down the process.
There were 4 participants,1 pulmonologist, 1 specialist nurse, 1 pulmonologist in training and 1 data scientist. Two participants joined online the session and two participants were physically present. See Figure B.1.1 for a visualization of the online teams meeting.

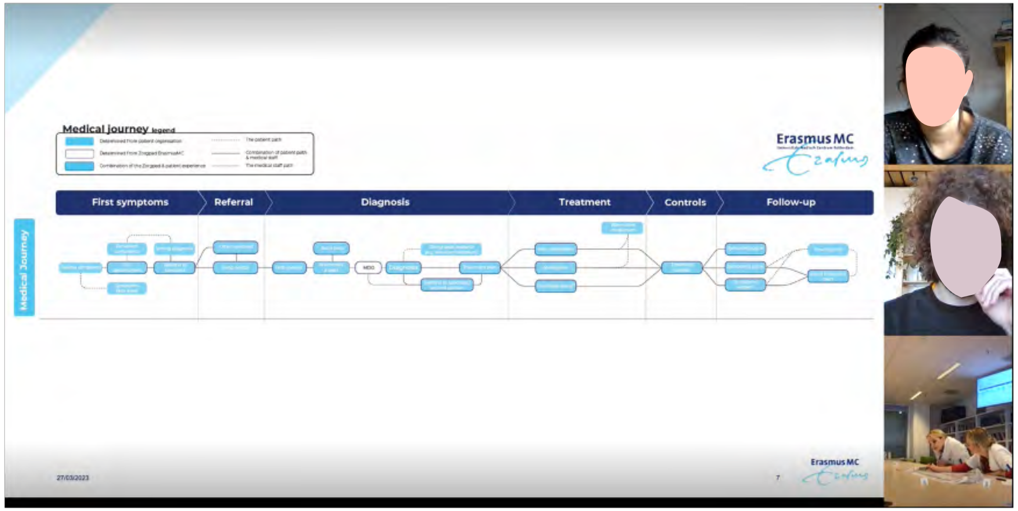


***Figure B.1.1:** Teams meeting snapshot*

Appendix B.2 - Co-creation session schedule

First co-creation session with healthcare professionals

Session work plan

Time: 1.5 hour [14:30 to 16:00]
Location: Erasmus MC, RG building and online Microsoft Teams
Participants: pulmonologists (2x), specialist nurse (1x), data scientist (1x) and designers (2x)

Research Questions:

1. Does the patient journey map based on open online data of patient experiences match the perspective of sarcoidosis specialists? (validation)
2. How are medical experts involved in the patient journey map at this moment? (Read: doctors, specialists, nurses)
3. How and when can medical experts be more involved in the patient journey map in the future?

The 5 participants in the session with expertise in sarcoidosis, patient care, hospital possibilities and limitations will result in an expert group that can validate and generate insights at the intersection of these research fields.

Time	Activity	Goal	Tasks for participants	Modality
20	**Introduction session and patient journey map**	Share: - Provide a schedule for the remainder of the session. - The research methods; - Patient journey map step by step;	Waiting for everyone to settle down & introduction by Jiwon (5min) Give a minor introduction about this session, with schedule. Look through and sign the informed consent form (5 min) Give presentation about project: show methodology (5min) and show step by step how the patient journey works (10).	PowerPoint IC form
35	**Validate patient journey map** **(First individual and group, 2x)**	Help participants to understand the timeline and to validate the patient journey map.	1. The participants will first go through the medical journey (first row). They are asked to give their opinion about comprehensiveness, truthfulness, and inclusiveness of that journey (15 min). 2. Next, the participants will go through the topic list. They get a white page with a timeline; here they can write down their expectations of the patient's feelings at certain moments (10 min). 3. Then the emotion line is shown, discuss together the differences and similarities (10 min).	Big patient journey map. (Physical and Miro version) Page with questions to ask Pages with empty emotion line (Physical and Miro version) Transparent page with the emotion line drawn on it (Physical and Miro version)
20	**Identify the current need's and how the hospital is involved** **(Group)**	Discussion if the hospital is involved and how the hospital can be involved at certain moments for the patients in the future.	1. The participants are asked to give input on how at certain emotions/ moments the hospital is involved at this moment. It is a group brainstorm session; they can write down on post-its (15 min). 2. Then the participants are asked to brainstorm how the hospital can be involved in certain emotions/ moments in the future. Think as a doctor, but later think as a social worker, or psychologist. Again, group brainstorm session, and write down on post-its (15 min)	One big patient journey map with involvement row (now and future) (Physical and Miro version) Post-its, 2 colors
5	**Closing remarks**	Close the session and thank the participants		

Materials needs to be prepared – Booklets to be handed out:

1. PowerPoint with:
    a. Introduction
    b. Methodology
    c. Patient journey map
    d. Explanation assignment
2. Questions to ask on the presentation
3. Printed:

   a. IC forms printed (4x)
   b. Big Patient Journey Map, with involvement row (present and future) (1x)
   c. Stickers for nurse and doctor
4. Send online IC form to Vivienne and Nick
5. Miro:
   a. Big Patient Journey Map, with involvement row
   b. Tabloid with emoticons
   c. Tabloid with instructions

Planning:

1. Thursday (TU Delft):
   a. Prepare PowerPoint (1abcd)
   b. Update Patient Journey Map
2. Friday (TU Delft):
   a. Finish Patient Journey Map (3b & 6a)
   b. Prepare and finish Miro board (6abc)
3. Monday (EMC):
   a. Print Patient Journey Map
   b. Finish PowerPoint with Jiwon
   c. Send online IC form to Vivienne (4)
   d. Print IC forms (3a)
   e. Print stickers

Appendix B.3 - Co-creation session feedback

The medical experts gave input on the Patient Journey Map, see Figures B.3.1 and B.3.2 for the online and physical comments.

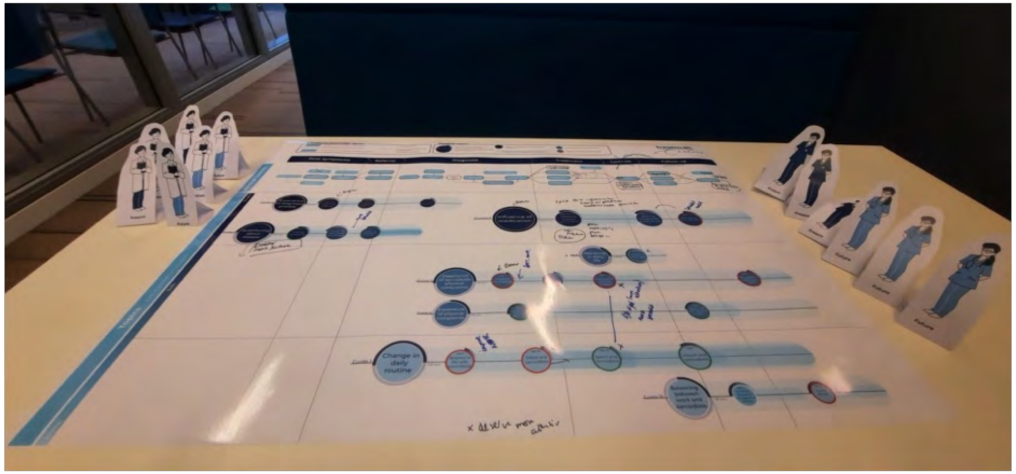


Figure B.3.1: Physical Patient Journey Map with medical specialists' remarks

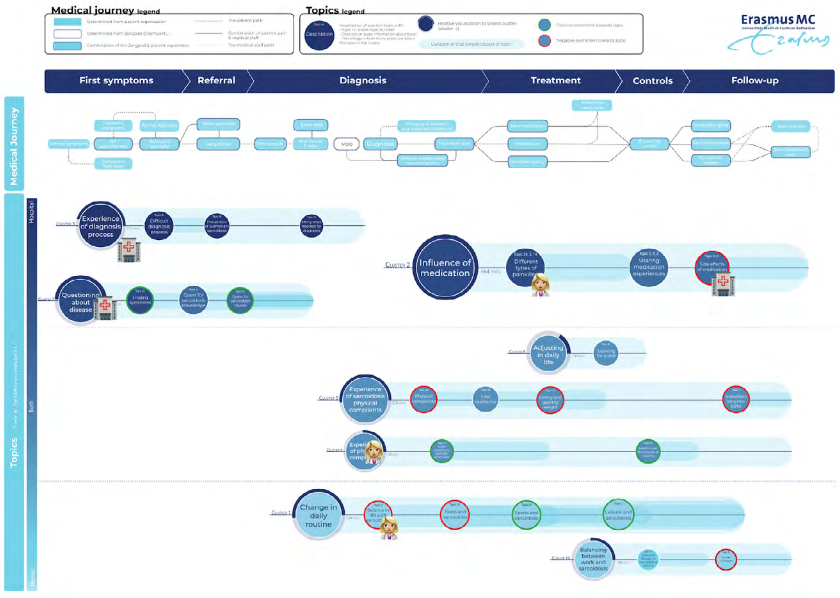
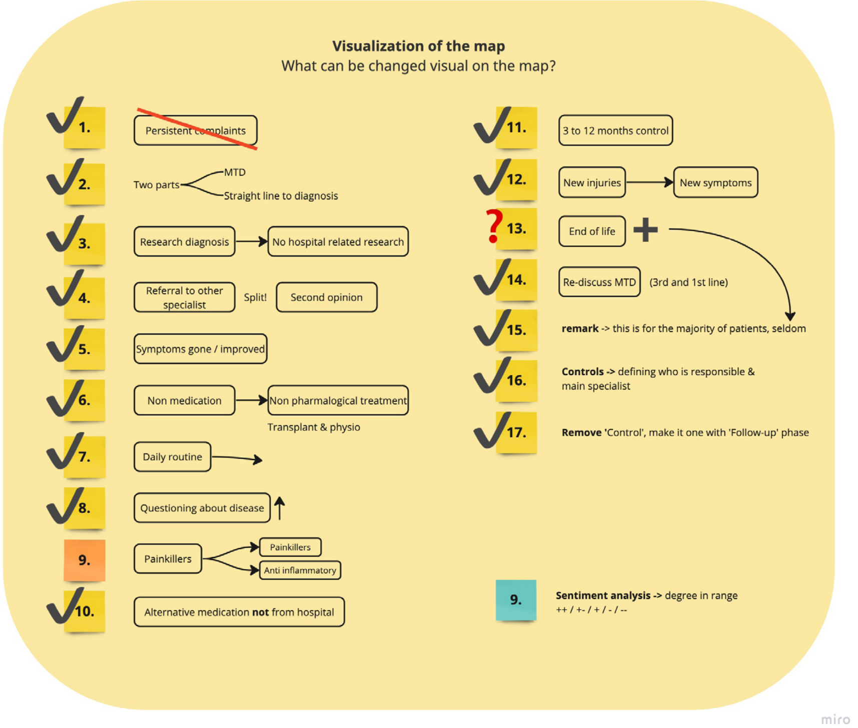


Figure B.3.2: Online Patient Journey Map with medical specialist's remarks, a snapshot from Miro

Feedback from session

The concluding feedback from this session was:

1. Update the visualization of the map, this included mainly the medical journey row and some alterations in the big topic row.
2. Expanding the data analysis, including mainly an addition to the topics that were included and some more details on certain topics.
3. The next steps for validating the patient journey map. The eventual conclusion is to validate it with two parts, namely:
    a. 1 co-creation session with patients from wijhebbensarcoidose.nl
    b. 1 questionnaire for sarcoidose.nl about the topics
4. Scope directions for the future process suggested a self-management tool for patients at home or a better informative first consult with sarcoidosis patients.

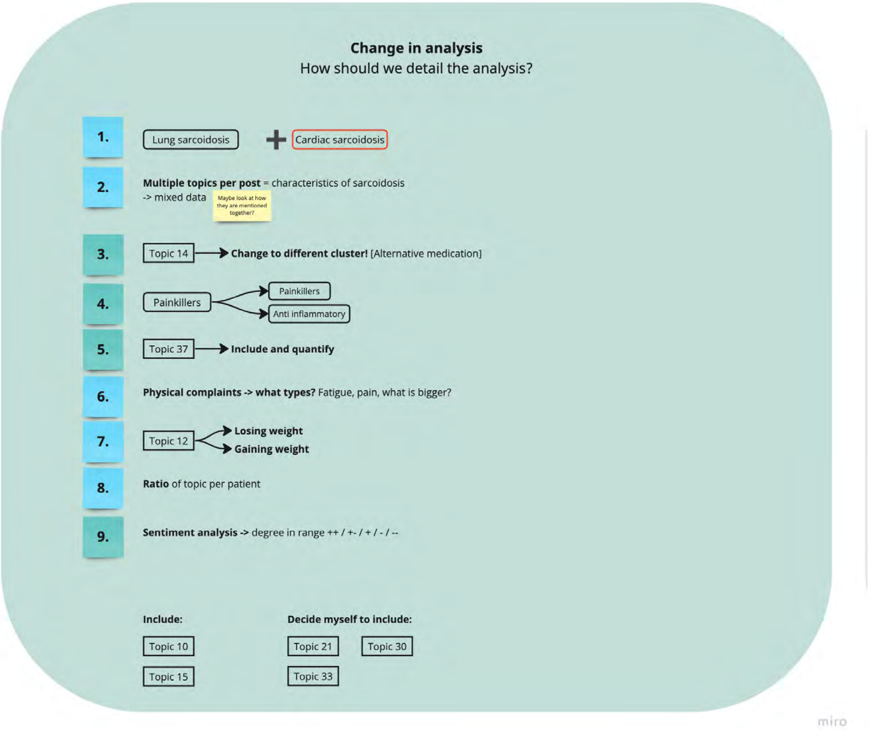


Visualization of the map
What can be changed visual on the map?

✓ 1. ~~Persistent complaints~~
✓ 2. Two parts → MTD / Straight line to diagnosis
✓ 3. Research diagnosis → No hospital related research
✓ 4. Referral to other specialist — Split! — Second opinion
✓ 5. Symptoms gone / improved
✓ 6. Non medication → Non pharmalogical treatment
Transplant & physio
✓ 7. Daily routine →
✓ 8. Questioning about disease ↑
9. Painkillers → Painkillers / Anti inflammatory
✓ 10. Alternative medication **not** from hospital
✓ 11. 3 to 12 months control
✓ 12. New injuries → New symptoms
? 13. End of life +
✓ 14. Re-discuss MTD (3rd and 1st line)
✓ 15. **remark** -> this is for the majority of patients, seldom
✓ 16. **Controls** -> defining who is responsible & main specialist
✓ 17. **Remove** 'Control', make it one with 'Follow-up' phase
9. **Sentiment analysis** -> degree in range ++ / +- / + / - / --

miro

Figure B.3.3: *Changes for: visualization of the map, after receiving the feedback.*



Change in analysis
How should we detail the analysis?

