GROW

Self-management support

Empowering Psoriaticarthritis and Rheumatoid arthritis patients with a low socioeconomic position in self-managing their disease

Master Thesis - Design For Interaction

By Lisa Eijkelkamp

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Author
Lisa Eijkelkamp

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Delft University of Technology

Graduation commitee
Chair **Dr J.J. Kraal**
Mentor **Ir. V.Pannunzio**

Erasmus Medical Center supervision
Dr J.J. Luime
Ir. P. De Groot

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Accepteren

Reuma een plekje geven

Reuma zal dingen veranderen in uw leven. Uw lichaam voelt anders dan u gewend was. Boos, verdrietig of bezorgd worden is normaal. Dat hoort bij het hebben van een ziekte

Reuma zal altijd een onderdeel blijven van uw leven. Daarom is het belangrijk reuma een plekje te geven en hier niet tegen te vechten.

U kunt zich laten inspireren door mensen om u heen en lotgenoten die hetzelfde meemaken.

Tips bij een dip

- Krop het niet op. Praat met mensen die u vertrouwd of schrijf uw gevoel op.
- Ontspanningsoefeningen kunnen helpen om met emoties en pijn om te gaan.
- Bewegen helpt voor uw lijf en uw hoofd
- Bedenk dat u vertrouwen mag hebben in uzelf en in alles wat u kan ondanks uw reuma.

Waarom accepteren?

Uw reuma accepteren helpt om op een gelukkige manier met uw reuma om te gaan.

U kunt bedenken wat u belangrijk vind in het leven en op zoek gaan naar aanpassingen die daarbij helpen.

Bespreken

Bespreken met uw dokter

U weet het meeste over hoe de reuma in uw lichaam werkt, en welke problemen u door u reuma heeft tijdens uw leven.

Het is belangrijk deze informatie goed met uw dokter te bespreken. Dan kan de dokter u helpen op een manier die past bij uw lichaam en leven. U kunt het hebben over dingen die u heeft geleerd of vragen die u heeft over het voelen, begrijpen, aanpassen en accepteren.

Bespreken met uw omgeving

Tijdens het omgaan met uw reuma maakt u momenten mee met de mensen om u heen. Door goed met hen te praten over uw reuma en wat u nodig heeft kunnen zij u beter begrijpen en helpen

Waarom bespreken?

U weet het beste hoe uw reuma werkt en hoe u hiermee om wil gaan. Door dit goed te bespreken met uw omgeving en uw dokter, kunnen zij uw reuma en uw behoeften beter begrijpen en u beter helpen

Leren omgaan met uw reuma

Elk lichaam met reuma en elk leven is anders. Het is belangrijk dat u uitzoekt hoe de reuma en medicatie in uw lichaam werkt en welke aanpassingen passen bij uw lichaam en leven.

Door bewust uw lichaam te voelen leert u uw reuma begrijpen. Dit geeft ideeen voor aanpassingen die u kunt uitproberen.
U merkt dan of de aanpassing werkt voor uw lichaam. U merkt of de aanpassing u helpt om de reuma te accepteren en te doen wat u belangrijk vind

Door te bespreken wat u voelt, leert en wilt aanpassen kunnen anderen u hierbij helpen

Hoe voelt je lichaam vandaag?

Preface

In your hands rests the embodiment of the project that finalizes my bachelor's and master's studies in Industrial Design Engineering: My final thesis project.

Psychology, behavior and health have always captivated my interest. I love to delve deeper into what makes people tick and why they behave the way they do. I firmly believe that design can serve as a remarkable tool for merging these fields of psychology and behavior with the field of health to create solutions that help people live their most optimal lives, both physically and emotionally.

Throughout my academic journey, this interest led me to undertake various health-related projects which helped me learn a lot about designing for interaction within the health field. This final master's thesis project, which focuses on empowering patients with limited health skills in self-managing their disease, is the cherry on top.

From the onset of this project, I quickly realized that I had chosen a challenging topic. A quote from one of the interviewed patients represents the course of the design process I went through very well:

'It is a journey, you have taken a bus, you have no idea in what direction it is heading, and along the way also the passengers change, an accident happens, you have to keep changing along with that.'

I entered the bus with a strong base of interest in the topic and the design process itself which is what kept me driving. Throughout the project, I discovered that this strong base is also a critical factor for the patients. As one of the interviewed rheumatologists stated:

'You keep encountering the same elements during the whole care path, but it starts at the beginning. When the fundamentals are not right, you have to fix that somewhere later on.'

This thesis project will show you why this strong base is of such importance and presents my suggestion for addressing this.

This project would not have been possible without the contribution of many people. There are a few people I would like to thank in particular.

First, I would like to thank my TU delft supervisors, Jos Kraal and Valeria Pannunzio. Jos, thank you for guiding me in exploring the topic of behavior change and providing me with the clear feedback I needed to translate my fuzzy stories into a clear vision, report, and design. Valeria, thank you for your incredible enthusiasm about the topic. This made our meetings fly by, always inspiring me with new ideas and valuable perspectives to continue working on.

Next, I would like to express my appreciation to my supervisors from Erasmus Medical Center. I want to thank Jolanda Luime for assembling the assignment and the research team. Thank you for your critical feedback during update meetings which helped me to be critical of my research findings and the implementability of my design directions. I want to thank my daily supervisor at Erasmus Medical Center, Patty de Groot, for connecting me to the right people and helping me arrange the hospital-related research and design activities. Also, I want to specifically thank you for supporting me in my daily challenges around the project and helping me keep an overview. I would have been way more lost in my own insights if I had not had you as a discussion partner on the other side of the desk.

Also, I would like to thank all the healthcare workers and patients that participated in this research project. Thank you for sharing your experiences and providing me with all the valuable insights that created the base for this user-centered design project.

Finally, I want to thank all the people in my surroundings, and my family in particular, who have been involved in this project and my graduation process in one way or another. Thank you for supporting me, brainstorming with me, and listening to my stories to help me manage this intense process of graduating. Also, thank you for sometimes reminding me to just let go. I am very grateful for the many kind and supportive people surrounding me.

This thesis project shows how I applied the learnings I gained during my studies in industrial design and design for interaction on the topic of using design to support patient self-management behavior.

Enjoy reading,

Lisa Eijkelkamp

July 2023

Executive summary

The rheumatology department of ErasmusMC wants to improve the effectiveness of their future Psoriatic Artritis and Rheumatoid Arthritis care paths to increase disease outcomes and patients' experienced Health-related quality of life. The expected lack of capacity on the department, because of the increasing life expectancy and the number of people living with a chronic disease such as arthritis, asks to solve this problem in a capacity-efficient way. Including remote monitoring in the care path and shifting towards a self-management approach where patients are enabled to take an active self-management role and become responsible for day-to-day disease management offer potential opportunities for this.

This thesis project aims to determine how ErasmusMC could improve the Psoriatic Arthritis and Rheumatoid Arthritis care paths to better support the patients in self-managing their disease and what opportunities remote monitoring could provide in this. The project focuses on designing a support approach that aligns with the characteristics and needs of patients with a low socioeconomic position. This patient group currently has worse disease outcomes and is associated with higher use of care and limited health skills. When shifting towards a self-management approach, which asks for more self-reliance of the patients, it is essential to take this patient group into account to prevent the gap in disease outcomes with patients iwth a higher socioeconomic position from increasing further.

A user-centered design approach was used to define and solve this complex problem were both stakeholders, including the patients as well as the healthcare workers, were included during both the research and the deisgn phase of the project.

During this research phase, it became clear that there is a lacking communication of information about the topic of self-management between healthcare workers and patients. Because of this, patients start their self-management journey with an insufficient knowledge base which negatively influences their motivation and ability to take an active self-managent role Along their self-management journey the patients experience various difficulties in self-managing their disease that complicate this further. It became clear that the patients need support in translating provided information and their own experiences into understanding about their personal disese and management situation to empower them to take an active self-management role. The patients need support in communicating about this with the healthcare workers to allow them to receive tailored support to improve this further.

Through co-creation with the stakeholders a future support approach was designed, consisting of a communication approach and a home support app. The support approach focuses on establishing a clear, consistent and engaging way of communicating about the topic of self-management between healthcare workers and patients and guiding and engaging the patient in developing an understanding of their disease and its management.

Evaluation showed that the support approach increases the patient's ability and motivation to take an active self-management role and provides healthcare workers a structure that supports them in obtaining input from their patients and conveying self-management information in a clear and engaging way. The benefits the support approach could establish regarding patient's health outcomes and self-reliance seem to outweigh the resources needed to establish this. Enabling connection with future remote monitoring interventions would positively influence the viability of the concept further. Further evaluation is needed to validate the actual effect of the support approach on the longer term.

The insights gained during this project about defining and modeling self-management, communicating about self-management and the characteristics and pains of patients with a low socioeconomic position show opportunities for future research and potential for generalization over the broader health domain.

Glossary

ErasmusMC	Erasmus Medical Center
PsA	Psoriatic Arthritis
RA	Rheumatoid Arthritis
HRQoL	Health Related Quality of Life
MDA	Minimal disease activity
LowSEP	Low Socioeconomic Position
IPROLEPSIS	Study about remote monitoring at ErasmusMC

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Introduction

This thesis project is derived from an assignment by the rheumatology department of Erasmus Medical Cener (ErasmusMC). The department wishes to increase the effectiveness and efficiency of the future Psoriatic Arthritis and Rheumatoid arthritis care paths, focusing on patients with a lower socioeconomic position. This section introduces the scope of this assignment ending with the problem statement that this thesis project is based on. The introduction concludes with a general overview of the project approach, including an overview of the set-up of the report

Chapter 1

Introduction

In this Chapter the thesis project is introduced by explaining the scope of the project. After this the problem statement is introduced that created the base for this thesis project.

1.1 Defining the scope

The assignment by ErasmusMC addresses three contextual aspects: Improving disease outcomes of Psoriatic Arthritis and Rheumatoid Arthritis patients, the future of healthcare, and targeting patients with a lower socioeconomic position. The scope of the assignment is formed by the intersection of these three contextual aspects, as visualized in Figure 1.

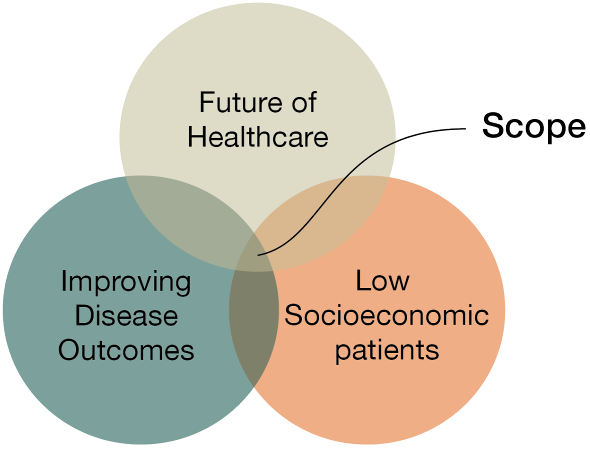


Figure 1 - Project scope

Improving disease outcomes of Psoriatic- and Rheumatoïd Arthritis patients

Psoriatic Arthritis (PsA) and Rheumatoid Arthritis (RA) are common chronic inflammatory diseases. A recent study by ErasmusMC has found that three years after diagnosis, 70% of the PsA patients have not reached the treatment target (Snoeck Henkemans et al., 2022). This treatment target, called Minimal Disease Activity (MDA), includes both remission and a certain acceptable level of low disease activity (Coates et al., 2010). The same study by ErasmusMC showed that failure to reach this MDA within the first year after being diagnosed is associated with worse quality of life outcomes, which persists over the years despite more intensified treatment (Snoeck Henkemans et al., 2022). When discussing the topic of health, the Health-Related Quality of Life (HRQoL) is used, which means how well a person functions in life and his or her perceived well-being in the physical, mental, and social domains of health (Karimi & Brazier, 2016).

ErasmusMC aims to increase the disease outcomes and the HRQoL of their PsA patients. As PsA is very similar in its clinical manifestations to RA (Merola et al., 2018), they want to focus on improving the effectiveness of both the PsA and the RA care path.

PsA and RA

PsA and RA are conditions caused by increased production of proinflammatory molecules that cause autoimmune inflammatory responses. The onset and progression of the diseases have been suggested to be triggered by an interplay between an individual’s genetics and environmental influences that trigger an immune response. RA is more common than PsA. In Europe, RA prevalence is estimated to be 0.5% - 1.0%. PsA prevalence in Europe is estimated to range from 0.1% to 0.4% (Merola et al., 2018). With RA, women are two to three times more likely to be diagnosed, and around three-quarters of the patients were first diagnosed at working age (Tracey, 2017). PsA affects men and women equally, and its incidence peaks between 30 and 55 years (Dures et al., 2019).

PsA and RA are characterized by pain and swelling in the affected joints. The level of inflammation in the affected joints can vary with flares of increase and periods of remission (Dures et al., 2019). The number of affected joints can increase over time (Merola et al., 2018). Besides pain, patients can also experience fatigue. The inflammation itself can cause this fatigue. However, it can also be caused by other insufficiently known factors or sleep disturbance because of the experienced pain (ReumaNederland, 2023). Finally, PsA complicates skin and nail psoriasis in up to 30% of the patients (FitzGerald et al., 2021).

The treatment of the diseases consists of drug treatment as well as non-pharmacological treatment.

Drug treatment conventionally consists of disease-modifying antirheumatic drugs (DMARD), which can be taken orally or as an injection. Also, biological medication is used, which is given as an injection. It can take some time before these drugs show their effect. This is why patients can also be offered corticosteroids such as prednisone, which have powerful anti-inflammatory effects and can relieve symptoms in the short term..

However, when used cumulatively, they have significant unwanted side effects such as weight gain and mood disturbances (Merola et al., 2018; Tracey, 2017).

The non-pharmacological treatment involves the patient committing to an overall healthy lifestyle, including a healthy diet, frequent physical activity, no smoking, and stress coping (FitzGerald et al., 2021; Schäfer & Keyßer, 2022). Along the care path, the patient has check-ups at the rheumatology department. The treatment effect is measured and monitored using the Disease Activity Score to identify the disease activity status ranging from high to remission (Coates et al., 2010).

During their daily life, patients need to commit to the medication regime and to daily management tasks such as exercising joints, pacing activity, and relaxation techniques (Dures et al., 2019). Therapies can support patients in this, including physical and occupational therapy and dietary approaches (FitzGerald et al., 2021). Various studies have tried to define the most critical impacts of PsA and RA on a patient's life. This includes, among other things: (1) impact on daily life activities and work productivity, (2) impact on social participation and relationships, and (3) emotional impacts such as feelings of frustration, depression, and anxiety (FitzGerald et al., 2021; Ogdie et al., 2020). These impacts do not only influence the patient's HRQoL but can also, in its turn, have a negative influence on the disease activity itself. Studies have, for example, shown that pain, flare, and increases in disease activity with RA tend to be preceded by interpersonal stress (Stanton et al., 2007).

The future of healthcare

The rheumatology department is dealing with an expected lack of overall capacity and a deficit in physicians in the future because of the increasing life expectancy and the number of people living with chronic diseases. (Miloslavsky & Marston, 2022). When attempting to increase the effectiveness of the PsA and RA care path regarding disease outcomes, ErasmusMC has to find solutions to establish this incapacity-efficientlyTwo of the various developments happening in the healthcare world: shifting towards a self-management approach and using the benefits of remote monitoring, could offer interesting opportunities.

Self-management approach

Shifting to a self-management approach means the responsibility for day-to-day disease management shifts from healthcare professionals to the individual. This could be a means to bridge the gap between fulfilling the needs of chronic patients and the capacity of the care systems to meet those needs (Barlow et al., 2002). The current healthcare system's methods are designed for acute diseases where the health professionals apply their knowledge to a passive patient. With chronic diseases, patients have unique changing clinical patterns, and the outcome of one step in therapy determines the next. For effective disease management, active involvement from the patient, who knows most about the consequences of the disease and its therapies, is essential (Holman & Lorig, 2004).

Research has shown that patients that succeed in taking an active role in managing their chronic disease have improved health and reduced incapacity (Dongbo et al., 2006) and get a greater sense of control over their chronic disease (Baumann & Dang, 2012). This active patient participation includes being engaged in the planning of care and exchanging knowledge, setting own goals, and carrying out self-management activities during daily life (Dineen-Griffin et al., 2019). Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle

changes inherent in living with a chronic condition (Barlow et al., 2002).
At the start of their care path, patients are inexperienced and lack the ability to take this active self-management role. Shifting towards a self-management approach thus creates a new important role for the healthcare system. Besides providing professional guidance, they also need to aid the patient in developing the necessary knowledge and skills to take an active self-management role (Holman & Lorig, 2004).

Remote monitoring

The concept of remote monitoring has risen since digital devices started to connect and communicate, and affordable portable consumer technology has become increasingly available (Awad et al., 2021).

Remote monitoring uses digital devices such as wearables and implantables to collect digital biomarkers. Digital biomarkers are objective, quantifiable physiological and behavioral data. Continuously collecting these biomarkers allows to explain, influence, and predict health-related outcomes without causing interference in the patient's life (De Groot et al., 2022).

The department's insight into this data would allow to improve and tailor the care path to the patient's individual needs. It would allow for care to go beyond hospital walls, decreasing the burden on physical healthcare establishments. Providing the data to the patients would allow them to make better-informed decisions when self-managing their disease (Awad et al., 2021).

The rheumatology department of ErasmsuMC is currently conducting a study called IPROLEPSIS. This study focuses on including a remote monitoring tool in the PsA care path. This thesis project was established as an addition to the IPROLEPSIS study as ErasmusMC is interested in discovering the opportunities of this tool when shifting towards a self-management support approach.

Low socioeconomic Patients

When attempting to improve the overall disease outcomes of the PsA and RA patients, ErasmusMC recognizes the importance of addressing the needs of patients with a low socio-economic position (lowSEP).
These patients have a higher chance of developing a chronic disease (Pharos, 2022) and have on the rheumatology department been associated with worse disease outcomes and higher disease burden (Jiang et al., 2015; Putrik et al., 2016)

A person's socioeconomic position (SEP) is determined by income, education, and occupation (Baker, 2014). In the Netherlands, this is often measured in educational level. In 2018 the percentage of lower-educated people was 29% (RIVM, n.d.). In present-day society, health disparities, which refer to differences in health status and health outcomes between social groups, have become a concerning issue (Stormacq et al., 2019). Research has consistently shown that having a lower SEP has a significant influence on a person's health lifestyle, where the health condition of the group with lower SEP is lower than that of the group with higher SEP (Haker et al., 2019). These health disparities are considered unnecessary, avoidable (Stormacq et al., 2019)

Current support and interventions are often focused on the general population but have been shown to be less effective for the lowSEP patient as they do not take their specific characteristics and needs into account (Al-Dhahir et al., 2022). LowSEP patients tend to make more use of care and have limited health skills meaning the skills to obtain, understand, assess, and use health information in making health-related decisions (Pharos, 2022).
When shifting towards a self-management approach which asks for more self-reliance of the patient, it is essential to take the lowSEP patient's characteristics into account to prevent the health disparities from increasing further. Currently, there is a lack of insight into these characteristics and needs as in most Western developed countries, people from socially disadvantaged groups like lowSEP patients are under-represented in health research (Bonevski et al., 2014).

1.2 The problem statement

Based on this defined scope around the assignment posed by ErasmusMC a problem statement could be defined that forms the base of this thesis project:

What should the future hospital self-management support look like to better support lowSEP PsA and RA patients with limited health skills in self-managing their disease, and what opportunities could remote monitoring provide in this?

Background at ErasmusMC

The assignment by ErasmusMC originates from a previously conducted thesis study from TUDELFT: PEPSA and a currently conducted study at the rheumatology department of ErasmusMC: IPROLEPSIS.

PEPSA

The PEPSA study is a Delft University of Technology master thesis project conducted at ErasmusMC by Drost on patient experience of newly diagnosed PsA patients in the at-home context. This study identified that most of the information currently focuses on the physical difficulties of PsA, while there are also a lot of mental difficulties. It also stresses that, especially right after diagnosis, patients get lost in the amount of information and have difficulty determining what information is relevant to them. Finally, it mentions that the changes in life and the need for dependence gives patients the idea that their disease takes control over their life (Drost et al., 2022)

IPROLEPSIS

This thesis project was established as an addition to the current IPROLEPSIS study conducted at ErasmusMC about developing a remote monitoring tool for the PsA care path. The tool aims to collect data around changes in movement patterns, pain, fatigue, and morning stiffness to predict changes from uninflamed to inflamed, which would provide the department with more insight into the disease developments during the daily life situation of the patient. The study currently tries to determine and test which digital biomarkers would be most interesting to include in this tool and how this data can be translated into usable insights. Data they are experimenting with are data on mood and stress levels and mechanical stress,s including physical activity and fatigue, as the presence of joint and tendon disease can be related to changes in these measures. They are considering measuring physical activity, vital signs, typing pattern analysis, and mobile phone screen time to collect this data (De Groot et al., 2022)

Chapter 2

Project Approach

This Chapter explains the User-Centered design approach that was used during this project. The Chapter describes the design process that was followed and explains the various research and design methods that were used during this.

2.1 Project approach

User-centered design

This thesis project works on the perspectives of design for health and well-being and design for behavioral change (Van Boeijen & Daalhuizen, 2020). It aims at creating a design intervention that should support lowSEP patients in realizing self-management behavior while at the same time taking into account the needs and expectations of the other stakeholder involved in this: the healthcare worker. Because of this, a user-centered design approach is used, which focuses on the user’s perspective regarding needs, desires, properties, and capabilities to create valuable and usable design interventions. Both stakeholders are included through co-creation, a collaborative design effort where the users are included during all project phases (Van Boeijen & Daalhuizen, 2020). This helps to establish a desirable, feasible, and viable design intervention. Additionally, including the healthcare workers in the process stimulates their feeling of investment, increasing the implementation chance of the final support approach.

Design process

This thesis project follows the double diamond design process developed by the Design Council, which maps the divergent and convergent stages of the design process. The first diamond includes the problem phase, focusing on getting inspiration and defining the problem. The second diamond consists of the solution phase focusing on developing and testing toward the delivery of a final solution (Design Council, 2005). Starting the project, the context of the rheumatology department was very unfamiliar. This helped to approach the problem with a very open-minded view but also asked for an elaborated phase of empathizing with the context. The assignment by ErasmusMC was very broad and open-ended. At the start of the project, there was no clear path or outcome, and extensive research had to be conducted to come up with a good definition of the right problem to solve. Because of this, this thesis project focused on the first diamond of the design process. Figure 2 shows a visual overview of the design process followed.

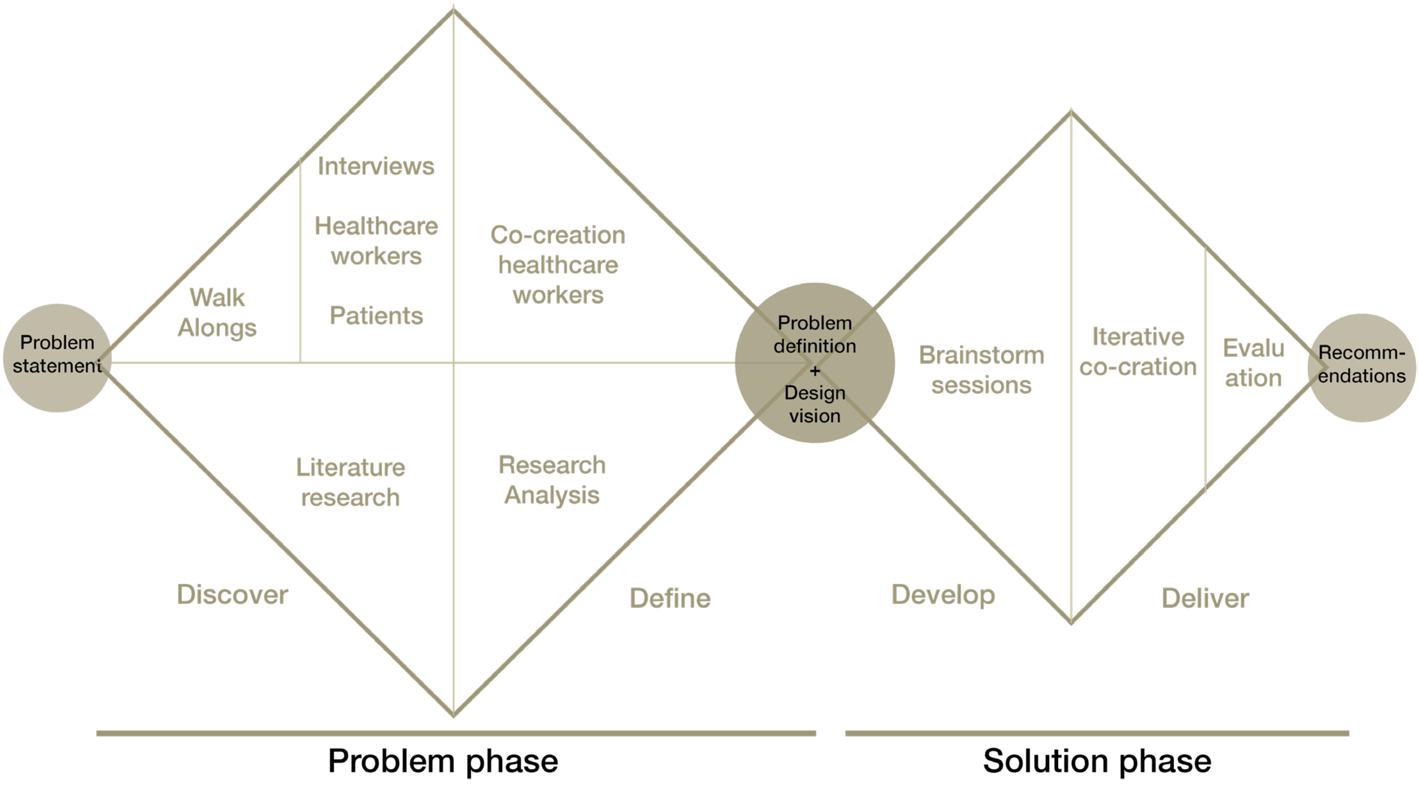


Figure 2 - Double diamond design process

Problem phase

During the problem phase, literature and various field research activities were conducted. The research methods helped to define the background of health and health behavior, the thesis context, the current experience, and the future vision of the stakeholders. An overview of this is given in Figure 3. Literature research was conducted throughout the thesis project, while the field research activities were undertaken in steps. One step in de field research created insights on itself but also set a base for the next activity.

The various research activities aimed to answer five sub-research questions that together allowed to explore and define the problem statement:

<u>Defining the context:</u>
Rq1 What does self-management entail for PsA and RA patients, and how is this currently supported?

Rq2 What are meaningful characteristics of lowSEP patients around engaging in self-management?

<u>Defining the current experience:</u>
Rq3 What difficulties do lowSEP PsA and RA patients experience in their current self-management journey?

Rq4 What difficulties do healthcare workers currently encounter in supporting lowSEP patients?

<u>Defining the future vision:</u>
Rq5 What is the stakeholders’ future vision on supporting patients in self-managing their disease, and what role could remote monitoring play in this?

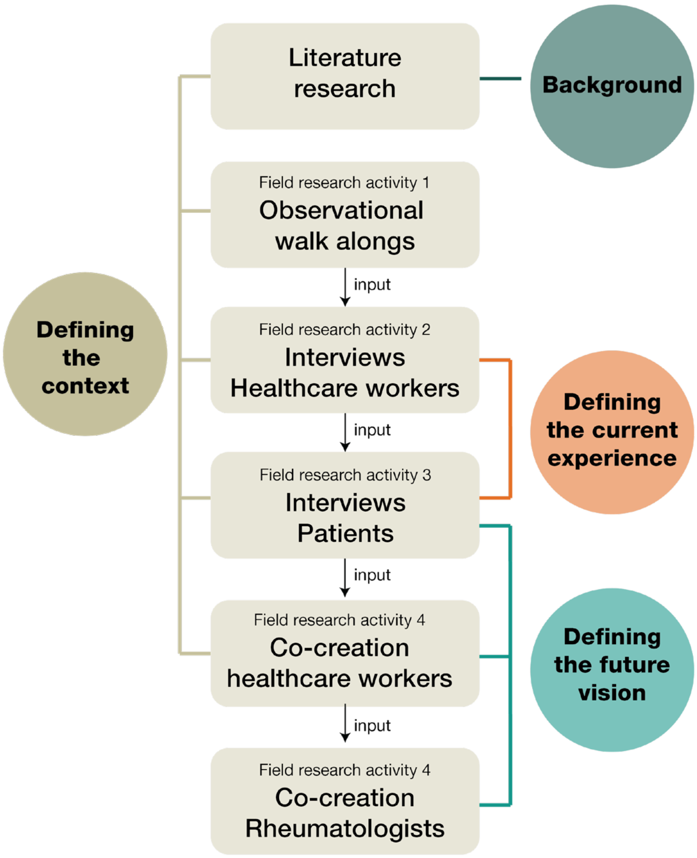


Figure 3 - Research set-up

Solution phase

The solution phase consisted of an ideation part as well as a testing part. Based on the problem definition, a design goal was formulated which describes the challenge of solving the problem right. During the ideation session, multiple concepts were generated. Through co-design with healthcare workers and a patient, these were iterated towards a final support approach concept. This support approach was evaluated to determine the stakeholders’ experience of the concept and establish recommendations for further development.

2.1 Research and design methods

Various research, analysis and design methods were used to define the problem and solve the problem. This section provides an overview of the methods used.

Research methods

This section gives an overview of the methods used during the problem phase of the project. This included literature research and various field research activities. A more detailed description of field research activity 3 can be found in Appendix A.

Literature research

A literature study was conducted to define the main aspects of the problem. This allowed to define the background of health and behavior and gain insights to define the context. Also, it provided first insights into patients' experiences around disease self-management. To do this in a structured way, the problem statement was divided into four aspects: PsA and RA, Self-management behavior, Behavior support, and lowSEP health lifestyles. Based on these four aspects, keywords could be generated that could be researched separately and combined. Throughout the project, literature research was used to define newly found keywords.

Field research activity 1
Observational walk along

Two walk alongs at the rheumatologist outpatient center and two walk-alongs at the consultant outpatient center of ErasmusMC were executed. A fly-on the wall approach was used, where observations were done without interfering the setting, to not bias the participants (Think Design, 2020). The observations allowed to emphasize with and define the context objectively and gave first insights in patient experiences. With every walk-along around 5 patients came in that were not specifically lowSEP but were varying in level of health literacy. Data was collected by taking notes.

Field research activity 2
Interviews healthcare workers

Three rheumatologists (ErasmusMC, HAGA, and Maasstad hospital) and three rheumatology consultants of ErasmusMC were interviewed. The interviews focused on the context of self-management within the PsA and RA care path, the lowSEP patient, and remote monitoring. This allowed to define the context further and gain insight into the current experience of healthcare workers. Data was collected by recording the interviews

Field research activity 3
Interviews lowSEP patients

Seven lowSEP patients were interviewed about self-managing their disease (figure 4). A context mapping approach was used. This approach uses creative means to help to bring latent knowledge to the surface (Sanders & Stappers, 2018).

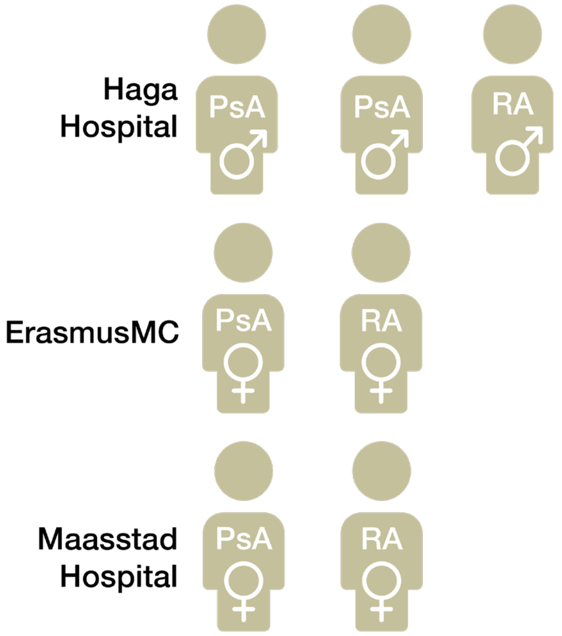


Figure 4 - Patient interview participants

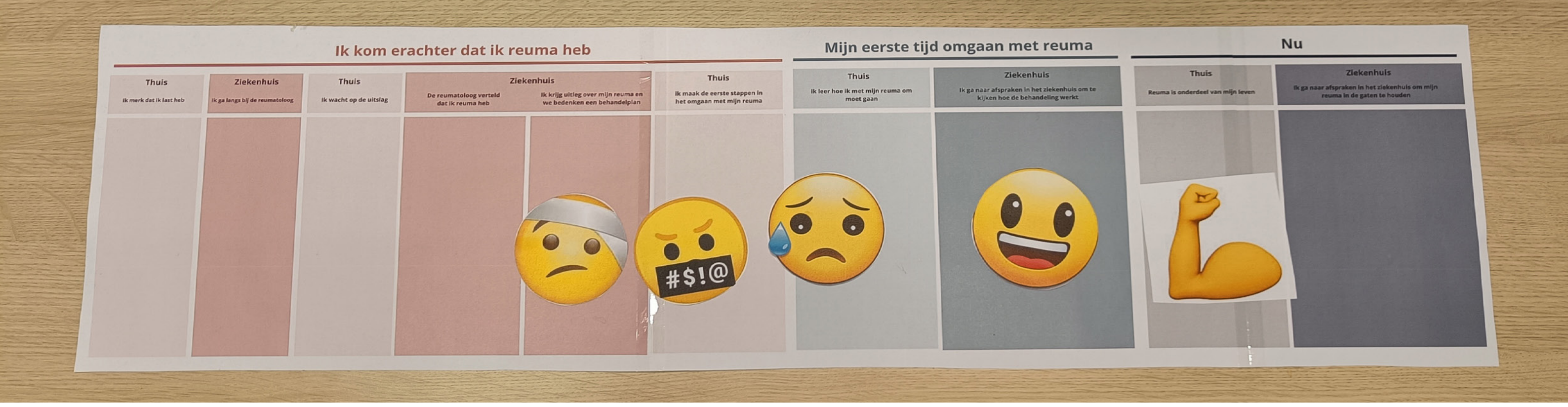


Figure 6 - Creative toolkit

The interviews were based on the path of expression (Figure 5) to stimulate patients to share experiences about the now, think about the past, and dream about future desired experiences (Sanders & Stappers, 2018). The context mapping set-up included a digital sensitizing assignment prior to the interviews and an interview set-up that followed the path of expression through creative toolkit use (figure 6) and conversation. With the interviews, insight was gained into the experiences of the lowSEP patients in self-managing their disease along their journey. Data was collected through recording interviews.

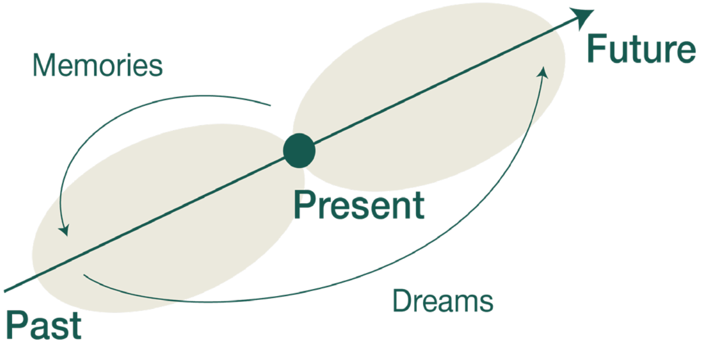


Figure 5 - Path of expression

Field research activity 4
Co-creation with healthcare workers

A co-creation session was executed with one rheumatologist and two consultants of ErasmusMC. This session consisted of two parts. The first part focused on determining meaningful lowSEP patient characteristics and establishing a future vision. Various creative techniques were used to stimulate the patients to think about the current and desired situation. The second part focused on evaluating an initial idea direction to develop further insight into the healthcare workers' needs around the future vision. Data was collected by recording the session and taking photos of the created

Field research activity 5
Co-creation with rheumatologists

An online co-creation session was held with three rheumatologists of ErasmusMC, HAGA, and Maasstad Hospital. An initial idea direction was evaluated, and the rheumatologists were asked to provide feedback for improvement on this. This provided additional insights into the healthcare workers' needs around the future vision. Data was collected by taking notes.

