

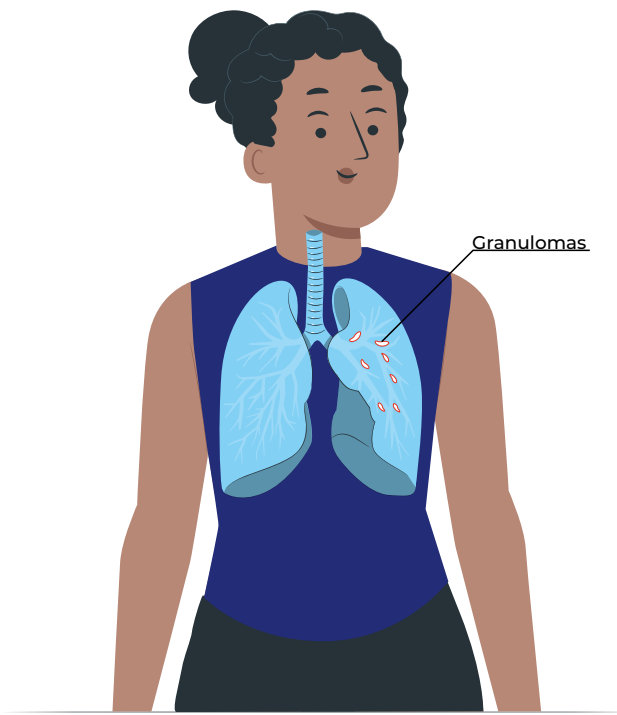
Self-management tool for sarcoidosis patients

CONTEXT

Sarcoidosis

Yearly, 7000 to 8000 patients in the Netherlands are diagnosed with sarcoidosis, making sarcoidosis 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 sarcoidosis. Sarcoidosis 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., sarcoidosis patients website:

wijhebbensarcoïdose.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 sarcoidosis patients.