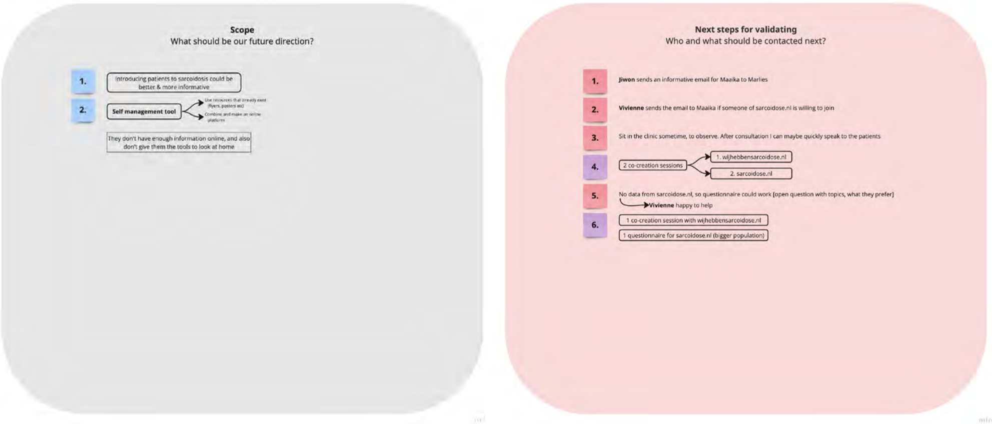
1. Lung sarcoidosis + Cardiac sarcoidosis
2. **Multiple topics per post** = characteristics of sarcoidosis -> mixed data
Maybe look at how they are mentioned together?
3. Topic 14 → **Change to different cluster!** [Alternative medication]
4. Painkillers → Painkillers / Anti inflammatory
5. Topic 37 → **Include and quantify**
6. **Physical complaints -> what types?** Fatigue, pain, what is bigger?
7. Topic 12 → **Losing weight** / **Gaining weight**
8. **Ratio** of topic per patient
9. **Sentiment analysis** -> degree in range ++ / +- / + / - / --

Include:
Topic 10
Topic 15

Decide myself to include:
Topic 21
Topic 30
Topic 33

miro

Figure B.3.4: *Changes for: change in analysis, after receiving the feedback.*



Scope
What should be our future direction?

1. Introducing patients to sarcoidosis could be better & more informative
2. **Self management tool** → Use resources that already exist (flyers, posters etc) / Combine and make an online platform
They don't have enough information online, and also don't give them the tools to look at home

Next steps for validating
Who and what should be contacted next?

1. **Jiwon** sends an informative email for Maaika to Marlies
2. **Vivienne** sends the email to Maaika if someone of sarcoidose.nl is willing to join
3. Sit in the clinic sometime, to observe. After consultation I can maybe quickly speak to the patients
4. 2 co-creation sessions → 1. wijhebbensarcoidose.nl / 2. sarcoidose.nl
5. No data from sarcoidose.nl, so questionnaire could work [open question with topics, what they prefer]
→ **Vivienne** happy to help
6. 1 co-creation session with wijhebbensarcoidose.nl
1 questionnaire for sarcoidose.nl (bigger population)

Figure B.3.5: *Changes for: (left) scope and (right) next steps, after receiving the feedback.*

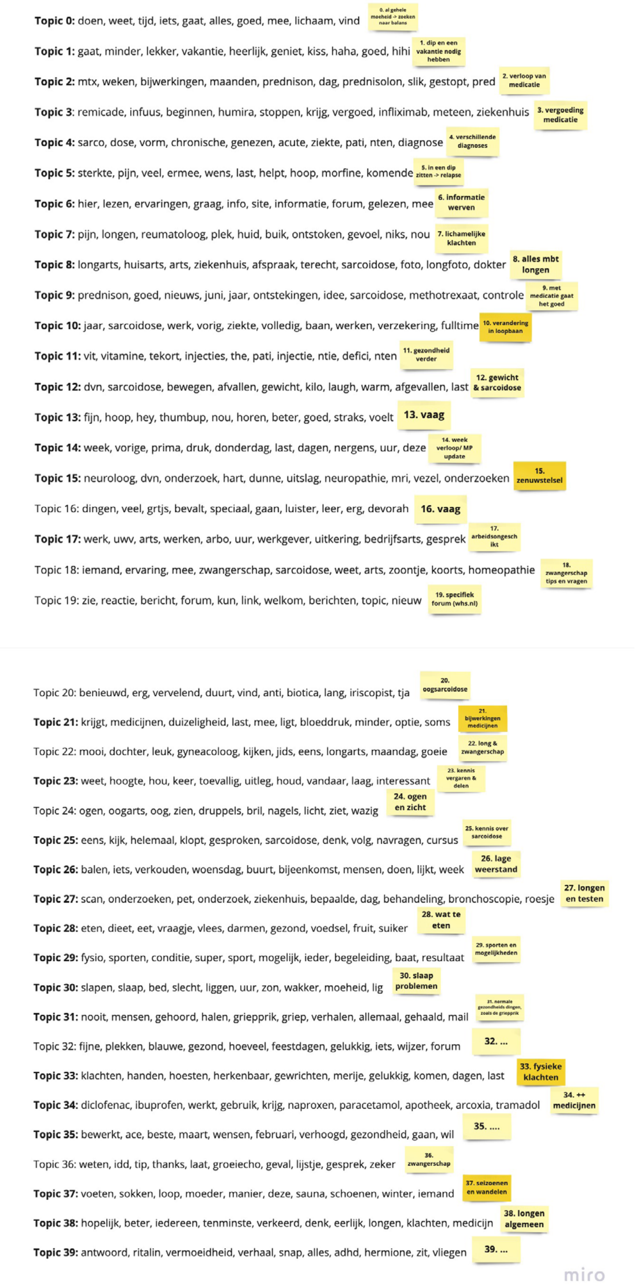
Appendix C.1 - Data analysis, excluded word list

For topic listing

Okkie

Arie
Bianca
Astrid
Hoi
Groetjes
Groeten
Dank
Bedankt
Ja
Nee
Bieke
Marshall
Jerry
Sorry
Hallo
Groet
Succes
Nijmegen
Maastricht
Nieuwegein
Drent

Appendix C.2 - Data analysis, keywords topic list



Topic 0: doen, weet, tijd, iets, gaat, alles, goed, mee, lichaam, vind
0. al gehele moeheid -> zoeken naar balans

Topic 1: gaat, minder, lekker, vakantie, heerlijk, geniet, kiss, haha, goed, hihi
1. dip en een vakantie nodig hebben

Topic 2: mtx, weken, bijwerkingen, maanden, prednison, dag, prednisolon, slik, gestopt, pred
2. verloop van medicatie

Topic 3: remicade, infuus, beginnen, humira, stoppen, krijg, vergoed, infliximab, meteen, ziekenhuis
3. vergoeding medicatie

Topic 4: sarco, dose, vorm, chronische, genezen, acute, ziekte, pati, nten, diagnose
4. verschillende diagnoses

Topic 5: sterkte, pijn, veel, ermee, wens, last, helpt, hoop, morfine, komende
5. in een dip zitten -> relapse

Topic 6: hier, lezen, ervaringen, graag, info, site, informatie, forum, gelezen, mee
6. informatie werven

Topic 7: pijn, longen, reumatoloog, plek, huid, buik, ontstoken, gevoel, niks, nou
7. lichamelijke klachten

Topic 8: longarts, huisarts, arts, ziekenhuis, afspraak, terecht, sarcoidose, foto, longfoto, dokter
8. alles mbt longen

Topic 9: prednison, goed, nieuws, juni, jaar, ontstekingen, idee, sarcoidose, methotrexaat, controle
9. met medicatie gaat het goed

Topic 10: jaar, sarcoidose, werk, vorig, ziekte, volledig, baan, werken, verzekering, fulltime
10. verandering in loopbaan

Topic 11: vit, vitamine, tekort, injecties, the, pati, injectie, ntie, defici, nten
11. gezondheid verder

Topic 12: dvn, sarcoidose, bewegen, afvallen, gewicht, kilo, laugh, warm, afgevallen, last
12. gewicht & sarcoidose

Topic 13: fijn, hoop, hey, thumbup, nou, horen, beter, goed, straks, voelt
13. vaag

Topic 14: week, vorige, prima, druk, donderdag, last, dagen, nergens, uur, deze
14. week verloop/ MP update

Topic 15: neuroloog, dvn, onderzoek, hart, dunne, uitslag, neuropathie, mri, vezel, onderzoeken
15. zenuwstelsel

Topic 16: dingen, veel, grtjs, bevalt, speciaal, gaan, luister, leer, erg, devorah
16. vaag

Topic 17: werk, uwv, arts, werken, arbo, uur, werkgever, uitkering, bedrijfsarts, gesprek
17. arbeidsongeschikt

Topic 18: iemand, ervaring, mee, zwangerschap, sarcoidose, weet, arts, zoontje, koorts, homeopathie
18. zwangerschap tips en vragen

Topic 19: zie, reactie, bericht, forum, kun, link, welkom, berichten, topic, nieuw
19. specifiek forum (whs.nl)

Topic 20: benieuwd, erg, vervelend, duurt, vind, anti, biotica, lang, iriscopist, tja
20. oogsarcoidose

Topic 21: krijgt, medicijnen, duizeligheid, last, mee, ligt, bloeddruk, minder, optie, soms
21. bijwerkingen medicijnen

Topic 22: mooi, dochter, leuk, gyneacoloog, kijken, jids, eens, longarts, maandag, goeie
22. long & zwangerschap

Topic 23: weet, hoogte, hou, keer, toevallig, uitleg, houd, vandaar, laag, interessant
23. kennis vergaren & delen

Topic 24: ogen, oogarts, oog, zien, druppels, bril, nagels, licht, ziet, wazig
24. ogen en zicht

Topic 25: eens, kijk, helemaal, klopt, gesproken, sarcoidose, denk, volg, navragen, cursus
25. kennis over sarcoidose

Topic 26: balen, iets, verkouden, woensdag, buurt, bijeenkomst, mensen, doen, lijkt, week
26. lage weerstand

Topic 27: scan, onderzoeken, pet, onderzoek, ziekenhuis, bepaalde, dag, behandeling, bronchoscopie, roesje
27. longen en testen

Topic 28: eten, dieet, eet, vraagje, vlees, darmen, gezond, voedsel, fruit, suiker
28. wat te eten

Topic 29: fysio, sporten, conditie, super, sport, mogelijk, ieder, begeleiding, baat, resultaat
29. sporten en mogelijkheden

Topic 30: slapen, slaap, bed, slecht, liggen, uur, zon, wakker, moeheid, lig
30. slaap problemen

Topic 31: nooit, mensen, gehoord, halen, griepprik, griep, verhalen, allemaal, gehaald, mail
31. normale gezondheids dingen, zoals de griepprik

Topic 32: fijne, plekken, blauwe, gezond, hoeveel, feestdagen, gelukkig, iets, wijzer, forum
32. ...

Topic 33: klachten, handen, hoesten, herkenbaar, gewrichten, merije, gelukkig, komen, dagen, last
33. fysieke klachten

Topic 34: diclofenac, ibuprofen, werkt, gebruik, krijg, naproxen, paracetamol, apotheek, arcoxia, tramadol
34. ++ medicijnen

Topic 35: bewerkt, ace, beste, maart, wensen, februari, verhoogd, gezondheid, gaan, wil
35. ....

Topic 36: weten, idd, tip, thanks, laat, groeiecho, geval, lijstje, gesprek, zeker
36. zwangerschap

Topic 37: voeten, sokken, loop, moeder, manier, deze, sauna, schoenen, winter, iemand
37. seizoenen en wandelen

Topic 38: hopelijk, beter, iedereen, tenminste, verkeerd, denk, eerlijk, longen, klachten, medicijn
38. longen algemeen

Topic 39: antwoord, ritalin, vermoeidheid, verhaal, snap, alles, adhd, hermione, zit, vliegen
39. ...

Appendix C.3 - Data analysis, manually excluded topics

Reasons to exclude certain topics based on:

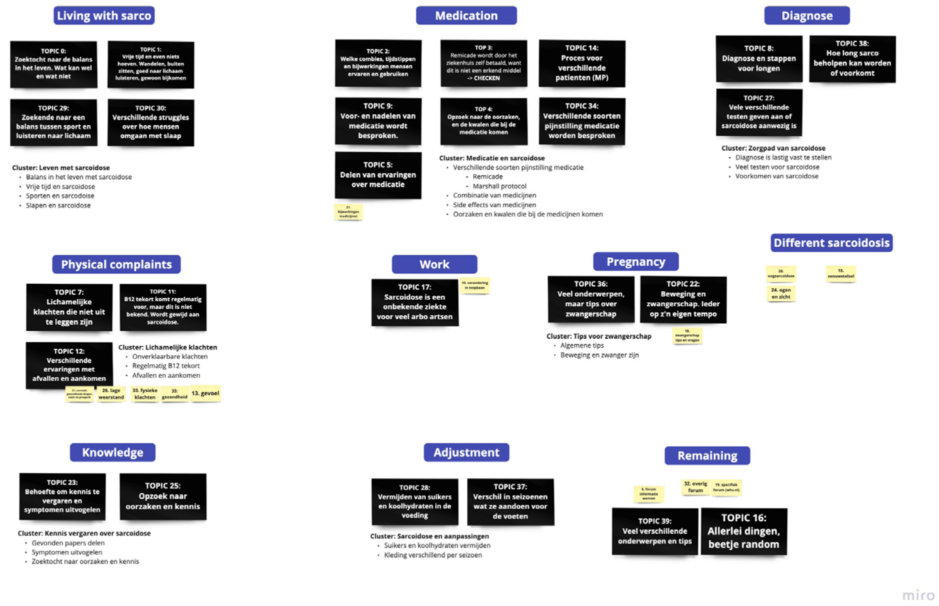
- Everything related to the forum:
    - Specific questions about buttons/ functions/ topics, like topic 19
- Topics that are not about sarcoidosis or health:
    - For example, topic 32 is about Christmas and wishing everybody a Merry Christmas.
    - But also topic 16 where patients are more chatting with each other.
- Topics that are very specific about pregnancy:
    - According to the specialist nurse pregnancy is not a characteristic that changes for the patients. The only thing is to know beforehand if the patient wants to become pregnant, this influences the medication treatment. This would be topics 18, 22 and 36.

Include (on second thought):

- Topics about specific eye sarcoidosis:
    - This would be topic 20 in general for eye sarcoidosis
    - Also topic 24 about eyes and sights.

Appendix C.4 - Data analysis, topics clustered

First clustering



Living with sarco

TOPIC 0: Zoektocht naar de balans in het leven. Wat kan wel en wat niet

TOPIC 1: Vrije tijd en even niets hoeven. Wandelen, buiten zitten, goed naar lichaam luisteren, gewoon bijkomen

TOPIC 29: Zoekende naar een balans tussen sport en luisteren naar lichaam

TOPIC 30: Verschillende struggles over hoe mensen omgaan met slaap

Cluster: Leven met sarcoidose
- Balans in het leven met sarcoidose
- Vrije tijd en sarcoidose
- Sporten en sarcodoise
- Slapen en sarcoidose

Medication

TOPIC 2: Welke combies, tijdstippen en bijwerkingen mensen ervaren en gebruiken

TOP 3: Remicade wordt door het ziekenhuis zelf betaald, want dit is niet een erkend middel -> CHECKEN

TOPIC 14: Proces voor verschillende patienten (MP)

TOPIC 9: Voor- en nadelen van medicatie wordt besproken.

TOP 4: Opzoek naar de oorzaken, en de kwalen die bij de medicatie komen

TOPIC 34: Verschillende soorten pijnstilling medicatie worden besproken

TOPIC 5: Delen van ervaringen over medicatie

21. bijwerkingen medicijnen

Cluster: Medicatie en sarcoidose
- Verschillende soorten pijnstilling medicatie
  - Remicade
  - Marshall protocol
- Combinatie van medicijnen
- Side effects van medicijnen
- Oorzaken en kwalen die bij de medicijnen komen

Diagnose

TOPIC 8: Diagnose en stappen voor longen

TOPIC 38: Hoe long sarco beholpen kan worden of voorkomt

TOPIC 27: Vele verschillende testen geven aan of sarcoidose aanwezig is

Cluster: Zorgpad van sarcoidose
- Diagnose is lastig vast te stellen
- Veel testen voor sarcoidose
- Voorkomen van sarcoidose

Different sarcoidosis

20. oogsarcoidose

15. zenuwstelsel

24. ogen en zicht

Physical complaints

TOPIC 7: Lichamelijke klachten die niet uit te leggen zijn

TOPIC 11: B12 tekort komt regelmatig voor, maar dit is niet bekend. Wordt gewijd aan sarcoidose.