Research methods

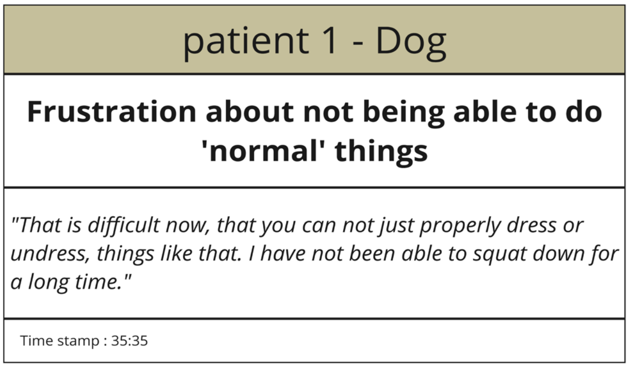
The Data, Information, Knowledge, and Wisdom (DIKW) hierarchy was followed to make sense of the collected data. Data is the most basic level, which is, through analysis turned into information, knowledge, and eventually wisdom. This way, more abstract insights are created that show patterns across users. Keeping all these layers in mind allows a deep understanding of the problem (Sanders & Stappers, 2018). During the analysis, the collected data was first interpreted and paraphrased into information. After this, to get to the knowledge and wisdom layer of the DIKW hierarchy, various clustering cycles were conducted.

Analysis phase 1

After research activities 1 and 2, a first analysis was conducted. The collected data was interpreted and written down as information divided into patient activities and pains and gains around patients self-managing their disease. Pains and gains specific to the lowSEP patient were highlighted. The activities found were mapped out over time to get an overview of patients' activities during their self-management journey. The pains and gains were clustered, resulting in eight clusters. Five clusters identified important aspects of self-management, and three clusters identified differences between patients. This first cluster set can be found in Appendix B.1.

Analysis phase 2

The recorded data during research activity 3, the patient interviews, was listened back and translated into information using statement cards (figure 10). Statement cards are often used with context mapping to facilitate working with the (DIKW) hierarchy as they allow data collection in quotes and force to directly interpret and paraphrase this into information (Sanders & Stappers, 2018). This helps to analyze the data efficiently and in an organized manner without losing the richness and emphasizing quality of the quotes. The statement cards were categorized into the five aspects of self-management found within the first analysis phase. After this, various iterations of clustering allowed to find generalized pains and gains, overarching clusters of pains and gains within the categories, and finally, pain themes that described meaningful connections between these overarching clusters. An overview of the final cluster set, including the overarching clusters and pain themes, can be found in Appendix B.2. During this second analysis phase, pains and gains around emotional experiences were copied and mapped out over time to gain insight into the patient's emotional journey.



patient 1 - Dog

Frustration about not being able to do 'normal' things

"That is difficult now, that you can not just properly dress or undress, things like that. I have not been able to squat down for a long time."

Time stamp : 35:35

Figure 7 - Statement card

Design methods

Brainstorm sessions with fellow students

To increase the creativity level of the ideation phase, including unbiased and out-of-the-box thinking, multiple brainstorming sessions were conducted with design students. Creative techniques for problem-finding and idea-finding were used to stimulate the participants to think about the topic they were unfamiliar with. (Heijne & Van Der Meer, 2019).

Design co-creation stakeholders

Three design co-creation sessions were executed: (1) a co-creation session with a focus group of healthcare workers, including two rheumatologists and two rheumatology consultants, (2) a co-creation session with a lowSEP patient, and (3) a co-creation session with a rheumatologist. During the sessions, concept directions were evaluated and iterated. Creative techniques for idea-finding were used to stimulate the participants' creative thinking. (Heijne & Van Der Meer, 2019).

2.3 Readers guide

Sections

Secion 1 - The Problem

In Section 1, the problem is explored and defined . Chapter 3 gives insight into the background of health and health behavior. After this, chapter 4 till 6 describes the current context, the current experiences of the stakeholders, and the future vision. This concludes with Chapter 7, where the the problem definition is given.

Secion 2 - The solution

In Section 2, the solution phase is described. Chapter 8 states the design vision that was established. Chapters 9 and 10 describe the designing process toward the final concept, which is explained in Chapter 11 and evaluated in Chapter 12.

Secion 3 - Project evaluation

In Section 3, the Thesis project is evaluated. In Chapter 11, a conclusion of the Thesis project is given, including a discussion of the project limitations and future research opportunities. In Chapter 12, a personal reflection on the project is provided.

Quick read

Three different colors in the layout distinguish the three sections. Every Chapter within these sections starts with an introduction page that explains the content of the Chapter. The Chapters of Section 1 include main takeaways that highlight the for this thesis project most important information of the Chapter. These main takeaways are distinguished by a clear colored background and allow for a quick read through the main research findings.

Section 1

Problem Phase

This section provides the results of the research conducted during the problem phase of the project. Literature research helped to define the project's background around health and health behavior. Both literature research as well as field research allowed to empathize with the context and to gain insights to answer the sub-research questions. With these answers, the thesis context, the current experience and the future vision of the patients and the healthcare workers were defined. The section concludes by using the insights gained to answer the sub-research questions and provide the problem definition.

Chapter 3

Background

This Chapter dives deeper into the topic of health and health behavior. The definition of health is given, after which health lifestyles and differences between health behaviors are explained. Through two behavior change models, the topic of health behavior change is explored.

Health

The World health organization (WHO) defines health as a state of complete physical, mental, and social well-being (World Health Organization, 2006). With the increasing rise of chronic diseases, the positive health philosophy established a broader, less utopian, and static perspective on health as ‘the ability to adapt and to self-manage, in the face of social, physical and emotional challenges’. The philosophy states the importance of distinguishing indicators of health and functioning from a person’s subjective appraisal of well-being and quality of life, as a person with certain impairments may still experience a good quality of life. The positive health philosophy identifies six main dimensions of health that give insight into what people perceive to be indicators of health on both this physical and subjective level: Bodily functions, Daily functioning, Mental well-being, Meaningfulness (a.o. purpose and striving for aims), Quality of life (a.o. enjoyment and happiness) and social-societal participation. (Huber, 2014).

Health lifestyle and health behavior

A healthy lifestyle refers to a series of behavioral patterns through which individuals maintain and promote good health (Wang & Geng, 2019). People with similar life chances share similar health lifestyles and health behaviors. This is because a person’s health lifestyle is influenced by life chances, including class circumstances, age and gender, race, collectivities, and living conditions and choices. Interaction between these chances and choices creates a person’s motivations, norms, abilities, and knowledge that determines whether the person will engage in certain health risks or health-promoting behaviors. (Cockerham, 2009).

Behavior change

Numerous theories have been developed around health behavior and health behavior change. An often-used theory is the social cognitive theory which distinguishes three factors of influence on behavior change (1) incentives; goals, facilitators, and barriers, (2) perceived outcomes consisting of beliefs about whether given behaviors will lead to given outcomes and a (3) a person’s self-efficacy which consists of beliefs about how capable one is of performing the behavior. (Riekert et al., 2014). A strong sense of self-efficacy leads to a feeling of control and willingness to take on and persist with new and difficult tasks. Around the topic of health, this suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal (Silva, 2011)

Stages of behavior change

The HAPA model is well applied to show how health behavior is established around chronic diseases and states that patients go through phases in forming an intention and executing a certain behavior (Figure 8). A patient starts in the motivational phase as a preintender that needs to develop the intention. This is influenced by the patient’s risk perception, perceived outcomes, and task self-efficacy. Once the intention is created, the patient becomes an intender that needs to translate

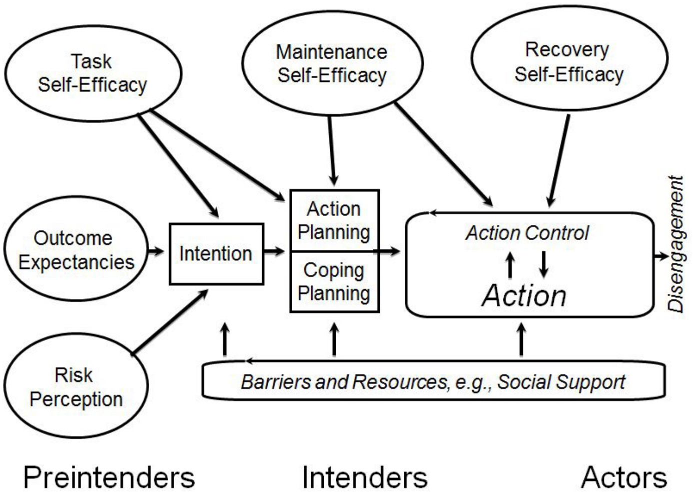


Figure 8 - HAPA model (Schwarzer et al., 2011)

the intention into detailed instructions to perform the action. Finally, the patient becomes an actor and needs to maintain and control the action. During these latter two phases, maintenance self-efficacy and recovery self-efficacy are of influence. During all phases, barriers and resources are of influence, where main barriers can vary among phases. (Schwarzer et al., 2011)

Supporting Health behavior change

The Fogg behavior model states that for a target behavior to happen, a person must have sufficient motivation, sufficient ability, and an effective trigger to get them above the activation threshold (Figure 9). Motivation and ability function as a trade-off. People with low motivation may perform a behavior if the behavior is simple enough. Conversely, when the ability is low, but motivation is high, people might find ways to increase their ability. The more motivation and ability the person has, the more likely the person is to perform the target behavior. The third factor, the trigger, is needed to tell people to perform the behavior. This can be done through sparks that aim at triggering motivation, facilitators that aim at triggering the behavior while also making the behavior easier to do, and through signals that aim at reminding behavior (Fogg, n.d.).

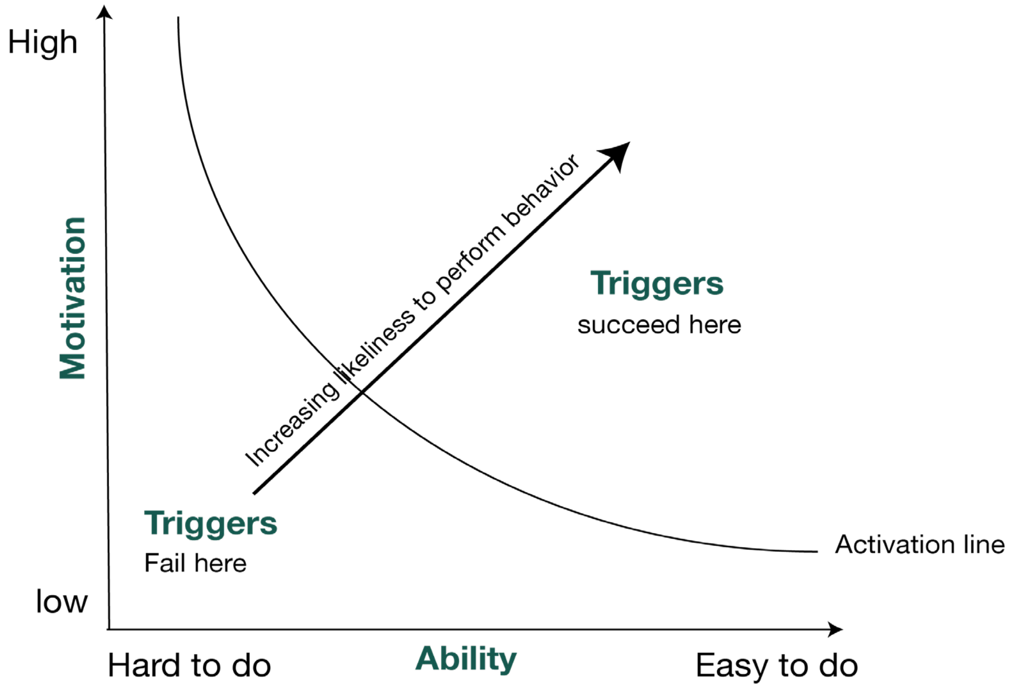


Figure 9 - Foggs behvavior model (own design of (Fogg, n.d.))

Main take aways

With the topic of health, it is essential to take both physical functioning as well as subjective well-being into account.

People with similar life chances share similar health lifestyles and health behaviors.

When establishing health behavior, people first create an intention. Then they need to translate this into an action after which they need to commit to the action. Outcome expectations and self-efficacy expectations are important factors of influence on establishing health behavior.

Supporting behavior change can be done by increasing the person's ability to perform the behavior, the person's motivation to perform the behavior, and by providing effective triggers to tell people to perform the behavior.

Chapter 4

Defining the Context

This Chapter focuses on defining the context through both literature and field research. The topic of self-management and self-management support are defined. Also, insight is given in what this specifically entails for PsA and RA patients and what support ErasmusMC currently delivers for this. Finally, the Chapter provides insight into meaningful characteristics of the lowSEP patient around engaging in health and self-management. The chapter aims to find insights to answer the following sub-research questions:

Rq1: What does self-management entail for PsA and RA patients, and how is this currently supported?

Rq2: What are meaningful characteristics of lowSEP patients around engaging in self-management?

4.1 PsA and RA self-management

Insights from Literature

Successful self-management

With chronic disease self-management, The patient needs to become sufficiently knowledgeable about their condition and its treatment to make informed decisions about their care, and need to develop strategies to manage the condition and maintain adequate psychosocial functioning (Clark et al., 1991). Successful self-management means that a dynamic and continuous process of self-regulation is established where the patient is able to monitor the body and effect the cognitive, behavioral, and emotional responses necessary to maintain a satisfactory quality of life (Barlow et al., 2002).

Self-regulation

Patients learn and improve their self-management strategies through self-regulation. Self-regulation means the patient being observant and making judgments based on the observations, after which the patient needs to react appropriately by establishing the strategy. When having reacted, the patient will observe and judge whether the strategy established produced the expected outcome towards their goal and whether they have the self-efficacy to continue the action. Over time, continuous observation, judgment, and reaction lead to the modification of management strategies. This process is influenced by internal factors such as knowledge and beliefs and external factors such as healthcare advice and social support. (Clark et al., 2014). This continuous modification is important with chronic diseases such as RA and PsA, which vary in disease progression, including moments of flare-ups (Stanton et al., 2007).

Self-management within the PsA and RA care path

The off-set of self-management

In this thesis project, the moment of diagnosis of arthritis is seen as the start of PsA and RA self-management, as a diagnosis is needed to start conducting targeted self-management.

A delay in diagnosis is related to worse long-term physical function and emotional impact (Dures et al., 2019). As initial symptoms are mild, they are often normalized and not linked to having a disease. Whether a patient takes action to seek medical help depends on many factors, such as the severity of symptoms or medical knowledge (Griffith & Carr, 2001). The patient’s reaction to and understanding of the diagnosis are important determiners of the offset of self-management. When a diagnosis does not fit with the patient’s expectations, this can cause rejection of the diagnosis. Also, illness uncertainty caused by uncertainties around the disease and prognosis and a lack of information is associated with difficulties in adjusting and unhelpful coping. (Dures et al., 2019).

Self-management activities

After diagnosis, the patient starts engaging in self-management behavior. In general, for PsA and RA patients, this includes (1) recognizing and acting on symptoms, (2) developing cognitive symptom management techniques that can reduce stress and depression that may be associated with arthritis, (3) using medication correctly, (4) getting the most out of health services by using them as effectively as possible, (5) taking adequate physical exercise, (6) managing relationships with professionals and family members, (7) maintaining a healthy diet and (8) using community resources. (Dongbo et al., 2006).

Insights from Field Research

Five activities of self-management

Field research provided a clearer overview of what self-management entails for PsA and RA patients. Five important core activities for PsA and RA self-management were distinguished: Feeling, understanding, adapting, accepting, and communicating (Figure 10). Here the first four activities are related to the patient establishing and engaging in his personal self-management strategies. The fifth activity of communication relates this self-management to the patient's surroundings, including the healthcare world, which is important to facilitate and improve strategies and allow the patients to take an active role in the hospital care path.

Feeling

Being consciously aware of how the body feels regarding the arthritis.

It is important that patients consciously feel how their disease manifests in their body, what type of symptoms arise, and how these might be changing. Awareness of this allows them to monitor the disease activity and notice the effect of adaptations. With this also non-symptoms-related feelings are important to monitor to detect medication side effects that might arise.

Understanding

Understanding own disease manifestations and how to manage this.

It is important that patients gain the necessary knowledge to understand their disease and how to manage this in a fitting way. They need to understand provided information and, as every patient is different, they need to develop this understanding further for their personal situation based on their own experiences. It is important that they develop an understanding of their disease manifestations and adaptations that they can and want to make to help them diminish the impact of these disease manifestations on their quality of life.

Adapting

Establishing and maintaining adaptations.

Patients need to establish the adaptations that they understand to make with their own resources and circumstances. The patient needs to be motivated to establish the adaptation and needs to commit to the adaptation during varying life circumstances. When engaging in adaptations, the patient needs to keep altering this to variations in disease activity and can keep improving the adaptation to better fit within their life.

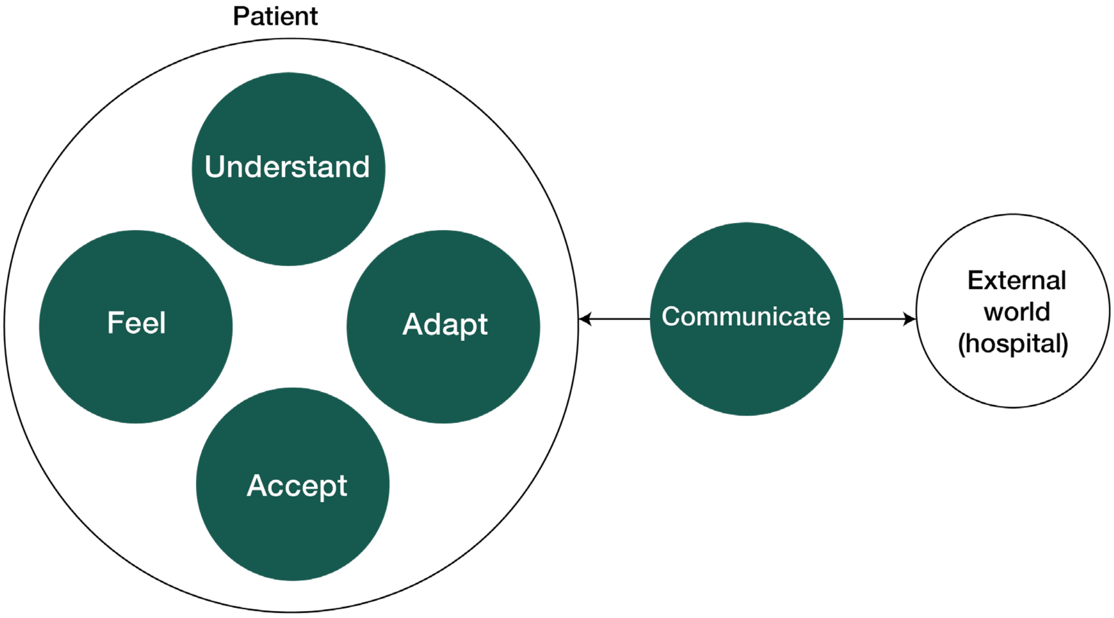


Figure 10 - Five core self-management activities

Accepting

Finding quality of life with the new situation.

To establish the highest quality of life possible, it is important that patients find acceptance with the disease and its management as part of living their life. In line with the positive health philosophy, this acceptance is essential to make self-management also establish the most optimal HRQoL on the patient's subjective appraisal of well-being instead of solely focusing on physical functioning and decreasing the physical disease activity.

Most optimal HRQoL providing self-management balances on the acceptance line between decreasing disease activity and symptoms and experiencing subjective well-being and emotional fulfillment in life. This is visualized in the acceptance balance shown in Figure 11.

When establishing or deciding to maintain self-management strategies, this acceptance influences the behavior change factor 'outcome expectations' described in the background chapter. This makes acceptance an important motivator for patients to engage in self-management, determining whether a patient is actually 'willing to engage' or whether they have a feeling of 'needing to engage' to decrease disease activity or decide not to engage at all.

Communicating

Communicating self-management insights and needs with surroundings and the healthcare world.

The aspect of communication links the self-management of the patient to the surroundings and hospital.

As most disease management happens at home, good communication about own insights and needs with the healthcare worker is important to optimize and tailor the support delivered by the hospital and thus allow the patient to improve his self-management strategies.

Good communication with surroundings, such as loved ones and employers, but also unknown surroundings, such as people on the bus, ensures that the surroundings understand the patient and the disease. This facilitates the patient in making necessary adaptations and allows them to receive support in self-managing their disease.

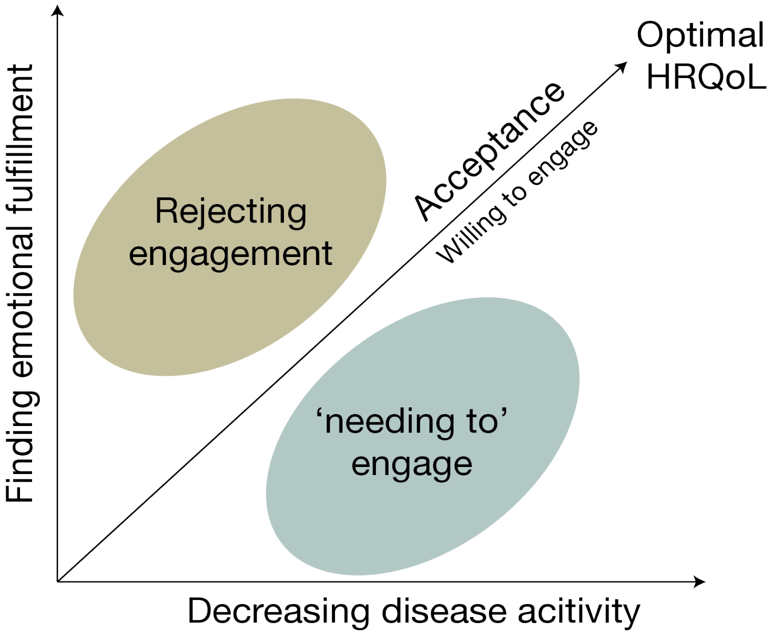
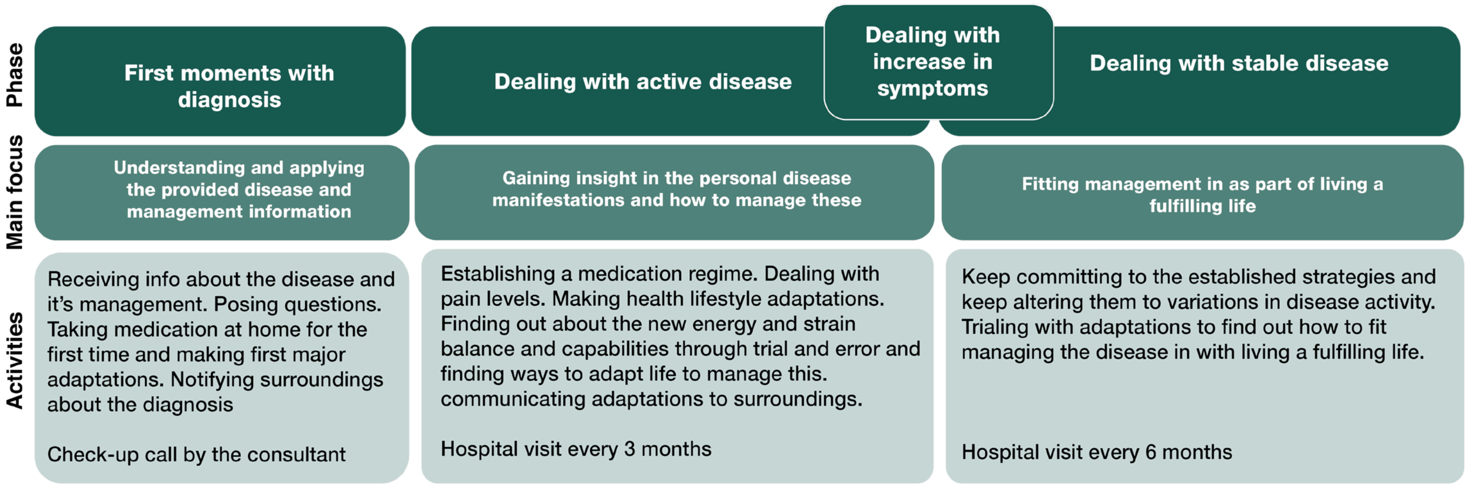


Figure 11 - Acceptance balance



Phase	First moments with diagnosis	Dealing with active disease Dealing with increase in symptoms	Dealing with stable disease
Main focus	Understanding and applying the provided disease and management information	Gaining insight in the personal disease manifestations and how to manage these	Fitting management in as part of living a fulfilling life
Activities	Receiving info about the disease and it's management. Posing questions. Taking medication at home for the first time and making first major adaptations. Notifying surroundings about the diagnosis Check-up call by the consultant	Establishing a medication regime. Dealing with pain levels. Making health lifestyle adaptations. Finding out about the new energy and strain balance and capabilities through trial and error and finding ways to adapt life to manage this. communicating adaptations to surroundings. Hospital visit every 3 months	Keep committing to the established strategies and keep altering them to variations in disease activity. Trialing with adaptations to find out how to fit managing the disease in with living a fulfilling life. Hospital visit every 6 months

Figure 12 - Self-management journey phases

Phases of self-management

Along their self-management journey, patients go through three phases (Figure 12) Throughout these phases, the main focus of the self-management activities shifts from understanding and applying the provided disease and management information to gaining insight into the personal disease manifestations and how to manage these, to fitting the management in as part of living a fulfilling life.

The three phases are based on the two phases that ErasmusMC distinghuishes in the disease management journey of PsA and RA patients after having established the diagnosis: (1) the intervention phase; when the disease is active, and the aim is to get the disease under control and (2) the monitoring phase; where the disease is stable and the aim is to remain this. Mapping out the patient activities over these two phases showed a crucial transitional phase between diagnosis and the intervention phase in the patient's self-management journey. This is when the patient receives the first disease and self-management explanation and makes the first new adaptations.

A detailed description of the activities during the three phases can be found in Appendix C..

Main take aways

For PsA and RA patients, self-management entails engaging in the activities of feeling, understanding, adapting, and accepting. The patients need to engage in the activity of communicating with their external world to facilitate and improve their self-management. and take an active role in their hospital care path.

Acceptance is essential to make self-management als improve the patient's HRQoL regarding their subjective well-being instead of solely regarding physical functioning. Acceptance determines the patients' motivation and willingness to engage in self-management.

Along the self-management journey, the main focus of engaging in self-management shifts. First the focus is on gaining an understanding and applying the provided disease and management information, then the focus is on gaining insight into the personal disease manifestations and how to manage these after which the focus shifts to fitting the developed management strategies in as part of living a fulfilling life.

4.2 PsA and RA self-management support

Insights from Literature

Supporting strategies

Supporting self-management means providing information and encouragement to help people maintain greater control by understanding their condition and being able to monitor and take appropriate action. Various self-management support initiatives exist, ranging from providing passive, more technical information to initiatives that focus on behavior change and increasing self-efficacy (Silva, 2011).

Motivational interviewing is a strategy that can encourage patients to recognize and resolve challenges in behavior change. With motivational interviewing, the interviewer uses directive open-ended questions such as ‘Why do you want to make this change’ to encourage the patient to participate and to reveal self-management issues (Baumann & Dang, 2012).

A self-efficacy-enhancing strategy that can be used is collaborative goal setting, where concrete and realistic goals and a specific action plan are set together with the patient. The active involvement of the patient and the inclusion of intermediate goals that provide shorter-term positive health outcomes allow the patient to feel more confident about performing a self-management task (Baumann & Dang, 2012).

Increasing the patient’s perceived knowledge through providing passive information such as literature can also improve self-efficacy. When a patient has a low literacy level, this can increase stress further, making it very important to determine the patient’s needs in this (Holman & Lorig, 2004).

Additionally, cognitive behavioral strategies have been shown to be effective around chronic diseases to reduce pain intensity and improve a patient’s coping skills. The most common interventions include acceptance and commitment therapy and cognitive behavioral therapy. Interventions based on these therapies use behavioral and emotional regulation strategies and techniques such as relaxation- and scheduling techniques and activity pacing. Both types of interventions have been found to increase patients’ readiness to adopt a self-management approach (Cosio & Lin, 2016; Murphy et al., n.d.)

Support means

The hospital has an important teaching role in aiding the patient in developing the necessary knowledge and skills to take an active self-management role (Holman & Lorig, 2004). Physiotherapists and occupational therapists are involved in delivering self-management support around topics of physical activity, disease-specific education, pain, fatigue and stress management, and joint protection (Richardson et al, 2014).

There are also self-management support options outside the standard hospital context including self-management programs, telehealth, and mobile phone applications.

Mobile phone applications have become increasingly interesting to use to deliver self-management support as it is an accessible and potentially effective way to increase self-efficacy and improve self-management behavior. Such applications can, for example, allow patients to record data, communicate and receive feedback from healthcare workers and access evidence-based educational materials (Farley, 2020). When supporting lowSEP patients, mobile phone applications could be an interesting means as they allow to reach diverse populations and can use video and audio to deliver information and skills in an accessible manner (Al-Dhahir et al., 2022).

Insights from Field Research

Current self-management support at ErasmusMC

Insights from field research – The current self-management support at ErasmusMC
In the current care path, patients receive self-management during the hospital appointments and through informational support material they can consult at home. During the appointments at the department, the patient can be sent through to non-medical therapies such as physiotherapy, occupational therapy, and psychosomatic therapy. They can also be notified about existing platforms that offer patients tips, communities, and sometimes even specific self-management therapies, such as ReumaNederland. As this thesis focuses on the support delivered by the rheumatology department, the most important support aspects provided by the rheumatology departments of ErasmusMC are described below.

Rheumatologist appointment

During all visits with the rheumatologist, there is a strong focus on clinical assessment. The time available for the patient is only short as it is limited to 15 minutes.

During the diagnostic appointment, there is only time for a first brief explanation about the disease and the medication. During check-up meetings, it depends on the patient's disease activity whether the appointment time is filled with medical procedures or whether there is more time to discuss the at-home situation. The appointment generally starts with some open questions about how dealing with the disease is going in daily life. The patient is involved through shared decision-making in making decisions about the next steps in the

Consultant appointment

After receiving the diagnosis, the patient gets an appointment with the rheumatology consultant for a 45-minute appointment. In the current care path, this is the appointment when the most self-management support is delivered regarding information provision.
The consultant explains the disease, the medication, and other lifestyle-related aspects and tips for living with the disease. Also, treatment options and therapies are discussed. The patient gets the opportunity to ask questions about, for example, the future perspective and things that were not yet understood. To add to their explanation, the consultants at EramusMC have a PowerPoint including visuals and text (figure 13). They leave room for the patient to stir the conversation with questions.

When limited understanding is assumed, The consultant decreases the amount of information by focusing on the disease and medication information, leaving out more additional information about lifestyle. Follow-up appointments are scheduled to be able to repeat information and provide information in small steps.

Along the care path, patients can get an appointment with the consultant when showing the need for support in managing their disease or when there is a medication change. This especially happens when patients need to start injecting themselves at home.

Information to take home

After the first meeting with the consultant, the patient receives a flyer called 'zorg op maat'. They can receive this physically on paper but primarily receive a link and login to use the digital version. This flyer contains the information discussed during the consultant appointment, including relevant information about the disease and medication and lifestyle-related information. This information touches upon sexuality, working, mindset, exercising, diet, and family wishes. The flyer can be slightly specified to the patient by the consultant by checking certain boxes about the type of medication or things like including pregnancy information.

Contact from home

The consultant ends the appointment stressing that the patient can always contact the rheumatology department through a phone call or an e-consult. Here they focus on the e-consult to be able to make the support to be delivered manageable. This allows the patient to contact the department from home.

ReumaApp

The ErasmusMC has developed an app designed for arthritis patients called the Reuma App (figure 13). The app is created for arthritis in general. Because of that, it does not provide any arthritis-type-specific information. The app consists of all the tips and information that the consultants and rheumatologists have gathered through the years, divided over five topics, including various subtopics:

- Energy: Dealing with energy, ‘Why is my energy decreased.’
- Daytime activities: Leisure time, work, and household
- Disease: Pain, symptoms and side-effects, knowledge about the disease, and participation in the treatment
- Relations: Social contacts, intimate relations, sexuality
- Lifestyle: finances, emotions and meaning, Disease and Relations, lifestyle, and mobility

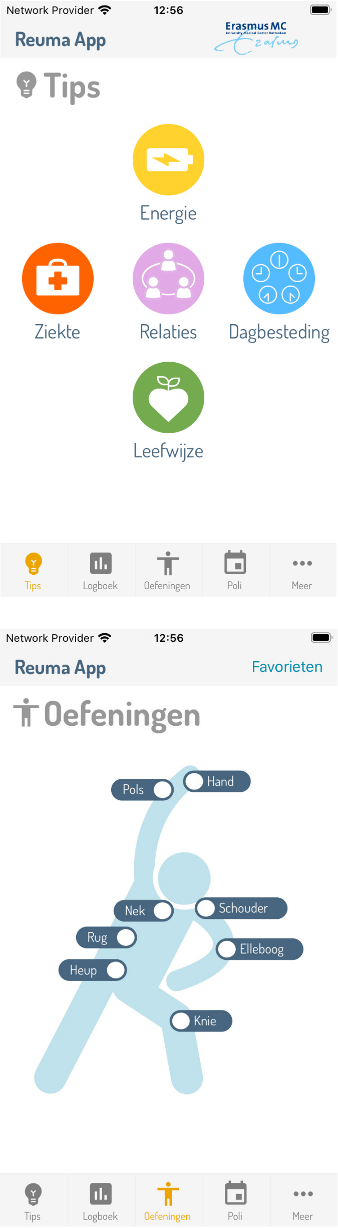


Figure 13 - Reuma app

Main take aways

Information provision and collaborative goal-setting can stimulate patients’ self-efficacy to engage in self-management. Motivational interviewing and cognitive behavioral exercises can help patients cope with behavioral and emotional challenges around self-management.

At ErasmusMC, self-management support is mainly delivered by the consultants. This support focuses on the post-diagnosis appointment with the consultant which is the moment when most information about self-management is provided.

Along their care path, patients generaly only visit the rheumatologist. These appointments focus on clinical assessment and leave limited time to discuss the at-home situation of the patient. Visits with the consultant are only scheduled when this seems needed.

The ReumaApp provides patients with tips for their specific problems. However, patients need to be aware of the specific problem they encounter and to what specific field this problem belongs to be able to navigate to the right tips.

4.3 Meaningfull lowSEP patient characteristics

Insights from Literature

As stated in the background section, people with similar life chances share similar health behaviors (Cockerham, 2009). This explains that lowSEP people share similar health behaviors and barriers towards health behavior. Many studies have been done about the characteristics and barriers of lowSEP patients engaging in health behavior. Some for this thesis project interesting characteristics and barriers are described below.

Ability characteristics

A patient's educational and literacy level is strongly linked to limited health literacy (Pharos, 2022). Health literacy is a person's knowledge, motivation, and competence to access, understand, appraise, and apply health information to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion to maintain or improve quality of life during the life course (Sørensen et al., 2012). This limited health literacy causes lowSEP patients to have limited health skills to obtain, understand, assess, and use health information in making health-related decisions. This can cause lowSEP patients to have difficulties taking medication correctly, understanding informational flyers and websites, communicating with healthcare workers, and understanding and applying explained information (Pharos, 2022).