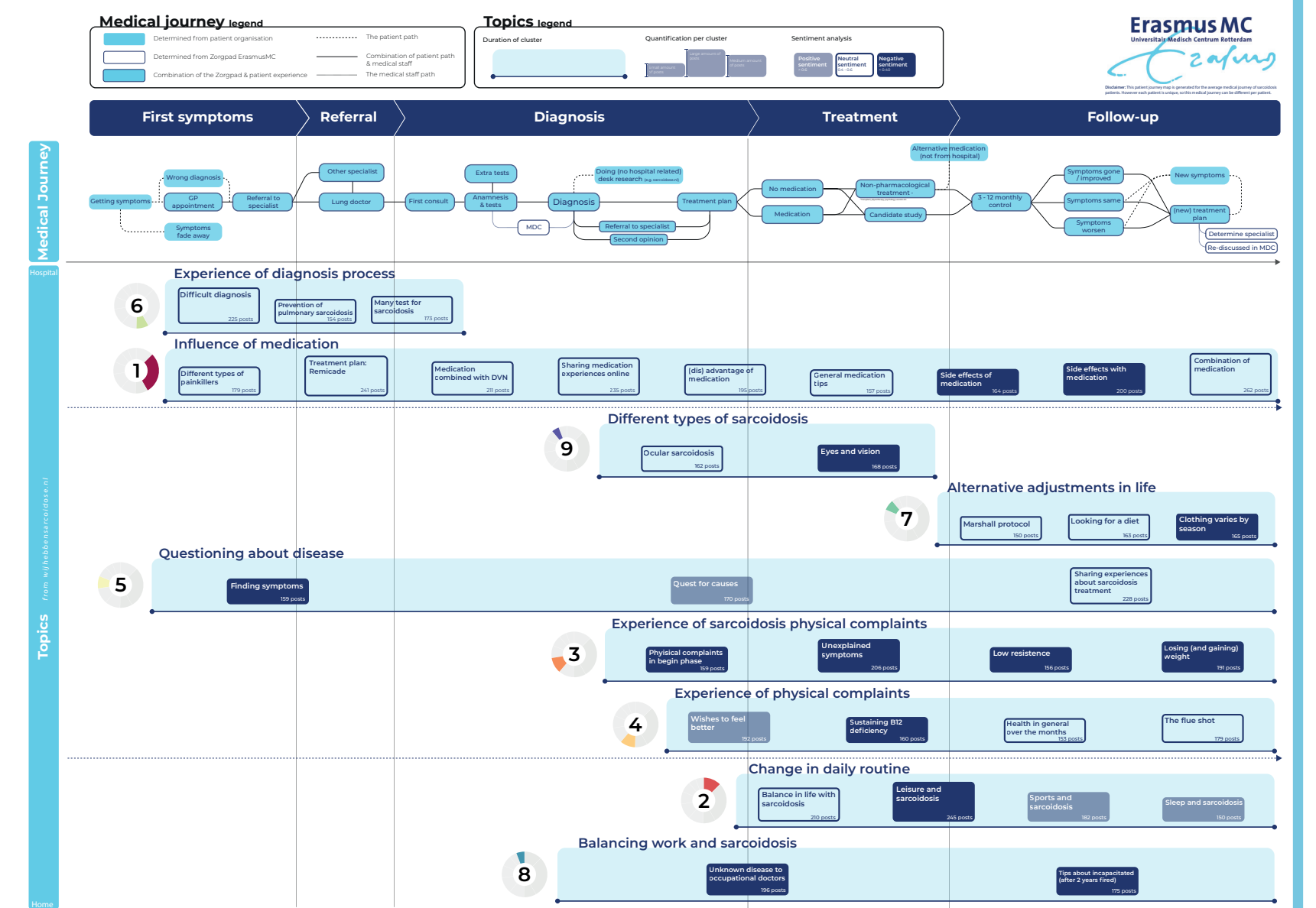
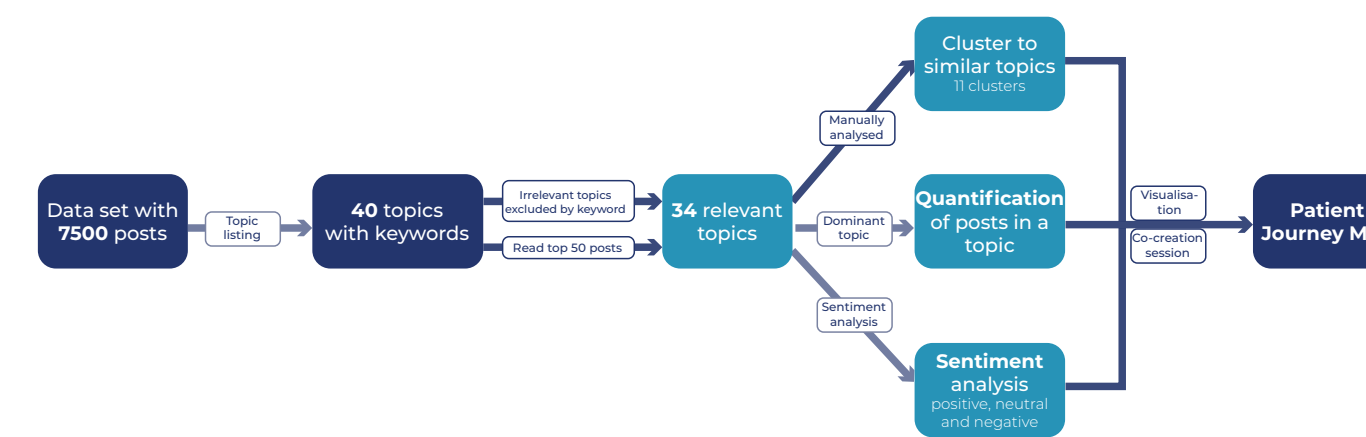
METHOD

Patient Journey Community 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 ana-

lyse 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.

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. On the right is this project eventual patient journey map visualised.



RESEARCH QUESTION

From the patient journey map finding a balance in life is found to be the thread for sarcoidosis 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 sarcoidosis patients manage and improve their quality of life?

The sub-research questions are:
 1. What aspects do sarcoidosis patients cope with regarding their quality of life?
 2. What enables to improve patients' quality of life?

OUTCOME

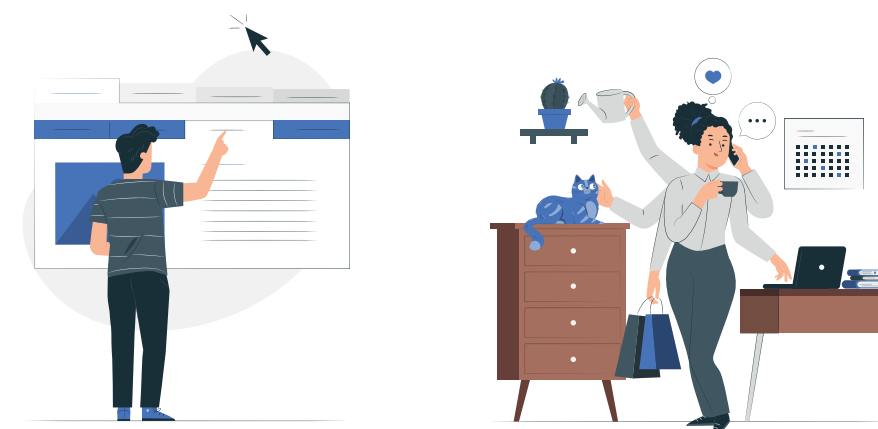
Four patient's needs

The interstitial lung diseases department of the Erasmus MC is in charge of this project and wants to see what can be improved for sarcoidosis 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. 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.