TOPIC 12: Verschillende ervaringen met afvallen en aankomen

Cluster: Lichamelijke klachten
- Onverklaarbare klachten
- Regelmatig B12 tekort
- Afvallen en aankomen

31. normale gezondheids dingen, zoals de griepprik

26. lage weerstand

33. fysieke klachten

35: gezondheid

13. gevoel

Work

TOPIC 17: Sarcoidose is een onbekende ziekte voor veel arbo artsen

10. verandering in loopbaan

Pregnancy

TOPIC 36: Veel onderwerpen, maar tips over zwangerschap

TOPIC 22: Beweging en zwangerschap. Ieder op z'n eigen tempo

18. zwangerschap tips en vragen

Cluster: Tips voor zwangerschap
- Algemene tips
- Beweging en zwanger zijn

Knowledge

TOPIC 23: Behoefte om kennis te vergaren en symptomen uitvogelen

TOPIC 25: Opzoek naar oorzaken en kennis

Cluster: Kennis vergaren over sarcoidose
- Gevonden papers delen
- Symptomen uitvogelen
- Zoektocht naar oorzaken en kennis

Adjustment

TOPIC 28: Vermijden van suikers en koolhydraten in de voeding

TOPIC 37: Verschil in seizoenen wat ze aandoen voor de voeten

Cluster: Sarcoidose en aanpassingen
- Suikers en koolhydraten vermijden
- Kleding verschillend per seizoen

Remaining

6. forum informatie werven

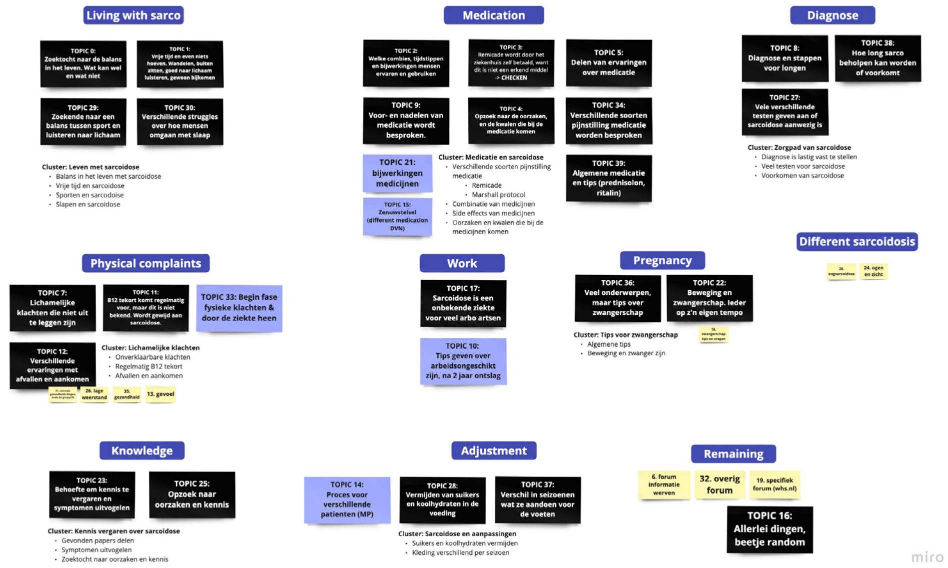
32. overig forum

19. specifiek forum (whs.nl)

TOPIC 39: Veel verschillende onderwerpen en tips

TOPIC 16: Allerlei dingen, beetje random

Second clustering



Living with sarco

TOPIC 0: Zoektocht naar de balans in het leven. Wat kan wel en wat niet

TOPIC 1: Vrije tijd en even niets hoeven. Wandelen, buiten zitten, goed naar lichaam luisteren, gewoon bijkomen

TOPIC 29: Zoekende naar een balans tussen sport en luisteren naar lichaam

TOPIC 30: Verschillende struggles over hoe mensen omgaan met slaap

Cluster: Leven met sarcoidose
- Balans in het leven met sarcoidose
- Vrije tijd en sarcoidose
- Sporten en sarcodoise
- Slapen en sarcoidose

Medication

TOPIC 2: Welke combies, tijdstippen en bijwerkingen mensen ervaren en gebruiken

TOPIC 3: Remicade wordt door het ziekenhuis zelf betaald, want dit is niet een erkend middel -> CHECKEN

TOPIC 5: Delen van ervaringen over medicatie

TOPIC 9: Voor- en nadelen van medicatie wordt besproken.

TOPIC 4: Opzoek naar de oorzaken, en de kwalen die bij de medicatie komen

TOPIC 34: Verschillende soorten pijnstilling medicatie worden besproken

TOPIC 21: bijwerkingen medicijnen

TOPIC 15: Zenuwstelsel (different medication DVN)

TOPIC 39: Algemene medicatie en tips (prednisolon, ritalin)

Cluster: Medicatie en sarcoidose
- Verschillende soorten pijnstilling medicatie
  - Remicade
  - Marshall protocol
- Combinatie van medicijnen
- Side effects van medicijnen
- Oorzaken en kwalen die bij de medicijnen komen

Diagnose

TOPIC 8: Diagnose en stappen voor longen

TOPIC 38: Hoe long sarco beholpen kan worden of voorkomt

TOPIC 27: Vele verschillende testen geven aan of sarcoidose aanwezig is

Cluster: Zorgpad van sarcoidose
- Diagnose is lastig vast te stellen
- Veel testen voor sarcoidose
- Voorkomen van sarcoidose

Different sarcoidosis

20. oogsarcoidose

24. ogen en zicht

Physical complaints

TOPIC 7: Lichamelijke klachten die niet uit te leggen zijn

TOPIC 11: B12 tekort komt regelmatig voor, maar dit is niet bekend. Wordt gewijd aan sarcoidose.

TOPIC 33: Begin fase fysieke klachten & door de ziekte heen

TOPIC 12: Verschillende ervaringen met afvallen en aankomen

Cluster: Lichamelijke klachten
- Onverklaarbare klachten
- Regelmatig B12 tekort
- Afvallen en aankomen

31. normale gezondheids dingen, zoals de griepprik

26. lage weerstand

35: gezondheid

13. gevoel

Work

TOPIC 17: Sarcoidose is een onbekende ziekte voor veel arbo artsen

TOPIC 10: Tips geven over arbeidsongeschikt zijn, na 2 jaar ontslag

Pregnancy

TOPIC 36: Veel onderwerpen, maar tips over zwangerschap

TOPIC 22: Beweging en zwangerschap. Ieder op z'n eigen tempo

18. zwangerschap tips en vragen

Cluster: Tips voor zwangerschap
- Algemene tips
- Beweging en zwanger zijn

Knowledge

TOPIC 23: Behoefte om kennis te vergaren en symptomen uitvogelen

TOPIC 25: Opzoek naar oorzaken en kennis

Cluster: Kennis vergaren over sarcoidose
- Gevonden papers delen
- Symptomen uitvogelen
- Zoektocht naar oorzaken en kennis

Adjustment

TOPIC 14: Proces voor verschillende patienten (MP)

TOPIC 28: Vermijden van suikers en koolhydraten in de voeding

TOPIC 37: Verschil in seizoenen wat ze aandoen voor de voeten

Cluster: Sarcoidose en aanpassingen
- Suikers en koolhydraten vermijden
- Kleding verschillend per seizoen

Remaining

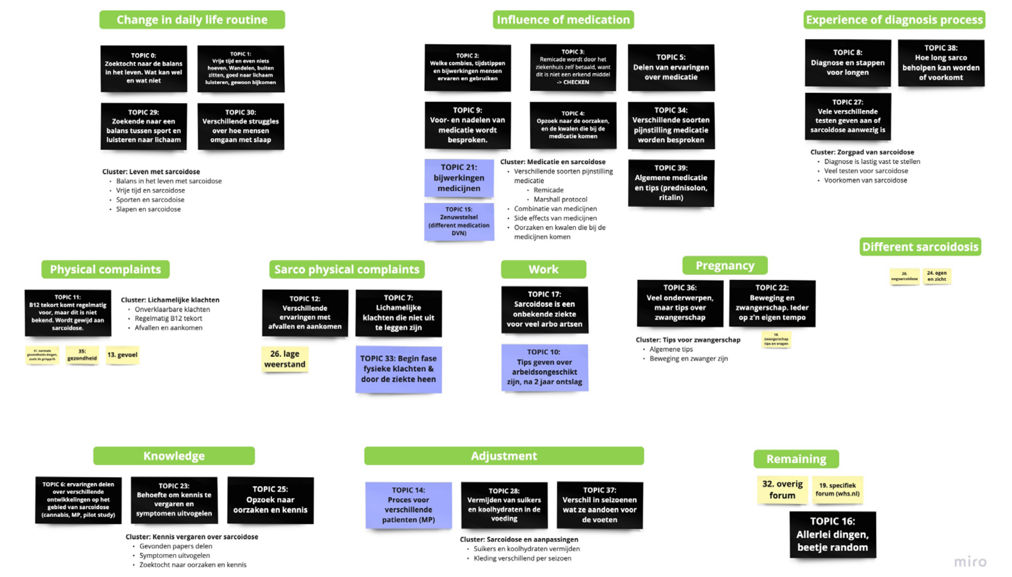
6. forum informatie werven

32. overig forum

19. specifiek forum (whs.nl)

TOPIC 16: Allerlei dingen, beetje random

Third clustering



Change in daily life routine

TOPIC 0: Zoektocht naar de balans in het leven. Wat kan wel en wat niet

TOPIC 1: Vrije tijd en even niets hoeven. Wandelen, buiten zitten, goed naar lichaam luisteren, gewoon bijkomen

TOPIC 29: Zoekende naar een balans tussen sport en luisteren naar lichaam

TOPIC 30: Verschillende struggles over hoe mensen omgaan met slaap

Cluster: Leven met sarcoidose
- Balans in het leven met sarcoidose
- Vrije tijd en sarcoidose
- Sporten en sarcodoise
- Slapen en sarcoidose

Influence of medication

TOPIC 2: Welke combies, tijdstippen en bijwerkingen mensen ervaren en gebruiken

TOPIC 3: Remicade wordt door het ziekenhuis zelf betaald, want dit is niet een erkend middel -> CHECKEN

TOPIC 5: Delen van ervaringen over medicatie

TOPIC 9: Voor- en nadelen van medicatie wordt besproken.

TOPIC 4: Opzoek naar de oorzaken, en de kwalen die bij de medicatie komen

TOPIC 34: Verschillende soorten pijnstilling medicatie worden besproken

TOPIC 21: bijwerkingen medicijnen

TOPIC 15: Zenuwstelsel (different medication DVN)

TOPIC 39: Algemene medicatie en tips (prednisolon, ritalin)

Cluster: Medicatie en sarcoidose
- Verschillende soorten pijnstilling medicatie
  - Remicade
  - Marshall protocol
- Combinatie van medicijnen
- Side effects van medicijnen
- Oorzaken en kwalen die bij de medicijnen komen

Experience of diagnosis process

TOPIC 8: Diagnose en stappen voor longen

TOPIC 38: Hoe long sarco beholpen kan worden of voorkomt

TOPIC 27: Vele verschillende testen geven aan of sarcoidose aanwezig is

Cluster: Zorgpad van sarcoidose
- Diagnose is lastig vast te stellen
- Veel testen voor sarcoidose
- Voorkomen van sarcoidose

Different sarcoidosis

20. oogsarcoidose

24. ogen en zicht

Physical complaints

TOPIC 11: B12 tekort komt regelmatig voor, maar dit is niet bekend. Wordt gewijd aan sarcoidose.

Cluster: Lichamelijke klachten
- Onverklaarbare klachten
- Regelmatig B12 tekort
- Afvallen en aankomen

31. normale gezondheids dingen, zoals de griepprik

35: gezondheid

13. gevoel

Sarco physical complaints

TOPIC 12: Verschillende ervaringen met afvallen en aankomen

TOPIC 7: Lichamelijke klachten die niet uit te leggen zijn

26. lage weerstand

TOPIC 33: Begin fase fysieke klachten & door de ziekte heen

Work

TOPIC 17: Sarcoidose is een onbekende ziekte voor veel arbo artsen

TOPIC 10: Tips geven over arbeidsongeschikt zijn, na 2 jaar ontslag

Pregnancy

TOPIC 36: Veel onderwerpen, maar tips over zwangerschap

TOPIC 22: Beweging en zwangerschap. Ieder op z'n eigen tempo

18. zwangerschap tips en vragen

Cluster: Tips voor zwangerschap
- Algemene tips
- Beweging en zwanger zijn

Knowledge

TOPIC 6: ervaringen delen over verschillende ontwikkelingen op het gebied van sarcoidose (cannabis, MP, pilot study)

TOPIC 23: Behoefte om kennis te vergaren en symptomen uitvogelen

TOPIC 25: Opzoek naar oorzaken en kennis

Cluster: Kennis vergaren over sarcoidose
- Gevonden papers delen
- Symptomen uitvogelen
- Zoektocht naar oorzaken en kennis

Adjustment

TOPIC 14: Proces voor verschillende patienten (MP)

TOPIC 28: Vermijden van suikers en koolhydraten in de voeding

TOPIC 37: Verschil in seizoenen wat ze aandoen voor de voeten

Cluster: Sarcoidose en aanpassingen
- Suikers en koolhydraten vermijden
- Kleding verschillend per seizoen

Remaining

32. overig forum

19. specifiek forum (whs.nl)

TOPIC 16: Allerlei dingen, beetje random

Appendix C.5 - Data analysis, quantification of topics within clusters

In Excel is an overview made with the quantification per topic.