LowSEP patients have also been shown to be associated with decreased digital access and skills. They are associated with decreased use of the internet for activities such as health information seeking, communicating with health care providers, monitoring health, or using personal health records (Cheng et al., 2020). Lower-educated people tend to have decreased problem-solving skills and ability to process information, making them less able to overcome barriers they experience toward health behavior. Also, they have more trouble learning from negative health events (Pampel et al., 2010).

LowSEP patients tend to have more unfavorable work conditions concerning health, including physically straining working conditions and psychosocial factors such as low job control and high job insecurity (Schaap et al., 2020). Also, LowSEP patients tend to have fewer resources to afford self-care support. Getting the right insurance plays a big part here, especially with ongoing treatment, as with chronic diseases (Baumann & Dang, 2012).

Motivation characteristics

lowSEP patients have certain motivational-related characteristics and barriers around engaging in health behavior. lowSEP patients tend to live in less health-stimulating areas, including lower availability of recreational facilities and increased exposure to bad health (Algren et al., 2015). Class distinction can motivate lowSEP people towards unhealthy behavior, which is in some contexts associated with independence, toughness, and freedom from convention to set themselves aside from the group of higher-SEP people who tend to set themselves apart with healthy behavior (Pampel et al., 2010).

Also, LowSEP is associated with various chronic stressors in daily living, such as economic worries, job insecurity, and criminality (Pampel et al., 2010). These stressors are often of a different level than those of higher SEP people and influence the person's motivation towards health. It makes it challenging to give health a high priority (Heutink et al., 2010)

Finally, LowSEP people tend to be attracted more to short-term gain. This may be due to poor parental socialization and the fact that the lower lifetime earnings and wealth of lowSEP groups are assumed to give less reason to invest in future longevity (Pampel et al., 2010)

Insights from Field Research

Two overarching lowSEP patient characteristics were identified: limited and protective. Also, two sets of distinguishing characteristics were identified: docile vs. self-governing and careful vs. impulsive lowSEP patients. The overarching characteristics were identified based on personality traits that came forward in the lowSEP personality trait exercise conducted during the co-creation session with healthcare workers (research activity 4). The distinguishing characteristics were based on opposing characteristics that came forward in the session and were analyse further keeping other research insights in mind.

Overarching characteristics

It was mentioned that lowSEP patients tend to have difficulties understanding information. This causes them to have a limited understanding of things. They tend to forget information and often come back with the same questions. lowSEP patients also tend to be limited in their opportunities to establish adaptations compared with higher SEP patients. This limited understanding and opportunity to adapt strongly relate to the in literature found limitations of lowSEP people around their ability to engage in health behavior. LowSEP patients tend to be protective of their original life and health lifestyle. The healthcare workers mentioned that they can be hesitant to make changes in this.

Distinguishing characteristics

The character traits that the healthcare workers chose showed two sets of opposing characteristics of lowSEP patients towards engaging in self-management and taking an active self-management role. This inspired to map them out over two axes. Keeping the insights gained during the lowSEP patient interviews in mind and mapping these patients out over the axis allowed to specify the axes further (figure 14). During this, the insights gained about lowSEP patients during the interviews with the healthcare workers were kept in mind.

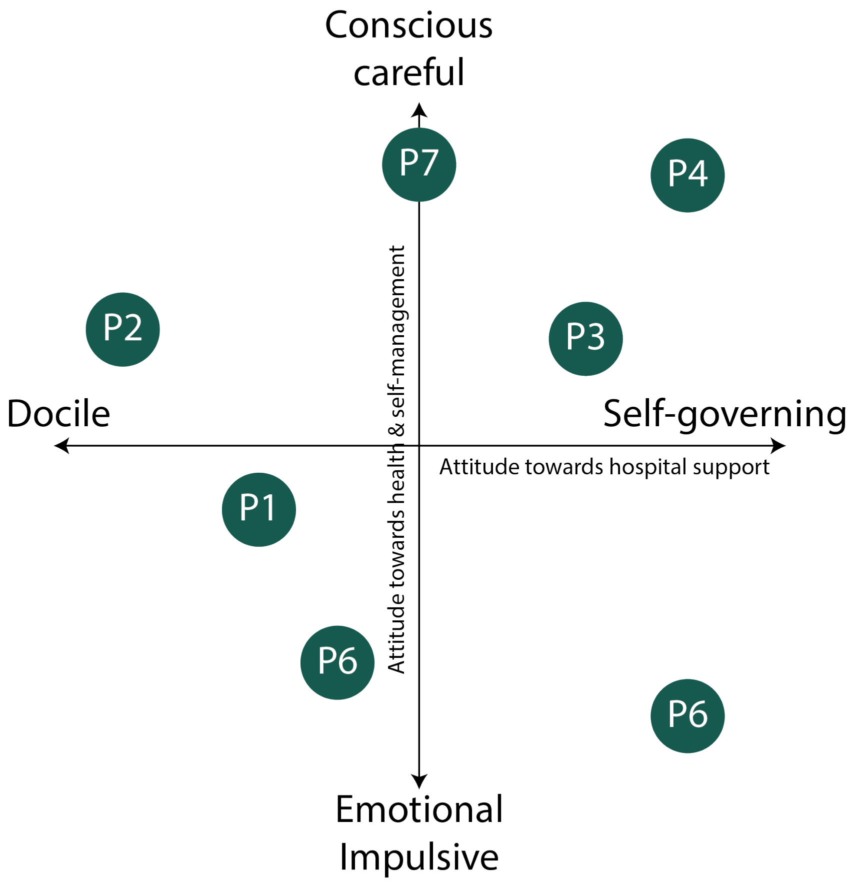


Figure 14 - Mapping patients on the axes

Attitude towards hospital support:
Docile vs. self-governing

Some patients tend to be more docile to the healthcare worker, relying on their expertise to decide what is best for them. This can make the patients become dependent on the heatlhcareworker to make decisions around their disease management instead of taking an active self-governing role in their self-management themselves.

‘I’ll hear it, as I say I just take my medication, and for the rest, I will hear from them’ – patient

On the other hand, a patient type was distinguished that is more confident about their own role and opinion in dealing with the disease and shows a more self-governing attitude. These patients can become very determined about their own view on things. Interesting to add to this is the fact that healthcare workers have difficulties pointing this type of lowSEP patients out during appointments as they can show a witty and talkative attitude, while their understanding might be decreased and their determined view might not be medically correct.

‘There has to be a balance between the treatment and the complaints, I am the expert of that, what I find acceptable is not acceptable for someone else’ - patient

Attitude towards health & self-management:
Conscious vs. emotional

Some patients have a more conscious and careful attitude in dealing with their disease. They are attentive about their health and careful and invested in trying to improve this. Looking at the six dimensions of positive health, these patients tend to put more importance on the domain of bodily functions.

‘On My Erasmus, you can track everything. Then I will take a look. I do want to be aware if they say something is too low, I want to know why it is too low and then what happens to me’ - Patient

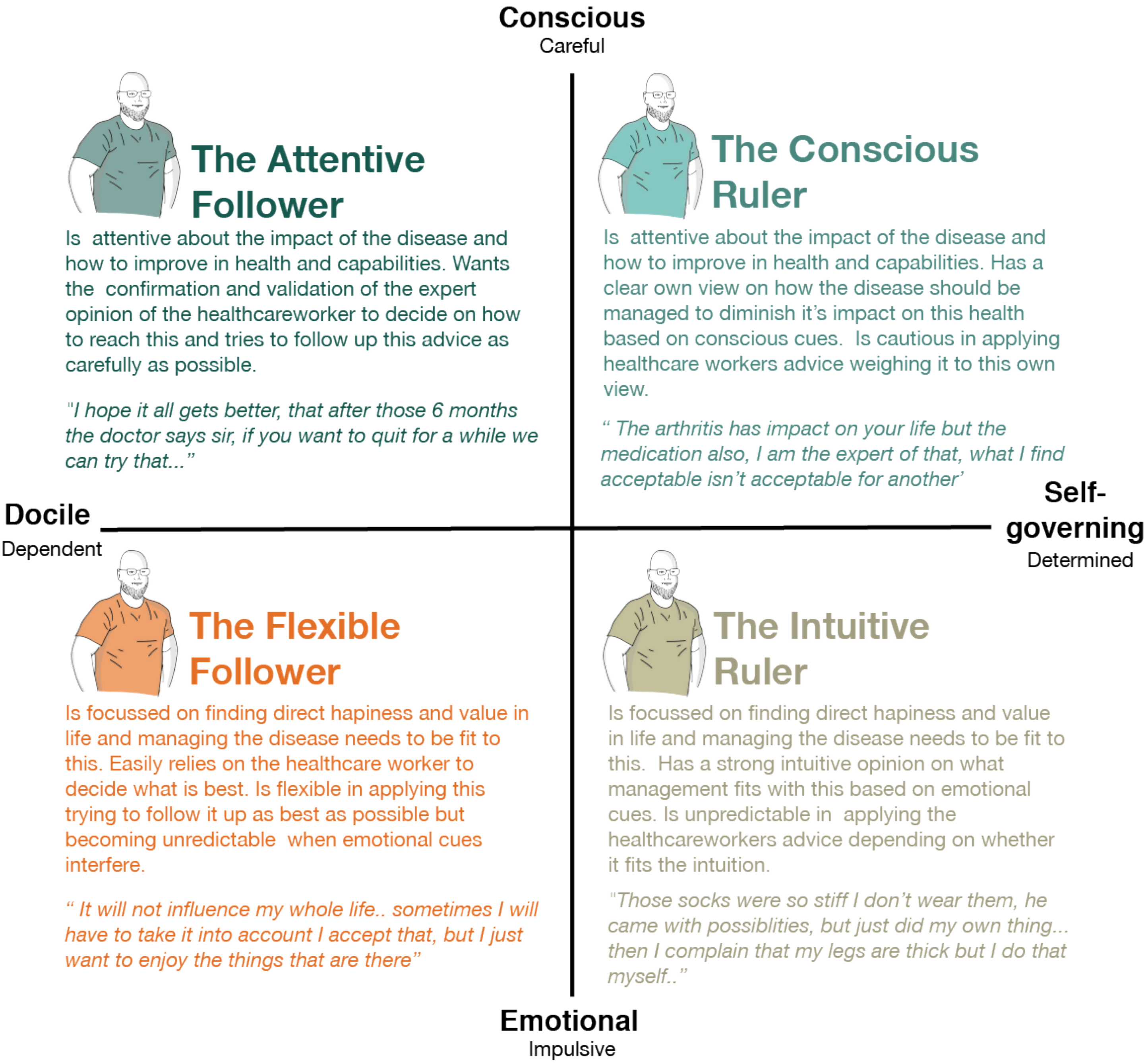
Another patient type was distinguished that has a more emotional and impulsive attitude in dealing with their disease. These patients are focused on fulfilling their life values and finding enjoyment in life, which can make them impulsive and less invested in managing their physical condition. Looking at the six dimensions of positive health, these patients tend to put more importance on the domains of participation, quality of life, and meaningfulness.

‘The things I like to do, as long as I can do them, I do them. Rheumatism does not stop me from that. Whether you work or not, the pain is there anyway.´ - Patient

Attitude profiles

Using the axes four types of lowSEP patient attitudes could be described which are shown in figure 15.

It is essential to highlight that these attitude profiles are extremes and that patients might have characteristics of multiple profiles. Also, it should not be forgotten that every patient is unique and that there are numerous other ways to make distinctions between patients. These attitude profiles should be approached as an indication of lowSEP patient characteristics to emphasize with and better understand these patients' attitudes during the research phase of this project and to inspire the design phase of this project.



The Attentive Follower

Is attentive about the impact of the disease and how to improve in health and capabilities. Wants the confirmation and validation of the expert opinion of the healthcareworker to decide on how to reach this and tries to follow up this advice as carefully as possible.

"I hope it all gets better, that after those 6 months the doctor says sir, if you want to quit for a while we can try that..."

The Conscious Ruler

Is attentive about the impact of the disease and how to improve in health and capabilities. Has a clear own view on how the disease should be managed to diminish it's impact on this health based on conscious cues. Is cautious in applying healthcare workers advice weighing it to this own view.

" The arthritis has impact on your life but the medication also, I am the expert of that, what I find acceptable isn't acceptable for another'

The Flexible Follower

Is focussed on finding direct hapiness and value in life and managing the disease needs to be fit to this. Easily relies on the healthcare worker to decide what is best. Is flexible in applying this trying to follow it up as best as possible but becoming unredictable when emotional cues interfere.

" It will not influence my whole life.. sometimes I will have to take it into account I accept that, but I just want to enjoy the things that are there"

The Intuitive Ruler

Is focussed on finding direct hapiness and value in life and managing the disease needs to be fit to this. Has a strong intuitive opinion on what management fits with this based on emotional cues. Is unpredictable in applying the healthcareworkers advice depending on whether it fits the intuition.

"Those socks were so stiff I don't wear them, he came with possiblities, but just did my own thing... then I complain that my legs are thick but I do that myself.."

Figure 15 - Attitude profiles

Main take aways

LowSEP patients tend to experience limitations in understanding and making adaptations because of a low health literacy, limited resources, limited problem solving skills and a protective mindset.

Four profiles can be distinguished to describe the lowSEP patients’ attitude towards taking an active self-management role and engaging in self-management behavior. These profiles range from docile to self-governing and emotional to conscious.

A docile attitude can make patients become dependent, relying on the expertise of the healthcare workers instead of taking an active self-governing role in their self-management themselves.

Patients with an emotional attitude tend to be more focussed on their subjective well-being and finding enjoyment in life and less invested in managing their physical symptoms.

Chapter 5

Defining the Current Experience

During the research, insights were gained about the stakeholders’ experiences in the current situation. This chapter first describes the current situation from the patients’ perspective. It describes their current experience around self-managing their disease and the difficulties they encounter in taking an active self-management role. After this, the Chapter describes the difficulties healthcare workers encounter in supporting the lowSEP patietns. The Chapter aims to find insights to answer the following sub-research questions:

Rq3: What difficulties do lowSEP PsA and RA patients experience in their current self-management journey?

Rq4 What difficulties do healthcare workers currently encounter in supporting lowSEP patients?

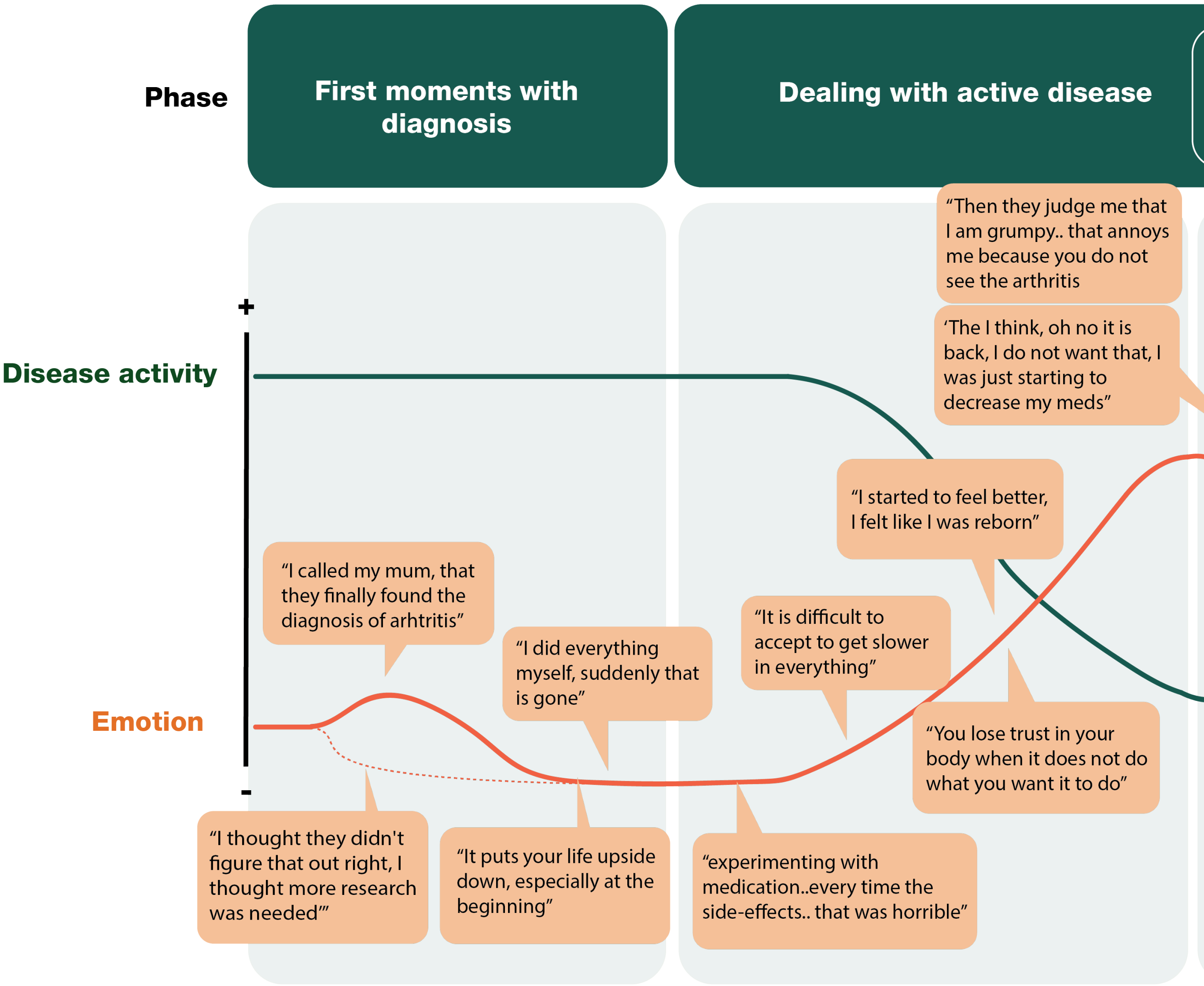
5.1 Patients’ perspective

Patient experience

Throughout the self-management journey the patients go through various emotions. In general, emotion increases once disease activity and thus the experience of pain and other symptoms start to decrease with short drops in emotions during temporary symptom increase. Besides direct symptom related emotions also two specific emotions are often occuring along the patients self-management journey: frustration and insecurity These two feelings cause the patient to experience a feeling of loss of control and negatively impact their emotion about dealing with the disease. Along their journey this shifts from loss of control over suddenly becoming a patient starting an uncertain carepath, to loss of control over the own body, to loss of control over living a fulfilling life. An overview of the general emotional journey along the three self-management phases is provided in Figure 16. The general emotion line is explained below.

At the start of the care path, receiving a diagnosis can create a small relief. However, for patients that have other beliefs about their complaints or a big aversion to becoming a patient, this might not be the case. Upon returning home the realization of suddenly being a patient and the life changes this will entail can be overwhelming and insecure especially when having a limited understanding of the disease and it’s prognosis.

The patient starts taking medication however, it takes time for this to show effect which can cause insecurity and frustration with the



“I called my mum, that they finally found the diagnosis of arhtritis”

“I thought they didn't figure that out right, I thought more research was needed’”

“I did everything myself, suddenly that is gone”

“It puts your life upside down, especially at the beginning”

“It is difficult to accept to get slower in everything”

“experimenting with medication..every time the side-effects.. that was horrible”

“I started to feel better, I felt like I was reborn”

“Then they judge me that I am grumpy.. that annoys me because you do not see the arthritis

‘The I think, oh no it is back, I do not want that, I was just starting to decrease my meds”

“You lose trust in your body when it does not do what you want it to do” patient, especially when needing to trial with multiple types of medication. Also, the patients can experience grief and frustration when suddenly losing major life activities.

Once the medication starts to show effect, the decreased symptom experience and a feeling of hope increases emotion. However, a disbalance between body and mind arises where the patient experiences feelings of insecurity and frustration around the new body's capabilities and the increase in symptoms when overdoing it. Especially when this keeps happening successively. Developing understanding and predictability around the cause and course of the increase in symptoms can decrease the insecurity. Awareness of the cause of the increase in symptoms being something that gave fulfillment can decrease the patient's frustration about the consequences.

Once the disease activity starts to stabilize, emotion also stabilizes as the patient starts to get used to the new capabilities. Additional adaptations can help decrease symptoms and give a feeling of investment which increases emotion further. After a certain period of stabilization, a drop in emotion can occur. This is caused by feelings of frustration over the realization of the chronic settlement and loss of valued activities, and insecurity around the future. At what level the emotion stabilizes after this depends on how well the patient's established adaptations fit with his or her acceptance balance as shown in Chapter 3.1.

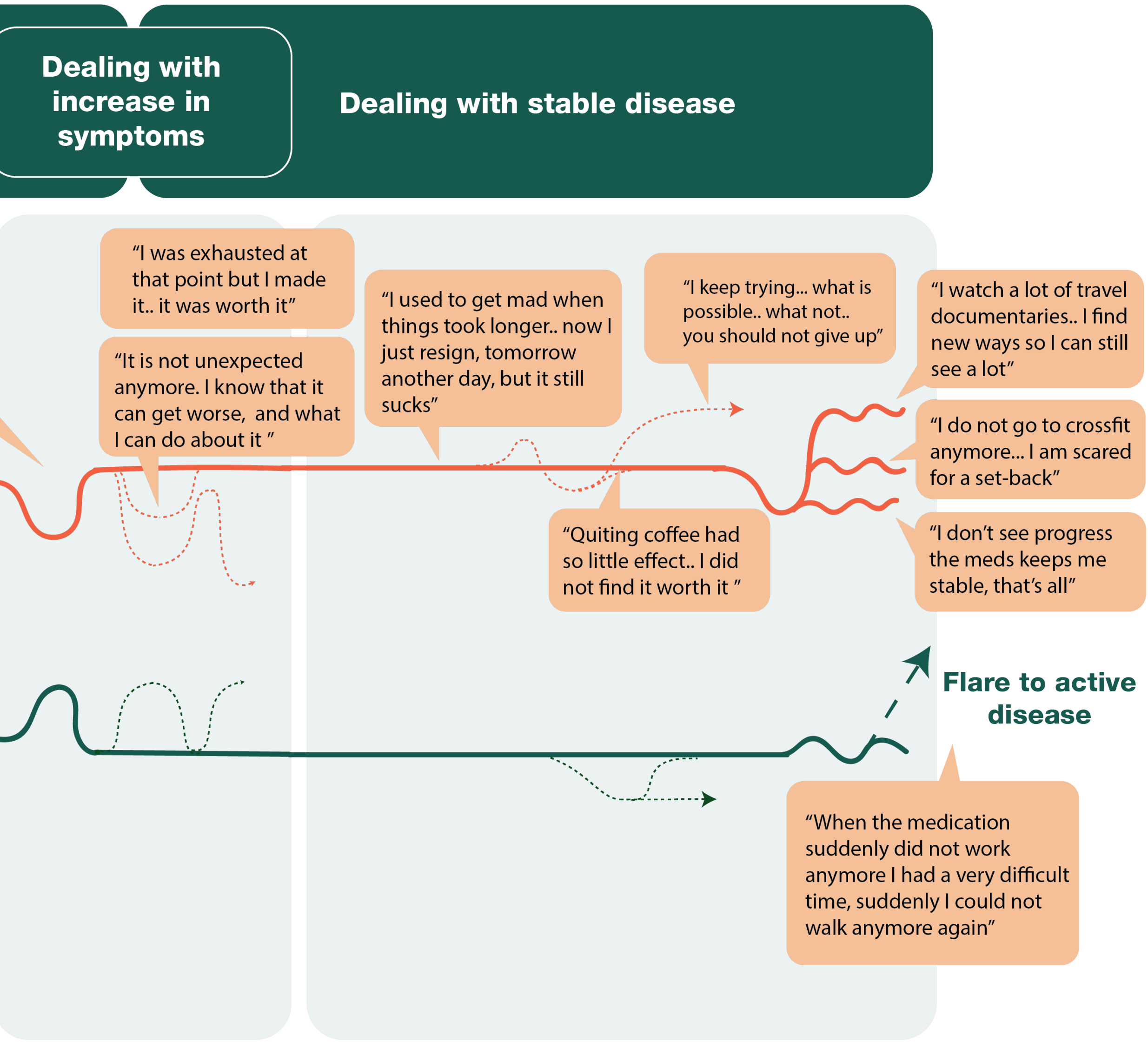


Figure 16- Patient experience journey

Difficulties in self-managing

Drivers for acceptance: influencing the overall motivation

As shown in the emotion journey patients experience feelings of insecurity and frustration that negatively influence the patients’ subjective well-being in managing their disease. As described in chapter 3.1 the subjective well-being is strongly related to the patients’ acceptance of the disease and overall motivation to engage in disease management. Research analysis showed that security and satisfaction turn out to be important drivers of this acceptance.

The driver of security is important for the patient to find acceptance in dealing with the uncertainties around the disease.
“at that moment you think, hey, it’s not so bad, I’ll get back to work. You are very naive; you underestimate it a bit”.

The driver of satisfaction is important for the patients to deal with the balance between the benefits and consequences of disease management. This driver can be divided into satisfaction around physical health progress and satisfaction around emotional fulfillment.
“Then I have to say sorry I can’t do that for you now...you go through fire for your children and if you can’t that is very difficult”.

Because of the unpredictability about the disease, physical health progress is a less concrete goal to strive towards. Satisfaction derived from physical health progress might drive acceptance of disease management in the moment. However, this driver is also linked to a feeling of hope, which makes patients keep raising the bar around their physical health which is less beneficial for accepting the disease and its management as part of living life when the disease stabilizes.

During the interviews various factors were found that influence these drivers positively or negatively. These factors can thus be perceived as barriers and facilitators for acceptance and thus the patients’ overall motivation to engage in self-management. Figure 17 provides an overview of the barriers and facilitators found. The facilitators are interesting to take into account to increase the patients’ overall motivation to engage in self-management.

Connecting to lowSEP attitude profiles

Docile patients will be more prone to external validation to drive them to engage in self-management strategies, which might make them less motivated to invest in developing their own understanding. Self-governing patients will be more motivated to develop their own understanding but, when not succeeding in this, might start lacking acceptance and not engage in self-management strategies at all.

Conscious patients tend to be more focused on physical health and are likely to be more prone to drivers around physical health progress. Starting the journey, conscious patients will be driven to engage by the strong driver of working towards health progress. However, once the disease stabilizes, this acceptance driver falls away, which can cause a feeling of settlement.

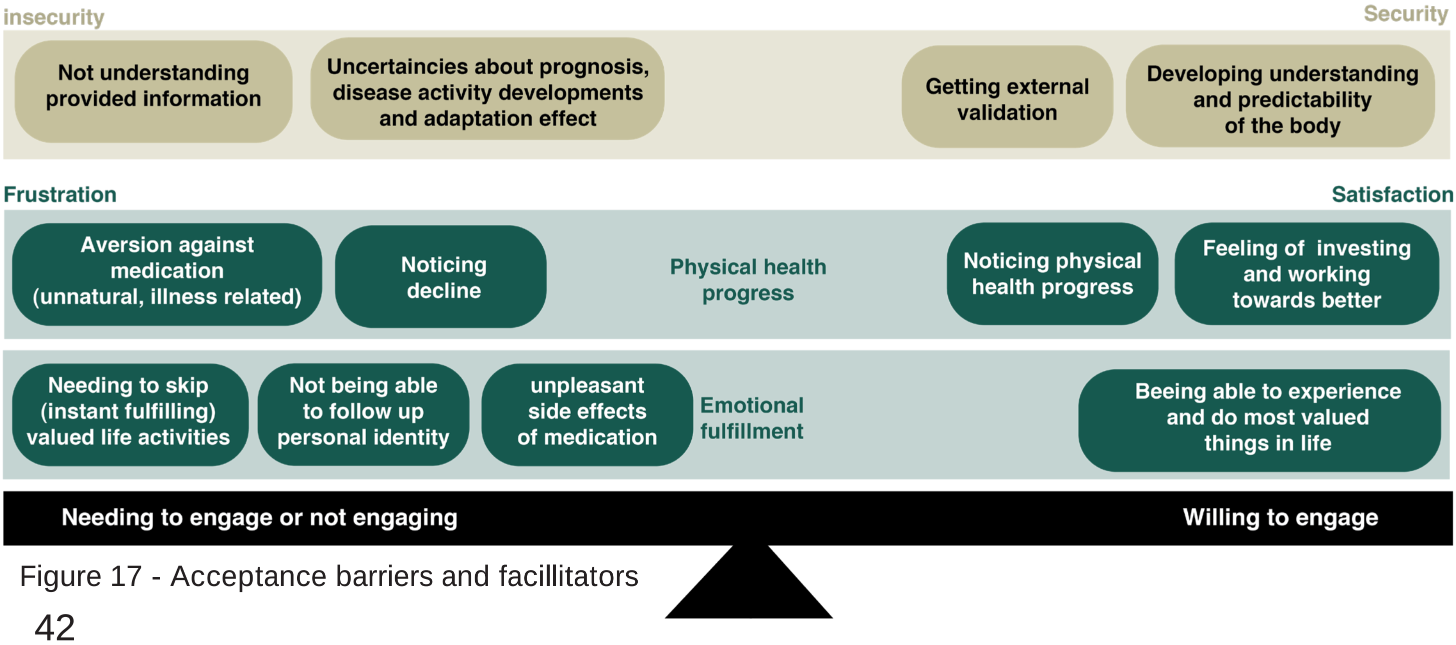


Figure 17 - Acceptance barriers and facillitators

Patients with an emotional attitude are more focused on the emotional aspects of health. They will thus be more prone to the barriers created by the consequences on emotional fulfillment and value, which can make them unpredictable in following up their physical management strategies.

For both types of attitude profiles, this stresses the importance of motivating patients with drivers around emotional fulfillment and value.

Specific difficulties in self-managing

Besides difficulties in the activity of accepting, five themes were found around specific difficulties patients experience in the other 4 core activities as described in chapter 3.1: Feeling, Understanding, Adapting and Communicating

Theme 1: Difficulties establishing a good knowledge base to start self-managing

Theme 2: Difficulties monitoring and developing an understanding of the body

Theme 3: Difficulties finding and establishing fitting adaptations

Theme 4: Difficulties committing to adaptations

Theme 5: Difficulties in communicating to facilitate and improve strategies

To get an indication of how these difficulties are of influence on the patient establishing and engaging in self-managment strategies, the themes were mapped out over the HAPA model of behavior change (Figure 18). The themes influence the patient's ability and motivation to create the intention to establish a strategy, to translate the intention into an adaptation to actually establishes the strategy and to commit to the strategy. This figure also includes how the themes negatively influence each other and negatively influence the patient's acceptance drivers and thus overall motivation to engage in self-management.

As strategies first need to be established before commitment becomes important, it was decided to focus this thesis project on the off-set and establishment of strategies. This leaves Theme 4 around difficulties in committing to strategies out of scope. Theme 1,2,3, and 5 and the most important pains and gains found within these themes are described below. A description of theme 4 can be found in Appendix D. An overview of all the pains and gains found within every theme can be found in Appendix D.

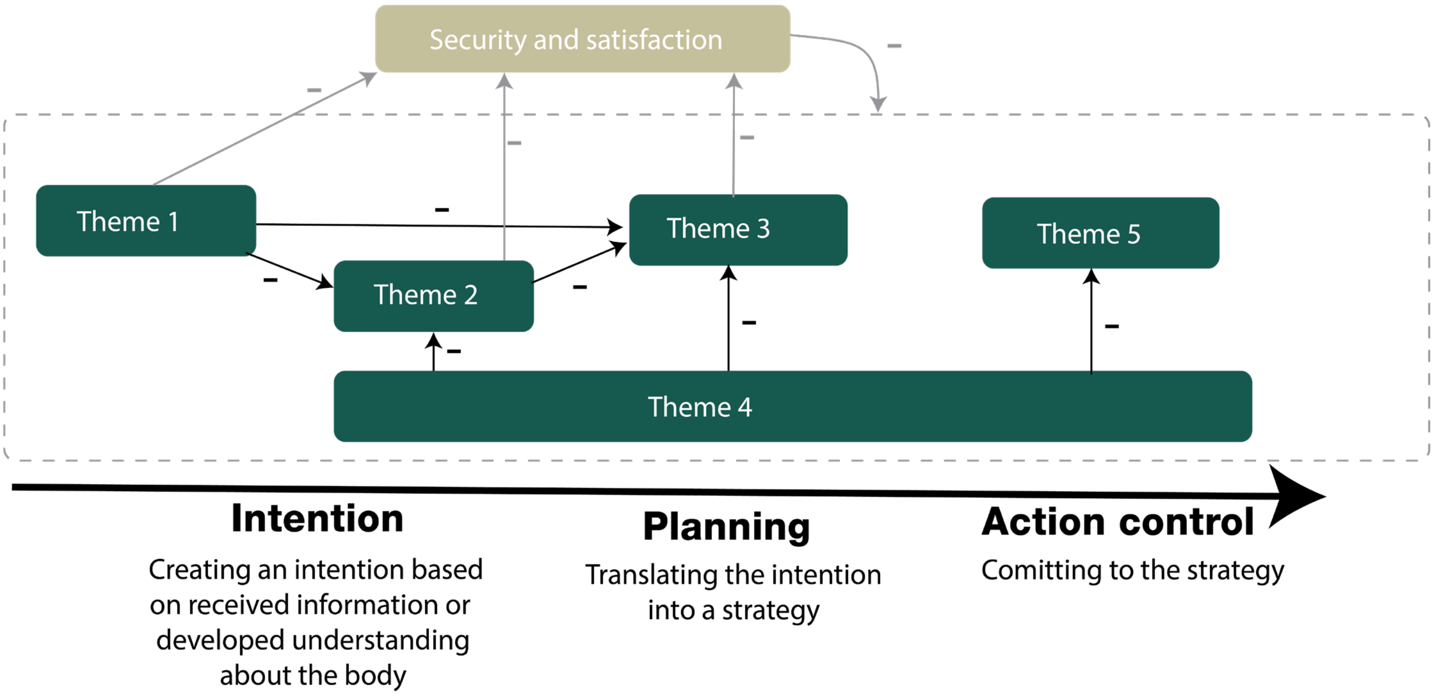


Figure 18 - Mapped out Themes on HAPA model

Theme 1: Difficulties establishing a good knowledge base to start self-managing

Ability
The patients can have difficulties understanding the complex and large amount of provided disease information. The information is easily forgotten or misunderstood, causing pains such as wrong medication intake and aversion against medication because of misinterpreting information. Being familiar with the disease and doing their own research can help patients understand the disease and fill in gaps in understanding. However, patients can encounter wrong information bases in this, such as medically conflicting advice from surroundings, or can lack health literacy to understand information on, for example, the medication leaflet.

'I hear everything, at the time I know everything, but later I quickly forget it, and I always go to checkups alone, and there is writing, but I cannot read that very well quickly'

Also, Patients mention that at the start of their care path they had no idea what was ahead of them. The information provided did not really prepare them for what managing the disease would entail during their daily life. They mention that they gained more insight in this along their journey, but that unpredictability about the disease and general life context factors makes it difficult to really get full insight in this.

'It is a journey, you have taken a bus, you have no idea in what direction it is heading, and along the way also the passengers change, an accident happens, you have to keep changing along with that'

Theme 2: Difficulties monitoring and developing an understanding of the body

Ability
Patients mention that they had difficulties understanding the maximum energy and strain balance because this is very vague to determine, varies over time, and only noticed when overdoing it. They mentioned that through trial and error, eventually, they found out about the minor physical signs that lead up to reaching the maximum and helped them develop an idea of what level of activity and strain their body can handle, but that this takes time and is still difficult to listen to. A lack of clarity about the disease symptoms can cause a patient to forget to link felt things to the disease or link things to the disease that are not linked at all. This can complicate monitoring and understanding how the disease manifests in the body. When patients notice changes in symptoms, they have difficulties translating this into insights into what might have caused this, as the symptoms generally vary over time, and the symptom of fatigue can also be caused by non-disease-related factors.