Medication overview for sarcoidosis patients **Monitoring quality of life**



Providing information about sarcoidosis **Finding balance in life with sarcoidosis**

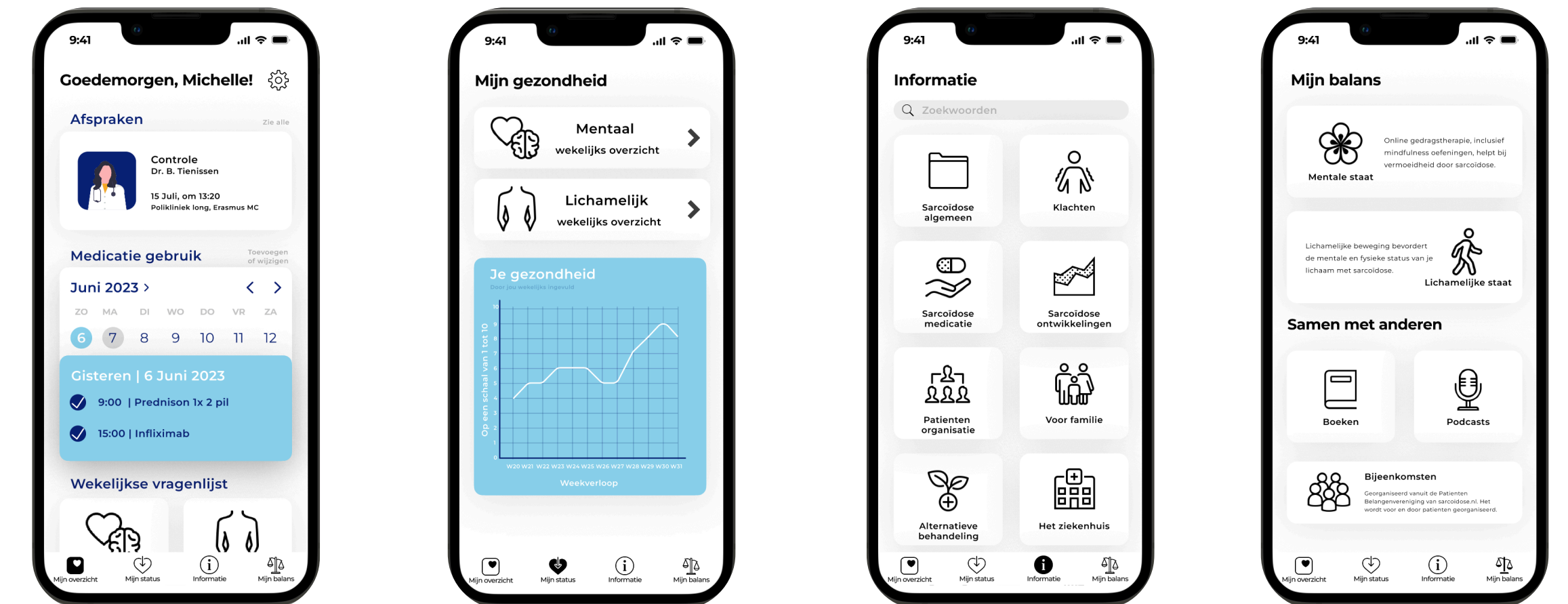
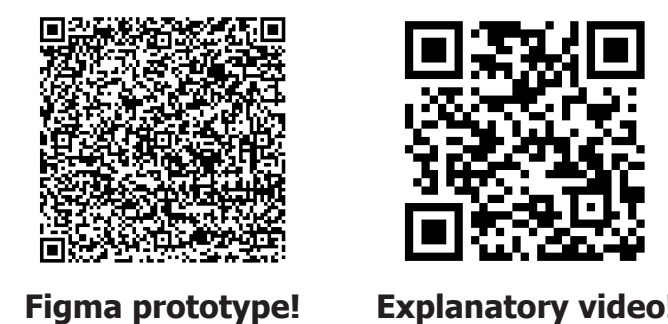


PROTOTYPE

Figma prototype

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. These needs and the application pages are shown on the right.

Scan the QR code on the left to scroll through the functional Figma application.
 Scan the QR code on the right to see a video how the functional Figma application works.



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