Old nr.	New nr.		Clusters	Topic	Frequency	Percentage in cluster	Cluster percentage in total	Percentage inside the cluster
1	**2**	**Change in daily life routine**	Balance in life with sarcoidosis	0	210	26,7	3,33	26,68
			Leisure and sarcoidosis	1	245	31,1	3,88	31,13
			Sports and sarcoidosis	29	182	23,1	2,88	23,13
			Sleep and sarcoidosis	30	150	19,1	2,38	19,06
			Total		**787**	**100,0**	**12,46**	**100**
2	**1**	**Influence of medication**	Different types of pain relief	34	179	9,7	9,99	9,71
			Treatment plan: Remicade	3	241	13,1	^	13,07
			Medication combined with DVN	15	211	11,4	^	11,44
			Side effects with medication:	4, 2, 21	626	33,9		33,95
			- Side effects of medication	21	164			
			- Combination of medication & side effects	2	262			
			- Side effects with medication	4	200			
			Medication experiences:	5, 9, 39	587	31,8		31,83
			- Medication experiences	5	235			
			- Advantage & disadvantage of medication	9	195			
			- General medication tips	39	157			
			Total		**1844**	**100,0**	**29,20**	**100**
3	**6**	**Experience of diagnosis process**	Difficult diagnosis	8	225	40,8		40,76
			Prevention of pulmonary sarcoidosis	38	154	27,9	2,44	27,90
			Many tests for sarcoidosis	27	173	31,3	2,74	31,34
			Total		**552**	**100,0**	**8,74**	**100**
4	**4**	**Experience of physical complaints**	Regular B12 deficiency	11	160	23,4		23,39181287
			Like flue shot	31	179	26,2		26,16959064
			Health in general over the months	35	153	22,4		22,37
			Wishes to feel better	13	192	28,1		28,07
			Total		**684**	**100,00**	**10,83**	**100,00**
5	**3**	**Experience of sarcoidosis physical complaints**	Unexplained symptoms	7	206	28,9		28,93
			Mainly losing weight and bit about gaining	12	191	26,8		26,83
			Low resistence	26	156	21,9		21,91
			Begin phase, physical complaints	33	159	22,3		22,33
			Total		**712**	**100,0**	**11,27**	**100,00**
-6	**-10**	**Pregnancy**	General pregnancy tips	36, 18	-			
			Movement and pregnancy	22	-			
			Total		**0**		**0,00**	**0**
7	**5**	**Questioning about disease**	Finding symptoms	23	159	28,5		28,55
			Quest for causes	25	170	30,5	2,69	30,52
			Sharing experiences about sarcoidosis treatment	6	228	40,9		
			Total		**557**	**100,0**	**8,82**	**59,06642729**
8	**7**	**Alternative treatments**	Avoiding sugars and carbohydrates	28	163	34,1		34,10
			Clothing varies by season	37	165	34,5		
			Marshall protocol	14	150	31,4		
			Total		**478**	**100,0**	**7,57**	**34,10041841**
9	**9**	**Different sarcoidosis**	Ocular sarcoidosis & random stories	20	162	49,1		
			Eyes and vision	24	168	50,9		
			Total		**330**	**100,0**	**5,23**	**5,225653207**
10	**8**	**Balancing between work and sarcoidosis**	Unknown disease to occupational health doctors	17	196	52,8		52,83
			Tips about incapacitated (after 2 years fired)	10	175	47,2		47,17
			Total		**371**	**100,0**	**5,87**	**100**
-11	**-11**	**Sharing of advice**	Various tips and topics	16	-			
			About the forum	19	-			
			Christmas	32	-			
			Total		**0**		0	0
			Total of totals:		**6315**		**100,00**	

Appendix C.6 - Data analysis, sentiment analysis per topic

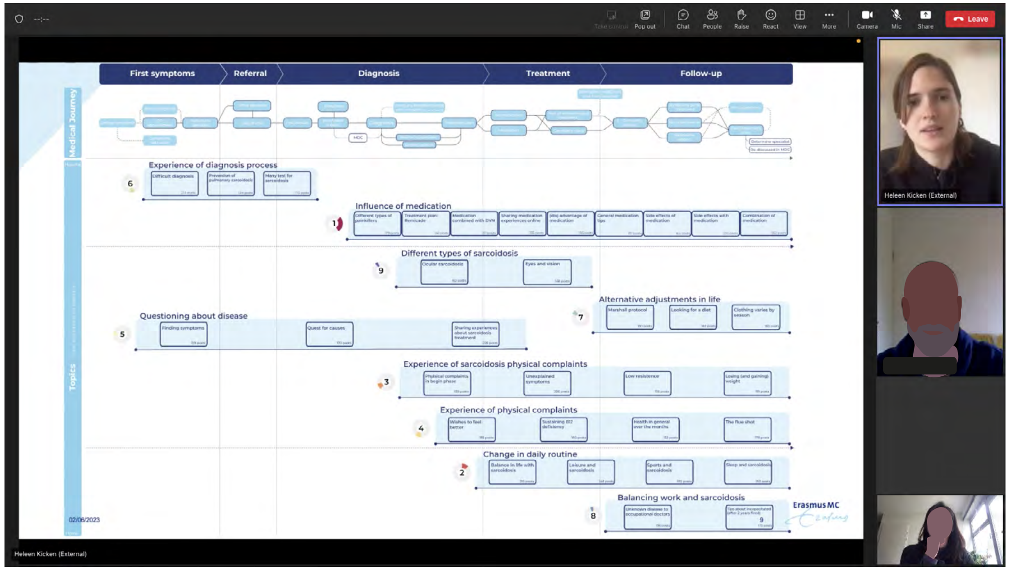
Count of sentiment_label	sentiment_label			
dominant_topic	negative	neutral	positive	Grand Total
0	102	30	78	210
1	50	15	180	245
10	90	42	43	175
11	34	110	16	160
12	100	26	65	191
13	37	8	147	192
14	59	28	63	150
15	81	68	62	211
17	88	57	51	196
2	117	63	82	262
20	68	18	76	162
21	93	38	33	164
23	52	39	68	159
24	90	33	45	168
25	53	46	71	170
26	62	26	68	156
27	56	70	47	173
28	57	45	61	163
29	41	46	95	182
3	84	60	97	241
30	79	23	48	150
31	68	58	53	179
33	97	20	42	159
34	69	61	49	179
35	45	42	66	153
37	80	32	53	165
38	62	29	63	154
39	56	41	60	157
4	78	87	35	200
5	119	27	89	235
6	49	88	91	228
7	146	27	33	206
8	68	93	64	225
9	75	54	66	195
(blank)	20	49	82	151
Grand Total	**2525**	**1599**	**2342**	**6466**

	Number for map
	+
0	0,43
1	**0,782608696**
10	0,32
11	0,32
12	0,39
13	**0,798913043**
14	0,52
15	0,433566434
17	0,37
2	0,412060302
20	0,53
21	0,261904762
23	0,57
24	0,333333333
25	0,57
26	0,523076923
27	0,46
28	0,516949153
29	**0,70**
3	0,535911602
30	0,38
31	0,438016529
33	0,30
34	0,415254237
35	0,59
37	0,398496241
38	0,50
39	0,517241379
4	0,31
5	0,427884615
6	**0,65**
7	0,184357542
8	0,48
9	0,468085106
(blank)	**0,80**

Appendix D - Patient's feedback on the journey map

The patient Journey Map was presented via Teams, and later send by email. The questions answered are shown below.

!The participant has signed the consent form and name can be used!



1. What do you think of the presented visualization, is it clear for you? (e.g., layout, comprehensiveness, text, legenda)

The visualization is clear to me as long as you verbally explain what and why you present it in this form. Starting from page 8 through page 12 it is my advice to verbally explain the steps with each slide, as more information becomes visible.

Page 8 is extremely helpful for patients because otherwise it will be an information overload and they already have elevated stress because of their diagnosis. It is my advice to implement this slide with the first doctor-patient contact when patients hear their diagnosis, so they know what to expect. Also, it is important to give the patients this slide to take home with them. The Legenda for patients is not necessarily just the patient's journey in general if the slide is used as a handout.

Page 9 is very helpful for doctors so they can see what is important for patients. If they want to dive deeper into the layers they will also use 10 to 12

2. Do the clusters make sense to you?

Yes, the overview makes it easy to see results. Perhaps it would be an idea to also put the percentage in the various slices because some of them are really close but i do not know if this is common practice.

3. Can you maybe tell me something about the duration?

The duration of the entire presentation is fine and fluent, meaning I never had the feeling of losing interest etc

4. Do you miss some moments that are not mentioned?

Perhaps this is not meant to be part of the thesis but I know balance is very important to all patients, which is a conclusion we spoke about Friday. Whether patients have an acute or chronic version of Sarcoidosis. Nearly all slices in the cluster are interlinked with finding the right 'balance'. Perhaps you can write something about this in your thesis if this is within the scope or implement it in the prototype app.

5. What comes to mind

- Sometimes during the GP appointment, the GP prescribes antibiotics or other medication because he/she feels the patient does not need to be referred to a specialist. The meds can have a negative or no effect on the symptoms. Therefore it is possible that the duration of cluster Slice 1 starts at the "first symptoms" part. I do want to highlight that this is only a small part of the patients but this was a much bigger issue 10 years ago.
- Duration of cluster slice 8 starts at the diagnosis part.
- Duration of cluster slice 5 starts and continues all the way through follow-up. Patients will always have questions regarding their illness.
- Sarcoidosis is a disease which should be handled multidisciplinary. Luckily Erasmus already does this but what I am missing from the patient journey "Diagnosis" is that patients should speak with a lawyer or check their work-related insurance. Perhaps this is something outside the scope of your thesis as you focus on data and medicine.
- I am curious to know if there is a difference between acute or chronic sarcoidosis and the patient journey. But I would advise this in another study otherwise it would become too complicated and would need a different time schedule to finish.

Appendix E - Patient Organisation flyer

Informative flyer that they provide on their website (Sarcoidose.nl, 2023)

Leeswijzer

De vier stappen die hier afzonderlijk genoemd worden kunnen elkaar deels overlappen en hoeven elkaar niet perse in de tijd op te volgen. Eerdere fases kunnen opnieuw aan de orde komen, bijvoorbeeld als de symptomen wijzigen.

Voor het samenstellen van deze informatie is, onder andere, gebruik gemaakt van diverse brochures van Sarcoidose.nl. Deze brochures en meer informatie over de zorg voor mensen met sarcoïdose vind je op: https://sarcoidose.nl/bibliotheek/

Daar tref je voor stap 1 een uitgebreide brochure over symptomen aan: *Symptomen bij sarcoïdose.*
Bij de voorbereiding van stap 2 kan het *Patiënten Kompas* van pas komen. Met dit Kompas zie je wat je al weet en waar je vragen over hebt. Het kan dienen om het gesprek met de arts voor te bereiden.
Na stap 2, als de diagnose gesteld is, komt de brochure *Diagnose: Sarcoïdose,... en nu?* van pas. Deze brochure heet in de volksmond de Huisartsenbrochure maar is uiteraard ook voor andere (eerstelijns) professionals en voor jezelf goed te gebruiken.

Tijdens de stappen 3 en 4 heb je wellicht behoefte aan contact met andere patiënten en informatie (door middel van bijeenkomsten in de regio) of een training samen met je partner, om zaken op een rijtje te zetten en te verwerken. De training *Sarcoïdose, en hoe nu verder?* biedt dan wellicht uitkomst. De actuele agenda vind je ook op de website.

Daarnaast vind je in de bibliotheek de brochure *SarcoïdoseZorg in Nederland.* Hierin presenteren we ons onderzoek naar de sarcoïdosezorg die geleverd wordt in Nederlandse zorginstellingen.

Dit model is ontwikkeld door ERN-Lung en EURORDIS en vertaald en aangepast voor de Nederlandse context door Sarcoidose.nl met medewerking van artsen en onderzoekers van het sarcoïdosecentrum in het ErasmusMC. Wij bedanken hen voor hun bijdrage en de prettige samenwerking.

Sarcoidose.nl

Postbus 418, 2000 AK Haarlem | 072 - 792 0767 | info@sarcoidose.nl
https://sarcoidose.nl | IBAN: NL20 RABO 015 839 9919
@SarcoidoseBN | Sarcoidose.nl

Sarcoidose.nl

Sarcoïdose Patiëntenpad

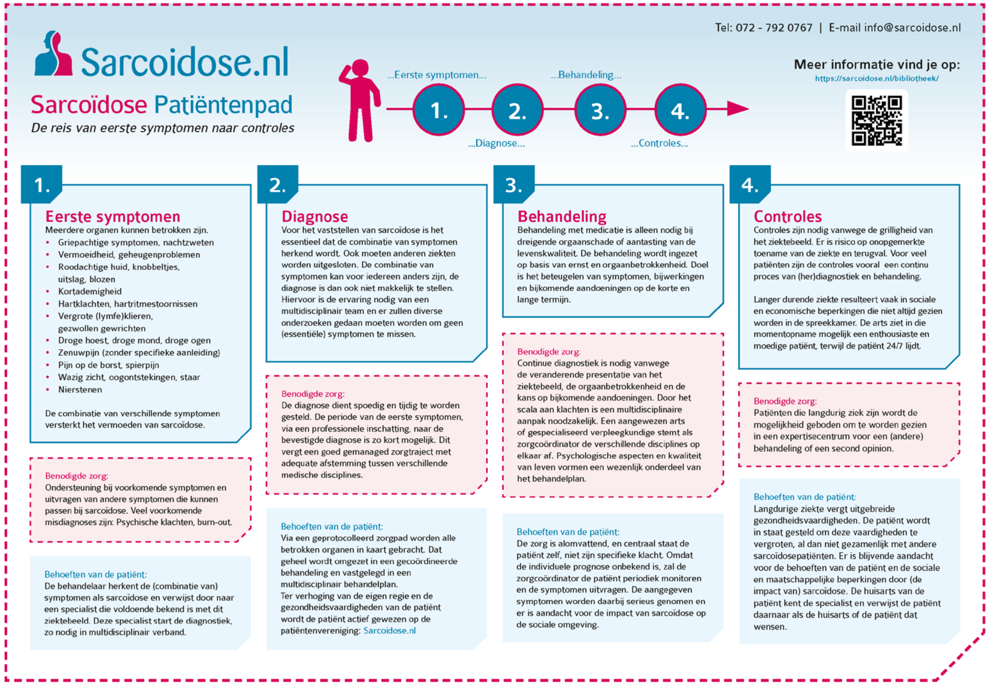
De reis van eerste symptomen naar controles

Dit vouwblad is mogelijk gemaakt door de leden en vrijwilligers van Sarcoidose.nl, de patiëntenorganisatie voor patiënten met sarcoïdose en hun partners.

Steun ons door lid te worden via onze website
of door te doneren op IBAN-nummer: NL20 RABO 015 839 9919.

Sarcoidose 6384 Patient Journey vouwblad A4 SB 01.indd 1-2

03-11-2021 13:49



Tel: 072 - 792 0767 | E-mail info@sarcoidose.nl

Sarcoidose.nl

Sarcoïdose Patiëntenpad

De reis van eerste symptomen naar controles

Meer informatie vind je op:
https://sarcoidose.nl/bibliotheek/

1.

Eerste symptomen

Meerdere organen kunnen betrokken zijn.

- Griepachtige symptomen, nachtzweten
- Vermoeidheid, geheugenproblemen
- Roodachtige huid, knobbeltjes, uitslag, blozen
- Kortademigheid
- Hartklachten, hartritmestoornissen
- Vergrote (lymfe)klieren, gezwollen gewrichten
- Droge hoest, droge mond, droge ogen
- Zenuwpijn (zonder specifieke aanleiding)
- Pijn op de borst, spierpijn
- Wazig zicht, oogontstekingen, staar
- Nierstenen

De combinatie van verschillende symptomen versterkt het vermoeden van sarcoïdose.

Benodigde zorg:
Ondersteuning bij voorkomende symptomen en uitvragen van andere symptomen die kunnen passen bij sarcoïdose. Veel voorkomende misdiagnoses zijn: Psychische klachten, burn-out.

Behoeften van de patiënt:
De behandelaar herkent de (combinatie van) symptomen als sarcoïdose en verwijst door naar een specialist die voldoende bekend is met dit ziektebeeld. Deze specialist start de diagnostiek, zo nodig in multidisciplinair verband.

2.

Diagnose

Voor het vaststellen van sarcoïdose is het essentieel dat de combinatie van symptomen herkend wordt. Ook moeten anderen ziekten worden uitgesloten. De combinatie van symptomen kan voor iedereen anders zijn, de diagnose is dan ook niet makkelijk te stellen. Hiervoor is de ervaring nodig van een multidisciplinair team en er zullen diverse onderzoeken gedaan moeten worden om geen (essentiële) symptomen te missen.

Benodigde zorg:
De diagnose dient spoedig en tijdig te worden gesteld. De periode van de eerste symptomen, via een professionele inschatting, naar de bevestigde diagnose is zo kort mogelijk. Dit vergt een goed gemanaged zorgtraject met adequate afstemming tussen verschillende medische disciplines.

Behoeften van de patiënt:
Via een geprotocolleerd zorgpad worden alle betrokken organen in kaart gebracht. Dat geheel wordt omgezet in een gecoördineerde behandeling en vastgelegd in een multidisciplinair behandelplan.
Ter verhoging van de eigen regie en de gezondheidsvaardigheden van de patiënt wordt de patiënt actief gewezen op de patiëntenvereniging: Sarcoidose.nl

3.

Behandeling

Behandeling met medicatie is alleen nodig bij dreigende orgaanschade of aantasting van de levenskwaliteit. De behandeling wordt ingezet op basis van ernst en orgaanbetrokkenheid. Doel is het beteugelen van symptomen, bijwerkingen en bijkomende aandoeningen op de korte en lange termijn.