Motivation
Awareness of a lack of understanding can cause patients to have low self-efficacy in developing their own understanding. This can make especially docile patients leave the monitoring of the body to the, in their eye, more experienced doctor. Also, when the level of experienced disease impact and symptoms decreases, the level of investment in developing own understanding can decrease. Multiple patients mentioned that they tried to start actively monitoring their body using a written diary but that they disengaged from it quickly because it took them too much effort and time.

'I do not have to monitor anything. They know exactly where I am coming from. They say, 'Sir, that does not matter, we are going to see it.' I do not have to explain anything'

Theme 3: Difficulties finding and establishing fitting adaptations

Ability
It was noticed that patients have difficulties coming up with solution-oriented adaptations to manage their symptoms and deal with their decreased capabilities other than 'not doing something'. This is complicated by the fact that patients can lack the resources to establish adaptations they can come up with. Patients mention getting little support from the hospital when engaging in their own trials for adaptations such as an adapted diet and lack clarity about therapies that could help them with this. Hearing tips from their surroundings or browsing patient platforms can inspire them. Also, experiencing changes in symptoms and awareness of the cause of these changes can inspire them for adaptations. Trialing with new and variations in existing adaptations and establishing clarity about the most valued

things in life can help them find ways to adapt that fit their body, life, and values. The varying disease activity can make it difficult to plan ahead, asking for short-term problem-solving. Keeping activities with lower priority open for canceling and scheduling in moments of rest can help with this.

‘In the beginning, the hardest thing was making the right adjustments, how you can do it without the rheumatism hitting right back’.

Motivation

When starting with new adaptations, patients sometimes have to overcome a barrier of fear, especially with medication and adaptations that have very uncertain outcomes.

Theme 5: Difficulties in communicating to facilitate and improve strategies

Ability

Patients can experience difficulties in communicating about the severity of their experienced symptoms because of the invisibility of the symptoms. This creates an extra barrier in establishing adaptations and can give patients a feeling of constantly needing to prove their disease. This also hinders communication with healthcare workers, as it can be challenging to describe the amount of pain or fatigue, especially when needing to recall from memory. Patients can also have difficulties coming up with topics and questions that are important for them to communicate, especially when the appointment’s goal is unclear. Appointments often focus on standardized procedures and medical steps, making patients experience little time to communicate their insights.

‘I had co-workers who thought I should not act up. Who thought: ‘Nah, he just does not feel like walking’

Motivation

Patients can be demotivated to communicate about their self-management strategies when it goes against their perceived personal identity and social role, like wanting to be an independent woman, a strong father, or a go-getter. Patients also mentioned that they often do not communicate because they feel not understood because of the invisibility of the disease. They tend to feel more comfortable communicating with people that have had similar disease experiences in life. Patients can be demotivated to communicate during appointments with healthcare workers because of the insecurity of not being taken seriously and not seeing the value of communicating their own insights.

‘You want to be able to do everything yourself anyway because you are a young woman ... I also have friends who say, I want to help you clean your house, but I do not like to ask for help so much’

Main take aways

Besides the experience of symptoms, feelings of insecurity and frustration and the feeling of loss of control this causes negatively influences the patient’s subjective well-being along their journey.

Feelings of security and satisfaction are important drivers of acceptance and thus the patients’ subjective well-being and overall motivation around engaging in self-management. The satisfaction facillitator ‘beeing able to experience valued things in life’ is an important motivator to stimulate patients to engage in self-management. To stimulate docile patients to take an active self-management role, It is important to motivate them to develop their own understanding instead of solely relying on external validation to get the feeling of security.

At the start of their journey, patients experience difficulties in establishing a good knowledge base to start self-managing. Difficulties in monitoring and developing an understanding of their body and coming up with good self-management strategies complicates their ability and motivation to self-manage further. The difficulties patients experience in communicating with the healthcare workers withold patients from taking an active role in the hospital care path and deny them the chance to get support in solving their difficulties in self-managing.

5.1 Healthcare workers’ perspective

Difficulties in providing support

Based on the observations and walk-alongs three categories of patient characteristics could be distinguished that cause differences between patients around taking an active self-management role: (1) The patient’s existing health literacy, norms, and beliefs, (2) the patient’s motivation to be involved and (3) the patient’s opportunity and willingness to adapt. various difficulties were found that healthcare workers experience around these factors when delivering support to lowSEP patients.

Difficulties in receiving the needed input to deliver support

The healthcare workers mention that with lowSEP patients, they can have difficulties receiving the needed input to deliver tailored support within the limited appointment time. They mention that they often need to ask for this explicitly and that patients tend to have difficulties recalling valuable insights and translating this into words.

‘With low-sep people, you do not really find out how things are at home. If they do not tell you, then you do not know’

Also, patients can start to communicate less relevant insights because of unclarity about the important things to communicate. Because of this, it can take longer to get to the most critical pains and topics within the limited appointment time.

‘As a rheumatologist, I have limited time to find out what witholds them.. I just repeat the information again.’

Patients can also leave out important information because of feeling shame to communicate when having misunderstood something. A current solution for receiving patient input is sending out questionnaires before the appointment. However, it was mentioned that these questionnaires are often not filled in by the lowSEP patients as they are text heavy and can be complicated to read.

‘Then they think, hey the disease is gone, and they quit. Then they came back with a flare and remember I said something about not quitting. When I then ask them if they took their medication, they feel shame and say yes.’

Difficulties in delivering information in a way that is well understood.

Healthcare workers stress the importance of establishing a good understanding base with the patient as a decreased understanding at the start keeps causing difficulties along the carepath.

‘You keep encountering the same elements during the whole care path, but it starts at the beginning. When the fundamentals are not right, you have to fix that somewhere later on.’

They mention that, having a higher health literacy themselves, they find it difficult to estimate what level of information provision can be understood.

‘You cannot think of that yourself; it sounds so simple, but you never know exactly what is going on in the other person.’

Patients often confirm but forget things once at home or feel shame to communicate not understanding things. To prevent this, information is repeated and the patient is asked to repeat information to to check whether it was understood. However, this makes that it takes more time to provide important, more general information, leaving less room for more tailored information. Also, healthcare workers can have difficulties discussing topics that are subjective to health lifestyle norms as they can have different norms then the lowSEP patients’

Difficulties fitting support to the decreased opportunities of the lowSEP situation

Healthcare workers mention that with lowSEP patients, it is more difficult to deliver support that can and will be actually applied. They mention that with lowSEP patients that have fewer resources, it is more difficult and sometimes impossible to come up with fitting solutions. They experience difficulties in motivating lowSEP patients to prioritize health and self-management behavior when other stressful contextual factors are happening in the patient's life that are more important to them at that moment.

You would like to offer opportunities in the home situation for patients to live a healthy life. It's easy to say, but they should eventually be able to incorporate it'

As these factors are very patient specific and often beyond the reach of the hospital support, this latter theme of difficulties is left out of the direct scope of this project. It is important to take away from this that delivering support to the lowSEP patient asks for more support in solution finding and that with the lowSEP patients, increasing motivation to also prioritize their self-management is an important issue.

'The biggest issues in self-managing are in the socio-economic domain, but I cannot do a lot about that' - Rheumatologist

Main take aways

Heathcare workers experience difficulties in obtaining the needed input from lowSEP patients to be able to deliver them tailored support.

When delivering support to the lowSEP patients they find it difficult to determine what level of complexity can be understood and experience that it takes more time to convey the information to the patient.

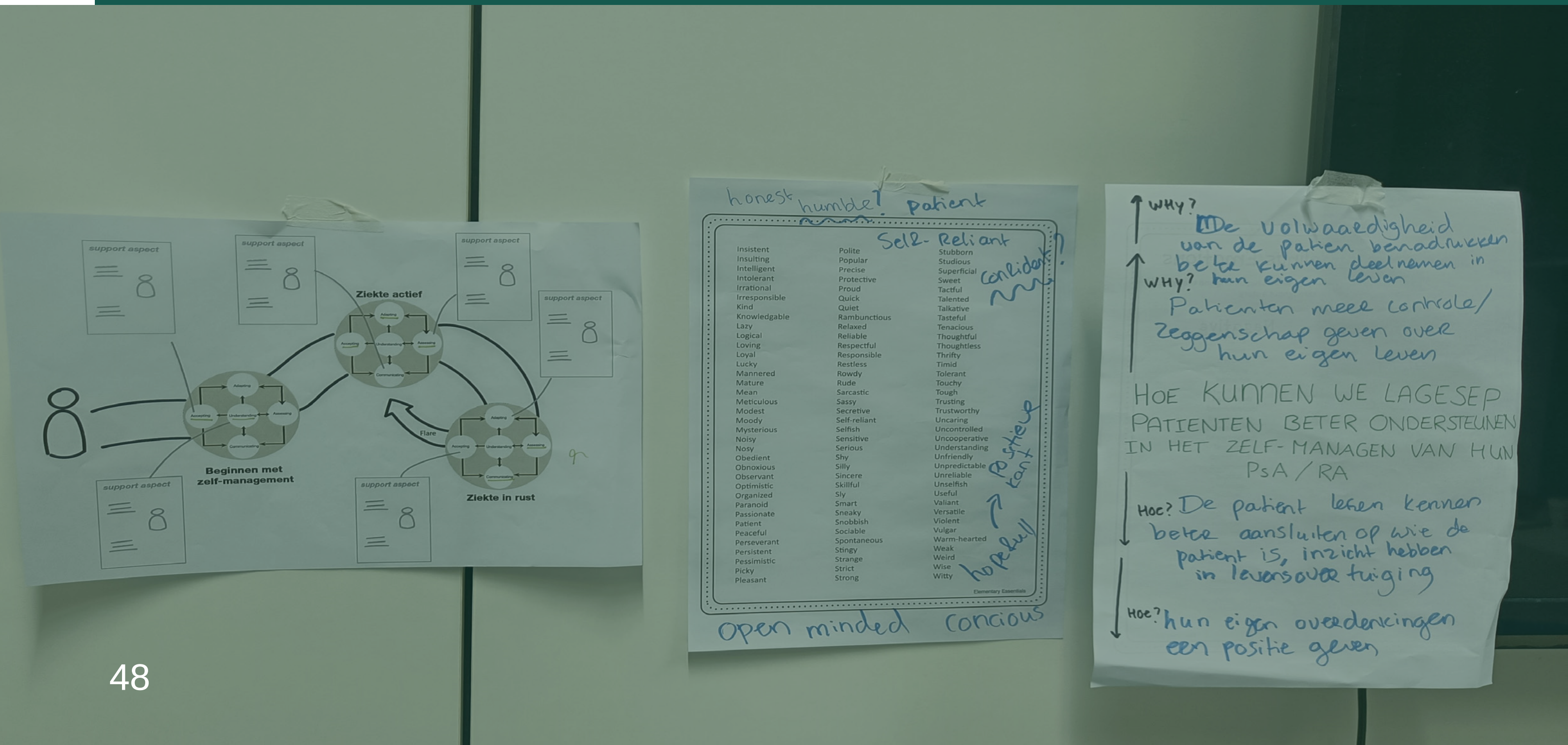
The limited resources of the lowSEP patient asks for more support in solution finding. The stressful context factors in the patient's life makes it important to motivate the patients to also prioritize their self-management.

Chapter 6

Defining the Future Vision

This Chapter provides the future vision that was established during a co-creation session with healthcare workers. After this, it provides additional insights gained during the various research methods that helped to specify this future vision further. During the research methods, insights were gained around the stakeholder's vision on including remote monitoring in the future support approach. This Chapter ends with the future vision around the opportunities of remote monitoring that was established based on this.
The chapter aims to find insights to answer the following sub-research question:

Rq5 What is the stakeholders' future vision on supporting patients in self-managing their disease, and what role could remote monitoring play in this?



6.1 Co-creating the future vision

A creative session was held to develop a future vision around the desired support situation. It was decided to conduct this session with healthcare workers as they are experienced in the field, having experienced multiple patient situations, and can thus approach the problem from a very broad perspective compared to patients who only encountered their own situation. At the start of the session, the healthcare workers were asked to think from a patient perspective when coming up with the future vision.

The session was set up to determine the underlying patient need to be fulfilled and the desired interaction the future support situation should establish with patients receiving the support. The healthcare workers were stimulated to think about this through three exercises using creative facilitation techniques derived from the Delft Road Map of Creative Problem Solving Techniques (Heijne & Van Der Meer, 2019). This included a ladder of abstraction exercise to define the problem more clearly and an interaction vision and personality trait exercise to define the current and desired situation around lowSEP patients' characteristics and experience in self-managing their disease.

The results of the exercises were combined into a future vision:

The future support approach should allow patients to get a feeling of control, hope, and satisfaction and should give attention to the patient's own thoughts and beliefs. It should support patients in becoming self-reliant, conscious, and open-minded in managing their disease.

6.2 Elaborating on the future vision

As the interviews followed the path of expression also the patient's dreams about improving the hospital self-management support were discussed. This provided insight in the future vision from the patient perspective. Co-creating on an initial idea direction provided insights in the healthcare worker's desires and needs for the future vision

Patient needs

During the interviews with the patients, desires for future support were discussed. Patients were asked what support they wished to have had or would still like to get. Patients mentioned varying needs highlighting the uniqueness of every patient. Multiple conscious patients mentioned the need to receive support in finding other ways to manage their symptoms besides taking medication. Other needs shared by conscious patients were getting more insight into medical results and getting more guidance around medication side effects. A patient with an emotional attitude highlighted the need for more support from the healthcare worker in finding ways to manage her symptoms that have less consequential unpleasant side effects. A docile patient mentioned the need to receive more external validation of her own insights and assumptions. Most self-governing patients mentioned the need to get more room for their own voices during appointments. These insights stress the importance of aspects in the future vision about giving attention to the patient's own thoughts and beliefs from a patient's perspective. It also shows an interesting addition to the future vision:

The future support approach should allow to address the patients specific attitude-related needs.

Healthcare workers needs

At the start of the thesis project, the aim was to design a self-management support map that shows what to support patients in over the various stages of their self-management journey. This would provide the healthcare workers of the department insight into what the support should focus on in every phase of the self-management journey. Chapter 3.1, describes the main goal of self-management in every phase, which indicates the main focus of the support that should be delivered. However, as mentioned above, the patient's support needs are very patient-specific. An idea direction had started to rise to translate the self-management support map into a digital tool that allows dividing the various needs over various clickable screens (Figure 19). The digital tool should become a living document where the healthcare workers can add new pains and needs discovered during the appointments.

Co-creation session healthcare workers

During the co-creation session with the healthcare workers (field research activity 4), the idea direction was evalueated. This showed that the healthcare workers appreciated getting more insight into important pains and needs of the patient. However, they mentioned that they did not desire to and would find it hard to decide which pains and needs would be relevant to discuss with the specific patient, as this would still be based on their assumptions. This inspired for an extension to the future vision addition derived from the the patient interviews:

The future support approach should enable patients to communicate their specific needs to the healthcare workers.to allow them to receive support tailored to their attitude-related needs.

Co-creation session rheumatologists

During the online co-creation session with rheumatologists (field research activity 5), an iteration of the previously mentioned idea direction was proposed. The iterated idea included a patient tool that allows the patients to establish a patient profile. Before the appointment they get proposed a set of pains and needs relevant to their profile and phase in the care path to inspire them for communication.

The evaluation highlighted that with this idea direction, the patient still stays very reliant on the healthcare workers to solve their problems The rheumatologists mentioned they do not have enough time to provide patients with this understanding, They stressed the importance of stimulating patients to learn about their own disease and adaptations themselves. This created a second addition to the future vision:

The future support approach should support patients in monitoring their body and learn from their own experiences to develop an understanding of their personal disease manifestations and fitting management strategies as far as they can themselves before reaching out to the hospital.

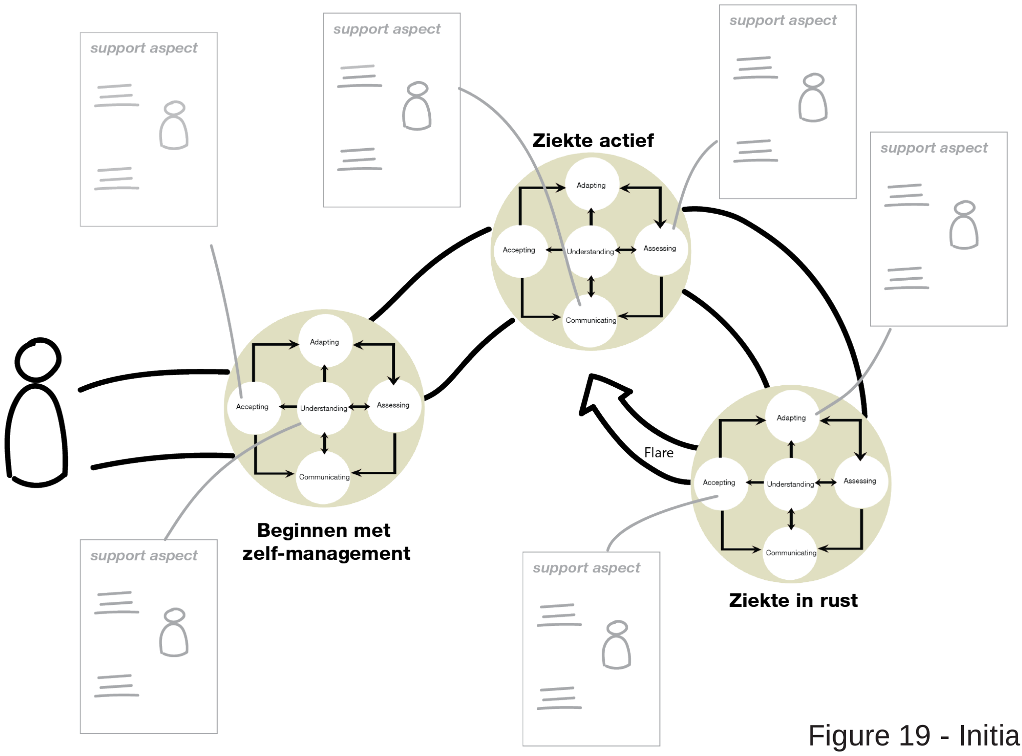


Figure 19 - Initial idea direction

6.1 Future vision on remote monitoring

The future opportunity of remote monitoring was discussed during the interviews with the patients and healthcare workers. This provided insight into opportunities to use remote monitoring in the future support approach. Also, the digital sensitizing technique during the patient interviews allowed to gain insight into the usability needs of patients around the use of digital tools.

Healthcare workers’ perspective

Healthcare workers mention that receiving information about the patient before the patient arrives for the check-up would allow them to deliver more tailored support. They mention that besides the physical data, the IPROLEPSIS study currently focuses on, they would also be interested in receiving data on the patient’s perception of his physical and mental state. They mentioned that this data should be provided to them in a way that is easy to translate into insights during their limited preparation time. They highlighted the opportunity to provide the data to the patient to support them in understanding their body.

Patients’ perspective

Discussing the topic of receiving remote monitoring output, a patient mentioned that receiving external signals around her symptoms could motivate her to take it slower instead of pushing through. It was mentioned that the type of output provided should be relevant to the patient instead of overwhelming the patient with data. Also, the importance of guiding the patient in using the data became clear. A patient mentioned that she does not use health apps such as step counters because she does not know what to do with the data.

Digital sensitizing with patients

When using a digital device to deliver or collect remote monitoring data, patients with basic digital skills should be taken into account. During the digital sensitizing, it became clear that three out of seven patients were not digitally skilled. These patients had a smartphone but mentioned only being able to conduct basic tasks such as calling. One patient succeeded but mentioned struggling with using digital tools and apps in daily life. The other three patients were able to do the digital sensitizing easily and mentioned they would like to have a digital support tool.

Main take aways

The future support approach should allow patients to get a feeling of control, hope, and satisfaction and should give attention to the patients’ own thoughts. It should support patients in becoming self-reliant, conscious, and open-minded in managing their disease.

The future support approach should enable patients to communicate their insights and needs to the healthcare workers to allow them to receive support tailored to their needs. Enabling patients to collect and share data about their experiences during daily life could support patients in this communication.

The future support approach should support patients in monitoring their body and learn from their own experiences to develop an understanding of their personal disease manifestations and fitting management strategies themselves instead of relying on hospital support in this. Providing the patients with relevant remote monitoring data and guiding them in how to use this data could support patients in developing this understanding.

When using a digital device to include remote monitoring data in the future support approach patients with basic digital skills should be taken into account.

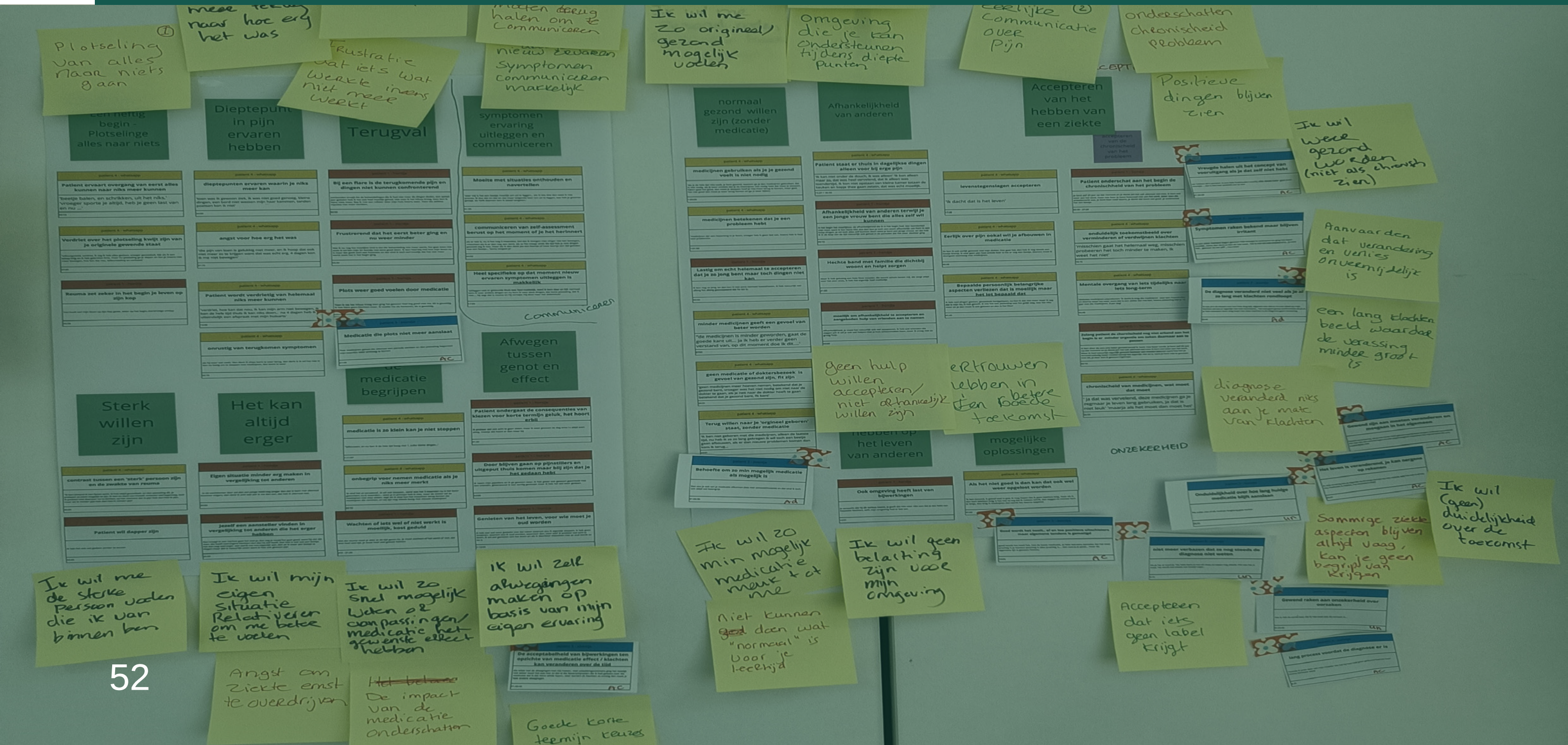
Chapter 7

Problem Definition

The problem phase started with the problem statement:

What should the future hospital self-management support focus on to better support lowSEP PsA and RA patients in self-managing their disease, and what opportunities could remote monitoring provide in this?

In this Chapter, the five sub-research questions are answered. After this, the problem definition is described, including a description of the problem to solve and a description of the goals to establish with the solution. This problem definition creates the transfer from the problem phase to the solution phase, where the aim is to solve the defined problem right.



7.1 Answering the sub-research questions

Rq1: What does self-management entail for PsA and RA patients, and how is this currently supported?

PsA and RA self-management entails the patient actively engaging in five important self-management activities: Feel, Understand, Adapt, Accept, and Communicate. Acceptance is essential to make self-management als improve the patient's HRQoL regarding their subjective well-being instead of solely regarding physical functioning and determines the patients' motivation and willingness to engage in self-management. Communication is important for patients to facilitate and improve their strategies and allows patients to take an active role in the patient-healthcare worker relationship.

Along their self-management journey, the patients go through three phases where the main focus of engaging in these five self-management activities shifts from understanding and applying the provided disease and managment information to gaining insight into the personal disease manifestations and how to manage these, to fitting management in as part of living a fulfilling life.

Based on the research conducted, self-managing PsA and RA can be described as the patient taking an active role in engaging in the 5 activities of self-management to strive towards reaching the main focus of every phase of the self-management journey.

The focus of the self-management support currently delivered at ErasmusMC is on the information provision during the post-diagnose appointment with the consultant and the informational material provided afterward. Along the journey, the short check-up appointments focus on the rheumatologist executing his expertise in clinical assessment and involving the patient as the expert of their experiences in decisions about the next steps in the care path. However, there is little time to support patients in monitoring their body to develop the knowledge to take this expert role and in establishing strategies besides taking medication.

Rq2: What are meaningful characteristics of lowSEP patients around engaging in self-management?

LowSEP patients tend to have overarching characteristics including limitations in understanding and making adaptations because of a low health literacy, limited resources, limited problem solving skills and a protective mindset. Four attitude profiles can be distinguished to characterize the lowSEP patients attitude towards taking an active self-management role. These profiles are shown in Figure 15 on page 39 and distinguish a docile vs. a self-governing characteristic and a conscious vs. a self-governing characteristic.

The docile and emotional attitude characteristics are least in line with taking an active self-management role. A docile attitude can make a patient dependent on the healthcare worker's external validation instead of being actively involved. An emotional attitude can cause patients to be less invested in managing their physical health and can make them unpredictable in engaging in management strategies when they encounter barriers to finding emotional fulfillment. For all attitude profiles, the facilitator of acceptance, 'being able to do valued things in life,' is an important driver to stimulate the patient's motivation around taking an active self-management role.

Rq3: What difficulties do lowSEP PsA and RA patients experience in their current self-management journey?

Along their self-management journey the experience of symptoms as well as feelings of frustration and insecurity negatively influences the patient's emotional well-being.

Succeeding in taking an active self-management role would allow patients to positively influence these feelings and find more acceptance in dealing with their disease. It would provided them more feeling of security by developing an understanding of the disease and their body and it would allow them to establish and engage in fitting self-management strategies that help them manage their symptomlevel and experience satisfaction about health progress and engaging in most valued life activities.

However the patient's experience difficulties in taking this active self-management role.
At the start of their journey, the provided information is complex and focuses on explaining the disease but does not provide the patient insight in what self-management entails during the patient's daily life. This causes the patients to have a bad offset in taking an active self-management role.
Along their journey the bad offset causes a decreased ability and self-efficacy to monitor the body and learn through trial and error to develop a further understanding of personal disease manifestations and fitting management strategies. This is complicated by the fact that personal disease manifestations are vague to determine and varying in nature. Also the patients can have difficulties in thinking in a solution-oriented way, often getting stuck at the adaptation of 'not doing something'. Difficulties in communicating withold patients to receive support in this.
The lack of security and satisfaction impacts the patients acceptance and causes patients to experience motivational difficulties to establish strategies or keep engaging in strategies.

Rq4: What difficulties do healthcare workers currently encounter in supporting lowSEP patients?

Healthcare workers strongly depend on the patient's input to deliver tailored knowledge and skills. However, LowSEP patients tend to be less actively involved or have difficulty delivering this input. Because of this, healthcare workers experience difficulties in getting to the main pains and needs to deliver support in within the limited appointment time. The increased solution-finding support that is needed ot fit with the complex situation of the lowSEP patients complicates this further.

When providing information to the patient, healthcare workers experience difficulties in providing this in a way that is well understood. They can find it challenging to estimate the level of complexity that can be understood because of their own higher level of health literacy. The need to repeat information makes that providing important general information takes up a lot of time, leaving less room for more tailored support.

Finally, Healthcare workers struggle to motivate patients around the importance of self-management behavior as lowSEP patients often encounter big contextual stressors in life.

Rq5: What is the stakeholders' future vision on supporting patients in self-managing their disease, and what role could remote monitoring play in this?

A future vision was established with healthcare workers around the future support approach: 'The future support approach should allow patients to get a feeling of control, hope, and satisfaction and should give attention to the patients' own thoughts. It should support patients in becoming self-reliant, conscious, and open-minded in managing their disease."

Patients should be enabled to communicate their needs to the healthcare worker to allow healthcare workers to deliver support tailored to their needs and attitude. Allowing patients to collect and share data about their disease experience with the department could support this communication of information.

Rheumatologists lack time during their appointment which is only going to increase further regarding the increasing pressure on the department's capacity. To keep the future vision viable, the future support approach should support patients in monitoring their body and learn from their own experiences to develop an understanding of their personal disease manifestations and fitting management strategies themselves instead of needing to rely on hosptial support in this. Providing the patients with relevant remote monitoring data and guiding them in how to use this data could support patients in developing this understanding.

Mobile phone applications are an accessible and effective way to deliver self-management support and could be an interesting means to establish this remote-monitoring opportunity. When deciding on such a means to deliver support, patients with basic digital skills should be taken into account.

7.2 Problem definition

In the current situation a viscious cycle is happening that negatively influences the lowSEP patients' ability and motivation to take an active self-management role and increase their HRQoL. This viscious cycle is caused by a lacking communication about the topic of self-management between healthcare worker and patient and patients' issues developing understanding of the personal disease manifestations and thinking in a solution oriented way (figure 20).

The vicious cycle

① when starting their self-management journey, the information provided is complex and is focused on explaining the disease instead of explaining what self-management entails and motivating the patient to engage in this. Because of this, lowSEP patients start off their self-management journey with an insufficient knowledge base which influences their ability and motivation to start taking an active self-management role.

② During their self-management at home, the insufficient knowledgebase decreases the patients ability and motivation to monitor their body and translate this into insights about their disease and fitting strategies to manage this. This is complicated by the fact that personal disease manifestations are vague to determine and varying in nature and by the patient's limited problem-solving skills. .

③ During appointments, the patients experience ability and motivational issues in communicating the limited developed insights and their support needs to the healthcare worker.

④ Not obtaining the needed input makes it difficult for the healthcare workers to deliver tailored support. They have difficulties providing the information they can deliver in a way that it is well understood.

⑤ The patient receives less tailored support and has difficulties understanding the provided information. This decreases their chances on improving their knowledge base which makes the cycle continue.

The consequence

Not succeeding in taking the active self-management role causes the patients to experience a lack of security and satisfaction in managing their disease. This negatively influences their acceptance of the disease and engagement in self-management strategies. This can cause rejection of self-management strategies, denying them the chance to improve their physical well-being, or engagement in strategies that are less beneficial for their subjective well-being, Both witholding the patient from obtaining their personal optimal HRQoL.

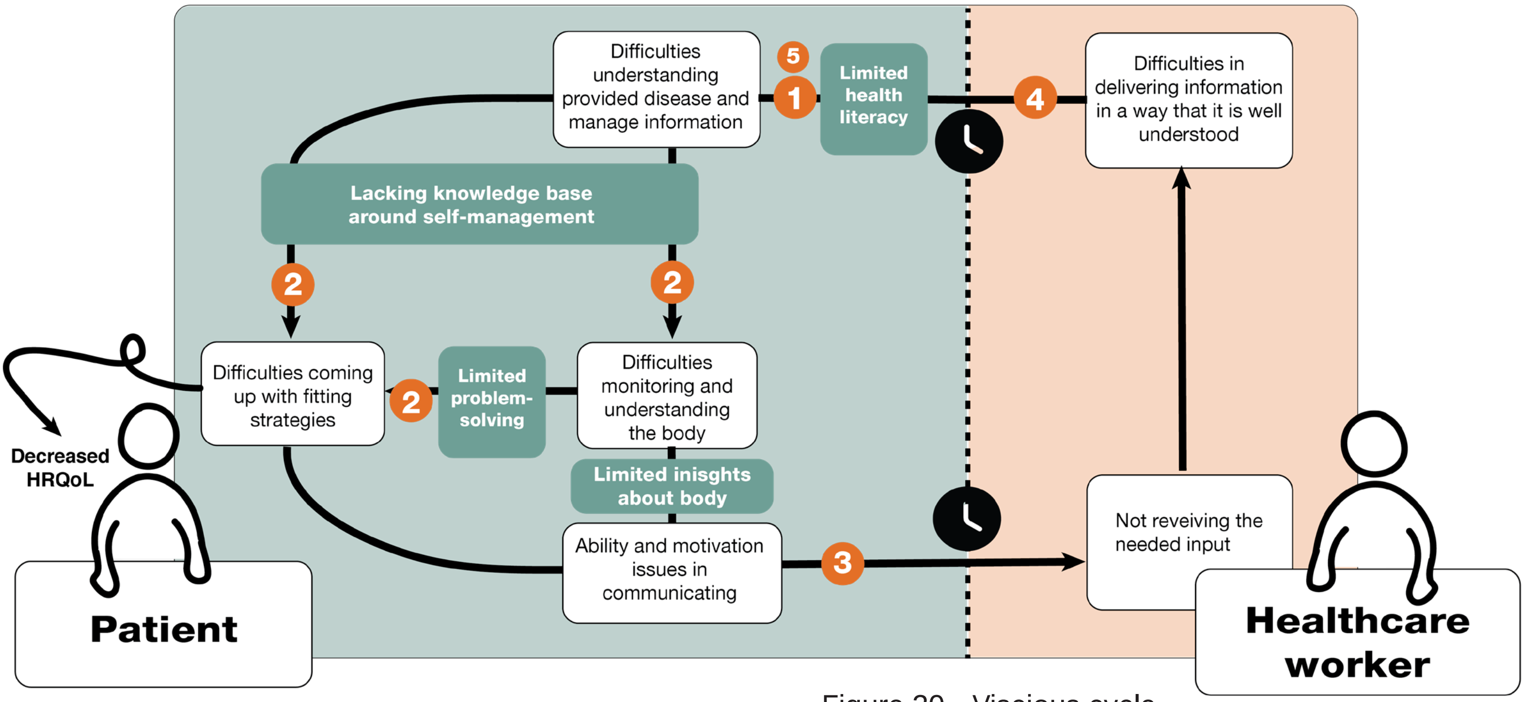


Figure 20 - Viscious cycle

7.3 Support goals

Combining this problem with the established future vision, a set of five support goals could be created that define this problem definition further and allow to translate the problem phase into the solution phase.

To empower lowSEP patients to take an active self-management role, the future support approach should support the patients in:

#1 … establishing a good knowledge base to start self-managing their disease.

Patients should be enabled to understand what disease self-management entails. They should be enabled to understand the relevant aspects of the provided disease information to start engaging in this self-management once at home.

#2 … gaining motivation to take an the active role and develop an understanding of their personal disease and management situation

Patients should be enabled to understand the benefits of active self-management the importance of developing an understanding of their disease and personal disease situation along their journey.

#3 … learning from their own experiences to develop an understanding of their personal disease manifestations.

Patients should be enabled to translate their own experiences around changes in symptoms and restrictions in their capabilities into insights about how their arthritis manifests in their body and the energy and strain balance and capabiilties related to this.

#4 … Thinking of solution-oriented adaptations that help them manage their symptoms and decrease the disease's impact on their daily life.