Benodigde zorg:
Continue diagnostiek is nodig vanwege de veranderende presentatie van het ziektebeeld, de orgaanbetrokkenheid en de kans op bijkomende aandoeningen. Door het scala aan klachten is een multidisciplinaire aanpak noodzakelijk. Een aangewezen arts of gespecialiseerd verpleegkundige stemt als zorgcoördinator de verschillende disciplines op elkaar af. Psychologische aspecten en kwaliteit van leven vormen een wezenlijk onderdeel van het behandelplan.

Behoeften van de patiënt:
De zorg is alomvattend, en centraal staat de patiënt zelf, niet zijn specifieke klacht. Omdat de individuele prognose onbekend is, zal de zorgcoördinator de patiënt periodiek monitoren en de symptomen uitvragen. De aangegeven symptomen worden daarbij serieus genomen en er is aandacht voor de impact van sarcoïdose op de sociale omgeving.

4.

Controles

Controles zijn nodig vanwege de grilligheid van het ziektebeeld. Er is risico op onopgemerkte toename van de ziekte en terugval. Voor veel patiënten zijn de controles vooral een continu proces van (her)diagnostiek en behandeling.

Langer durende ziekte resulteert vaak in sociale en economische beperkingen die niet altijd gezien worden in de spreekkamer. De arts ziet in die momentopname mogelijk een enthousiaste en moedige patiënt, terwijl de patiënt 24/7 lijdt.

Benodigde zorg:
Patiënten die langdurig ziek zijn wordt de mogelijkheid geboden om te worden gezien in een expertisecentrum voor een (andere) behandeling of een second opinion.

Behoeften van de patiënt:
Langdurige ziekte vergt uitgebreide gezondheidsvaardigheden. De patiënt wordt in staat gesteld om deze vaardigheden te vergroten, al dan niet gezamenlijk met andere sarcoïdosepatiënten. Er is blijvende aandacht voor de behoeften van de patiënt en de sociale en maatschappelijke beperkingen door (de impact van) sarcoïdose. De huisarts van de patiënt kent de specialist en verwijst de patiënt daarnaar als de huisarts of de patiënt dat wensen.

Appendix F - Peer brainstorm session

The sessions took place at the Industrial Design Engineering faculty with fellow students. The first one was with one Integrated Product Design master student and with one Strategic Product Designer master student. The project goal was presented and the research question was asked, with this in mind, they generated ideas. See Figure F.1 for their drawings with ideas.

The second session was with one Strategic Product Designer master student and one Design for Interaction master student. Again the project goal was presented with the research question, and they came up with the ideas shown in Figure F.2.

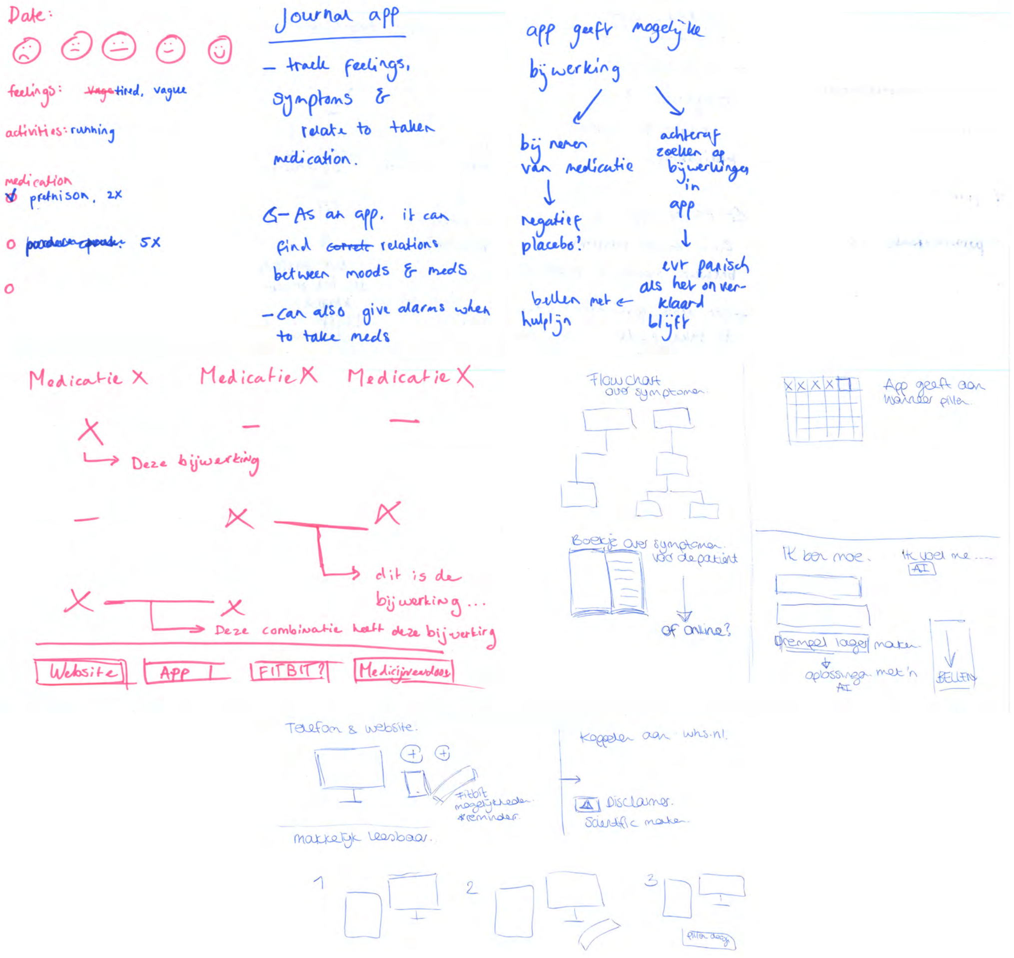


Figure F.1: First peer brainstorming session ideas

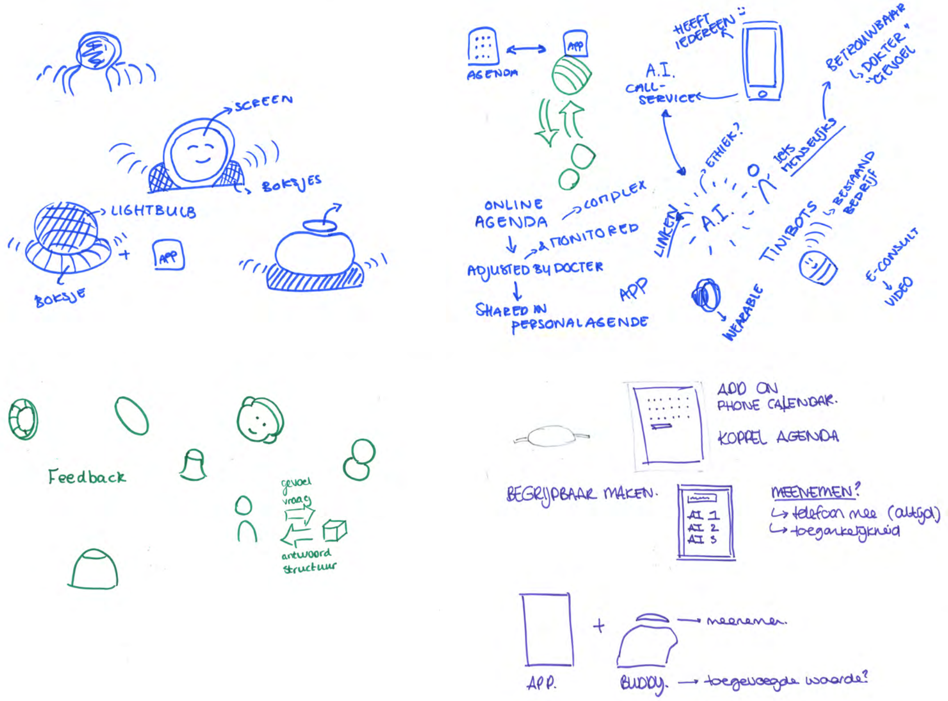


Figure F.2: Second peer brainstorming session ideas

Appendix G - HKJ’s for research question

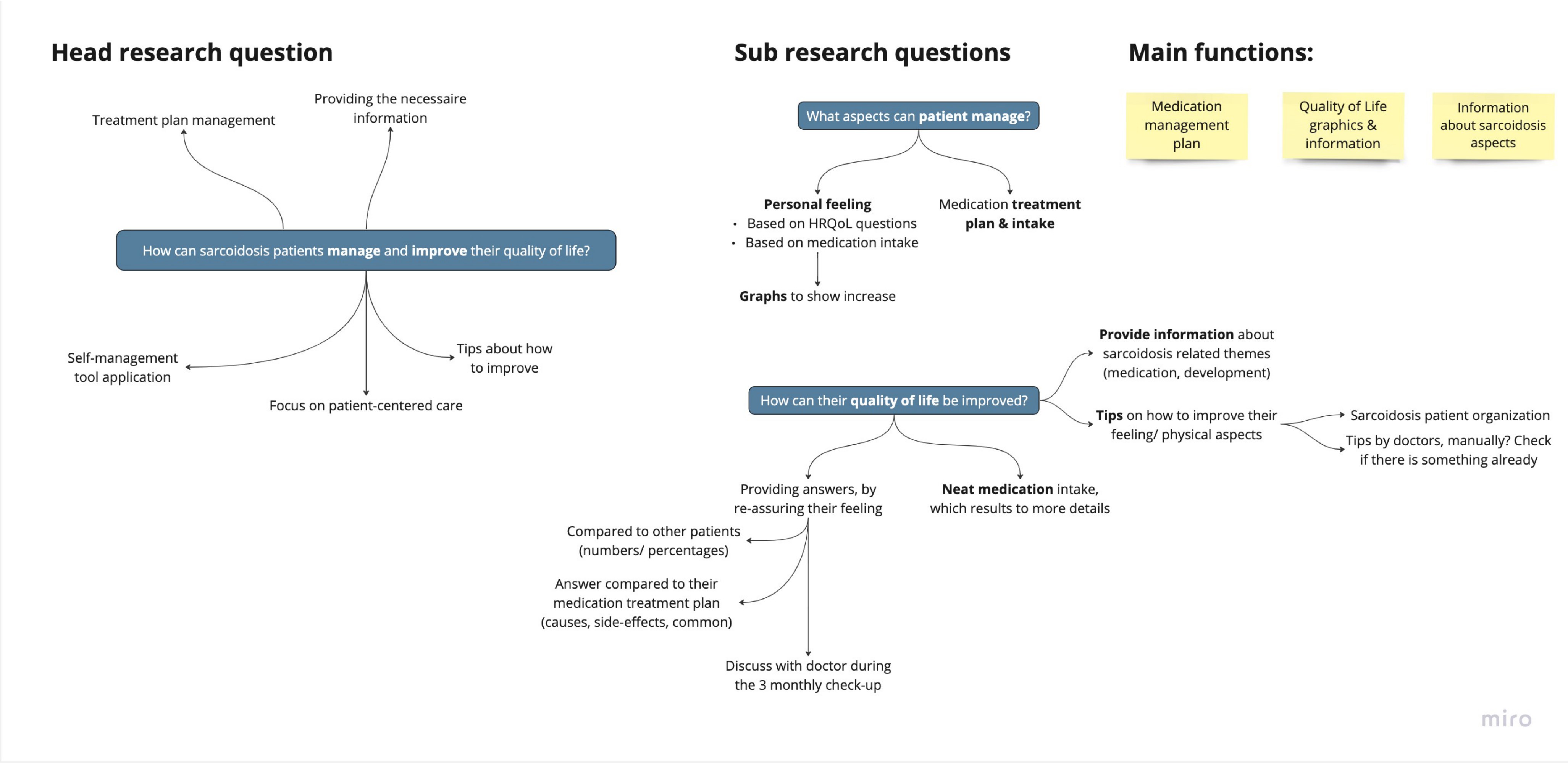
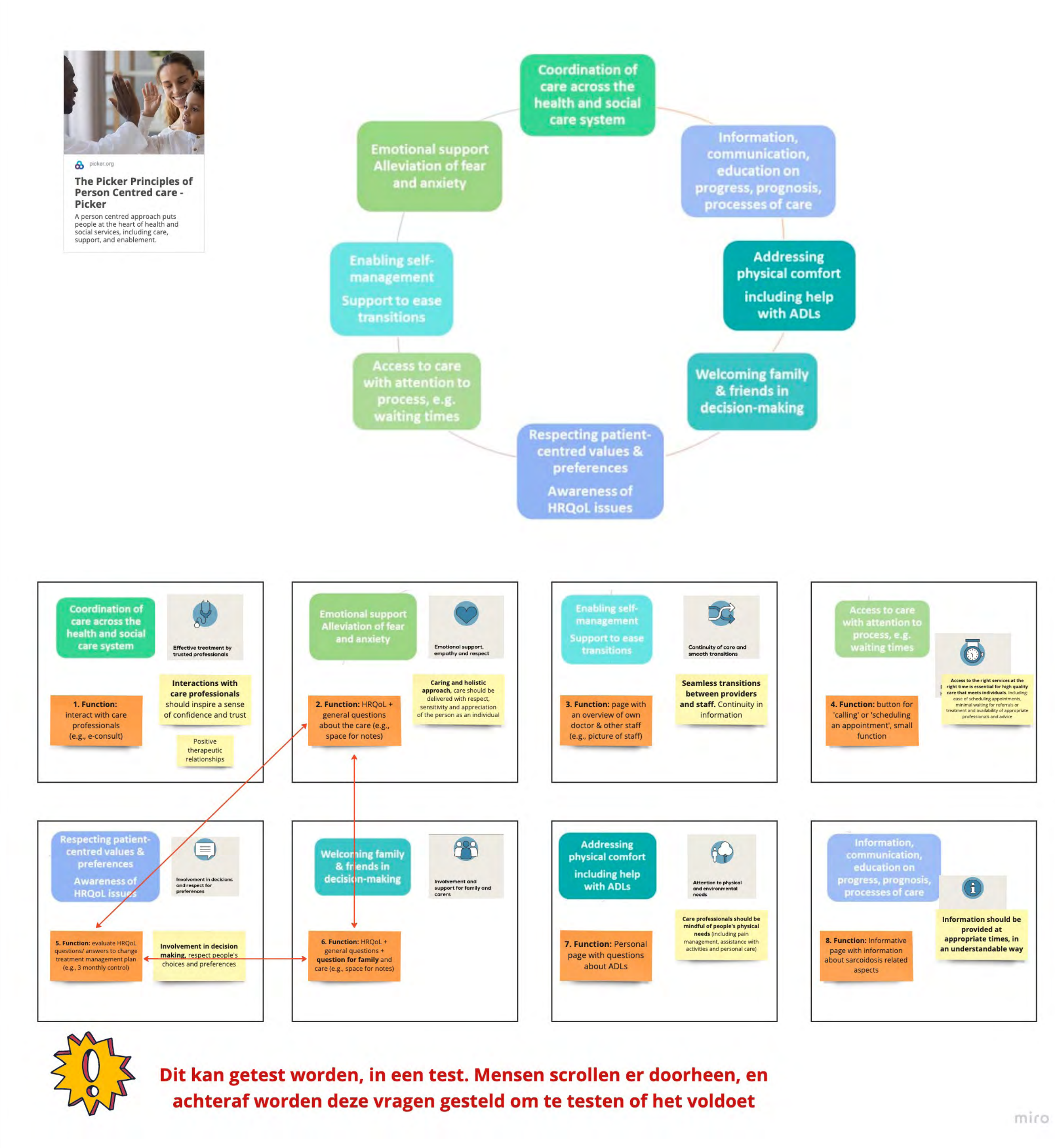


Figure G.1: Brainstorm session about the research question, snapshot from Miro board

Appendix H - Patient-centred care brainstorm



picker.org

The Picker Principles of Person Centred care - Picker

A person centred approach puts people at the heart of health and social services, including care, support, and enablement.