Patients should be enabled to translate their understanding of their personal disease manifestation into an understanding of adaptations that help them manage their disease symptoms and increase their capabilities. This should focus on enabling patients to find adaptations that fit with their acceptance balance.

#5 … Communicating their insights and needs with healthcare workers.

Patients should be enabled to communicate their needs and insights with the healthcare worker. They should be made aware of the value of communicating and should be inspired and provided with time to share their insights and needs during appointments.

Section 2

Design Phase

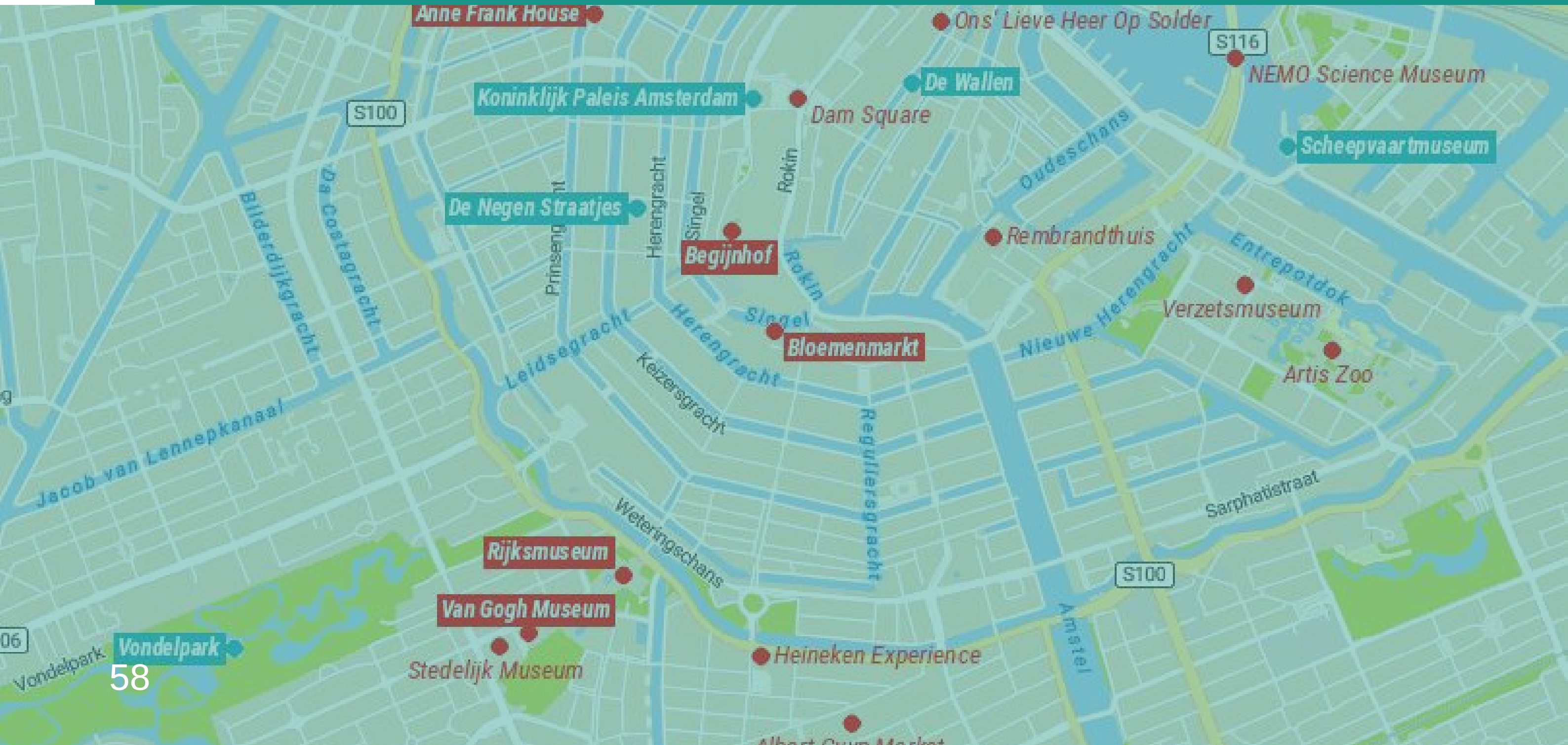
Based on the problem definition, a design vision could be established. An essential function of the design vision is to support patients in learning from their own experiences to develop self-management understanding. An overview was created that maps out how this learning through experience works around self-management. An ideation phase was started, where ideas were generated on translating this overview into a solution to reach the design goal. Through multiple co-creation sessions a final support approach was established which was evaluated with both stakeholders. This section describes the design vision, the created model and the ideation process and concludes with the Final concept and concept evaluation.

Chapter 8

Design Vision

This Chapter describes the design vision that was created. An interaction vision is given that envisions the feeling that the future support approach should evoke.

Figure 21 - Interaction vision (source : Touropia, 2023)



Design goal

Designing a future support approach, including a **communication approach** and **home support tool** that enables lowSEP patients to get a **feeling of control** in managing the disease's impact on their lives.

By supporting them in establlishing a good knowledge base to start self-managing their disease, and learn from their own experiences to develop this understanding further for their personal disease situation.

Main function

The most important function of the support approach is to motivate and guide patients in developing an understanding of their disease and management situation and enable patients to communicate their insights and needs for support to the healthcare workers. This function can be divided into the five support goals described in the previous chapter.

Main target group

The target group of the support approach is the lowSEP patient with limited health skills. Besides having ability issues, the research

phase showed that also motivational issues withhold lowSEP patients from taking an active self-management role. The research phase showed that lowSEP patients have distinguishing attitude profiles. The 'docile' and ' emotional' attitudes are least in line with being motivated to take an active self-management role. A docile attitude can make patients dependent on the healthcare worker. The emotional attitude can cause patients to be less invested and unpredictable in managing their physical health condition.

To increase the prospects of the design working for most of the target group patients, it is interesting to focus on this patient group that faces the most motivational issues to take the active self-management role. In this design phase, the focus thus lies on the Flexible

Context of use

The primary contexts of use of the support approach are the at-home situation of the patient and the interaction between the patient and healthcare workers during appointments at the hospital.

Means of use

To enable connection with the IPROLEPSIS remote monitoring intervention, it is desired to include a digital aspect in the home support tool.

Interaction vision

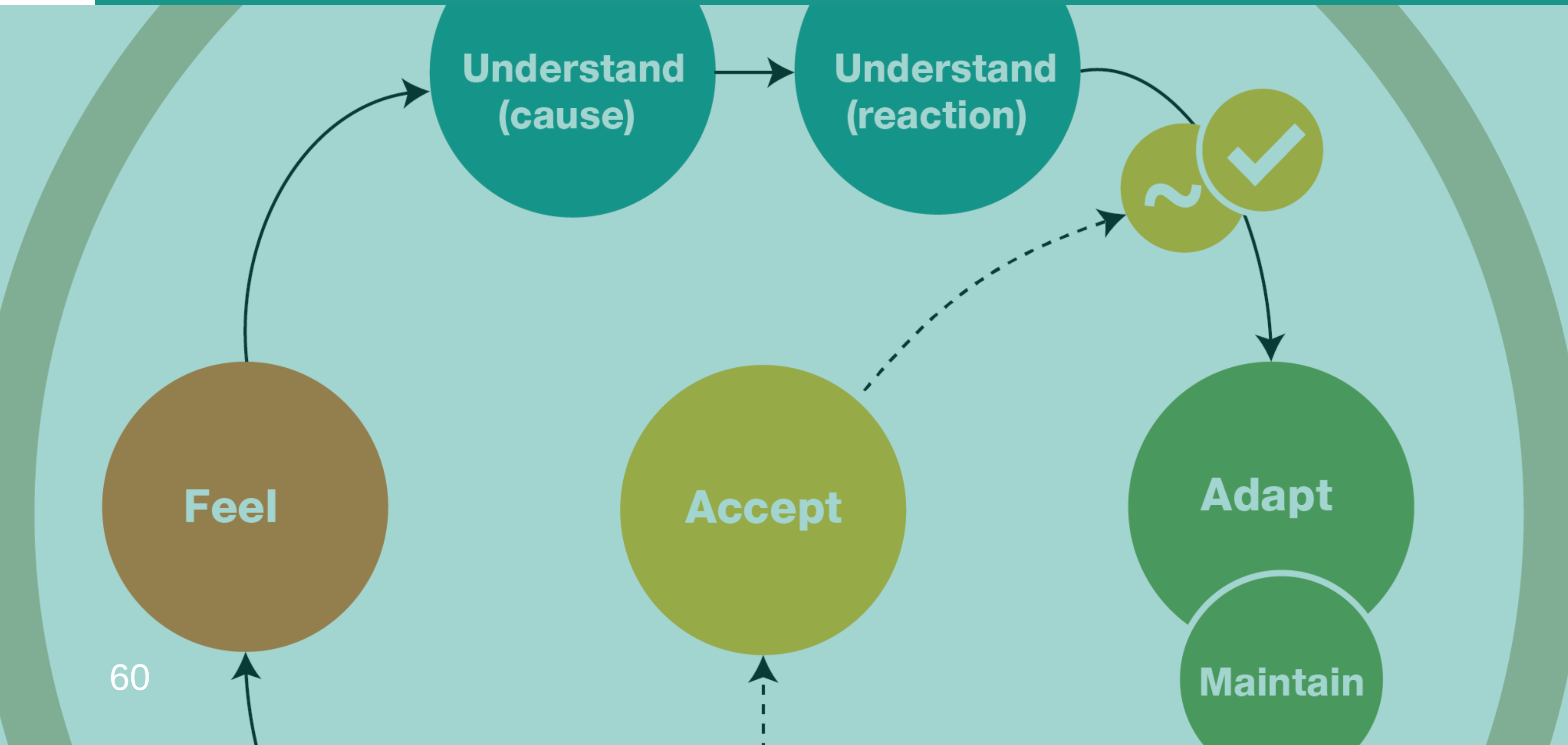
The interaction this support approach should evoke with the patient should be like receiving a map when arriving in a new city for the first time (figure 21). Arriving in a new city can be overwhelming and feel out of control as you have no idea where you are and where to go. When receiving a map of the city, you gain control back. You get an overview of the city and get motivated to start exploring the city yourself. Having the map with you gives you a sense of footing and guides you around. Once you know the routes, the map can be put away but is always there to fall back to when needed.

When receiving the diagnosis, the patient feels overwhelmed and 'lost', having little idea how to start managing the disease. The support approach should provide the patient with a **sense of overview** and **guidance** when starting to self-manage their disease. It should stimulate their sense of **consciousness** to start learning about their disease management. But once the patient begins mastering this, it should leave the patient be, being there as a backup when needed.

Chapter 9

Self-management Learning Cycle

This Chapter explains the model that was created to map out how learning through experiences works around self-management. This model shows how engaging in the five activties of self-management enables the patients to positively impact their experienced HRQoL.



Modeling the self-management learning cycle

A model was created that maps out how learning through experience works around self-management. This model was created based on the five self-management aspects described in Chapter 3.1 and the insights gained during the interviews with the patients in the research phase. The model shows how going through a cycle of feeling, understanding, adapting, and accepting allows patients to learn about their personal disease manifestations and self-management strategies to decrease the impact of the disease on their experienced HRQoL. Communicating with their surroundings and the healthcare workers allows patients to facilitate and improve this process. The complete model created is shown in Appendix F.1. A simplified version of this self-management learning cycle is explained in this Chapter

Explaining the cycle

The model (figure 22) starts at the moment the patient feels a change in symptoms. This is a cue to action to try to understand the cause of what is felt. The patient needs to translate this understanding of the cause into an understanding of how to act on this. Once this action is thought of, the patient has to also accept this action. Here two types of accepting can make the loop proceed: accepting and wanting to engage or tolerating and needing to engage. Once the action is accepted, the patient has to start to realize the action. This includes establishing an adaptation influenced by various barriers and facilitators in the patient's life. Once the patient adapts, a self-management strategy is established.

Because of the adaptation, the patient will experience effects on his life and the level of symptoms. The patient will develop an understanding of the effect of the adaptation on their symptoms. This improves their knowledge about the original adaptation, which can be to maintain, drop or enhance. The patient will also change their acceptance depending on the consequences and benefits of the adaptation experienced in life. Because of this, the original level of acceptance of the adaptation might have changed positively or negatively, where a negative change might cause the patient to drop the strategy. When the newly understood adaptation is accepted, the patient maintains or improves the originally established strategy, which causes new changes in the patient's life and felt symptoms, starting the loop all over again.

Flow Failure

During every step of the loop, the patients can experience barriers that withhold them from going to the next step and make them 'fall out' of the cycle. This means that the patient is not establishing or improving a self-management strategy and denies the patient the chance to have a positive experience on his HRQoL. These flow failures are visualized in the full model shown in Appendix F.1 and explained in more detail in Appendix F.2.

A vital flow failure to highlight is when the patient 'falls out' of the loop at the moment of acceptance. This relates to the research finding about acceptance, where not engaging in a strategy might establish higher HRQoL than having a feeling of 'needing to engage.'. This might thus not necessarily be a failure. However, it is essential that the patient is aware of this 'accepting not to adapt' to also accept the consequences that not adapting might have.

In the ideal loop situation, patients would be aware of this acceptance barrier and stimulated to develop their understanding far enough to come up with adaptations that allow them to reach the best of both worlds.

Flow influencers

During the loop, the patient can encounter external input. This input is established through communication between the patient and his external world, including the hospital. This external input in the various steps is visualized in the full model shown in Appendix F.1 and explained in more detail in Appendix F.3. The external input can create facilitators and barriers for the patient to go through the loop. The patient can, for example, receive information from the hospital about an adaptation to try out or be hindered in their acceptance when surroundings show grief when a planned activity needs to be canceled.

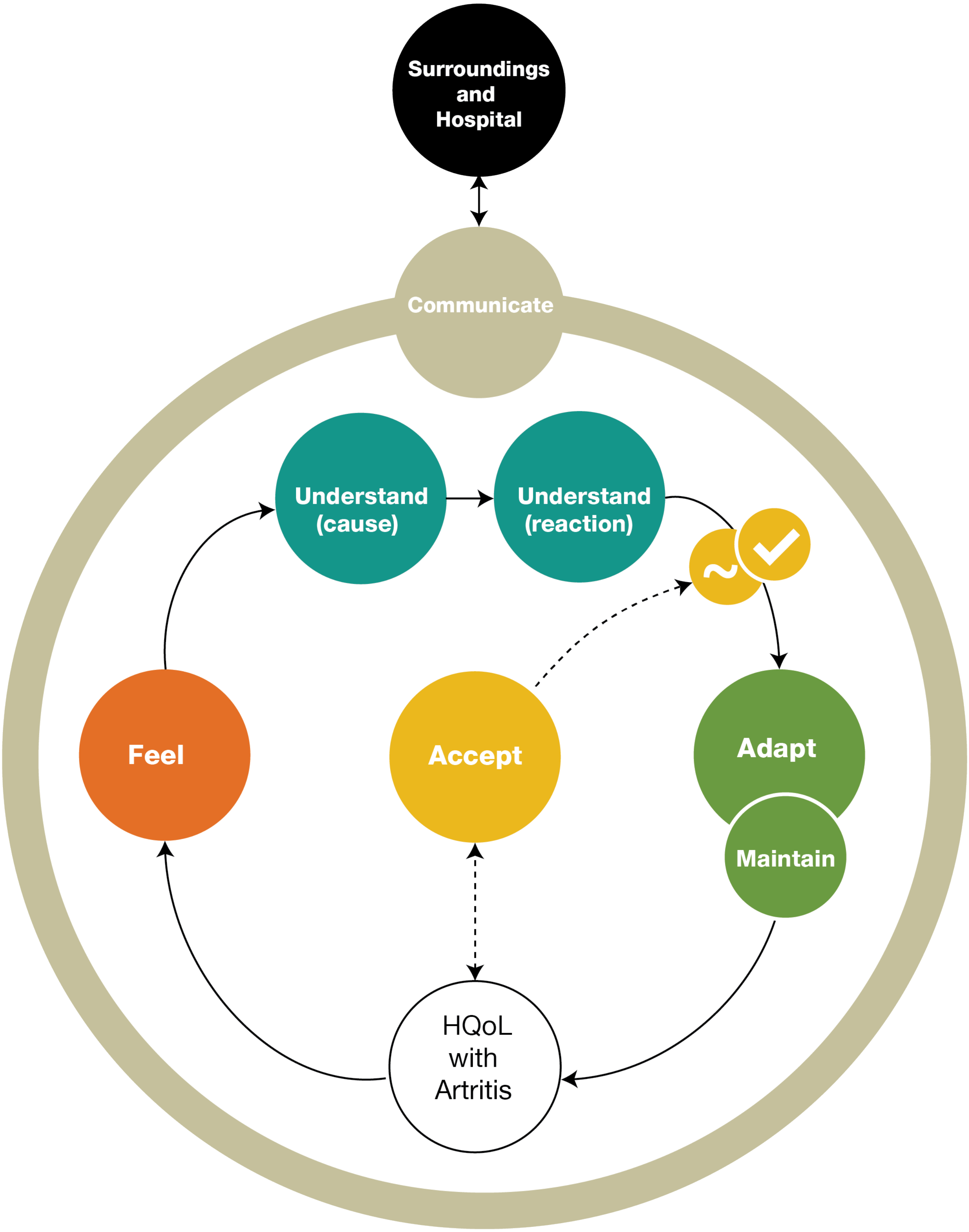
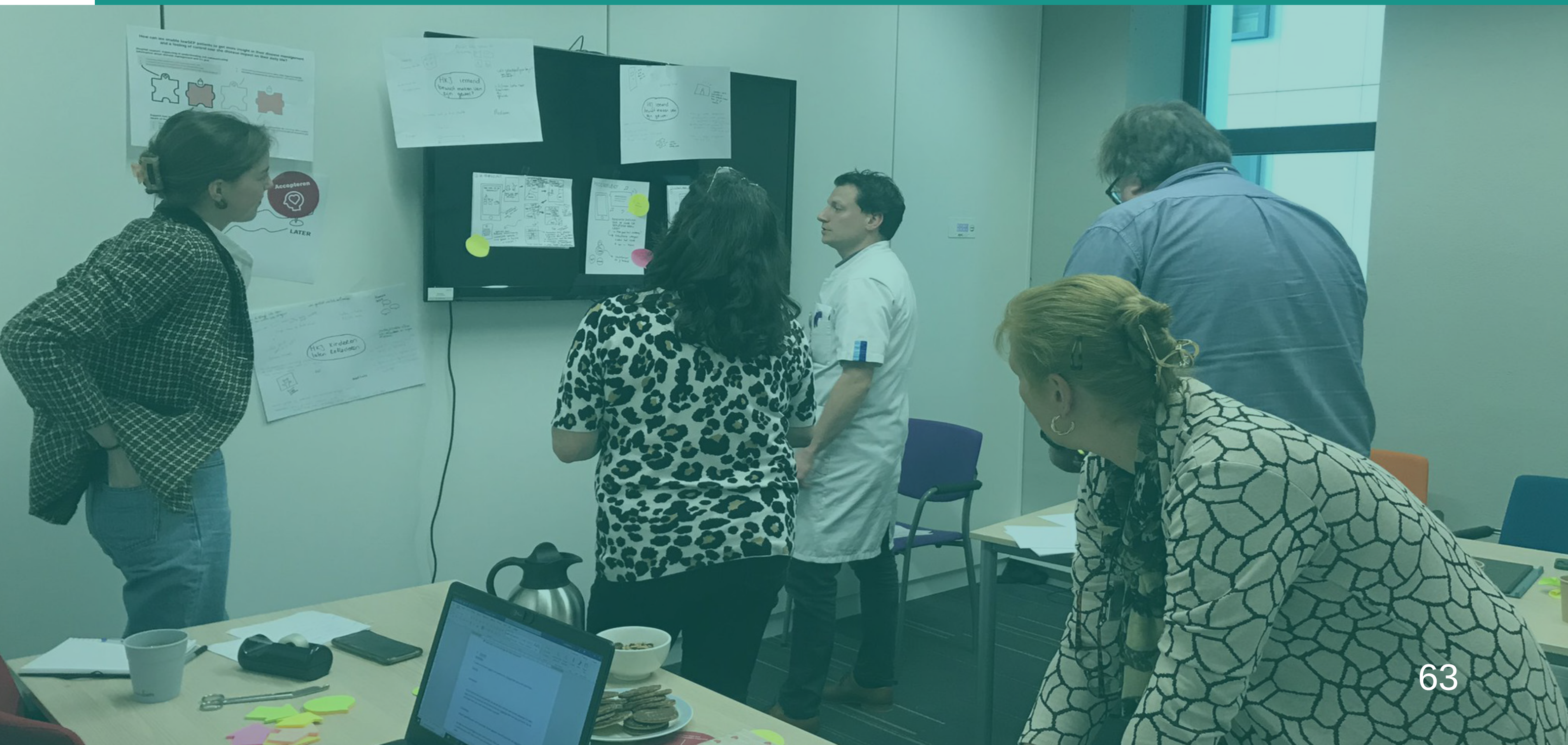


Figure 22 - Self-management learning cycle

Chapter 10

Ideation

This Chapter describes the ideation process that was gone through towards creating the final concept. The ideation started with a phase of divergent thinking through brainstorming sessions. After this, a converging phase started where ideas were combined into concept directions. Through an iterative process of co-designing with the stakeholders, these concepts were translated into a final concept. During the concept development, existing design guidelines found in literature around designing for low literacy and low digital skills were considered. The main guidelines taken into account are provided in
Appendix G.



10.1 Brainstorming phase

Approach

The ideation phase started with a brainstorming phase. Brainstorms were conducted both individually and with focus groups of design students. The sessions with design students were executed with a creative facilitation approach. Various creative techniques around problem finding and idea finding were used to allow the participants to emphasize with the problem and generate out-of-the-box ideas. Early in this brainstorming phase, the direction was chosen to design a communication approach that explains self-management to patients using the five self-management activities and the self-management learning cycle. This direction was chosen because the five activities and the cycle helped me, as the researcher, who, like the patients, started off with little understanding of the topic to understand what self-management entails. Also, it helped me in explaining the topic of self-management to the participants of the brainstorming sessions who had little knowledge about the topic. The brainstorming sessions focused on generating ideas on what this communication approach should look like, how patients could be supported to engage in the self-management learning cycle at home, and how this could be translated into a digital tool.

Main insights

Daily life examples could be interesting to use to clarify this connection between cause and consequence.

To stimulate patients to be conscious about how they feel, they should be actively reminded. This could be done with a phone notification or by including it in something they see or do daily.

The patients could be stimulated to learn from their experiences by asking or showing provocative questions that make a patient think about next steps. Focusing on thinking and creating awareness instead of needing to write things down could help overcome the pain found during research about patients losing motivation to track their experiences in a diary because of the high effort required. Patients could be stimulated to do this by linking it to a fun aspect, such as getting further into a game or keeping a figure alive.

Patients with low digital skills could be included in using a digital tool by making the needed actions as simple as taking up a phone, including only one click on something that pops up on the screen.

10.2 Concept directions

Based on the ideas created during the brainstorming sessions, a set-up for a communication approach and three concept directions for the home support tool were created.

Communication approach

The communication approach (Figure 23) uses the five core activities of self-management to categorize information when providing this to the patient. During the appointment,

Figure 23 - Communication approach

the consultant uses five separate flyers to convey the general information in steps. The appointment ends with a 6th flyer which shows a simplified version of the self-management cycle. This explains to the patients how they can learn from their feelings and experiences about their bodies and adaptations. The PowerPoint used during the appointments is divided into the same categories.

Home support tool

Three mobile phone app concepts (Figure 24) were designed. All three concepts use the during the brainstorming sessions developed idea of provocative questioning to guide patients in learning from their experiences. This to stimulate them to develop insights in factors that cause changes in their symptoms and how they can adapt to this. Focus was put on creating awareness without having to write everything down.

Concept 1

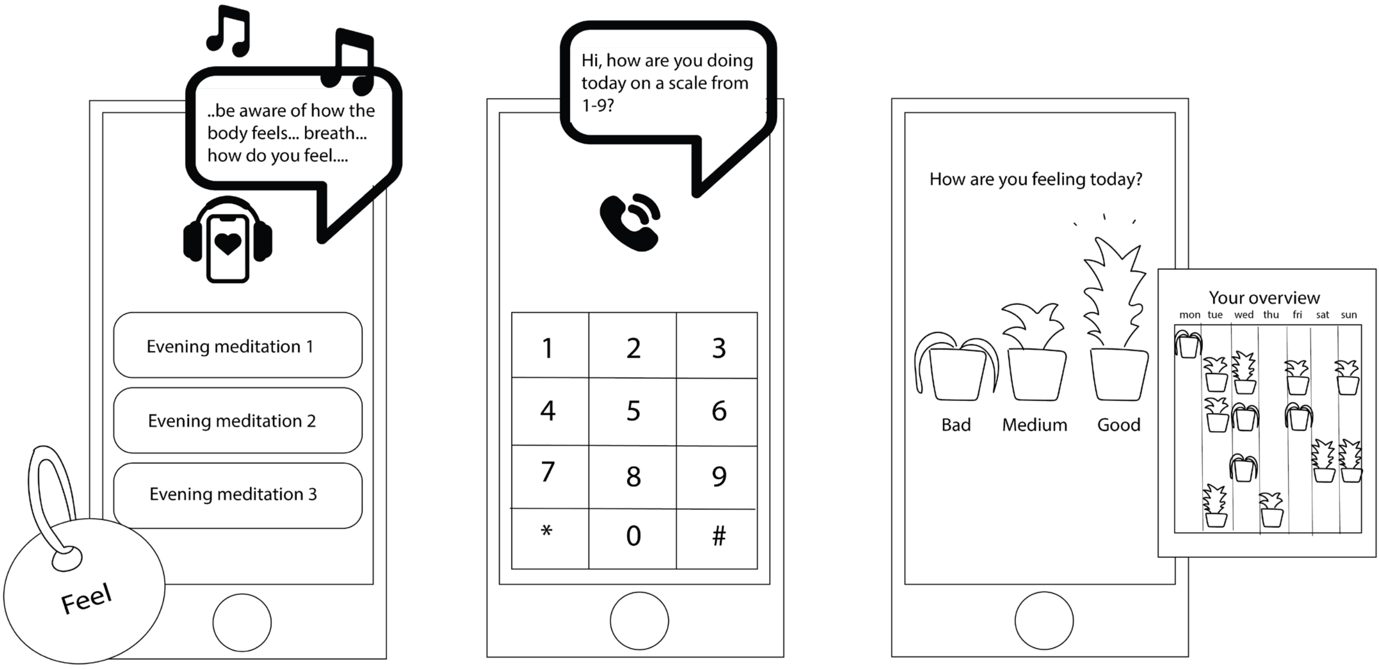
This first concept was based on the increasing use of acceptance and commitment therapy, including mindfulness exercises for chronic pain patients. It includes a podcast-like app that provides patients with meditation podcasts to listen to at the end of the day. During the day, the patient is reminded to be conscious about his felt symptoms with a keychain. The meditation at the end of the day stimulates the patient to recall these experiences and learn from them.

Concept 2

The second concept was based on the fact that the mobile phone app should be usable for patients with minimal smartphone skills. It includes a customer-service-like app that automatically starts on the patient's phone at random moments like a call. The patient hears a recorded voice of the consultant on the other side of the line asking him or her provocative questions. The patient goes through these questions in a customer service way by entering in digits on his phone based on which the next question is asked.

Concept 3

The third concept was based on the metaphor about the cause-consequence relation of growing a plant. The tracking-style app sends the patient a notification to go through various learning screens. This starts with the question of how the patient feels that day, choosing between a happy, a normal, and a sad plant. After this, the provocative questions are asked through triggering screens to click through. The goal is to grow a forest that shows the patient an overview of the feel data of that period.



Medireflect ChitChat Reumaplant

Figure 24 - Three home-support tool concepts

10.3 Iterative co-creating on the concept

Co-creation was executed on the communication approach set-up and the three concept directions with a focus group of healthcare workers and a patient that was categorized as the main target group: the flexible follower. After this, the insights gained were used to iterate further towards establishing an improved communication approach and a final concept direction for the home support tool. A co-creation session was executed with a newly involved rheumatologist on these two support approach aspects. The insights gained with this allowed to iterate toward the final concept direction.

Focus group healthcare workers

Method

The co-creation session was executed with two rheumatologists and two rheumatology consultants of ErasmusMC (figure #). The communication approach set-up was shown to the healthcare workers through role-playing. The setting of the consultant appointment was envisioned, and the way of communicating using the flyers was shown. Concept evaluation was conducted to get feedback about things they liked, disliked, and missed. The three concepts were shown through visual sketches. Using creative techniques, the participants were invited to iterate on the concepts further by combining, adapting, and eliminating aspects.

Main insights

It is essential that consultants can start the conversation with an open approach instead of them stirring the conversation into the five topics straight away. They first need to get to know the patient in front of them and want to leave room for the patient to share what was already understood and ask questions.

The communication approach should be applicable to every type of patient. Consultants do not want to have to decide on a simplified approach based on assumptions about the patient. The importance of the approach not becoming too childish for higher educated people is stressed.

Providing an overview of developments over time could be interesting to stimulate learning and motivate patients to ‘collect’ information. It could also be interesting for healthcare workers during check-up appointments.

The app should not withhold patients from reaching out when things worsen. It should include an emergency signal when patients fill in alarming data.

Co-creation patient

Method

A co-creation session was executed with one of the in the research phase interviewed patients characterized by a flexible follower attitude. The same role-playing used during the co-creation session with healthcare workers was conducted to show the communication approach. The patient was asked to evaluate this and think of ideas for improvement. The three concepts were made into low-fi prototypes that the patient could use to envision the concepts (figure 25) After each concept, the patient was asked to evaluate the concept and share ideas for improvement.

Main insights

The patient appreciated the fact that concept 3 also gave her visual cues and that this clearly connected with the steps of the communication approach.

Figure 25 - Prototype testing patient

A sudden notification or call can be perceived as intrusive. However, it was mentioned to be important to get a reminder for consciously investing in the disease. Especially, during better days or moments the patient mentioned to lack motivation to fill in questionnaires or tracking diary's. Setting own notifications at prefered moments would be desirable.

It is important that the patient can take the time needed to come up with insights. The patient mentioned that the concept of the Reumaplant allowed her this time to think, while the other concepts made her feel rushed. Also, needing to fill in the insight increased consciousness. The patient preferred a combination of hearing and reading the question.

The app should consider that motivation to invest in dealing with the disease decreases when the disease activity is lower.

A gamified element is not essential to include. The aim of getting to know the body might be sufficient. The patient mentioned she would rather deal with her disease in a serious way.

Co-creation rheumatologist

Method

Based on the insights gained multiple iterations were done on the two aspects of the support approach. This resulted in a final concept direction for both the communication approach and the home support tool. The two aspects were evaluated with a newly involved rheumatologist with a design background. The communication approach was shown through role-playing. The mobile phone application was shown as an online app prototype. Some of the screens are shown in figure 26.

Main insights

It could be interesting to make use of the database already existing in the ReumaApp.

Patients should be guided in the feeling aspect personalized to their situation. They can have unclarity what symptoms are related to their arthritis and what things they feel have other causes. The app should be very person-specific regarding the location of inflammations instead of showing general disease symptoms.

It is important to distinguish causes of changes in symptoms that the patient has an influence on, such as lack of sleep or overdoing, and causes that the patient has little influence on, such as hormones and the weather. The latter is interesting for the patient to understand the disease but will not inspire adaptations.

Hoe gaat het vandaag?

Als je denkt aan de verschillende reuma symptomen

Heel veeldingen kunnen invloed hebben op hoe erg je je reuma voelt

Ook als je je slecht voelt is bewegen belangrijk dit maakt de pijn en stijfheid minder

Figure 26 - App prototype screens

Chapter 11

Final Design

This Chapter explains the final design of this master thesis: The GROW support approach. First, an introduction of the overall support approach is given. After this, the aim of the support approach is explained. A storyboard shows the use scenario of the support approach. After this, the two aspects of the support approach: a communication approach and a mobile phone app, are explained.

lichaam voelt anders dan u gewend was. Boos, verdrietig of bezorgd worden is normaal. Dat hoort bij het hebben van een ziekte

Reuma zal altijd een onderdeel blijven van uw leven. Daarom is het belangrijk reuma een plekje te geven en hier niet tegen te vechten.

U kunt zich laten inspireren door mensen om u heen en lotgenoten die hetzelfde meemaken.

Tips bij een dip

- Krop het niet op. Praat met mensen die u vertrouwd of schrijf uw gevoel op.
- Ontspanningsoefeningen kunnen helpen om met emoties en pijn om te gaan.
- Bewegen helpt voor uw lijf en uw hoofd
- Bedenk dat u vertrouwen mag hebben in uzelf en in alles wat u kan ondanks uw reuma.

Waarom accepteren?

Uw reuma accepteren helpt om op een gelukkige manier met uw reuma om te gaan.

U kunt bedenken wat u belangrijk vind in het leven en op zoek gaan naar aanpassingen die daarbij helpen.

U weet het meeste over hoe de reuma in uw lichaam werkt, en welke problemen u door u reuma heeft tijdens uw leven.

Het is belangrijk deze informatie goed met uw dokter te bespreken. Dan kan de dokter u helpen op een manier die past bij uw lichaam en leven. U kunt het hebben over dingen die u heeft geleerd of vragen die u heeft over het voelen, begrijpen, aanpassen en accepteren.

Bespreken met uw omgeving

Tijdens het omgaan met uw reuma maakt u momenten mee met de mensen om u heen. Door goed met hen te praten over uw reuma en wat u nodig heeft kunnen zij u beter begrijpen en helpen

Waarom bespreken?

U weet het beste hoe uw reuma werkt en hoe u hiermee om wil gaan. Door dit goed te bespreken met uw omgeving en uw dokter, kunnen zij uw reuma en uw behoeften beter begrijpen en u beter helpen

Door bewust uw lichaam te voelen leert u uw reuma begrijpen. Dit geeft ideeen voor aanpassingen die u kunt uitproberen.
U merkt dan of de aanpassing werkt voor uw lichaam. U merkt of de aanpassing u helpt om de reuma te accepteren en te doen wat u belangrijk vind

Door te bespreken wat u voelt, leert en wilt aanpassen kunnen anderen u hierbij helpen

11.1 Introduction: GROW support approach

The GROW support approach is specifically designed to empower patients with limited health skills because of a lowSEP, to take an active role in self-managing their disease and control it's impact on their daily lives. GROW consists of the GROW communication approach and the GROW app. The GROW support approach focuses on facilitating the communication between healthcare workers and patients and guiding and engaging the patients in developing an understanding of their disease and its management.

The GROW communication approach is focused on establishing a clear, consistent, and engaging way of communicating about the topic of self-management between healthcare workers and patients. It highlights five important activities of self-management, which create a link between information provided in the hospital and the patient self-managing the disease at home.

It uses a visual GROW map that shows how these activities together allow the patients to learn about their disease and control its impact on their lives. Starting the communication approach at the start of the patients' self-management journey provides newly diagnosed patients more insight into the topic of self-management, motivates them to engage in this self-management, and guides them in understanding the information needed to engage in this.

The GROW-app extends the hospital support to delivered to the at-home situation of the patient. It triggers and guides the patient in learning from their own experiences to develop a deeper understanding of their personal disease manifestations and how to adapt to this in a personally fitting way. It provides a clear information base consistent with the communication approach and supports patients in keeping track of their feelings and insights to communicate during appointments.

11.2 The aim

The main aim of the support approach can be explained using the behavior change model by Fogg described in the background chapter. The communication approach aims to increase the patients' motivation and increasing the patients' ability to succeed in taking an active self-management role (figure 27). Along their journey, the app triggers the patients to engage in this role.

Increasing ability

By providing the patient insight into the five core activities and the self-management learning cycle. By guiding patients in establishing the knowledge to start engaging in this through categorizing and repeating information.

Increasing motivation

By showing the patients how taking an active role in engaging in the self-management learning cycle allows them to gain security and control over the disease and its impact on their lives. By setting emotionally valued goals with the patients.

Trigger behavior

- Sparks: Using active words and sentences to motivate patients to engage.
- Facilitators: Guiding the patient through the learning cycle with multiple inspiring app screens.
- Signals: Using app notifications to remind patients to learn about their self-management consciously.

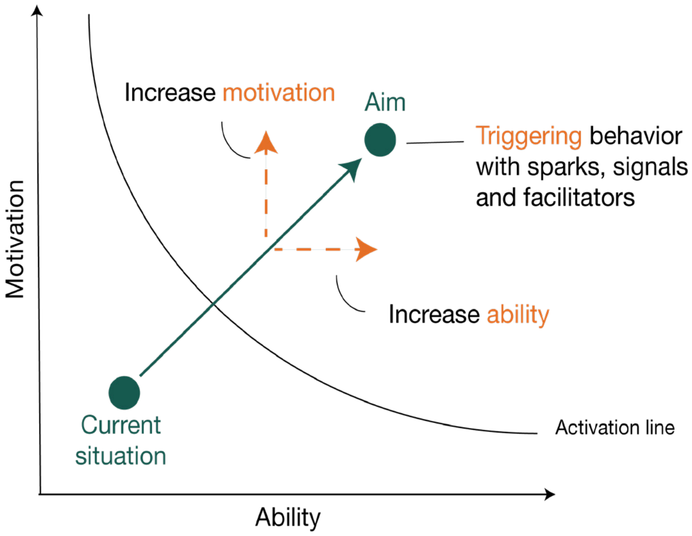


Figure 27 - Explaining the aim

11.3 Use Scenario

A storyboard describes the implementation of the communication approach during the hospital appointments and the use of the GROW app at home (Figure 28).

1 General explanation

An open conversation is started leaving room for the patient to share her current understanding and questions. During this the consultant already introduces the GROW activity words inexplicitely.

2 Explaining self-management

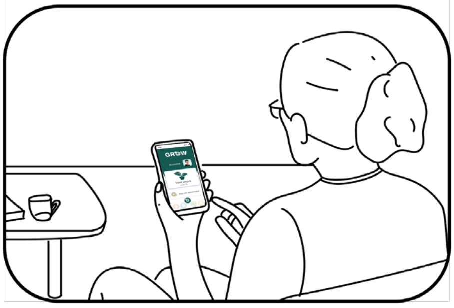
The GROW flyer and the GROW map are used to explain self-management and how the patient can learn about her disease and it's management herself.

3 Guided repetition of information

The most important information is repeated divided over the 5 GROW activities. The patient's specific symptom and medication details are written down on the flyer.

4 Introducing the GROW app

The consultant highlights the existence of the GROW app and writes down the patient's personal settings on the flyer.

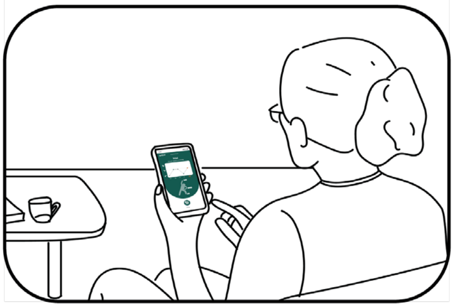


5 Patient installs the app

The patient installs the app and fills in personal settings. The patient gets her first Feel Check and sets the timer for her weekly notification. She can browse the menu's to search for additional information.

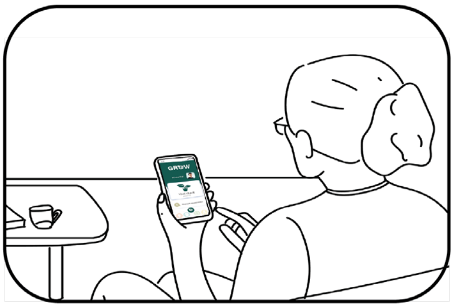
6 Weekly Feel Check

The patient receives a weekly Feel Check She fills in her experienced symptoms and follows the learning loop to learn about her disease and think about adaptations.



7 Monthly Check

The Month Check provides the patient a visual overview of the Feel data allowing her to learn about symptoms developments over time She fills in her main emotion that month based on which she is provided with tips.



8 Appointment preparation

The appointment preparation function guides patients in using the collected Feel data to prepare for check-up appointments

9 Check-up appointments

The GROW- map is used to inspire patients and guide the conversation between healthcare worker and patient. The GROW app can be used to share insights about collected data.

Figure 28 - Storyboard

11.4 GROW communication approach

Main functions

Establishing clarity from day 1

The GROW communication approach highlights the five core activities of self-management: Feeling, Understanding, Adapting, Accepting, and Communicating. The GROW map (figure 29) visualizes how these core activities are related and together allow the patients to develop insights about their personal disease manifestations and how to manage this in a personally fitting way. Explaining the five core activities and showing the GROW map at the start of the care path provides the patients more clarity on what managing their disease will entail in their daily lives and shows them the importance of taking an active role in this.

Guiding understanding

Using the GROW activities as the core of the communication approach allows to create a link between the information communicated during hospital appointments and the patient self-managing their disease during daily life. It allows categorizing provided information into relatable and actionable parts, guiding the patient in understanding how the information is relevant when managing their disease at home. During the post-diagnosis consultant appointment, the GROW flyer (Figure 30) is used to conduct this explanation in a clear and engaging way. The backside, consisting of full-colored blocks with the activity icons, is used to introduce the core activities in a visual and non-text-heavy way. The front side is used to repeat the information in the above-described categorized manner. Patient-specific information about inflammation locations and medication details are filled in together with the patient to highlight the relevance of this personal information. Both sides of the example flyer can be found in Appendix H.

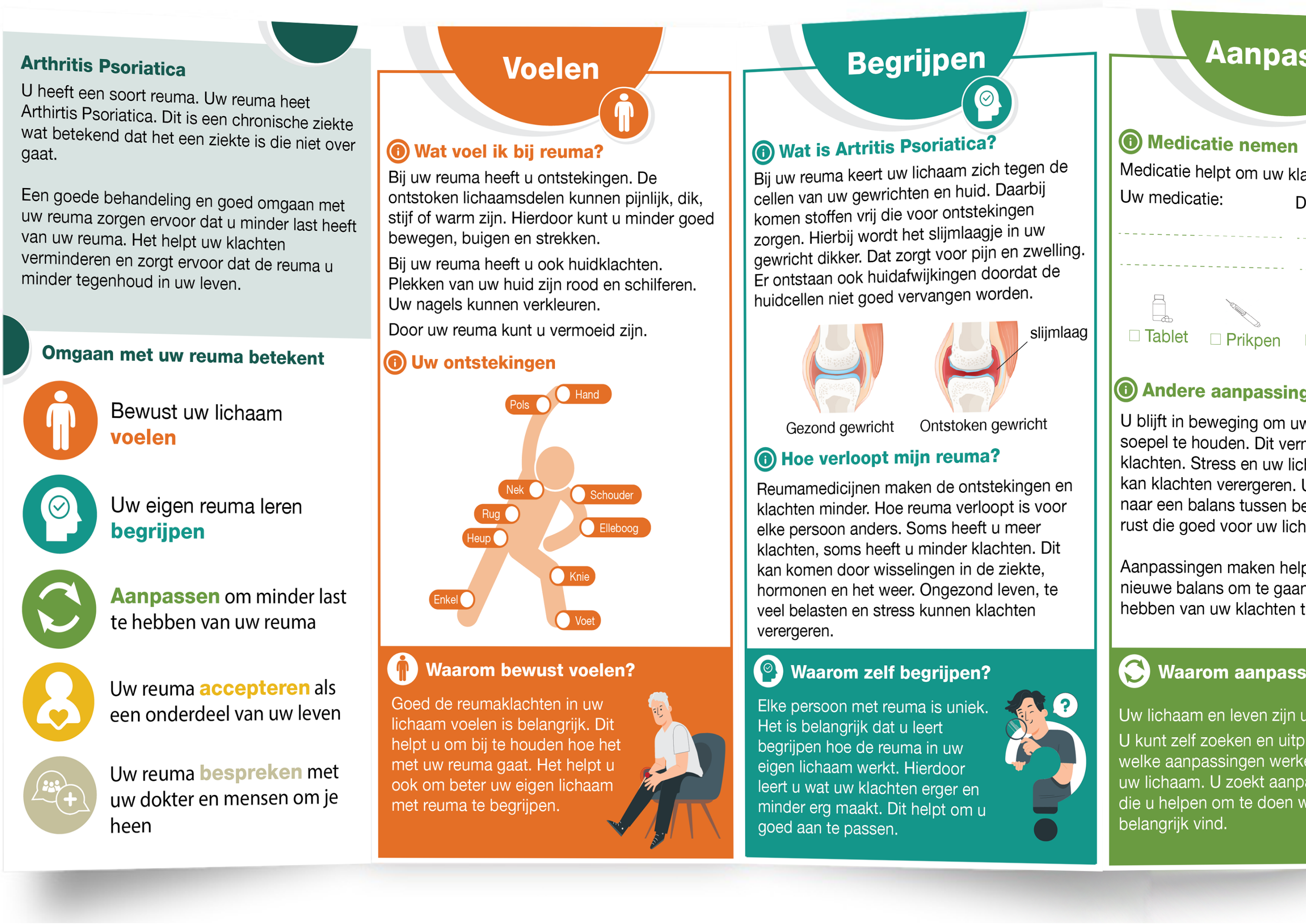
Figure 29 - GROW map

Triggering engagement

During appointments, healthcare workers can use the GROW map to stress the patient's own influence on gaining security and control over managing their disease and its impact on their life. This provides patients insight into the importance of their engagement and motivates them to become actively involved. Healthcare workers can use the GROW map to establish concrete fitting goals with the patient. Based on the research conducted, focusing these goals on valuable and fulfilling activities and experiences is beneficial. As the five core activities are verbs, the information is provided in a stimulating way.

Establishing a consistent and engaging way of communicating

By starting the communication approach at the start of the patient's self-management journey, a consistent and engaging way of communicating about the topic of self-management between healthcare workers and patients is established. During check-up appointments, the GROW map is put on the table to inspire patients to recall experiences and insights around the core activities gained at home and communicate these to the healthcare worker. This allows healthcare workers to obtain the input they need to deliver tailored support. The healthcare worker can keep the complete model of the self-management learning cycle in mind to determine bottlenecks.



Arthritis Psoriatica

U heeft een soort reuma. Uw reuma heet Arthirtis Psoriatica. Dit is een chronische ziekte wat betekend dat het een ziekte is die niet over gaat.

Een goede behandeling en goed omgaan met uw reuma zorgen ervoor dat u minder last heeft van uw reuma. Het helpt uw klachten verminderen en zorgt ervoor dat de reuma u minder tegenhoud in uw leven.

Omgaan met uw reuma betekent

- Bewust uw lichaam **voelen**
- Uw eigen reuma leren **begrijpen**
- **Aanpassen** om minder last te hebben van uw reuma
- Uw reuma **accepteren** als een onderdeel van uw leven
- Uw reuma **bespreken** met uw dokter en mensen om je heen

Voelen

Wat voel ik bij reuma?

Bij uw reuma heeft u ontstekingen. De ontstoken lichaamsdelen kunnen pijnlijk, dik, stijf of warm zijn. Hierdoor kunt u minder goed bewegen, buigen en strekken.

Bij uw reuma heeft u ook huidklachten. Plekken van uw huid zijn rood en schilferen. Uw nagels kunnen verkleuren.

Door uw reuma kunt u vermoeid zijn.

Uw ontstekingen

Waarom bewust voelen?

Goed de reumaklachten in uw lichaam voelen is belangrijk. Dit helpt u om bij te houden hoe het met uw reuma gaat. Het helpt u ook om beter uw eigen lichaam met reuma te begrijpen.

Begrijpen

Wat is Artritis Psoriatica?

Bij uw reuma keert uw lichaam zich tegen de cellen van uw gewrichten en huid. Daarbij komen stoffen vrij die voor ontstekingen zorgen. Hierbij wordt het slijmlaagje in uw gewricht dikker. Dat zorgt voor pijn en zwelling. Er ontstaan ook huidafwijkingen doordat de huidcellen niet goed vervangen worden.

Hoe verloopt mijn reuma?

Reumamedicijnen maken de ontstekingen en klachten minder. Hoe reuma verloopt is voor elke persoon anders. Soms heeft u meer klachten, soms heeft u minder klachten. Dit kan komen door wisselingen in de ziekte, hormonen en het weer. Ongezond leven, te veel belasten en stress kunnen klachten verergeren.

Waarom zelf begrijpen?

Elke persoon met reuma is uniek. Het is belangrijk dat u leert begrijpen hoe de reuma in uw eigen lichaam werkt. Hierdoor leert u wat uw klachten erger en minder erg maakt. Dit helpt om u goed aan te passen.

Aanpas

Medicatie nemen

Medicatie helpt om uw kla

Uw medicatie: D

☐ Tablet ☐ Prikpen

Andere aanpassing

U blijft in beweging om uw
soepel te houden. Dit verm
klachten. Stress en uw lich
kan klachten verergeren. U
naar een balans tussen be
rust die goed voor uw lich

Aanpassingen maken help
nieuwe balans om te gaan
hebben van uw klachten t

Waarom aanpass

Uw lichaam en leven zijn u
U kunt zelf zoeken en uitp
welke aanpassingen werke
uw lichaam. U zoekt aanpa
die u helpen om te doen w
belangrijk vind.

visual consistency

A clear visual communication style is established to allow patients with lower literacy levels to recognize and engage with the information more easily. The five core activities all have a specific color and icon to make them recognizable in the visual components of the support approach. This allows patients to distinguish information more easily and increases the visual link between information and the GROW map.

Relevant design elements

A healthcare workers manual was created to allow healthcare workers to understand the communication approach and implement it within their current support situation. The manual describes the communication steps during the post-diagnose consultant appointment and the check-up appointments, accompanied by the main goal of every step and guidelines on implementing the communication approach within the step. The goals and guidelines described in the manual give insight in the relevant design elements of the approach. An indication of this manual is shown in Figure 31. The complete manual is provided in Appendix I.

ssen

chten te verminderen
osering:

☐ Injectie ☐ Infuus

jen

v lichaam sterk en
mindert stijfheid en
haam teveel belasten
U gaat zelf op zoek
ewegen, belasting en
aam werkt.

pt u om met deze
n en minder last te
ijdens uw leven.

ingen zoeken?

uniek.
roberen
en voor
assingen
vat u

Accepteren

Reuma een plekje geven

Reuma zal dingen veranderen in uw leven. Uw lichaam voelt anders dan u gewend was. Boos, verdrietig of bezorgd worden is normaal. Dat hoort bij het hebben van een ziekte

Reuma zal altijd een onderdeel blijven van uw leven. Daarom is het belangrijk reuma een plekje te geven en hier niet tegen te vechten.

U kunt zich laten inspireren door mensen om u heen en lotgenoten die hetzelfde meemaken.

Tips bij een dip

- Krop het niet op. Praat met mensen die u vertrouwd of schrijf uw gevoel op.
- Ontspanningsoefeningen kunnen helpen om met emoties en pijn om te gaan.
- Bewegen helpt voor uw lijf en uw hoofd
- Bedenk dat u vertrouwen mag hebben in uzelf en in alles wat u kan ondanks uw reuma.

Waarom accepteren?

Uw reuma accepteren helpt om op een gelukkige manier met uw reuma om te gaan.

U kunt bedenken wat u belangrijk vind in het leven en op zoek gaan naar aanpassingen die daarbij helpen.

Bespreken

Bespreken met uw dokter

U weet het meeste over hoe de reuma in uw lichaam werkt, en welke problemen u door u reuma heeft tijdens uw leven.

Het is belangrijk deze informatie goed met uw dokter te bespreken. Dan kan de dokter u helpen op een manier die past bij uw lichaam en leven. U kunt het hebben over dingen die u heeft geleerd of vragen die u heeft over het voelen, begrijpen, aanpassen en accepteren.

Bespreken met uw omgeving

Tijdens het omgaan met uw reuma maakt u momenten mee met de mensen om u heen. Door goed met hen te praten over uw reuma en wat u nodig heeft kunnen zij u beter begrijpen en helpen

Waarom bespreken?

U weet het beste hoe uw reuma werkt en hoe u hiermee om wil gaan. Door dit goed te bespreken met uw omgeving en uw dokter, kunnen zij uw reuma en uw behoeften beter begrijpen en u beter helpen

Leren omgaan met uw reuma

Elk lichaam met reuma en elk leven is anders. Het is belangrijk dat u uitzoekt hoe de reuma en medicatie in uw lichaam werkt en welke aanpassingen passen bij uw lichaam en leven.

Door bewust uw lichaam te voelen leert u uw reuma begrijpen. Dit geeft ideeen voor aanpassingen die u kunt uitproberen.
U merkt dan of de aanpassing werkt voor uw lichaam. U merkt of de aanpassing u helpt om de reuma te accepteren en te doen wat u belangrijk vind

Ik leer mijn reuma begrijpen en bedenk aanpassingen

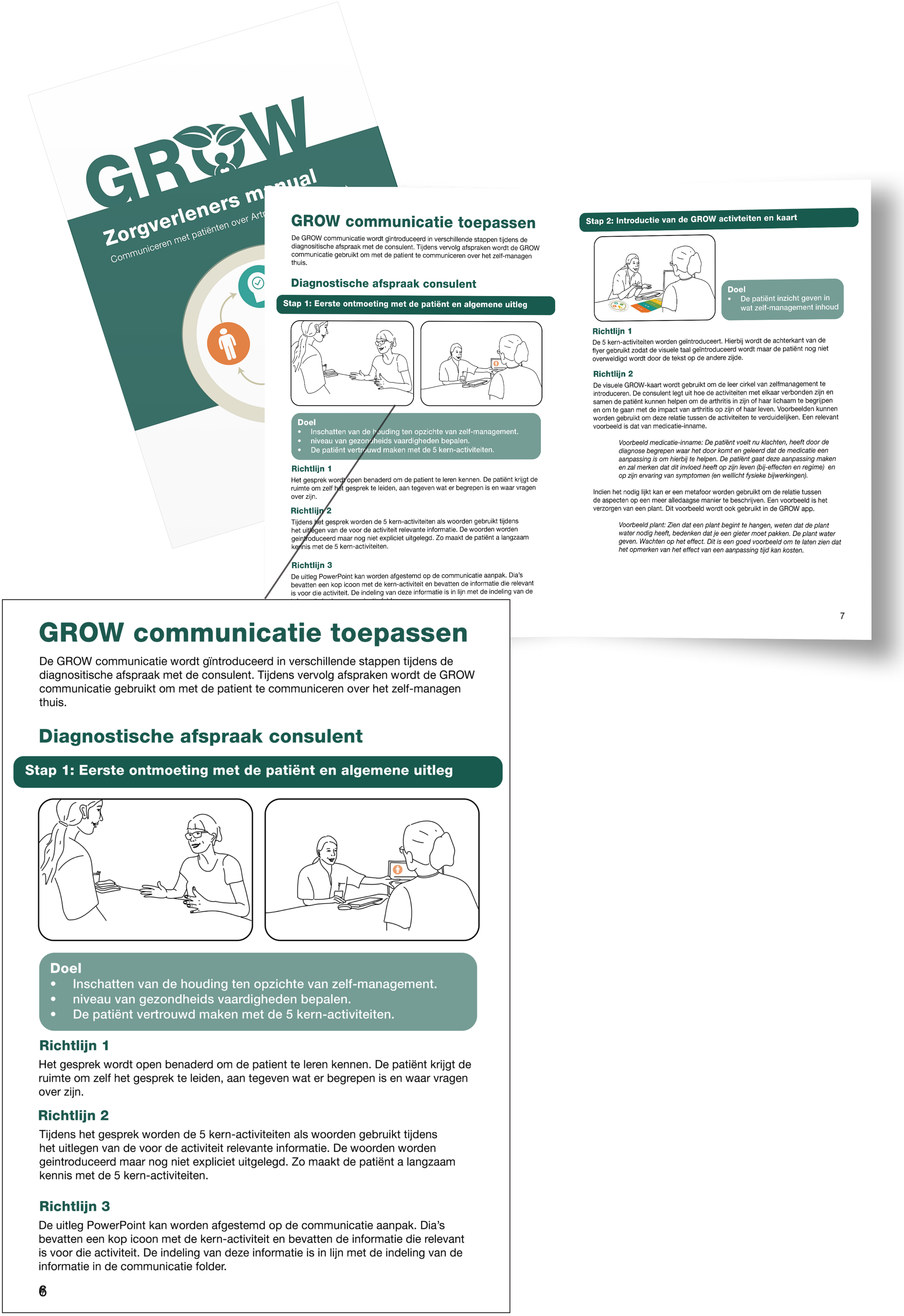
Ik pas me aan

Ik merk het effect op mijn leven

Ik voel mijn klachten

Door te bespreken wat u voelt, leert en wilt aanpassen kunnen anderen u hierbij helpen

Figure 30 - GROW flyer



GROW

Zorgverleners manual

Communiceren met patiënten over Art

GROW communicatie toepassen

De GROW communicatie wordt gïntroduceerd in verschillende stappen tijdens de diagnositische afspraak met de consulent. Tijdens vervolg afspraken wordt de GROW communicatie gebruikt om met de patient te communiceren over het zelf-managen thuis.

Diagnostische afspraak consulent

Stap 1: Eerste ontmoeting met de patiënt en algemene uitleg

Doel
- Inschatten van de houding ten opzichte van zelf-management.
- niveau van gezondheids vaardigheden bepalen.
- De patiënt vertrouwd maken met de 5 kern-activiteiten.

Richtlijn 1

Het gesprek wordt open benaderd om de patient te leren kennen. De patiënt krijgt de ruimte om zelf het gesprek te leiden, aan tegeven wat er begrepen is en waar vragen over zijn.

Richtlijn 2

Tijdens het gesprek worden de 5 kern-activiteiten als woorden gebruikt tijdens het uitlegen van de voor de activiteit relevante informatie. De woorden worden geintroduceerd maar nog niet expliciet uitgelegd. Zo maakt de patiënt a langzaam kennis met de 5 kern-activiteiten.

Richtlijn 3

De uitleg PowerPoint kan worden afgestemd op de communicatie aanpak. Dia's bevatten een kop icoon met de kern-activiteit en bevatten de informatie die relevant is voor die activiteit. De indeling van deze informatie is in lijn met de indeling van de informatie in de communicatie folder.

6

Stap 2: Introductie van de GROW activteiten en kaart

Doel
- De patiënt inzicht geven in wat zelf-management inhoud

Richtlijn 1

De 5 kern-activiteiten worden geïntroduceert. Hierbij wordt de achterkant van de flyer gebruikt zodat de visuele taal geïntroduceerd wordt maar de patiënt nog niet overweldigd wordt door de tekst op de andere zijde.

Richtlijn 2

De visuele GROW-kaart wordt gebruikt om de leer cirkel van zelfmanagement te introduceren. De consulent legt uit hoe de activiteiten met elkaar verbonden zijn en samen de patiënt kunnen helpen om de arthritis in zijn of haar lichaam te begrijpen en om te gaan met de impact van arthritis op zijn of haar leven. Voorbeelden kunnen worden gebruikt om deze relatie tussen de activiteiten te verduidelijken. Een relevant voorbeeld is dat van medicatie-inname.

> *Voorbeeld medicatie-inname: De patiënt voelt nu klachten, heeft door de diagnose begrepen waar het door komt en geleerd dat de medicatie een aanpassing is om hierbij te helpen. De patiënt gaat deze aanpassing maken en zal merken dat dit invloed heeft op zijn leven (bij-effecten en regime) en op zijn ervaring van symptomen (en wellicht fysieke bijwerkingen).*

Indien het nodig lijkt kan er een metafoor worden gebruikt om de relatie tussen de aspecten op een meer alledaagse manier te beschrijven. Een voorbeeld is het verzorgen van een plant. Dit voorbeeld wordt ook gebruikt in de GROW app.

> *Voorbeeld plant: Zien dat een plant begint te hangen, weten dat de plant water nodig heeft, bedenken dat je een gieter moet pakken. De plant water geven. Wachten op het effect. Dit is een goed voorbeeld om te laten zien dat het opmerken van het effect van een aanpassing tijd kan kosten.*

7

Figure 31 - Healthcare workers manual

11.5 GROW app

Introduction

The GROW app (figure 32) connects the support from the hospital with the patient's daily life. The app focuses on guiding and motivating patients to learn about their personal disease and management situation.

A weekly Feel Check reminds the patient to feel the body consciously. Based on the entered data, the app guides the patient through a learning loop that supports them in learning about their disease and personal disease manifestations. It stimulates patients to think about solution-oriented adaptations to manage their arthritis symptoms and decreased capabilities.

The Month Check provides the patient overview of the disease developments to stimulate patients to learn about their symptom developments. Also, it makes patients aware of their emotional state dealing with the disease.

The menus in the GROW app create a clear information base, including additional information, tips, and exercises, in a way that is consistent with the communication approach.

The app includes an appointment preparation function to guide patients in using the gained insights to prepare for their appointments.

The main functions allow for various use cases of the app. In this section, the most important use case of the app for the design goal is described, accompanied by visuals of the app screens. The other use cases, including: (1) Installing the app, (2) Using the GROW menus, and (3) Preparing appointments, are described in Appendix J.

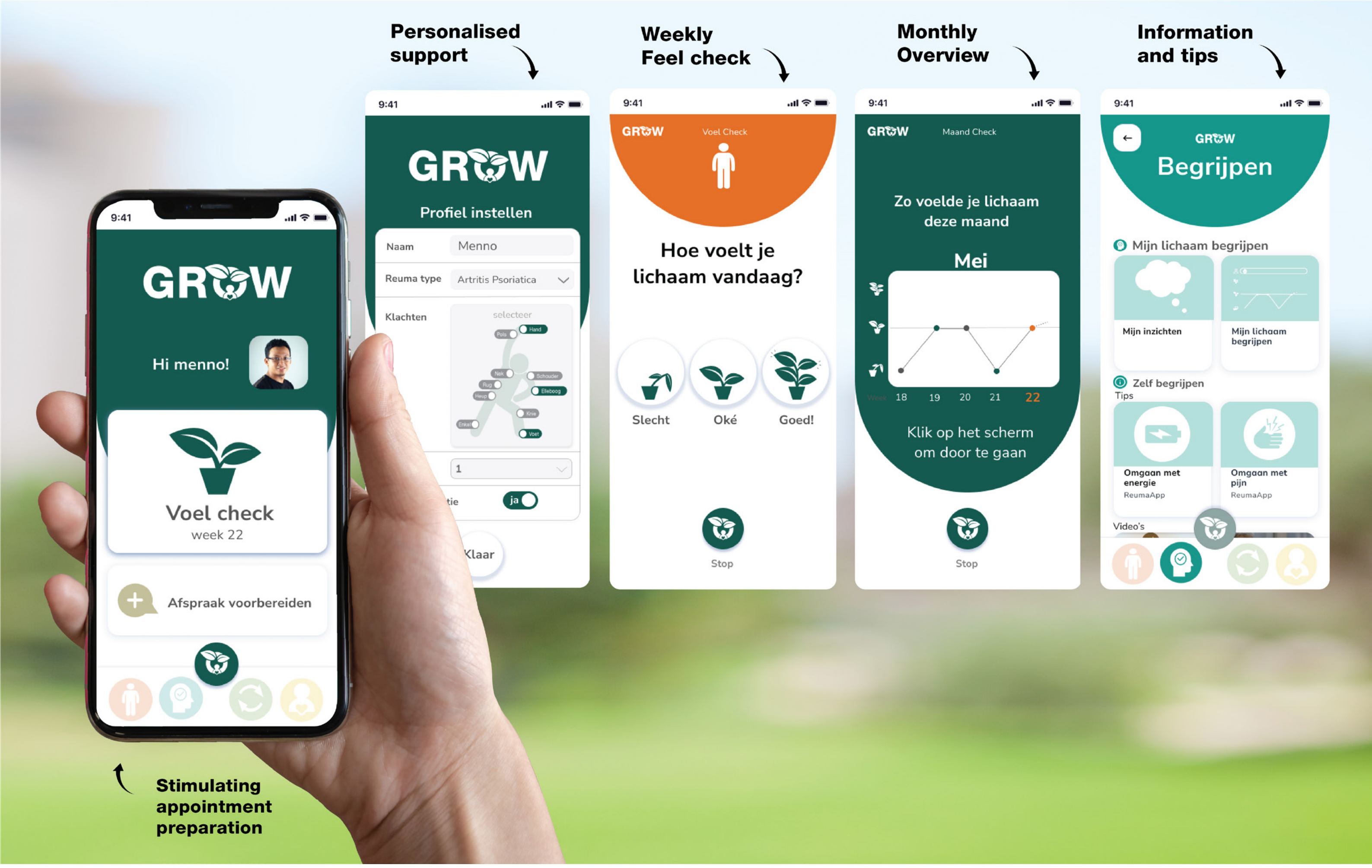


Figure 32 - GROW app overview

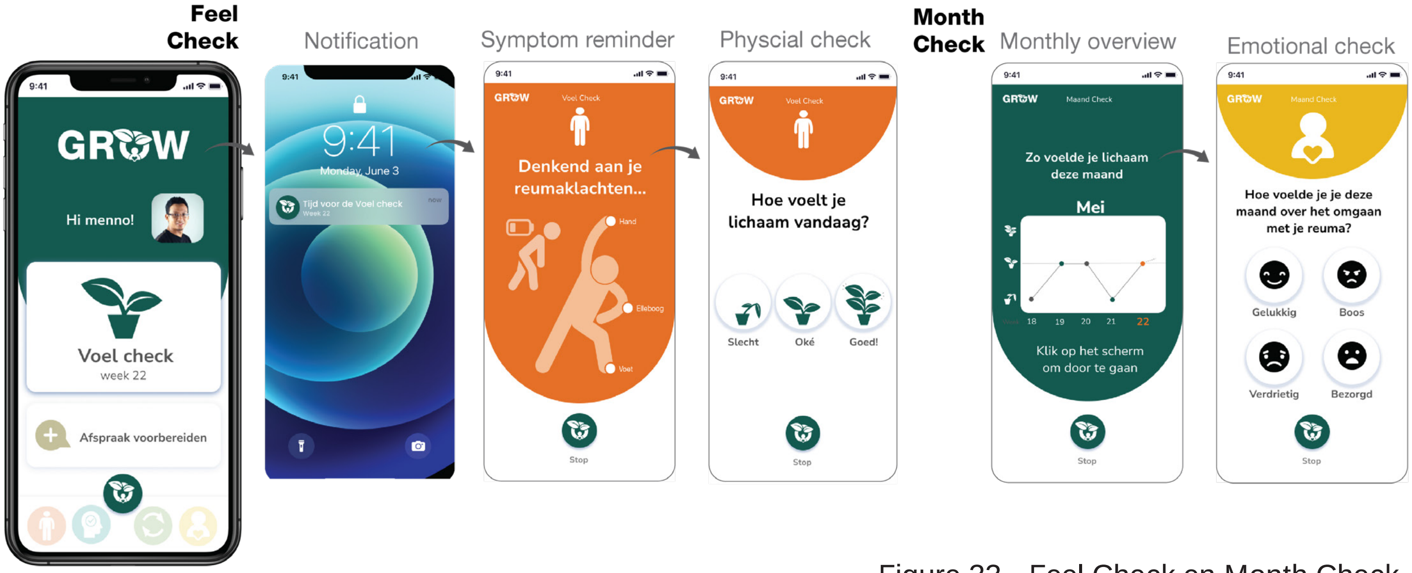
Feel Check and Month Check

Every week, the patient gets a notification to conduct the Feel Check, every month the patients get’s a notification to conduct the Month Check (figure 33).

The weekly Feel Check focuses on the patient’s physical symptoms. First, the patient is reminded of his symptoms, after which the patient is asked to assess his experienced symptom level.

After this, the patient is sent through the at that moment relevant learning loop.

The Month Check provides an overview of the filled in Feel data that month and stimulates the patient to learn from the symptom developments over time. It asks the patient to assess his overall emotion about the disease that month to rais awareness and provide the patient with tips fitting the selected emotion.



Tijd voor de Voel check
Week 22

Denkend aan je reumaklachten...

Hoe voelt je lichaam vandaag?

Zo voelde je lichaam deze maand

Klik op het scherm om door te gaan

Hoe voelde je je deze maand over het omgaan met je reuma?

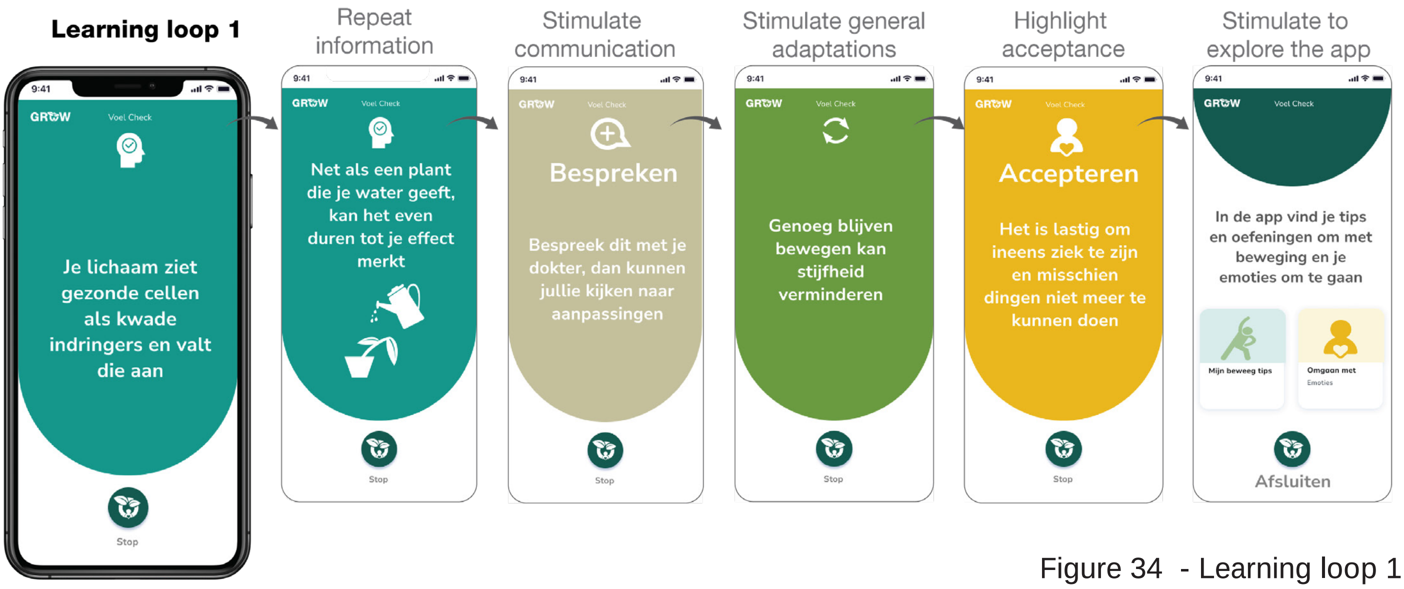
Figure 33 - Feel Check en Month Check

Learning loop 1 - Repeating information

In the first weeks, the Feel Check is followed by a learning loop 1 (Figure 34). This loop focuses on repeating information within the various core-activity categories.

Over the weeks, the focus of the information provided shifts from disease cause, medication, and movement information towards information about dealing with changes in energy and pain. The importance of communicating before quitting medication on own terms is highlighted.

The learning loop ends with a screen that links to tips or exercises in the app. This stimulates patients to explore the app menus.