Coordination of care across the health and social care system

Information, communication, education on progress, prognosis, processes of care

Addressing physical comfort including help with ADLs

Welcoming family & friends in decision-making

Respecting patient-centred values & preferences Awareness of HRQoL issues

Access to care with attention to process, e.g. waiting times

Enabling self-management Support to ease transitions

Emotional support Alleviation of fear and anxiety

Coordination of care across the health and social care system

Effective treatment by trusted professionals

Interactions with care professionals should inspire a sense of confidence and trust

1. Function: interact with care professionals (e.g., e-consult)

Positive therapeutic relationships

Emotional support Alleviation of fear and anxiety

Emotional support, empathy and respect

Caring and holistic approach, care should be delivered with respect, sensitivity and appreciation of the person as an individual

2. Function: HRQoL + general questions about the care (e.g., space for notes)

Enabling self-management Support to ease transitions

Continuity of care and smooth transitions

Seamless transitions between providers and staff. Continuity in information

3. Function: page with an overview of own doctor & other staff (e.g., picture of staff)

Access to care with attention to process, e.g. waiting times

Access to the right services at the right time is essential for high quality care that meets individuals. Including: ease of scheduling appointments, minimal waiting for referrals or treatment and availability of appropriate professionals and advice

4. Function: button for 'calling' or 'scheduling an appointment', small function

---

Respecting patient-centred values & preferences Awareness of HRQoL issues

Involvement in decisions and respect for preferences

5. Function: evaluate HRQoL questions/ answers to change treatment management plan (e.g., 3 monthly control)

Involvement in decision making, respect people's choices and preferences

---

Welcoming family & friends in decision-making

Involvement and support for family and carers

6. Function: HRQoL + general questions + **question for family** and care (e.g., space for notes)

Addressing physical comfort including help with ADLs

Attention to physical and environmental needs

Care professionals should be mindful of people's physical needs (including pain management, assistance with activities and personal care)

7. Function: Personal page with questions about ADLs

Information, communication, education on progress, prognosis, processes of care

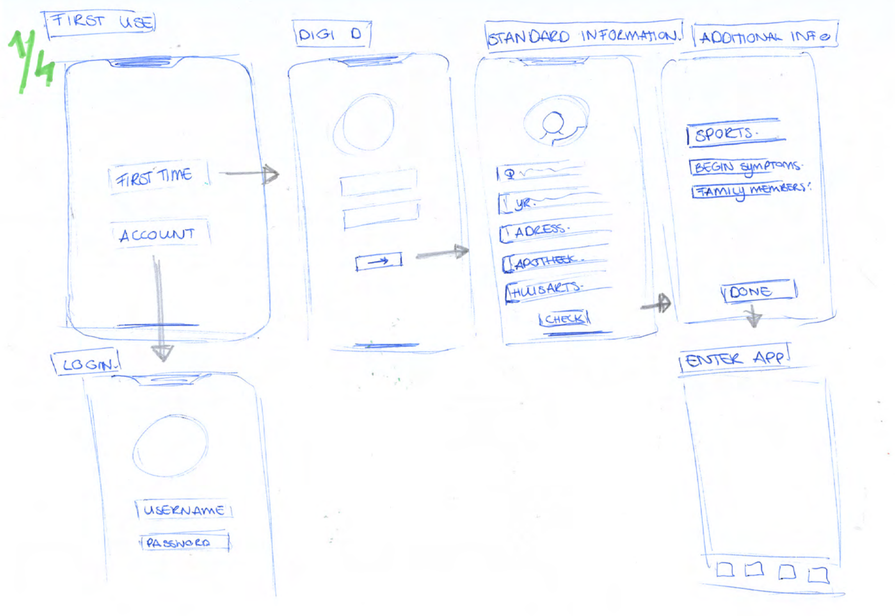
Information should be provided at appropriate times, in an understandable way

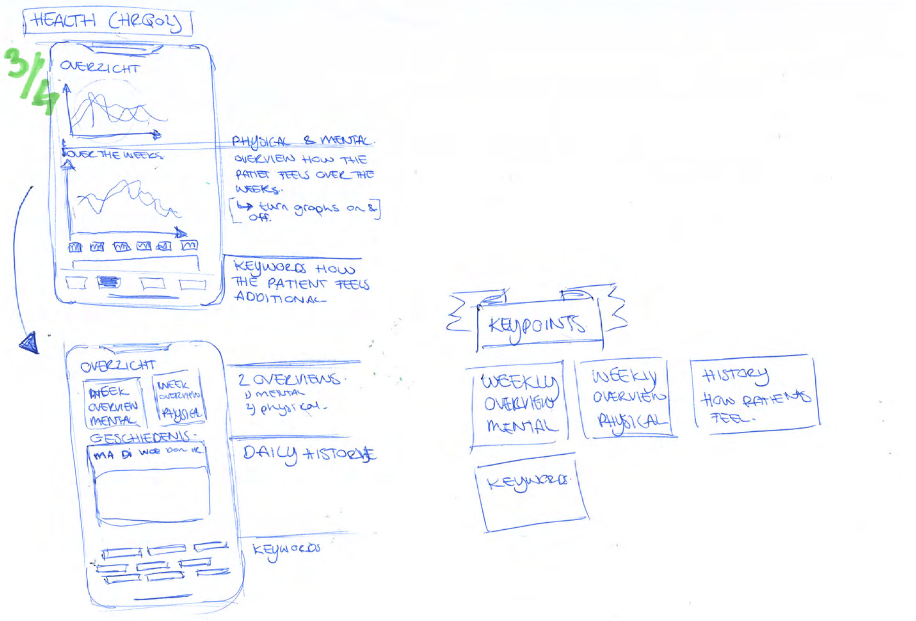
8. Function: Informative page with information about sarcoidosis related aspects

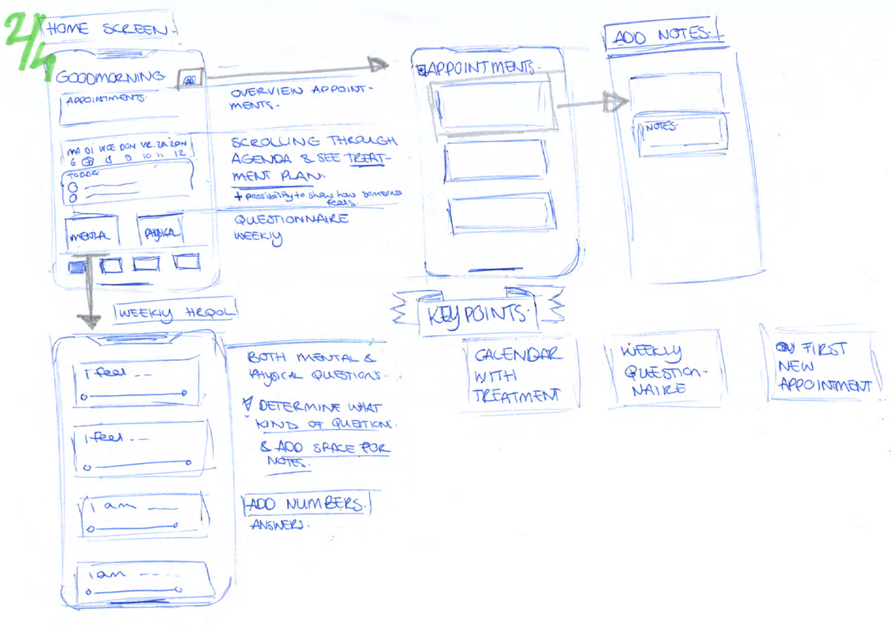
---

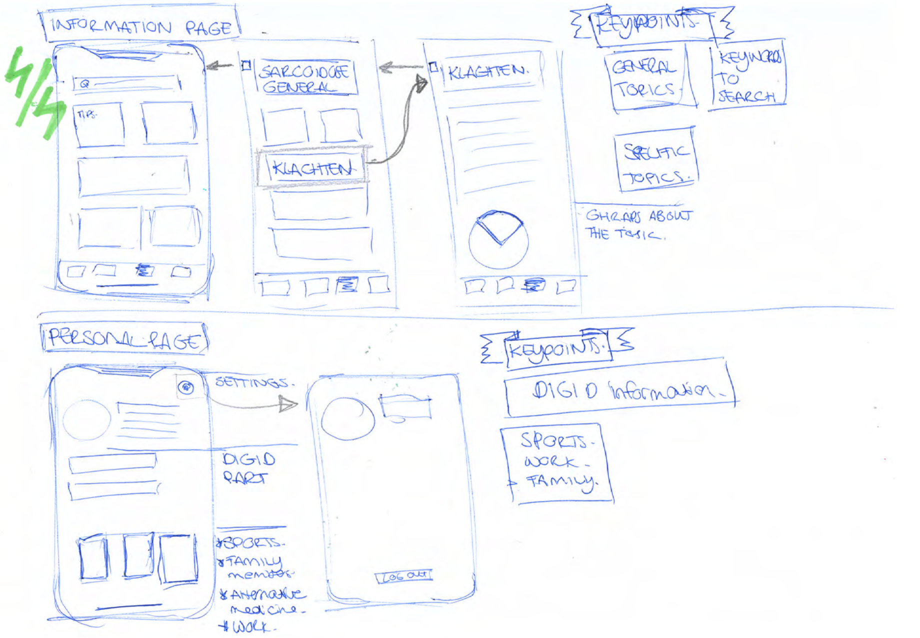
Dit kan getest worden, in een test. Mensen scrollen er doorheen, en achteraf worden deze vragen gesteld om te testen of het voldoet

Appendix I - Paper sketches of the main pages









Appendix K.1 - Peer test, set-up

!All participants have signed the consent form and names can be used!

USER INTERFACE APPLICATION TEST PLAN

Goal:

Test the application's interface on:

- Does the interface work? Is everything linked to a page?
- Is the application intuitive on a functional level? Are buttons big enough, is scrolling smooth enough, is the font big enough, etc?

Who?

Everyone can use a mobile phone. I will recruit my roommates and peers.

When?

This will be done on Thursday or/and Friday, next week on the 22nd or/and 23rd of May.

How?

Explain the project and the aim of this product. They don't need to think as patients, because it is about functionality so, therefore, everybody (an average human being) should be able to use this app.

I will start by explaining the main functions:

- Personalized profile, with information for the doctors
- Provide the patient with information
- Manage the quality of life with questionnaires

Then I will give them instructions/ exercises and ask them to think out loud:

- You have your 3 monthly control next week; you need to prepare for this control. What will you do in the application?
- You forgot what you have to take for medication! What will you do in the application?
- You feel very tired, but you are not sure if this is normal, and you want to know what you can do about it. What will you do in the application?
- A week passed and you want to update the app with how you feel physically. What will you do in the application?
- You feel a bit less tired, and you want to see how your mental state has been processed in the last few weeks. What will you do in the application?

Then I will ask them the following questions:

- What did you think of the app in general?
- What do you think of the buttons of the application?
- What do you think of the fonts that are being used?
- And what about the images?
- What do you think of the functions? (Like calendar, quality of life questionnaire, appointment list, graphics of the health, control big questionnaire)
- And what do you think about the information provided?
- Do you have any comments besides the things that you already mentioned?
- Tips?

In Dutch/ In het Nederlands

Ik zal beginnen met het uitleggen van de belangrijkste functies:

- Gepersonaliseerd profiel, met informatie voor de artsen
- De patiënt van informatie voorzien
- De levenskwaliteit beheren met vragenlijsten.

Dan zal ik instructies/oefeningen geven en ze vragen hardop te denken:

1. Je hebt volgende week je 3 maandelijkse controle; je moet je voorbereiden op deze controle. Wat ga je doen in de app?
2. Je bent vergeten wat je voor medicijnen moet innemen! Wat gaat je doen in de app?
3. Je voelt je erg moe, maar je weet niet zeker of dit normaal is en je wilt weten wat je hieraan kunt doen. Wat ga je doen in de app?
4. Er is een week voorbij en je wilt de app updaten met hoe je je lichamelijk voelt. Wat ga je doen in de app?
5. Je voelt je minder moe en wilt zien hoe je mentale gesteldheid de afgelopen weken is verwerkt. Wat ga je doen in de applicatie?

Introductie.
Deze applicatie is gemaakt voor patiënten met sarcoidose. Na uitvoerig onderzoek was de conclusie dat deze patiënten begeleiding thuis nodig hebben, zodat ze hun levenskwaliteit met sarcoidose kunnen beheren en verbeteren.

Daarom ligt de focus van dit systeem op het volgende:
- Ze voorzien van allerlei **informatie** thema's met betrekking tot sarcoidose;

- Ze helpen hun **medicatie inname** meer te beheren;

- Een overzicht geven van meerdere aspecten van hun **kwaliteit van leven**.

De test.
Met deze test wil ik de user flow van de interface testen. Is het duidelijk? Intuïtief?

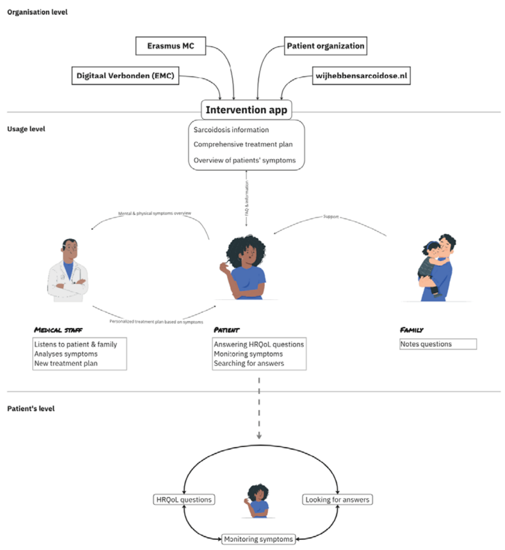
Stap 1.
Je kunt beginnen door gewoon te browsen en door de app te scrollen. Om te weten wat wat is. Denk hardop.

Stap 2.
U krijgt 5 scenario's waarbij u zich moet voorstellen dat u de patiënt bent, en u iets wilt van het systeem/applicatie.

Stap 3.
Daarna krijg je een aantal vragen die je moet invullen. Wees zo eerlijk en kritisch als je wilt.

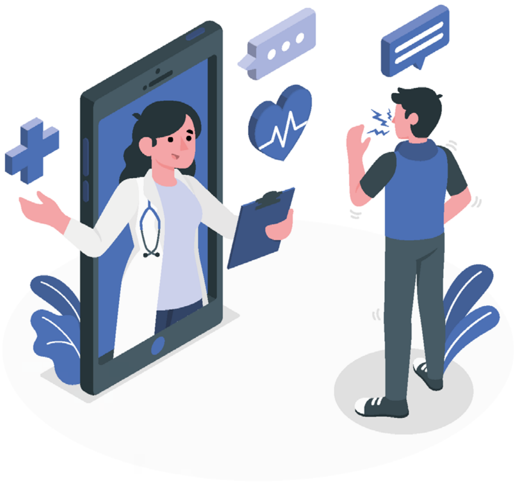
Bedankt voor uw tijd!

Systeem.