Je lichaam ziet gezonde cellen als kwade indringers en valt die aan

Net als een plant die je water geeft, kan het even duren tot je effect merkt

Bespreek dit met je dokter, dan kunnen jullie kijken naar aanpassingen

Genoeg blijven bewegen kan stijfheid verminderen

Het is lastig om ineens ziek te zijn en misschien dingen niet meer te kunnen doen

In de app vind je tips en oefeningen om met beweging en je emoties om te gaan

Figure 34 - Learning loop 1

Learning loop 2 - learning from experiences

After a certain period, every Feel Check is followed by a phase 2 learning loop (Figure 35). Loop 2 guides and stimulates the patients with multiple triggering app screens to learn from their own experiences.

Patients are stimulated to develop an understanding of their personal disease manifestations and encouraged to think in a solution-oriented way for acceptable strategies to manage this. The app compares the answer on the Feel check with the response of the previous week and decides which loop is needed. Every loop ends with a link to relevant menu functions, such as adaptation tips and tips about dealing with energy and pain. An example of a learning loop 2 for a change is feeling is given in Appendix K.

<u>Types of loops:</u>
Change in feeling: Thinking of the cause of the increase or decrease in feeling and what adaptations could fit with this to avoid or maintain this. The patient can save insights about the cause to revisit later.

Constant feeling - OK or Good: Thinking of problems in capability that were encountered during the week and how adaptations could improve this.

Constant feeling - Bad: Providing additional information about managing energy and pain levels and encouraging thinking about energy planning and overburdening.

Ai dat is vervelend...

Dat is minder dan vorige week

Misschien kan dit gevoel je helpen om te leren over het omgaan met je reuma

Als je terugdenkt aan je levenswijze de afgelopen tijd..

Kan je iets bedenken wat dit gevoel kan hebben veroorzaakt?

Als je zelf denkt in oplossingen

Zou je iets kunnen aanpassen om beter met je ziekte om te gaan?

Accepteren

Denk goed aan aanpassingen die je ook zou willen maken

Misschien kan je tips vinden in de app

Figure 35 - learning loop 2

Relevant design elements

Multiple versions

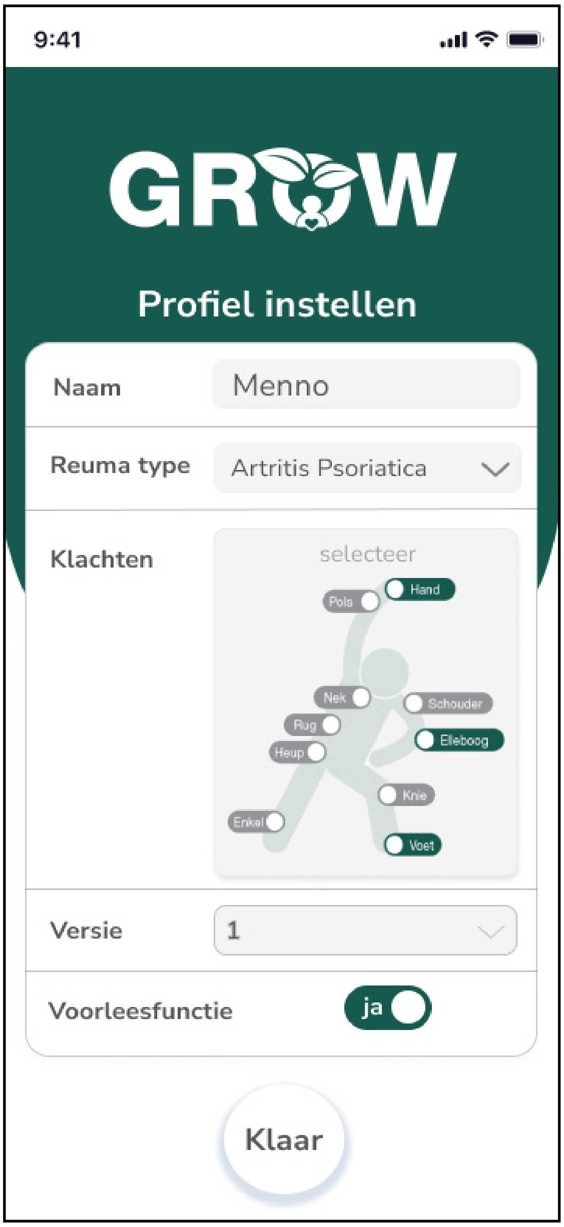
The starting level and course of disease activity significantly vary among patients and types of medication. As a result, certain patients may have high pain levels and minimal capabilities during the first weeks as they wait for the medication to take effect. These patients are not yet mentally and physically prepared for the phase 2 loop. In contrast, other patients may experience lower disease impact and would benefit from starting the phase 2 loop earlier in their journey.

To accommodate this, the app offers two versions, determining whether the patient undergoes the phase 1 – repeating information loop for two weeks (version 1) or four weeks (version 2) before transitioning to the phase 2 loop about learning from experiences. Healthcare workers need to estimate the impact of disease activity over the first weeks to advise on a version type. When installing the app, the patient can choose this version type in the settings (figure 36)

Low literacy and digital skills

With the design of the app, low literacy, and low digital skills are considered. The sentences in the Feel Check are short and active and are accompanied by icons to visualize written information. When installing the app and filling in the settings, the patients can select a read-out-loud function (figure 36). This means that on every screen, a speaker icon arises that explains the written text.

By setting the notification for the Feel-check, patients with minimal digital skills can use the app's most essential functions: The Feel Check and the Month Check. The notification allows the patient to directly go to the necessary screen with only one click, after which the patient can continue with the easy and linear navigated Feel Check.



Naam: Menno

Reuma type: Artritis Psoriatica

Klachten: selecteer
- ○ Pols
- ● Hand
- ○ Nek
- ○ Schouder
- ○ Rug
- ● Elleboog
- ○ Heup
- ○ Knie
- ○ Enkel
- ● Voet

Versie: 1

Voorleesfunctie: ja

Figure 36 - Settings screen

A Feel Check that learns

The Feel Check learns from the data about how the patient is feeling. Because of this, the app can provide additional support to the patient when the patient successively chooses the feel bad or feel good.

When the patient has selected to feel 'bad' for multiple weeks in a row, the app could notify the patient to take action in time and contact the department before symptoms increase further. Regarding privacy constraints, a direct notification could be sent to the department.

When the patient has selected to feel 'good' for multiple weeks in a row, the app can suggest t to decrease the Feel Check frequency to once a month. This monthly check would then combine the Feel Check and Month Check, prompting the patient to reflect and learn from moments from the past month.

The research phase and co-creation session showed that patients become less engaged in managing their disease when their disease activity decreases. Decreasing the Feel Check frequency is important to prevent the Feel Check from becoming burdensome, causing annoyance and potential app abandonment. The app will start to interfere less with the patient’s life while still encouraging consciousness and learning about the disease every month. If the patient reports a lower feel level on the monthly check, the app can propose reverting to the weekly Feel Check.

Als je terugdenkt aan je levenswijze de afgelopen tijd..

Figure 37 - Remote monitoring opportunity

Connecting to remote monitoring

The GROW app can be connected to remote monitoring interventions to increase its functionality for the patient and the healthcare worker.

For patients, remote monitoring data can provide additional support in understanding symptom changes. During the Feel Check, the trigger screen could present this data clearly and comprehensibly, helping patients identify potential causes for their changes in symptoms (figure 37). During the Month check and in the Feel menu, weekly summaries of the remote monitoring data could be provided to offer patients support in understanding changes in their Feel developments. Also, remote monitoring could be interesting to interfere in time when monitored data assumes an increase in disease activity. Then patients could be notified with an additional Feel Check to make them aware of the potential increase in symptoms before overdoing it.

For the healthcare workers, the collected physical Feel Check and emotional Month check data would be a valuable addition to the clinical data collected through the to-be-designed remote monitoring intervention. This would offer healthcare workers a holistic view of the patient’s disease, including clinical and experience aspects. Privacy constraints should be considered before implementing a function like this.

Chapter 12

Evaluation

The final concept was evaluated with both stakeholders to determine how the final design is experienced and whether the design fulfills the design vision. In this Chapter the method of evaluation and evaluation results are described. The Chapter concludes with an assessment of the desirability, feasibility and viability of the design and recommendations for further research and design.

12.1 Method

Approach

Three evaluation studies were conducted to test multiple aspects of the support approach and include both stakeholders. During all three evaluations, both the communication approach and the GROW app were evaluated. Testing the communication approach focused on evaluating whether function goals 1, 2, and 5 were met. For the GROW app, the focus was on evaluating whether function goals 3 and 4 were completed. For the GROW app, it was decided to evaluate the to the design goal most relevant function: The Feel Check. Here it was decided to evaluate a learning loop 2 Feel Check to determine whether the various screens guided and triggered the patients enough to reach function goals 3 and 4.

Testing procedure

The testing procedure during the three types of evaluation varied.

Evaluation 1: Real-life evaluation patients

The real-life evaluation was conducted with two patients chosen based on the attitude profile they were categorized in during the research phase and were most related to the main target group: a flexible follower and an intuitive ruler. The Focus of the real-life evaluation was on evaluating the communication approach. The evaluation consisted of two parts: Roleplaying the communication approach by going through the various steps described in the healthcare workers manual and testing the Feel Check of the GROW app.

Evaluation 2: Digital evaluation patients

The digital evaluation was conducted with two digitally skilled patients. The digital evaluation focused on evaluating the Feel Check of the GROW app. It was decided to do this digital evaluation to test the experience of receiving a FeelCheck notification, the individual nature of the FeelCheck, and the weekly frequency. The test included a link to a digital app prototype that briefly explained the communication approach, after which the Feel Check started. The test was conducted two times, with one week in between.

Evaluation 3: Evaluation with consultants

Due to a lack of time with the consultants at ErasmusMC, the evaluation was conducted with two consultants from the Albert Schweitzer Hospital. The in the healthcare manual described steps of the communication approach were explained, highlighting important guidelines. The GROW app was explained, and the Feel Check prototype was shown.

Data collection

During the real-life testing, observations about the concept's usability were made. With the digital testing, questions were asked about usability after testing. All evaluations ended with questions focusing on specific aspects of the communication approach and the app and whether the five main function goals were met. With the consultant evaluation, the questions around the goals were translated into whether it would help them support the patient in reaching the goal. At the end of the patient evaluation sessions, the participants were asked to rank their experienced feeling on the IV qualities on a scale from 1-5. The conversations were recorded.

12.2 Results

Usability insights patients

When explaining the communication approach flyer, the patients seemed to understand the text and visual language

‘The colors are nice, and the icons match well with the activity word.’

The real-life evaluation was done with two less digitally skilled patients. This was noticeable in the way they used the app. The ‘click to continue’ shown on the first app screen of the learning loop did not inspire them enough to keep clicking. Also, they tried to select icons that were provided as a visual addition to the text. The digital evaluation was conducted with digitally skilled patients. These patients mentioned that they could easily go through the learning loop.

Results on functionality goals

#1 … establishing a good knowledge base to start self-managing their disease.

Patients

Dividing the information into the five core activities seems beneficial for increasing understanding.’It is short and simple; by dividing it into those headers it becomes more clear, and it helps to process the information when you can visualize it’. The communication approach highlights things that patients were not aware of themselves at the start of their journey. ‘something like feeling, I did not learn that’. One patient mentioned that the GROW map would provide insight into where she got stuck in her self-management. Including the flyer to allow revisiting of information was mentioned as important ‘It was explained the arthritis, but then you are so nervous you don’t hear half of the things said, then it is nice that you can read it back’. This provides insight in the importance of learning loop 1.

Consultants

Consultants mention that using the non-text-heavy backside of the flyer to do the first explanation would help them convey the message without scaring patients off. They liked how logical the explanation feels and that it gives them a structure to fit their explanation to. ‘I think I could really use this, to me it feels more concrete than, for example, a tool such as the self-management web’. They like that it gives them a structure to fit their story too and provides them insight in where the patient gets stuck. It was mentioned that the communication approach would help them stress important aspects of self-management. ‘It is important that patients realize that there will be adaptations needed, they often want to go back to how it was before, this is a nice way to convey this message’. The consultants mention that time issues might interfere with the communication approach from being established. ‘It asks for a bit more work and counseling from the consultant’s side, and whether there is time to raise the topic during the 10-minute appointments with the rheumatologist again is questionable’.

#2 … gaining motivation to invest in taking an active role in developing an understanding of their personal disease situation.

Patients

The communication approach seems to motivate patients to take an active role. ‘In the beginning you have no clue what is ahead of you and what you should do, then this can be very nice, it is a sort of manual’. The motivation to invest in developing understanding can vary over time. Two patients mentioned that they would not always have taken the time to invest in this.

Consultants

Consultants mentioned that the support approach would help them explain the importance of self-management in a clear and orderly manner. ‘I think they come to us with the goal of finding out what the disease is going to mean in their lives, finding that out is their main aim’. The visual GROW map would help them highlight to the patient that their involvement is essential to allow them to understand their disease and what this means in their life. They mention that the GROW map would create a good base to establish a concrete goal with patients. However, this is not possible with all patients because of high disease activity or uncertainties about disease progress. The consultants also mention that it is very dependent on the patient whether this approach and the app would motivate them. ‘Some patients will really like the consciousness, some patients might not like this and get stubborn, but you also have that now’.

#3 … learning from their own experiences to develop an understanding of their personal disease manifestations.

It was observed that the questions triggered the patients to become aware of the cause of increased symptoms. Learning from things that hindered during daily life seemed less triggering ‘I am not hindered by anything because I just continue, but that is my problem, I have difficulties setting boundaries.’ Most patients would have liked the guided learning at the start of the care path and the simplicity and low time effort. ‘In the beginning, those steps are nice, every time the reminder, and after a while, you will start doing it yourself automatically’.

The opinions about writing insights down varied, ranging from increasing consciousness and wanting to revisit them later to finding it unnecessary, as solely thinking about it would be sufficient. The monthly overview was perceived as a good addition ‘When you fill it in every week, you can use your short-term memory, and then the month overview really tells you things about development over time’. One patient strongly disliked the learning loop and did not know what to do with the data the Month graph provided her. ‘I do not think about it that much, I have arthritis, and I deal with it, I do not find it necessary to think through like that, I will see it all happening’.

#4 … Thinking of solution-oriented adaptations that help them manage their symptoms and decrease the disease’s impact on their daily life.

Patients

It was observed that the app guided the patients toward a general adaptation direction but did not always trigger them enough to end with a concrete solution. Additional questions were needed to end with a concrete solution. The patient’s motivation when using the app plays an essential factor in this ‘Yesterday I was a bit simple in the thinking, I was just tired of the day.’ The tips were perceived as a nice addition to translate their insights into actions ‘ the tips give some feeling of support, I did not have that’. One patient mentioned that the individual use of the app allowed her to be more honest about acceptance of the adaptations. ‘To others, you would maybe more easily say that you accept it but to a device, you can maybe be a bit more honest to yourself about that.’

Consultants

The consultants mentioned that they really appreciate how the app makes the patients conscious to think about adaptations. ‘Now thinking about adaptations only starts when it is too late, and they already come to us for an injection, that external stimulation to make us conscious about it, we all need that a bit’.

#5 … Communicating their insights and needs with healthcare workers.

Patients

The communication approach seems to support communication. ‘Dividing it into those headings might also make it easier to verbalize the message to the doctor’. The GROW map seems to inspire patients with topics to discuss during the appointment, as they started to mention aspects of the map. ‘With an appointment, I would then tell what I felt, and I would take along those steps, where I got stuck’. The app was mentioned to be a nice addition as it would help to show the development of the symptoms over time.

The communication approach seems to improve the patient's feelings around communicating with the healthcare worker. 'The way you tell it, it feels like you understand what I am dealing with, it feels less general, more personal'.

Consultants

Consultants mention that they think the communication approach and app would stimulate the patient to think about their disease and management before the appointment and feel invited to communicate about this during the appointment. 'when you make this communication tool visible during the appointment, I believe it really shows the patient that they can talk about this'. They mention that the data collected in the app would allow them, as consultants, to start the conversation about this in a focused manner. The consultants stress the importance of alignment in communication between the consultant and the rheumatologist. 'Then we give this explanation, but their check-up appointments are with the rheumatologist, then I am afraid that nothing is done with it'.

Interaction vision qualities

Looking at the collected data about the interaction vision qualities (Figure 38), the 4 patients ranked the support approach high on the sense of overview, guidance, and consciousness. One of the participants rated the Interaction vision quality of Consciousness high but stated that she was unsure whether she liked that. She mentioned that doing this every week might make her too conscious, while she does not want to think about her disease that much.

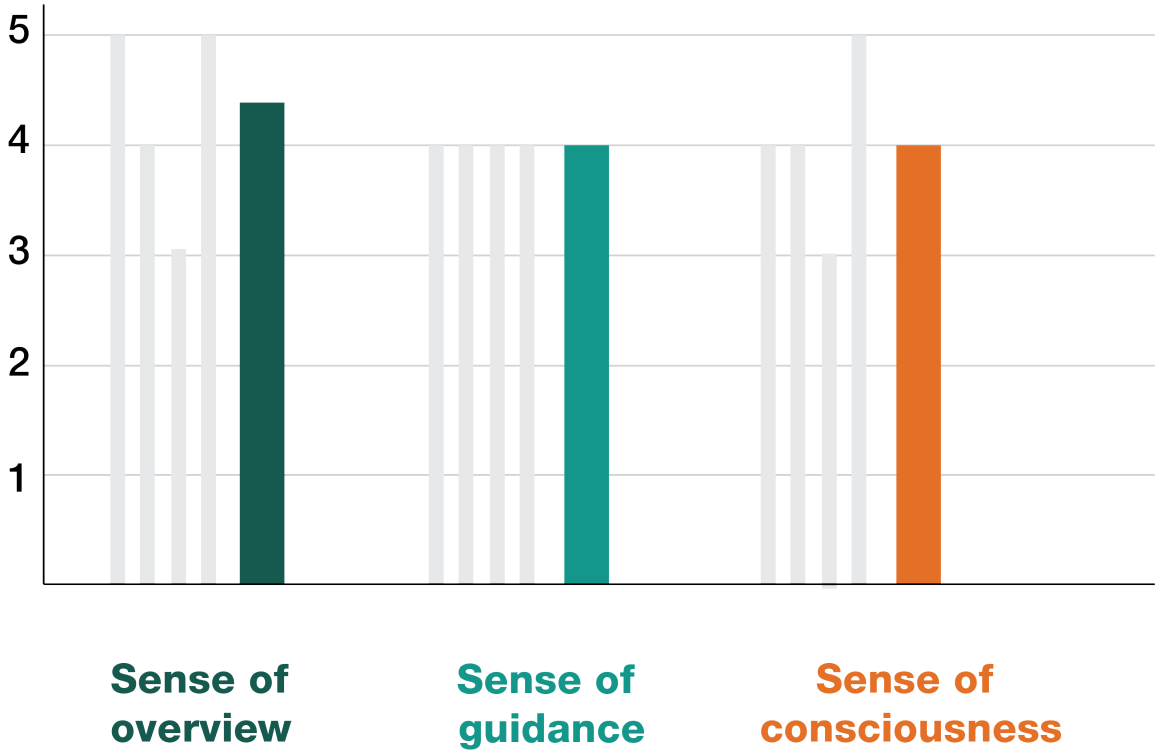


Figure 38 - Interaction vision results

12.3 Conclusion

To evaluate the success of the user-centered design created, it is interesting to assess the design using IDEO's Desirability, Viability, and Feasibility framework. This framework states that successful design thinking brings together what is desirable from a human point of view with what is technologically feasible and economically viable (IDEO, n.d.).

Desirability

Based on the evaluation findings, the support approach gives patients a sense of overview, guidance, and consciousness in self-managing their disease. The communication approach gives patients a feeling of being understood, empowers patients to comprehend the provided information, and provides insight into how they can manage the disease's impact on their lives. The GROW app aids patients in developing a deeper understanding of their disease manifestations and encourages them to search for adaptations to manage their physical symptoms. For some patients, the app might increase their consciousness about the disease above their desired level. This is more likely to occur with patients with an emotional attitude that tend to be more impulsive in investing in their physical health. The support approach contributes to raising patients' awareness of acceptance. The evaluation did not show clear results on whether the support approach supports patients in establishing fitting adaptations they accept to make. The support approach stimulates patients to share their insights and needs during appointments, allowing them more tailored support around this topic of acceptance.

Overall, the support approach proves to be desirable for patients. It supports them in taking an active self-management role and is assumed to evoke a sense of control over managing the disease's impact on their lives. With this, it is essential to acknowledge that patients, and patients with an emotional attitude in specific, may find the app less desirable due to the increased consciousness it evokes about having a disease.

Regarding healthcare workers, the evaluation indicates a willingness to implement the communication approach in their daily practice. They appreciate its simplicity, structure, and the support it delivers in effectively conveying important messages about self-management clearly and engagingly. It supports them in inviting and inspiring patients to communicate during check-up appointments and in gaining insight in the bottlenecks of the patients learning cycle. They appreciate that the GROW app would allow them to start a more focussed conversation.

Based on these positive outcomes, it can be concluded that the final design is desirable for healthcare workers.

Feasibility

Since the design primarily focuses on the lowSEP patient group, it is important to consider the feasibility in terms of usability for this target group. The evaluation proved the communication approach feasible for the target group as it revealed that the language and visual elements of the communication approach were well understood. The evaluation showed less promising results for the app's feasibility in terms of usability. During the research phase, it became evident that nearly half of the patients interviewed lacked digital skills. This was taken into account when designing the app by creating a very linear user navigation and simple acces through a notification.

Digitally skilled patients found the app usable, but less digitally skilled patients encountered difficulties. When considering direct implementation, It can be stated that the feasibility of the GROW app could be more optimal in terms of usability as less digitally skilled patients might experience difficulties using it. As modern technology is increasingly present in society, it can be assumed that over the years, while developing the app and IPROLEPSIS remote monitoring intervention, the digital skills of patients will increase, which will simultaneously increase the app's feasibility.

The technological feasibility of the support approach was not evaluated with the evaluation method, however assumptions can be made based on existing knowledge technology. The communication approach involves ready-to-print materials that does not entail techonolical elements. Rhe GROW app utilizes a basic design without complicated features. Special features include the artificial intelligence needed to make the Feel Check learn and the read-out loud function. These are functions commonly found in current technology. Consequently, the current communication approach and app design are highly feasible in terms of material and technological resources, making them suitable for implementation in the near future.

The future design vision involves integrating the GROW app with the remote monitoring intervention of the IPROLEPSIS study. This integration would require additional technological elements, complicating the app design. However, considering the extended timeframe needed for the IPROLEPSIS study's research and development, it can be concluded that the future vision of the GROW app is technologically feasible to implement.

Viability

The research phase showed that patients succeeding in taking an active self-management role increases disease outcomes and patients' experienced quality of life. This is a very valuable outcome for society. Also, the decreased disease outcomes and the increased self-reliance of the patient, could decrease the pressure on the healthcare force, which is valuable considering the expected lack of capacity of the rheumatology department in the near future.

Based on the evaluation findings, the support approach enhances the patient's ability and motivation to take an active self-management role. It fosters the patient's understanding of their disease and its management. Also, it stimulates patients to consider adaptations earlier on in the increase of their disease activity, increasing their chance on acting in time before needing to reach out to the hospital. It facilitates communication of information between patients and healthcare workers, which allows healthcare workers to deliver support more efficiently and effectively. The GROW app allows to expand the hospital support without relying on the rheumatology department's capacity.

This shows valuable benefits of the implementation of the support approach. However, to ensure the viability of the support approach within the hospital, it is crucial to establish these favorable outcomes at reasonable costs and capacity levels. Implementing the communication approach would incur low material costs. Evaluation highlighted that for the support approach to be valuable all healthcare workers should have clarity on implementing the support in their daily practice which asks for time investement in employee training and deparmental alignment. Also, evaluation highlighted that the support approach requires slightly increased capacity from the consultants at the start of the patient's care path to establish the communication approach.

The GROW app requires further development with associated costs and the need for a dedicated development team.

Concluding, the support approach and especially the communication approach are assumed viable as the benefits seem to outweigh resource requirements. Nevertheless, the higher level of resources needed to implement the GROW app makes it important to carefully evaluate the benefits of the app before investing in further development. Enabling the connection between the GROW app and the IPROLEPSIS remote monitoring intervention would significantly increase the usefulness of the GROW app and positively influence its viability.

12.4 Discussion

Limitations

Because of the limited project time, decisions had to be made in developing and evaluating the concept. This caused various limitations in the evaluation of the final concept.

Participants

The evaluation was done with a limited number of patients that already received their diagnosis a time ago and have already developed an understanding of their disease. The support approach is designed for patients that are newly diagnosed. A larger-scale evaluation with this newly diagnosed patient group is needed to validate the impact of the support approach on the patient's motivation and ability to self-manage. With this, the focus should also be on assessing the usability of the support approach regarding usability with low literacy and digital skills.

The healthcare worker evaluation was conducted with consultants from the Albert Schweizer Hospital. This increased the strength of the evaluation in terms of broader usability as it was not evaluated with the healthcare workers that provided the insights the design was based on. However, the evaluation did not provide insight into implementing the support approach within ErasmusMC. Future evaluation should be done with the consultants and rheumatologists of the ErasmusMC rheumatology department to develop insight into this.

Testing method and time

The communication approach was evaluated using roleplay between the patient and researcher. Because of this the evaluation insights might have been influenced. Also, no insights were gained in the feasibility in terms of usability from a healthcare workers perspective. It is essential to conduct future evaluation of the communication approach in the actual context of use: the hospital and include the second main stakeholder: the consultant.

Limitations were also present in testing the Feel Check function of the GROW app. The Feel Check prototype did not yet compare the entered Feel data with the previous week to base the learning loop on. The patients were asked to do this themselves. Also, the Feel Check was only tested over a period of 2 weeks. Long-term testing with a fully functioning Feel Check prototype is needed to determine the effect on the patient's understanding of their disease management over time and whether the patients keep engaged in the Feel Check for a more extended period.

Untested elements

It was decided to develop and prototype the for the design goal most relevant function of the GROW app: the Feel Check learning loop 2. It is essential also to develop, prototype, and test the other described functions of the GROW app, including (1) learning loop 1, (2) the Month Check, (3) the appointment preparation, (4) the four menus and (5) the personal settings. This is needed to find out whether the functions are fulfilling their goals and find out opportunities for further improvements.

Design recommendations

Quantifying Feel Check data

To allow direct use of the Feel Check data by the healthcare workers, the chosen 'plants' to enter the level of felt symptoms should be linked to the VAS score that healthcare workers use to assess the patient's symptoms.

Including GROW map in the waiting room

The GROW map could be visualized in the hospital waiting room, such as on the screens, to remind patients of the GROW core activities and trigger them to think about their experiences before entering the appointment room.

Flyer improvements and extensions

The GROW flyer was now designed to focus on PsA patients as this is the Focus of the IPROLEPSIS study. It was decided to focus the Feel page of the flyer on the inflammation symptoms because the research phase indicated that these are the most important symptoms to monitor to learn about the body. A patient and a consultant mentioned that they experienced the skin condition as not highlighted enough. Design alterations could be done to include the skin disorders and their locations more prominently in the flyer. In general, the GROW flyer was designed to only contain information relevant to every patient to minimize the total amount of text and information. It could be interesting to create flyer extensions to provide patients with more specified information on specific aspects, such as adaptation flyer extensions about pregnancy or work.

Alignment within the department

The healthcare workers' manual was created to share the vision of implementing the communication approach in the current situation. To ensure this is understood well, and all healthcare workers are aligned, a suggestion would be to organize a training moment where healthcare workers get a consistent explanation about the approach and share their vision on implementing it during their appointments.

Recommendations for further research

Trigger questions

The adaptation questions did not sufficiently trigger the patients to get to solution-oriented adaptations. The ability to browse tips might increase this. Also, the question currently asked when there is no change in experienced symptoms about what arthritis hindered the patient from doing was not triggering enough. More research could be done about questions to trigger patients to think about solution-oriented adaptations and to trigger patients to learn when there is no change in symptoms.

Feel Check timing and frequency

During the evaluation, a patient mentioned that the first moments with arthritis are dedicated to processing the diagnosis and that learning starts after this. It is important to conduct further research about the Feel Check's optimal timing and frequency. This research should focus on when patients should be invited to start filling in the Feel Check, what period should be linked to the two learning loops, how this should vary among version types, and when the Feel Check should propose to decrease the frequency. When diminishing the frequency, research should also be done on how the questions should be posed to guide and stimulate patients to learn over a more extended period.

Setting goals

Literature research showed that collaborative goal-setting could make patients more confident in performing self-management tasks (Linda Baumann & Tran Ngoc Dang, 2012). Field research showed that it could be interesting to focus on goals related to emotional value to facilitate patients' acceptance in managing the disease. Especially patients with an emotional attitude could benefit from this to increase their motivation to engage in self-management strategies at the start of their journey. The evaluation showed that the consultants perceive the GROW map as a good base for collaborative goal-setting. Also, the evaluation showed that patients can perceive the app as too conscious. As these patients are likely to have an emotional attitude, goal-setting might increase their motivation to engage in this consciousness. More research could be done about how goal-setting could be included in the communication approach.

Learning loop 3

The research phase showed that the self-management journey generally consists of three phases. During these phases, the focus shifts from understanding the provided information to getting to know the body and developing management strategies to fitting management in as part of living a fulfilling life. Currently, learning loop 1 focuses on phase 1, and learning loop 2 mostly focuses on phase 2, and already including some slight acceptance aspect of phase 3. It could be interesting to conduct further research on creating a learning loop that supports patients in phase 3. Here the focus could shift from basing the learning loop on physical to emotional feelings. Research should then be done into what trigger questions this learning loop should include.

Acceptance support

Literature research showed that cognitive behavioral strategies can be effective in reducing pain intensity, improving a patient’s coping skills, and increasing the patient’s readiness to adopt a self-management approach (Cosio & Lin, 2016). In the current design, the emotional aspect is included by making patients aware of acceptance in the learning loop and providing patients with mindfulness exercises in the acceptance menu. It could be interesting to conduct more research into how elements of cognitive behavioral therapies could be implemented in the learning loop and the acceptance menu to better support patients in dealing with pain and the emotional aspects of the disease.

High SEP

This thesis project focused on the needs and characteristics of the lowSEP patient group. During the co-creation sessions, the healthcare workers mentioned that they do not desire and find it hard to categorize a patient as a lowSEP patient. Because of this, it is important that the support approach applies to all patients. This was considered during the design phase. However, research should be conducted to determine how the support approach could be improved further to appeal to the higher SEP patient.

Section 3

Project Evaluation

In this section the project is evaluated. The project is concluded and project limitations and recommendations for further research opportunities are given. The section wraps up with a personal reflection on the graduation process.

Chapter 13

Project Conclusion

In this Chapter a final conclusion on the project is given. The problem statement is revisted and answered through design. A discussion is provided including project limitations and recommendations for further research.

Conclusion

This thesis project works on the perspectives of design for health and well-being and design for behavioral change and aims to anser the following problem statement through design:**What should the future hospital self-management support look like to better support lowSEP PsA and RA patients with limited health skills in self-managing their disease, and what opportunities could remote monitoring provide in this?**

The future support approach should facilitate the communication about the topic of self-management between healthcareworkers and patients and should guide and engage patients in translating provided information and their own experiences into insights about their personal disease and management situation.

The support approach designed to establish this consists of a communication approach and a mobile phone application. The communication approach focuses on establishing a clear consistent and engaging way of communicating about the topic of self-management between healthcare worker and patient. The mobile phone application extends the hospital support delivered to the at-home situation of the patient. This app focuses on triggering and guiding patients in learning from their own experiences to develop a deeper understanding about their personal disease manifestations and how to adapt to this in a personally fitting way. Connecting the support approach to remote monitoring interventions allows to provide patients additional input in learning from their own experiences and allows to provide healthcare workers with insight into the patient's perceived experiences of their health.

This support approach was established through executing a user-centered design process. This included literature research, field research, and design activities where both stakeholders, the patient, and the healthcare workers, were actively involved through interviews and co-creation. This resulted in two main research conculsions and two main design conclusions.

(1)In the current situation, a lacking communication about the topic of self-management between healthcare worker and patient, and patients' issues developing understanding of the personal disease manifestations and thinking in a solution oriented way, negatively influences the lowSEP patients' ability and motivation to take an active self-management role and increase their HRQoL

Research showed that LowSEP patients start their self-management journey with an insufficient knowledge base. Along the journey healthcare workers do not receive the needed input from the patient to deliver tailored support to increase this knowledge base. During their self-management at home, the insufficient knowledgebase decreases the patients ability and motivation to monitor their body and translate this into insights about their disease and fitting strategies to manage this. This is complicated by the fact that personal disease manifestations are vague to determine and varying in nature and by the patient's limited problem-solving skills. A lack of security and satisfaction arises which negatively influences the patient's acceptance of the disease and engagement in self-management strategies. This can cause rejection of self-management strategies, denying the patient the chance to improve their physical well-being, or engagement in strategies that are less beneficial for their subjective well-being, Both witholding them from obtaining their personal optimal HRQoL.

(2)The future support approach should enable lowSEP patients to translate their own experiences into understanding about their disease and its management and should stimulate them to communicate their insights gained and support needs with the healthcare workers

The stakeholder's needs for the future support approach.showed that patients' wish to receive support tailored to their needs. However, to be able to deliver this healthcare workers need to gain insight in these needs, stressing the importance of the patients communicating needs for support. Because of the lack of time during check-ups with the rheumatologists and and the lack of capacity only to increase further the healthcare workers share the need to enable the lowSEP patients to become more self-reliant and gain insight in their disease and how to manage this themselves and arrive at appointments with more developed insights and needs.

Based on these two conclusions the design goal of the thesis project was established: supporting lowSEP patients in establlishing a good knowledge base to start self-managing their disease and learn from their own experiences to develop this understanding further for their personal disease situation.

(3)Patients can be guided and engaged in understanding provided information and learning from their own experiences by providing them insight in five important activities of self-management and providing them insight and stimulating them to go through a self-management learning cycle that connects these activities.

Five core activities of self-management; Feeling, Understanding, Adapting, Accepting and Communicating can be idenitified that can be used to explain the topic of self-management and disease information in relatable and actionable parts. These activities can be translated in a visual model that shows how patients can learn from their own experiences to increase their disease understanding and establish fitting self-management strategies and how communication can positively influence. This was used as the base to solve the design goal which resulted in the final support approach.

(4)The support approach empowers patients to take an active self-management role and provides them a feeling of control over their disease and provides healthcare workers support in receiving the needed input and conveying the information to the patient to support them in this.

Evaluation showed the support approach to be desirable by both stakeholders. It increases the patient’s ability and motivation to develop understanding about their disease and its management and communicate about this to their healthcare worker. Healthcare workers showed willingness to implement the communication approach in their daily practice because of its simplicity and the support and structure it provides them in obtaining input from the patient and conveying the self-management message clearly and engagingly. The support approach is considered feasible to establish within the foreseeable future . It does not require complicated technological resources and the communication approach is easy to understand and usable by the lowSEP patient. The feasibiltiy of the GROW app is less optimal in terms of usability by the lowSEP patient because of difficulties in using the various app screens. Assuming the digital skills of patients to increase in the future, this feasibility will increase during development of the app. Finally, the support approach is considered viable as the benefits it establishes to solve the problem seem to outweigh the resource requirements in terms of cost and capability resources. Enabling connection with future remote monitoring interventions would positively influence the viability.

Discussion

Project limitations

The scope of this thesis project was quite broad considering the limited timeframe of six months, especially due to delays in obtaining approval from the Medical Ethical Committee of ErasmusMC. As a result, there were time constraints for analyzing research findings and developing a fully functional design.

The research focused on understanding the needs and characteristics of lowSEP patients. However, the definition of a lowSEP patient is difficult to categorize, making it challenging to determine whether a patient fits into the category or not. A zip-code recruitment method guided this patient selection. Although all the research participants showed some lowSEP patient characteristics, it cannot be guaranteed that they fully represented the lowSEP patient group. Additionally, the study included only seven participants. Since the analysis aimed to identify overarching pains and needs among patients, the design may have been influenced by insights primarily related to patients with a higher SEP and might have overlooked specific lowSEP needs.