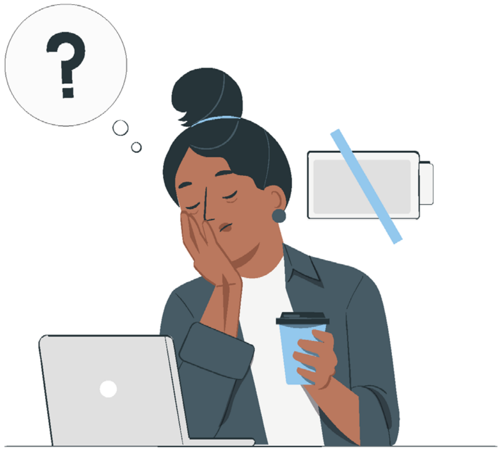


Je bent vergeten wat je vandaag voor medicijnen moet nemen! Wat ga je in de app doen? En hoe zit het met morgen?

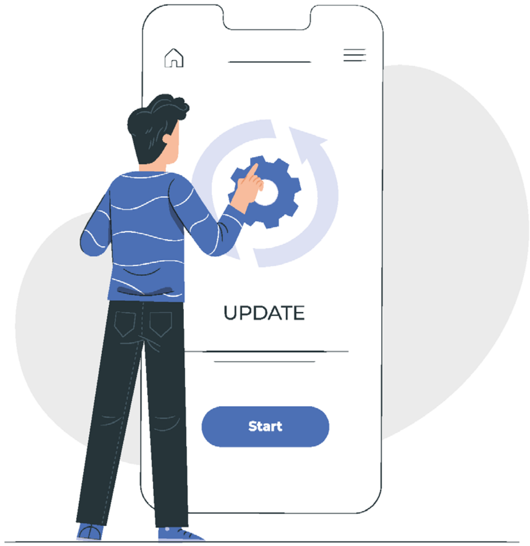
Je hebt volgende week je 3 maandelijkse controleafspraak in het Erasmus MC; je moet je voorbereiden op deze controle. Wat ga je doen in de aanvraag?



Je voelt je erg moe, maar je weet niet zeker of dit normaal is, en je wilt weten wat je eraan kunt doen. Wat ga je doen in de app?



Er is een week voorbij en je wilt de app updaten met hoe je je fysiek voelt. Wat ga je doen in de applicatie?



Je voelt je wat minder moe, en je wilt kijken hoe het de afgelopen weken met je mentale gesteldheid is gesteld, vooral wat betreft de vermoeidheid. Wat ga je doen in de app?

Dan stel ik ze de volgende vragen:

- Wat vind je van de app in het algemeen?
- Wat vind je van de knoppen van de applicatie?
- Wat vind je van de gebruikte lettertypes?
- En hoe zit het met de iconen?
- Wat vind je van de functies? (Zoals: kalender, vragenlijst over levenskwaliteit, afsprakenlijst, gezondheidsgrafieken, controle grote vragenlijst)
- En wat vind je van de verstrekte informatie?
- Heb je nog opmerkingen naast de dingen die je al hebt genoemd?
- Tips?

Formulier

Deze app is voor patienten die de ziekte sarcoidose hebben. Ze kunnen dit eenmalig hebben voor een korte periode, of juist chronisch en moeten hiermee leven. Daarom is deze app ontwikkeld, om de patienten thuis te helpen met hun ziekte.

De focus ligt op het medicatie gebruik en alle opkomende vragen die daarbij komen kijken. Het kan voor mensen erg stressvol zijn, om thuis met vragen te zitten over bijwerkingen, sarcoidose symptomen of andere kwaaltjes en deze vragen niet te kunnen stellen. Ze weten ook vaak niet hoe ‘gewoon’ het is om bijvoorbeeld zich moe te voelen. Verder zit er een kwaliteit van leven enquete bij, deze moet ingevuld worden voordat ze op controle in het ziekenhuis moeten komen. Dit wordt gedaan zodat dokters het behandelplan kunnen aanpassen a.h.v. de symptomen die de patient ervaart.

Ik zou je graag de volgende situaties voor willen leggen, het zijn er 5. Ik stel je een vraag en jij kan in de app opzoek naar het antwoord. Denk vooral hardop na en stel vragen mocht je die hebben.

1. Je hebt volgende week je 3 maandelijkse controle; je moet je voorbereiden op deze controle. Wat ga je doen in de app?
2. Je bent vergeten wat je voor medicijnen moet innemen! Wat gaat je doen in de app?
3. Je voelt je erg moe, maar je weet niet zeker of dit normaal is en je wilt weten wat je hieraan kunt doen. Wat ga je doen in de app?
4. Er is een week voorbij en je wilt de app updaten met hoe je je lichamelijk voelt. Wat ga je doen in de app?
5. Je voelt je minder moe en wilt zien hoe je mentale gesteldheid de afgelopen weken is verwerkt. Wat ga je doen in de applicatie?

Bedankt voor het opzoek gaan naar de antwoorden. Ik zou graag nog wat vragen willen stellen.

Algemene vragen over de app

Wat vind je van de app in het algemeen?

____

Wat vind je van de knoppen van de applicatie?

____

Wat vind je van de gebruikte lettertypes?

____

En hoe zit het met de iconen?

____

Wat vind je van de functies? (Zoals: kalender, vragenlijst over levenskwaliteit, afsprakenlijst, gezondheidsgrafieken, controle grote vragenlijst)

____

Hoe intuitief vind je de app?

1 2 3 4 5

Waarom?

____

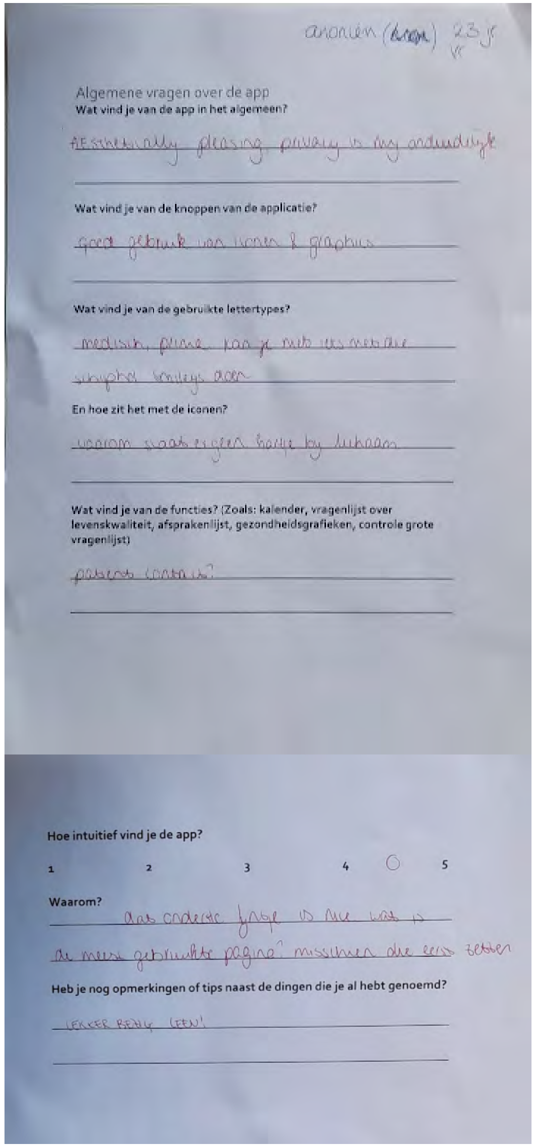
Heb je nog opmerkingen of tips naast de dingen die je al hebt genoemd?

____

Appendix K.2 - Peer test, feedback on the app

!All participants have signed the consent form and names can be used!

Participant 1, female, 23 years old



anoniem ([illegible]) 23 jr vr

Algemene vragen over de app

Wat vind je van de app in het algemeen?

Aesthetically pleasing, privacy is nog onduidelijk

Wat vind je van de knoppen van de applicatie?

goed gebruik van iconen & graphics

Wat vind je van de gebruikte lettertypes?

medisch, plane kan je niet iets met die [illegible] [illegible] doen

En hoe zit het met de iconen?

waarom staat er geen hartje bij lichaam

Wat vind je van de functies? (Zoals: kalender, vragenlijst over levenskwaliteit, afsprakenlijst, gezondheidsgrafieken, controle grote vragenlijst)

patiënt contact?

Hoe intuitief vind je de app?

1 2 3 4 ○ 5

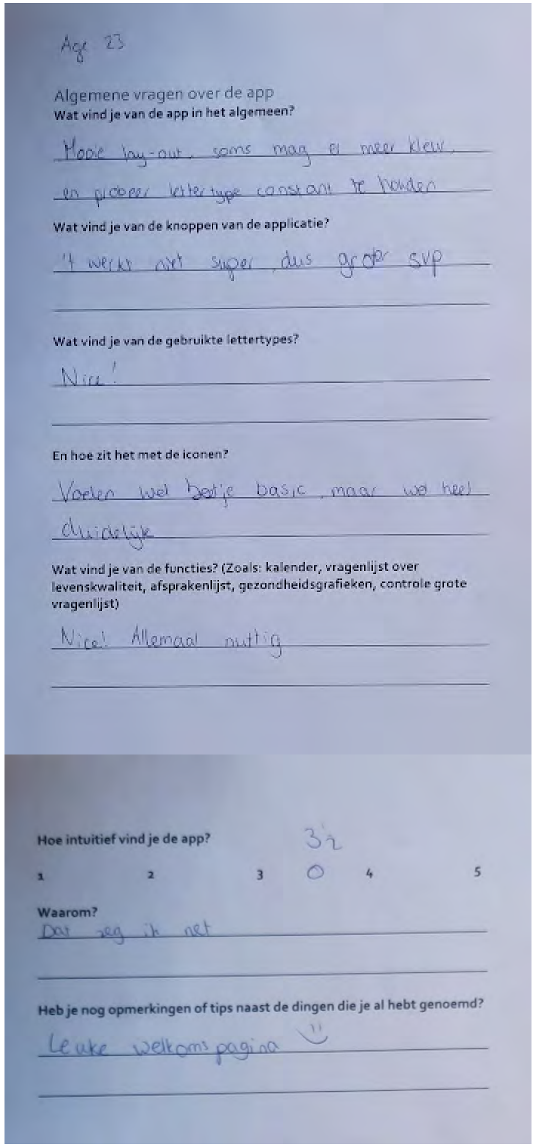
Waarom?

dat onderste [illegible] is nu wat is de meest gebruikte pagina? misschien die eerst zetten

Heb je nog opmerkingen of tips naast de dingen die je al hebt genoemd?

LEKKER BEZIG LEEN!

Participant 2, female 23 years old



Age 23

Algemene vragen over de app

Wat vind je van de app in het algemeen?

Mooie lay-out, soms mag er meer kleur, en probeer lettertype constant te houden

Wat vind je van de knoppen van de applicatie?

't werkt niet super, dus groter svp

Wat vind je van de gebruikte lettertypes?

Nice!

En hoe zit het met de iconen?

Voelen wel beetje basic, maar wel heel duidelijk

Wat vind je van de functies? (Zoals: kalender, vragenlijst over levenskwaliteit, afsprakenlijst, gezondheidsgrafieken, controle grote vragenlijst)

Nice! Allemaal nuttig

Hoe intuitief vind je de app? 3½

1 2 3 ○ 4 5

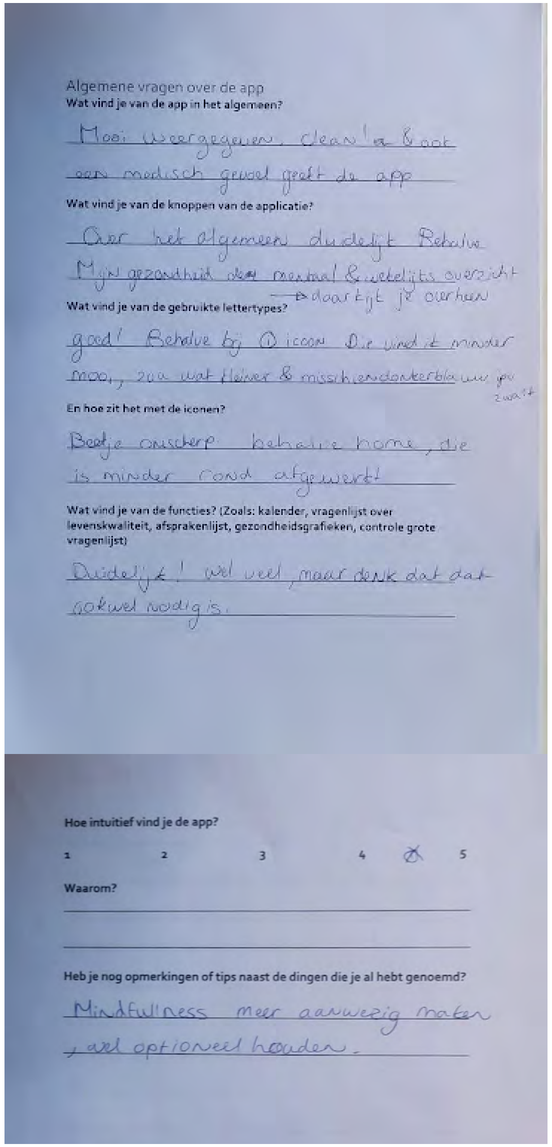
Waarom?

Dat zeg ik net

Heb je nog opmerkingen of tips naast de dingen die je al hebt genoemd?

Leuke welkomspagina ☺

Participant 3, female, 23 years old



Algemene vragen over de app

Wat vind je van de app in het algemeen?

Mooi weergegeven, clean! & ook een medisch gevoel geeft de app

Wat vind je van de knoppen van de applicatie?

Over het algemeen duidelijk. Behalve Mijn gezondheid ~~[illegible]~~ mentaal & wekelijks overzicht → daar kijk je overheen

Wat vind je van de gebruikte lettertypes?

goed! Behalve bij ⓘ icoon. Die vind ik minder mooi, zou wat lichter & misschien donkerblauw of zwart

En hoe zit het met de iconen?

Beetje onscherp behalve home, die is minder rond afgewerkt!

Wat vind je van de functies? (Zoals: kalender, vragenlijst over levenskwaliteit, afsprakenlijst, gezondheidsgrafieken, controle grote vragenlijst)

Duidelijk! wel veel, maar denk dat dat ook wel nodig is.

Hoe intuitief vind je de app?

1 2 3 4 ☒ 5

Waarom?

Heb je nog opmerkingen of tips naast de dingen die je al hebt genoemd?

Mindfulness meer aanwezig maken, wel optioneel houden.

Participant 4, male, 24 years old | General notes

Grotere knoppen bij ‘akkoord gaan’
De informatie knoppen geven waarom aan —> maar normaal is het wat je moet invullen.
Te grote vingers —> grotere knoppen
Medicatie calendar =
Grafieken beetje onduidelijk —>
    Heel veel om op ’t eerste oog te zien.
    Misschien
    Kleurenblindheid?
Andere patiënten aan het woorden -> tekst klein & je kan er niet op klikken maar er staat wel … dus je zou er op moeten klikken. ‘Ervaringen’ van anderen naar boven verplaatsen, want het zijn geen tips.
Meditation = 2/6
Informatie: hele kleine buttons, moet eigenlijk groter. Termen hoeven niet de extra uitleg
    Dat springen gaat nog niet helemaal goed
Profiel —> profielfoto aanpassen ding

Questions about the application

Wat vind je van de app in het algemeen?
    Heel duidelijk en mooi gedesignde. Wel veel functies, kan ook voorstellen voor alleen 1 functie. Home pagina geeft niet echt duidelijk aan dat er ook informatie is.
Wat vind je van de knoppen van de applicatie?
    Knoppen groter bereik —> pijltjes zijn klein
Wat vind je van de gebruikte lettertypes?
    Duidelijk en consistent gebruik, af en toe te klein. Consequentie gebruik van de titel grootte
En hoe zit het met de iconen?
    Zwangerschap icoon lijkt net op een pil, voor de rest fijn
Wat vind je van de functies? (Zoals: kalender, vragenlijst over levenskwaliteit, afsprakenlijst, gezondheidsgrafieken, controle grote vragenlijst)
    Overzicht is heel fijn, maar informatie
Heb je nog opmerkingen naast de dingen die je al hebt genoemd?
    Nee.

Participant 3, male, 23 years old | General notes

Terug knop zou wel echt handig zijn
Kalender = vaag cirkel bij ‘vandaag’ & pijltjes naar volgende week sturen & dagen in de week met 2 letters ipv 3. Bolletje met ‘vul je vragenlijst nog even in’ bij vrijdag bijv.
3 maandelijkse controle gaat met de toolbar naar ‘gezondheid’ maar je zit nog in home.
Informatie op de home page zou wel handig zijn, want nu mist de informatie knop.
Grafieken —> bam veel kleuren. Beginnen met 1 grafiek. Concentratie is heel moeilijk te zien, vanwege de witheid. ‘Ernst in mate’ misschien beetje gekkig.

Algemeen vragen over de app

Wat vind je van de app in het algemeen?
    Nice overzicht op homescreen. ‘Hoe voel je je deze week’ is een beetje verwarrend.
Wat vind je van de knoppen van de applicatie?
    Af en toe iets te klein, dikke worstenvingers. Frame moet groter.
Wat vind je van de gebruikte lettertypes?
    Fijn, altijd.
En hoe zit het met de iconen?
    Nice iconen, duidelijk. Maar af en toe niet helemaal scherp. Algemene sarcoidose vervangen in wat is sarcoidose? / sarcoidose in het kort. Werk en sarcoidose —> alleen werk. ‘Het ziekenhuis’ —> ‘Het Erasmus MC’. Voelt niet helemaal alsof het klopt dat de informatie knoppen zo bij elkaar staan.
Wat vind je van de functies? (Zoals: kalender, vragenlijst over levenskwaliteit, afsprakenlijst, gezondheidsgrafieken, controle grote vragenlijst)
    Functies zijn duidelijk.
Heb je nog opmerkingen naast de dingen die je al hebt genoemd?
    Nee. Afspraken staan vast, kun je niets meer aan wijzigen. Contact met het ziekenhuis kun je niet vinden, misschien contact erbij. Knop met doorverwijziging naar de poli kliniek.

Appendix L.1 - Interview medical staf: specialist nurse

With Y. Gur-Demirel*, on 30th of May 2023.

*She signed the form and thereby allows me to use her name.

Setup:

Presentation and a demonstration of the application, with scrolling through the app.
Discussion when scrolling through the app.

Feedback:

Medication treatment plan calendar: how will the treatment plan implement in the calendar? First: it is connected to the doctors' software, however, according to specialist nurse Y. Gur-Demirel is this not the most logistic solution. She suggests that the patients add the medication to the calendar, when it changes they can change it themselves.

Graphs about quality of life: different time periods would be nice. Per month, per week, or per year (for example). This would be more convenient for doctors because they don't want to see every week sometimes.

Resembling software:
Gezondheidsmeter PGO and Sarconline.nl are quite similar to my system.
Talk to Nakshbandi G. (microsection number: 595021), she knows the gezondheidsmeter.
idlnetwerk.nl gives the appropriate information

Tips page: add something for the physical condition, now it's only 'mindfulness'. It appears to be that for fibrosis physical rehabilitation helps in the short term. This could also be the case for sarcoidosis, ask M. Wijsenbeek (head pulmonologist).

Inclusion of family: for the medical staff, it is important to have a contact person.

Suggestions: give a notification when they have a blood test and a button that gives a notification to the doctors/ nurses that the blood test is done and where it is done (when and where).

Appendix L.2 - Interview medical staff: head pulmonologist

She signed the form and thereby allows me to use her name.

On Friday, the 9th of June, a meeting took place with Prof. Dr M. Wijsenbeek. She is the supervisor from the Erasmus MC for this project and the head pulmonologist of the pulmonary department. Figure L.2.1 shows what the meeting looks like.

Figure L.2.1: *Meeting with head pulmonologist Dr M. Wijsenbeek*

In general was M. Wijsenbeek very enthusiastic about the work and functional prototype. She is eager to make this work in the future. Some feedback:
How to monitor the patients as the healthcarers? And how do we have access to the data?

The provided information can also be shown in a video format, where the doctors and specialist nurse explain a certain topic. M. Wijsenbeek suggests to already implement this in the current prototype. She is enthusiastic about the delivering information, because this can be improved indeed.

Suggestion is in the future to connect the medication overview with the pharmacy. They have a clear overview of the patient and here is final step to what the patient also actually takes.

If this prototype really is converted to a real working prototype, then there should take a trial place. A trial to test if this improves the healthcare for sarcoidosis patients.

Thoughts on an award system, this way people really use the app. M. Wijsenbeek is hesitant that patients will be kept motivated to use the app. This coudl be helped with push notifications, but maybe there is more?

In general very good principle. This could really help sarcoidosis patients in their life with the diagnosis. M. Wijsenbeek was impressed by the prototype and wants to make it tangible. She suggests to make the prototype by paying me for it and continue with a PhD to test if it actually improves the healthcare.

Appendix L.3 - Interview medical expert: pulmonologist in training

She signed the form and thereby allows me to use her name.

On the 14th of June, an interview was conducted with the pulmonologist in training: V. Kahlmann. She is in charge of the Sarconline.nl website and showed that this is in particular a study and not something that every patient gets in their care.

Setup:

A presentation where the four patient's needs are explained and what it looks like in the application that is made.

External company:

Curavista. They use this company to make the tools, however, this is indeed quite expensive and they are in charge of the layout. They don't have the functions that I would like to use in the application.

Graphs.

The well-being state questionnaire and results in graphs could be visualised in bars. But the answers on these questionnaires should at least be on a different scale. Based on the research of K. Moore, it would be an idea to use the VAS answer modules in this app. This is mainly because that research was in operation for the Erasmus MC and they are using it in their questionnaires.

Blogs of other patients.

Quite difficult to implement, because the medical experts are not in charge of what these patients are writing. So they don't have an influence on it, this makes it quite difficult to monitor what the patients will see then in the app with these stories.

Medical events.

It would be nice to implement the Erasmus MC event calendar. They want to organise 4 times a year a medical event for sarcoidosis patients.

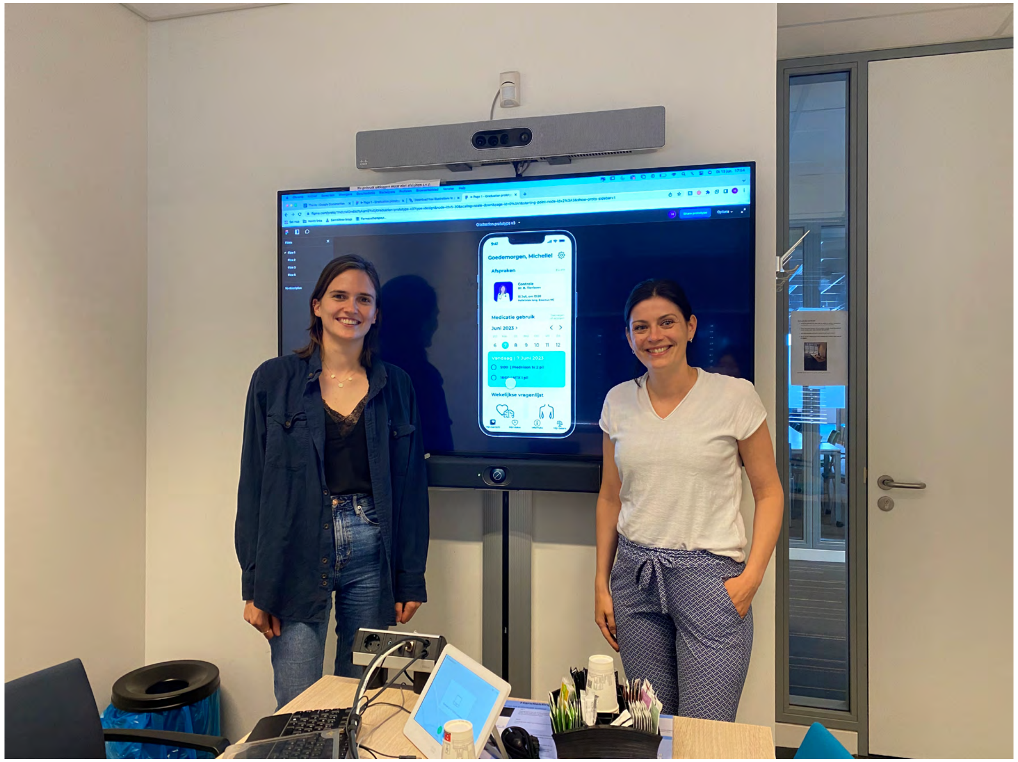


Figure L.3.1: *Meeting with V. Kahlmann*

Appendix M.1 - First patient’s feedback

! He signed the form and thereby allows me to use her name.

On the 2nd of June, there was an online meeting with a patient to discuss the patient journey map and the application with the main functions. Here are the notes from that session.

Application in general

Logistics part: something similar already exists. So there should be a well-thought plan to make this valuable. Also, it needs to be up to date, so there should be a team behind it to keep it updated.

People will forget about the application after a while or don’t want to be reminded of sarcoidosis. Therefore, it is valuable to take the key-value ‘finding balance in life’ as a more pillar in the application.

Main screen
It is really helpful to have the calendar function with a medication plan.

Health screen:
This screen helps to visualise the balance. Maybe change ‘mijn gezondheid’ to ‘my balance’.
The application would help if the word balance keeps coming back.

If I would download the app, I would use it for the appointments overview and balance page.

Information screen:
General practitioners are in connection with sarcoidose.nl, the patient organisation. Sarcoidosis in app sounds good. For my thesis, the patients would say that it is perfect! Go for it! But out of the thesis? Fix logistics.

Appendix M.2 - Second patient’s feedback

! He signed the form and thereby allows me to use her name.

On the 12th of June, a clinic visit took place. As a result of this one patient interview was conducted, with a middle-aged man that was diagnosed 5 years ago with sarcoidosis.

The medication calendar is a good feature, however, he in particular is not disciplined enough to use lists. And he already found his routine with the disease, so he would need some motivation to keep using this.

He would need a notification to be motivated, so for his medication intake and for the short questionnaires.

The alternative treatment on the information page would be interesting. Because he knows that people are looking for it.

Overall he thinks that the important needs are there. It differs of course per patient, maybe when this will be developed this will be taken into account.

Mindfulness works for him, he already uses it himself when he is angry or frustrated.

The mental and physical page at ‘balance’ works for him, because at the beginning when he was diagnosed, he was afraid to die and he thinks that more patients have that when they are diagnosed. Especially in the beginning.

Also for the family, it is important to have a tool like this. For the patient, his wife is struggling with the disease more than him. Because he has his emotions, but she has to deal with them also. So, she sees him struggling when he lost it a bit.

Appendix M.3 - Third patient's feedback

! She signed the form verbally and thereby allows me to use her name.

Thursday 22 June, the third and final patient interview occurred. The patient was a middle-aged woman, and she is a general practitioner. Therefore, she has a lot of knowledge and knows how patients in general like things.

Questionnaires. She mentioned that for her it makes the most sense to combine the big questionnaire with the smaller questionnaires. Because if you use the tool to weekly fill in the questionnaires, automatically there is an insightful progress line about the disease. So, to fill in a questionnaire for 20 minutes feels like a lot of effort.
Also, it feels as if the specialists gain more insights from the overview, and not from the 'moment' when the questionnaire was filled.

Patient skill. Keep in mind how skilled the patients are, because not everyone is waiting for a difficult application.

Medication calendar. She uses the calendar application from her mobile phone, where she will be reminded of her medication intake. So, she uses it already therefore it would be very functional to use this feature. It could be connected to the mobile phone calendar app. And give a notification when medication needs to be taken.

Enthusiastic about:

- Weekly filling out the HRQoL questionnaires, she would definitely use this tool.
- Also, the medication calendar would be a nice addition. Especially, because she explained that she has all kinds of medication and uses different reminder alarms on her phone. So, integrating this would help her.
- Information is also really helpful because she is often looking for information. Especially the segment about sarcoidosis development. This needs to be updated of course, but for her intelligence, this would be helpful.

Tips. It would be nice to connect to the patient's number (MijnZiekenhuis).

It would definitely be an addition to use this application, next to the existing programs.

Most important is the information page, providing more background information.

Appendix N - UX/UI experts' feedback

Two types of UX/UI experts are asked for feedback, namely:

- Digitaal Verbonden, the intern company of Erasmus MC makes a hospital application
- ICT eHealth specialist from the Utrecht Medical Centre.

Both meeting setups:

Presentation with an introduction about myself, the purpose of this meeting, an explanation of the project and the direction. Then showing the prototype and the system compared to other platforms.

Digitaal Verbonden feedback:

Their aim is to create one application for the Erasmus MC that helps patients. It started with a designer patient that became sick and got treatment at the EMC. There they helped her and she got better. However, she missed her journey of digital guidance. Her aim became to create an application to get more information at the hospital.

- With regards to my project, there is a lot of resemblance between my project and their application. They have the software for the majority of the functions I want, namely:
    - Appointment overview (via Hixx software)
    - Questionnaire tool
    - Healthcare staff can see/monitor the questionnaires
    - Chat function
    - They are working on a medication calendar where the patients have an overview of their treatment plan per day/ week.
- They don't have the 'Balance' page, however, according to Annemarie she feels as if that could be something that they should include. To provide guidance when patients are looking for balance in life with their new diagnosis.
- Curavista is a lot of money for the Erasmus MC, and therefore it would be better if the pulmonary department asks for help at Digitaal Verbonden. They have the resources to create the thing that I want to make but also what Curavista is providing now.
- The only thing is that Digitaal Verbonden is not fond of making multiple applications for patients. They already have at the moment applications via Lusci or Beter Dichtbij. This could be way more efficient.

ICT eHealth specialist feedback:

[M. Bluemink, 6 June, at 15h in the Erasmus MC building]
The overall main message was that it is complicated to realise everything that I have implemented in my application. This is due to the medical side and how it works with inclusivity and politics, it delays everything. The following tips were discussed:

- Watch out for the attention that users often lose after a while. The aim is that they fill in a questionnaire once a week, however, this is quite highly aimed for application use. Certainly with the thought that patients don't want to be reminded of their disease each week.
- Use protocol lines in the app. Make a distinction between the intensity of the patient's disease progress. Maybe: beginner, medium, or expert. This could also be for the recommendation and that in this case, I made an app for…?
- The calendar feature is quite complex and not realisable. Because of the software that hospitals now use. And medication is very precise, so if users fill it in themselves, then it can go wrong. Will this be checked?
- Risk analysis can help, otherwise, it could go wrong with the medication calendar for example.
- DigiD: it is an option to use it, however, often it goes with an email address that is known in a hospital. Patients can make an account with this address.
- The big questionnaire is quite long for scrolling. A bar would be the most intuitive thing to add. Otherwise, people won't see that they have to scroll. An arrow pointing downwards could also help.
- The graphics: check with patients, is this really the case that they want to see this? And add a button to the 'balance' page, then patients can do something about a decreasing feeling for one aspect of sarcoidosis for example. Loops are nice to have!
- It is very important that the information that is stated inside the app, is also validated with the medical staff. Otherwise, it makes no sense. And also these medical doctors need to agree with the content that will be added.
- Everything in the application needs to be inclusive for everyone… 'walking' and people in a wheelchair then? For example.
- What are doctors giving now to patients? Is the application adding something new?
- It could be interesting that doctors or patients themselves can see: hey I don't want to have this 'button/page', and that it will be excluded in their interface.
- Risk analysis can be interesting to do. What if someone is going bad with one certain sarcoidosis aspect? Are the doctors checking this?