The field research activities involved stakeholders from multiple hospitals, which increased the applicability of the research insights and developed design in the broader rheumatology context. However, this approach also increased the likelihood of overlooking specific implementation insights within the ErasmusMC rheumatology department. Nevertheless, by including only consultants and rheumatologists from the ErasmusMC rheumatology department during the design phase, the viability of implementation in this particular setting was positively influenced.

Further research opportunities

During this thesis project, focus was on self-management and the lowSEP patient. The insights gained about these aspects show interesting opportunities for future research.

Self-management

During this thesis project, a comprehensive model was developed to visualize the cycle that patients go through when developing an understanding of their disease and establishing self-management strategies. The interactions with the healthcare workers during the project showed that this model was appreciated for its simplicity and ability to provide insights into the different stages involved in establishing a self-management strategy, and thus also, where patients can get stuck. The created bears a resemblance to the self-regulation model proposed by Clark. This model states that self-regulating means being observant, making judgments based on the observation and reacting in order to establish and continuously evaluate and improve on self-managing strategies that help the patient reach a certain goal (Clark et al., 2014). This model substantiates the validity of the model created in this project. There is potential to further develop the model devised in this project into a practical tool for understanding patient self-management. Further research could be done to develop the model further. Also, it could be interesting to discover the potential to extend the applicability of the model and the core aspects of the communication approach beyond the rheumatology department in the broader context of patient self-management.

The lowSEP patient

During this thesis project, insights were gained about the lowSEP patient. Meaningful characteristics around self-management behavior were determined through creating attitude profiles of the lowSEP patients and various pains and gains around self-management were revealed. As this thesis project did not include highSEP patients, it was not possible to find out whether the insights gained were lowSEP patient specific or applied to the general patient. further comparison research could be done to define what aspects of the attitude profiles and pains found are characteristic for the lowSEP patients. As the lowSEP patient group is currently underrepresented in healthcare studies, gaining insight in these specific characteristics would be very valuable for the design of future healthcare interventions around self-management behavior that apply for all.

Chapter 14

Personal reflection

As the reader, you have reached the final Chapter of this thesis project; the personal reflection. Compared to the whole report, this Chapter might become under-highlighted. However, for me, as the writer, this Chapter is highly valued. I think I can say I have never had a period in my life in which I gained so many insights about myself. This personal reflection Chapter highlights some of the most important learnings I gained about me as a designer. However, if you would ask me to write a book about all the personal insights these past few months taught me, I could.

Main learning

Throughout the project, I discovered why there is still so much to gain around the topic of supporting patients in dealing with their health issues; the complexity is enormous. I increasingly realized that every patient's body, thoughts, behaviors, and experiences are so different that it is very difficult to develop general solutions.

Diving into this complex problem, my interest in psychology and behavior was my biggest strength but also my biggest weakness. It triggered my interest to dive into the various behavioral models. It also motivated me to think and analyze beyond the obvious to discover the patients' and healthcare workers' latent needs. This resulted in designing my own behavior model that has become the core of the research and design phases of my thesis project and was very much appreciated by the stakeholders.

However, because of the longer timespan for explorative research caused by the delay of the patient interviews, my interest in psychology and behavior also made me dive into the topic way deeper than usual for a design process of 6 months. The further I came along in the project and the more insights I gained, the more complicated it got. Especially because of the individual nature of graduating, thismade me get lost in my own insights a lot. This taught me the most important lesson about myself as a designer.

I learned that I am a visionary. My enthusiasm drives me to keep gaining insights, analyze deeper, and constantly improve my vision further. However, during this, I sometimes forget to take a step back, set my backlog straight, and work things out more concretely. Also, it withholds me from making converging decisions, which in the end, is needed to get to a final deliverable. Towards reaching the greenlight moment, I had a head full of research insights and a well-developed vision for the future that I loved to convey to others verbally. However, because of all the deeply analyzed interrelations between things and the lacking backlog of converging decisions, I had great difficulties translating the research findings I gained into a written report within the limited time left and the delay in converging caused me to have limited time to translate my developed vision into a concrete solution. I think my greenlight report can be described with a quote by Blaise Pascal:

'I have made this letter longer than usual because I have not had time to make it shorter.'

All the iterations to improve the greenlight report towards this final thesis report, learned me a lot about clear report writing

Being a visionary and wanting to put the effort in searching for the beyond obvious is something I can perceive as a strength that allowed me to create a final design that I am proud to share. However, for upcoming projects, I am definitely advising myself to occasionally take a step back to make insights concrete and make converging decisions in time to prevent myself from getting lost in reporting again.

Revisiting learning ambitions

Research

Looking back at the learning ambitions I set up at the start of this Thesis project, I would also like to address some more specific learnings.

With this project, I aimed to use and improve my qualitative research skills. Especially the interviews with the patients provided me with learnings in this. Being a student surrounded by highly educated people most of my life, it was very interesting to discover how conducting interviews with these patients with a lower educational level was very different than what I was used to.

Starting the project, I saw great value in using a context-mapping approach to support these patients in conveying their stories with visual material. However, throughout the interviews, I learned that the creative toolkit did not stimulate the patients like I was used to with previous research projects, as they tended to have difficulties with the level of abstract thinking required.

I learned that with this target group, the best approach is just letting them tell their stories. This improved my skills in interviewing as it gave me the responsibility to guide the conversation away from focusing too much on a specific topic without interfering them or stirring them in certain directions.

Analysis

I already adressed the topic of the analysis process itself in the main learning. However, the project also thaught me insights about the analysis outcome.

At the start of the project, I decided I wanted my analysis outcome to be a patient journey. This was because I wanted to further develop my skills in creating such a deliverable, and I saw great potential in its visual strength to allow for communication of the insights I gained within the department. However, is quickly discovered that the complexity of this project's topic was challenging to map out.I learned a lot by diving into examples of patient journey maps and care pathways. Ultimately, this helped me create a general patient journey that allowed me to me gain insight into the topic, convey the message to others, and lay a base for the final design. I think I could still improve on creating these kinds of visual overviews by making strong decisions in what to include and what not and visualizing them in a way that others can also use them to pass on the message further.

Design

Kicking off the project, the final deliverable decided on was a map that showed the care path of the future, including the patient's needs and opportunities for support. Midway through the project, I realized that the deliverable I aimed to create was more the result of a research project, mapping out the patient's needs to show what the future support should focus on. However, because of the uniqueness of every patient, I had difficulties adding more concrete support opportunities to this map to be able to also address the second solution finding diamond and fulfill the requirements of a design thesis project.

This first caused me a bit of a setback. However, I quickly realized that my vision of what the support should focus on showed a great opportunity to create a single more concrete solution. I realized that by establishing such a clear vision of the future and designing the self-management model, I had already started designing the base of my solution. By using the co-creation method, I was able to translate the vision into a very concrete solution quite quickly.

Looking back, I am happy with this shift, as it allowed me to create a more concrete and more Design for Interaction type of deliverable. Also, it taught me a new way of designing where research and design were way more closely connected than I had ever done before. Finally, the need to create the final solution within a limited time made me use the co-creation efficiently to improve ideas before working them out in full detail. This was something I had difficulties with at the start of my studies, and I am pleased to find out that I have now developed the confidence to do this.

Context

I wanted to use this thesis project to gain more experience and knowledge about conducting research and design activities within the healthcare world.

Regarding research, I learned that the medical ethical requirements can really counteract the fluency of the design process. It makes you very dependent on others which in my case caused a lot of delay.

Regarding design, I learned that the healthcare world is working on significant technological interventions to improve the health outcomes of their patients. But that also making small changes, such as a different type of communication, can have a positive impact on the patient's experience of the healthcare delivered and maybe even on the patient's health outcomes too. During the co-design sessions, I experienced great joy in making the healthcare workers think more open-mindedly and beyond their usual way of doing things by showing my ideas and stimulating them to brainstorm on these ideas further. However, the project also showed me that, in the end, the way of doing things at the department is quite fixed and that, despite the open-mindedness, changes take very long to implement.

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Image sources

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Appendices

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Appendix A - Patient interviews

Recruitment

The patients were recruited with support of ErasmusMC, HAGA and Maastad hospitals. With the use of a zipcode-lowSEP scaling system a list of patients was generated that according to their zipcode would be fitting within the target group of LowSEP patients. The rheumatologists at the various hospitals were sent this list to start recruiting these patients. Here they were told to also do a personal check whether they agreed with the patient having lowSEP characteristics. LowSEP people tend to have lower literacy levels which can scare them away from long written study explanations. Because of that it was decided to provide the patient with a visual flyer including a QR-code to a video that explained the most important information of the research. On the flyer as well as in the video the researcher was made visual to make the situation more familiar to the patient. The patient information flyer and agreement form needed to include specific text however was made as easily readable as possible using short simple sentences and big font type. When a patient was willing to participate his or her number was provided to the researcher and an appointment for the interview moment could be made.

Set-up

Digital sensitizing

To prepare the patient for the interviews and already get them in the right mindset of thinking the patients were sensitized on the 3 days before the interview (Appendix figure 1). It was decided to do this sensitizing by means of Whatsapp as this had various advantages. It enabled the use of voice memo's decreasing the need for a lot of text. Also it made it possible to provide the information in steps making it more comprehensible for the patient. Finally it also allowed the patient to ask questions when the provided task was unclear and it allowed the researcher to remind the patient about the task when this was not yet completed. An additional advantage was the fact that it already created a simulation of a remote monitoring using the mobile phone which gave insight in the mobile phone use of the patients and could be used to get some insights in their experiences around this during the interview.

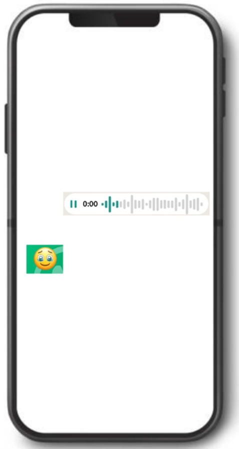
Creative toolkit

The interview started with an introduction where a printed version of the carepath timeline (Appendix figure 2) and the patients sensitizing inputs of emotions and experiences experienced were used. This helped to warm up the patient towards the topic of discussing emotions around their disease and made them familiar with the phases that were going to be discussed. Also the printed timeline was a good communication tool during the whole interview to steer the conversation towards certain moments along the journey. During the last 3 interviews the focus was already slightly put towards the feeling of control. During these interviews an additional trigger set was used where the patient was provided with images related to emotions and control (Appendix figure 3) They were asked to choose an image that fits with when they experience control over their disease and an image that fits with when they don't experience control. This was used to start a conversation about the feeling of control

Conversation

The interviews were conducted in the home environment of the patient to get a good view of the actual at-home situation. The set-up of the interviews often followed the path of expression including the now, the past and the future (Sanders & Stappers, 2018). The interview guide was build upon insights from the previous research steps around the aspects of self-management. The interview started with using the creative toolkit including the visual overview of the 3 phases of the care path and the answers to the sensitizing exercises to discuss the sensitizing exercises. This allowed to start the conversation and gain first insights. After this the interview guide discussed the various aspects one by one where for every aspect focus was put on the various phases of the carepath. Tackling all 5 aspects and all the phases helped to get a broad overview of the whole care path and prevented from focusing too much on specific topics.

Elke keer

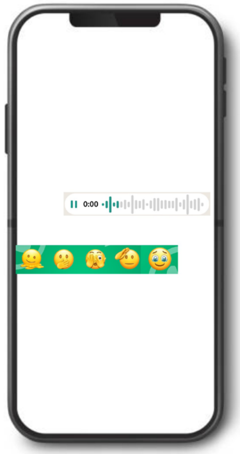


Goedenmiddag, hoe voel je je vandaag? kan je een emoji uitkiezen die hierbij past en deze naar mij opsturen?

Goedendag, tijd voor dag 2, hoe voel je je vandaag? kan je een emoji uitkiezen die hierbij past en deze naar mij opsturen?

Goedendag, tijd voor de laatste dag met opdrachtjes, hoe voel je je vandaag? kan je een emoji uitkiezen die hierbij past en deze naar mij opsturen?

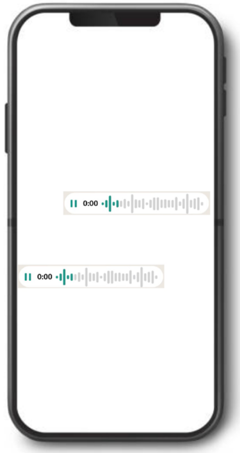
1



Dan is het nu tijd voor opdracht 1. Sinds het moment dat je wist dat je ziek was heb je waarschijnlijk veel dingen meegemaakt in het leren omgaan met je ziekte, je bijvoorbeeld medicijnen gaan slikken en stoppen of juist beginnen met sommige activiteiten.

Als je terugdenkt aan de ervaringen die jij zelf hebt meegemaakt, kan je 5 emoji's naar mij opsturen die een beeld geven bij hoe je je op deze momenten voelde?

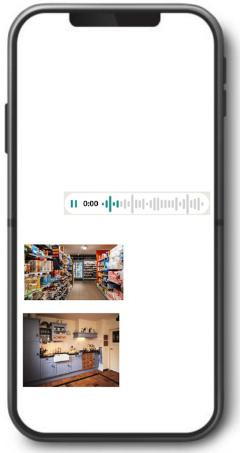
2



Dan is het nu tijd voor opdracht 2. Tijdens het omgaan met je ziekte heb je op meerdere momenten contact gehad met de reuma-afdeling van het ziekenhuis. Je ging op afspraak en hebt misschien wel eens vanuit thuis contact gehad.

Als je terugdenkt aan deze momenten dat jij contact had met het ziekenhuis. kan je een ervaring omschrijven die heel fijn was. Kan je daarna een ervaring omschrijven die minder fijn was? Dit mag je uittypen maar je kan het ook inspreken in een spraakopname

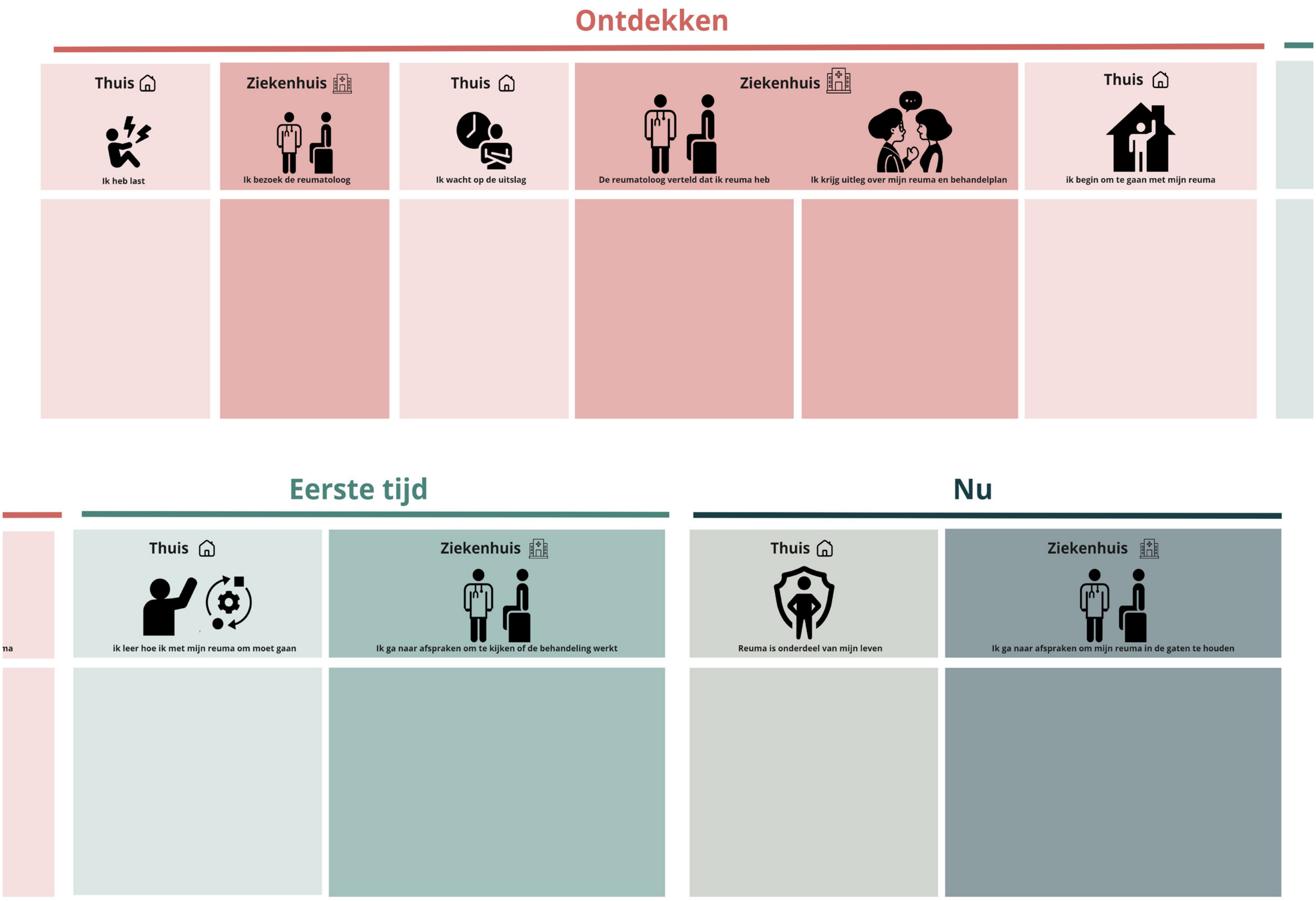
3



Dan is het nu tijd voor opdracht 3. Tijdens de dag kom je soms momenten tegen dat je merkt dat je reuma hebt. Misschien gaat iets lastig of voel je pijn of misschien merk je juist iets fijns, zoals wanneer iemand vraagt hoe het met je gaat.

Als je vandaag een moment tegenkomt waarop je merkt dat je reuma hebt, kan je dan een foto sturen van de plek waar je bent? Dit mogen zoveel momenten en foto's zijn als je zelf wilt, maar zorg wel dat er geen voor jou persoonlijke informatie in beeld is die je niet wilt delen

Appendix figure 1



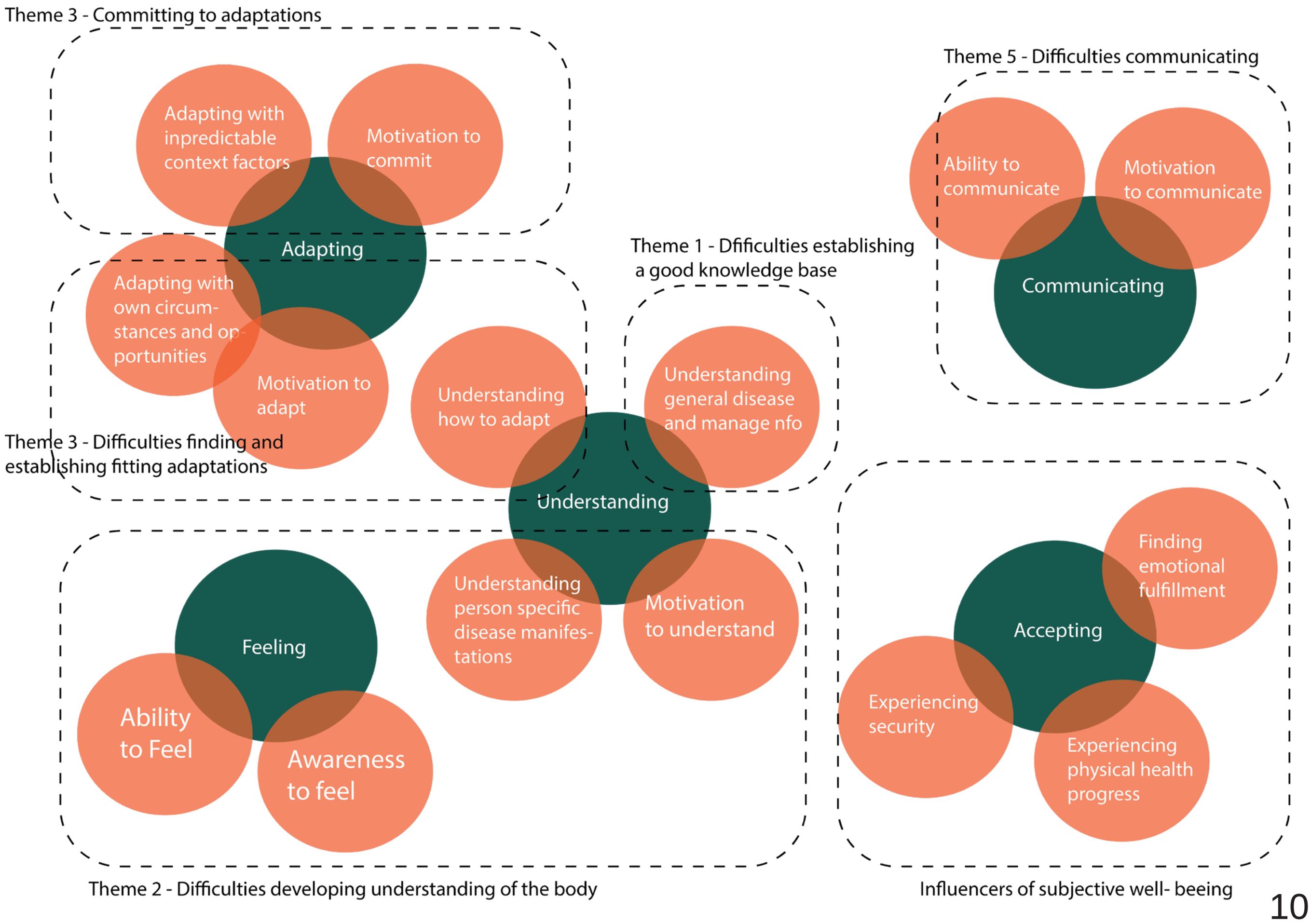
Appendix figure 2

Appendix figure 3

Appendix B - Analysis cluster sets

B.1 Cluster set analysis phase 1

B.2 Cluster set analysis phase 2



Appendix C - Phase activities description

First moments with arthritis

After having received the PsA or RA diagnosis, the patient gets a short explanation on the disease and the treatment plan by the rheumatologist. To explain everything in full detail, the patient has a separate appointment with the rheumatology consultant afterwards. This is often scheduled directly after the rheumatologist visit. The appointment with the consultant focusses on explaining the disease, the treatment and the most important lifestyle aspects related to disease management. The patient has the opportunity to ask questions and discuss insecurities. After the appointments the patient goes home and experiences the first moments in daily life when knowing to have PsA or RA. The patient might start to search for additional information himself and will often contact people that are close to them about the diagnosis. The patient starts to take medication for the first times and has to make direct life adaptations when needed. This often includes good communication. An example of this is (temporarily) adapting work facilities when the original way of doing is not possible with the new (temporarily) diminished capabilities. This asks for good communication with the employer. When the patient is insecure about the medication intake the rheumatology department can be contacted for questions. At ErasmusMC the patient is called after two weeks to check how the disease management at home is going so far.

Dealing with active disease

After having taken the medication for the first time, the patient has to commit to this. This asks for the establishment of a medication regime that fits within their day-to-day schedule. Besides taking medication, the patients can also adapt aspects of their lifestyle to diminish disease activity such as quitting smoking and taking up movement. Next to lifestyle adaptations patients can also make adaptations to allow them to conduct their daily life activities with their new decreased capabilities. There are a lot of tools available for patients with arthritis like special cutlery, thickened pens, and lifted toilet seats. It depends on the patient and his disease manifestations which tools are needed. Patients learn during their daily life what their new capabilities withhold them from and need to search for adaptations that could help them with this. Also, patients start to find out what level of movement and strain works best for their body to not get stiff but also not ask too much of it. As every patient is different there is no golden rule for this asking the patient to consciously learn with trial and error what works best for them. Because of this decreased energy and strain level activities take more time and more moments of rest are needed making patients often cannot commit to as many daily life activities as they were used to. This asks for adaptations in the patient’s daily life planning. Through experience patients find out what works them, keeping their priorities in mind. When establishing adaptations, they can encounter interaction moments with their surroundings asking for good communication. A patient can get help with adapting their lives to the disease from nonmedical therapies like physiotherapy, psychosomatic therapy or occupational therapy. Also family and friends can experience the effect of the patient’s self-management or can offer additional support.

This phase of dealing with active disease fits within the intervention phase of the hospital carepath. During this phase the patient has relatively frequent visits at the hospital. The exact frequency differs per hospital but is around 1 month (HAGA)– 3 months (EMC). During these visits the disease activity and the medication effect is monitored.

Dealing with stable disease

Once the disease stabilizes the patient has already learned a lot about the new capacities of the body and how to manage this. Now patients need to keep engaging in this consistently. The experience of symptoms and thus the disease impact can vary over time because of among other things changing medication effects, whether conditions or the patient crossing his energy or strain balance. Because of that the patient will keep altering their management strategies to the at that moment most fitting strategies. During stabilized disease activity it might be possible to start decreasing the amount of medication. This is often decided during a shared decision-making moment with the rheumatologist. Here the patient has to make a trade-off between staying with something that works or changing to something with uncertain results but which might be better. Decreasing medication also asks for adaptation of strategies as the medication regime and maybe the disease activity might slightly change With some room for adaptation, in general the strategies established in this phase will be permanently part of the patient's life. Because of that the patient will also start to find out how to incorporate managing the disease in their lifes as best as possible to reach highest quality of life possible.

This phase of dealing with stable disease fits within the monitoring phase of the hospital carepath. During this phase the patient has occasional visits at the hospital. The frequency varies among patients but is around every 6 months – 1 year.

Appendix D - Description theme 4

Ability

When engaging in adaptations patients' circumstances can withhold them from committing to the adaptation. People in their surroundings can interfere with them adapting because they are not aware of the disease because of it's invisibility. Also, other illness related aspects or life circumstances that need priority can cause the patient to not be able to commit to their medication regime, creating unclarity on how to continue. Finally, life circumstance can force patients to push through their energy balance while aware of the need to make adaptations.

'I didn't feel well and I dropped a glass ... but my little son comes home so you just have to clean it up at that point.... you can push through that but it does tire you out a lot more" .

Motivation

During increased symptoms or stressful life circumstances, patients can have less strength to commit to the lifestyle adaptations they have established. Especially keeping the body moving to not get stiff while experiencing physical symptoms can be hard. On the other hand patients can also have less motivation to commit to adaptations during lower symptom experience as it then also gets lower priority compared to other things in life. Finally, patients can forget about adaptations when they have not become habitual yet.

' In the beginning, you take it 100% seriously, because you want to get better. After a while when you are feeling better then you start to forget a bit"

Appendix E - Full set of pains and gains

Theme 1: Difficulties establishing a good knowledge base to start self-managing

Understanding the general disease and management information

Ability: Difficulties understanding the provided complex health information

- The provided information is too complex or too much to understand or easily forgotten causing lack of knowledge about about symptoms and the disease cause
- Developing aversion for medication because of misunderstanding information
- Misunderstanding the chronicicy of medication causing an early quit
- Having clearity about the kicking in process of the medication
- Misunderstanding the medication information causing wrong execution or early quiting because 'it does not work'

Ability: Difficulties in filling in own information

- Higher entry level beause of beeing familiar with the disease (family, medical background)
- Beeing able to find information you miss yourself
- understanding information through experiencing it
- Gaining own information from a wrong information base (surroundings of incluence)

Ability: information does not provide an idea of what self-mangement entails

- Information provided does not give an idea what the disease actually entails in daily life / having little clue of what is coming

Theme 2: Difficulties developing understanding about

Ability: difficulties translating felt things into understanding

Understanding the person specific disease manifestations

- Previous experiences enabling to judge feelings and predict the body better
- Getting external validation on own assumptions about increase in symptoms from HW or others
- Difficulties understanding the increase in symptoms because of the ambiguity of the symptoms and the factors that can cause them
- unclearity what pain should be moved trhough and what not
- unclear communication about medical results and changes in treatment by the hospital

Ability: Difficulties consciously feeling symp

Ability to feel

- The exact position of the energy/strain level compaired to the max is difficult to feel
- Body needing time to respond to medication / adaptation making it impossible to immediately notice th effect
- consciously experimenting with lifestyle adaptations makes it easier to determine the effect instead of overlooking it

Forgetting to feel

- Forgetting to link symptoms to the disease, and thus not consicously feeling them
- Getting external reminders of the symptoms to take into account
- Linking non-disease related symptoms to the disease
- Unclearity about the side-effects th you should be aware of

Theme 3: Difficulties finding and establishing fitting adaptations

Ability: Difficulties coming up with ways to adapt to increase QoL

Understanding how to adapt to increase QoL

- Knowing the cause of the increase gives new information for adaptations
- Not beeing able to come up with alternatives of doing things instead of 'not doing it'
- Little hospital support in finding therapys and additional adaptations that could help increase capabilities or QoL
- A sudden increase in symptoms asks for sudden adaptations
- Finding out flexibility in adaptations that help to maintain qol with trial and error
- Establishing clearity about priorities and most valued things in life that should be maintained as much as possible
- Not beeing able to plan for the future because things keep changing
- Preparing for last-minute adaptations (e.g. notifying work, scheduling with opportunity for rest)
- Hearing about opportunities for adaptations from other's

Ability: Circumstances complicating the oppor-tunities for adaptations

Adapting with own resources and opportunities

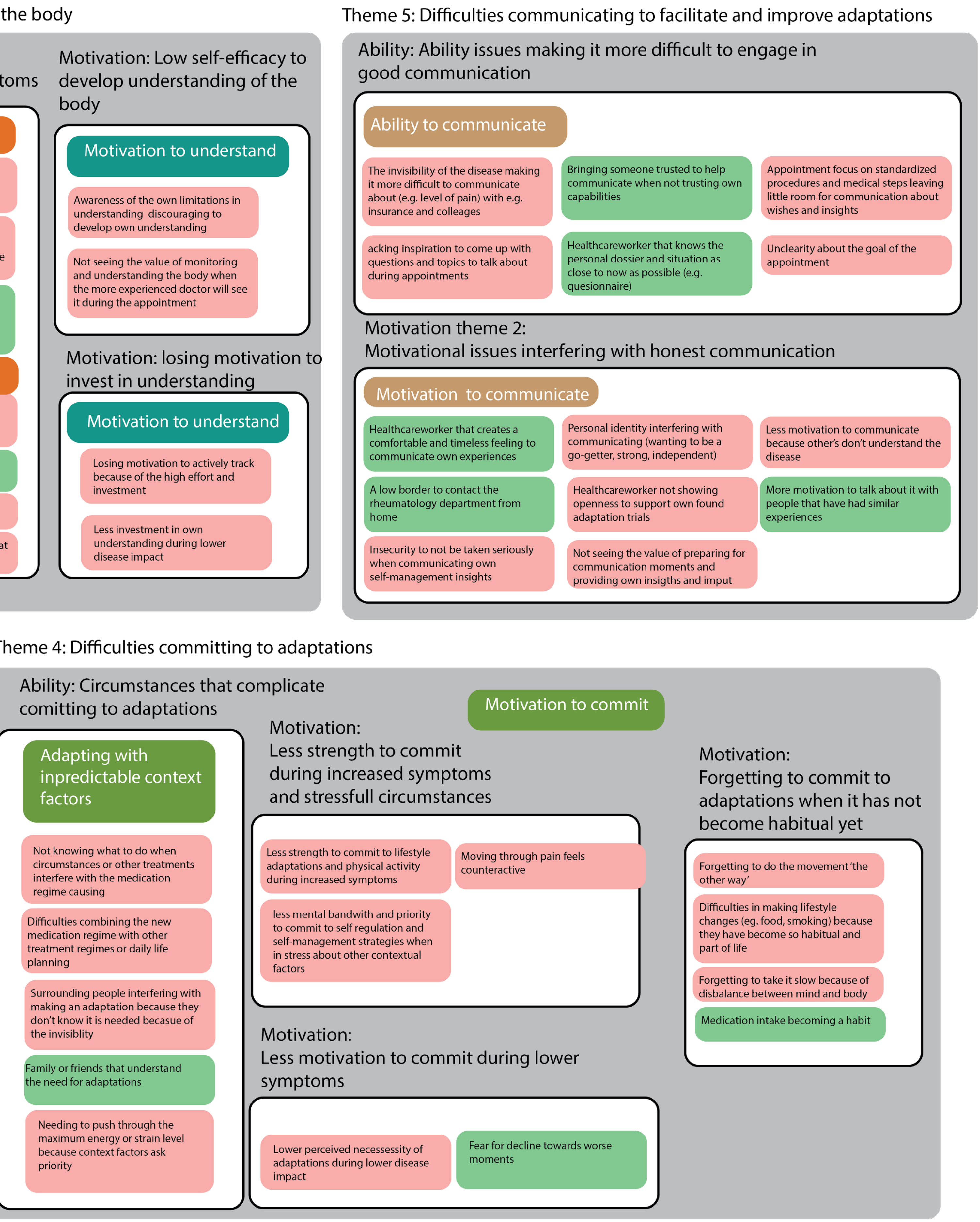
- Difficulties in establishing adaptations in the work environment or obtaining a full work disability especially when in physical jobs
- Difficulties in establishing needed or fulfilling additional adaptations because of lack of resources and strigglies with insurance
- Family or friends that can help support while having decreased capabilities

Motivation:
Fear when trying out new adaptations

Motivation to adapt

- Fear and feeling inexperienced with first times medication
- Fear to leave what you have for an uncertain goal that might dissapoint or be worse
- Feeling a slight tense when trying out adaptations for the first time

T



the body

toms

e

at

Motivation: Low self-efficacy to develop understanding of the body

Motivation to understand

- Awareness of the own limitations in understanding discouraging to develop own understanding
- Not seeing the value of monitoring and understanding the body when the more experienced doctor will see it during the appointment

Motivation: losing motivation to invest in understanding

Motivation to understand

- Losing motivation to actively track because of the high effort and investment
- Less investment in own understanding during lower disease impact

Theme 5: Difficulties communicating to facilitate and improve adaptations

Ability: Ability issues making it more difficult to engage in good communication

Ability to communicate

- The invisibility of the disease making it more difficult to communicate about (e.g. level of pain) with e.g. insurance and colleages
- Bringing someone trusted to help communicate when not trusting own capabilities
- Appointment focus on standardized procedures and medical steps leaving little room for communication about wishes and insights
- acking inspiration to come up with questions and topics to talk about during appointments
- Healthcareworker that knows the personal dossier and situation as close to now as possible (e.g. quesionnaire)
- Unclearity about the goal of the appointment

Motivation theme 2: Motivational issues interfering with honest communication

Motivation to communicate

- Healthcareworker that creates a comfortable and timeless feeling to communicate own experiences
- Personal identity interfering with communicating (wanting to be a go-getter, strong, independent)
- Less motivation to communicate because other's don't understand the disease
- A low border to contact the rheumatology department from home
- Healthcareworker not showing openness to support own found adaptation trials
- More motivation to talk about it with people that have had similar experiences
- Insecurity to not be taken seriously when communicating own self-management insights
- Not seeing the value of preparing for communication moments and providing own insigths and imput

heme 4: Difficulties committing to adaptations

Ability: Circumstances that complicate comitting to adaptations

Adapting with inpredictable context factors

- Not knowing what to do when circumstances or other treatments interfere with the medication regime causing
- Difficulties combining the new medication regime with other treatment regimes or daily life planning
- Surrounding people interfering with making an adaptation because they don't know it is needed becasue of the invisiblity
- Family or friends that understand the need for adaptations
- Needing to push through the maximum energy or strain level because context factors ask priority

Motivation to commit

Motivation: Less strength to commit during increased symptoms and stressfull circumstances

- Less strength to commit to lifestyle adaptations and physical activity during increased symptoms
- Moving through pain feels counteractive
- less mental bandwith and priority to commit to self regulation and self-management strategies when in stress about other contextual factors

Motivation: Less motivation to commit during lower symptoms

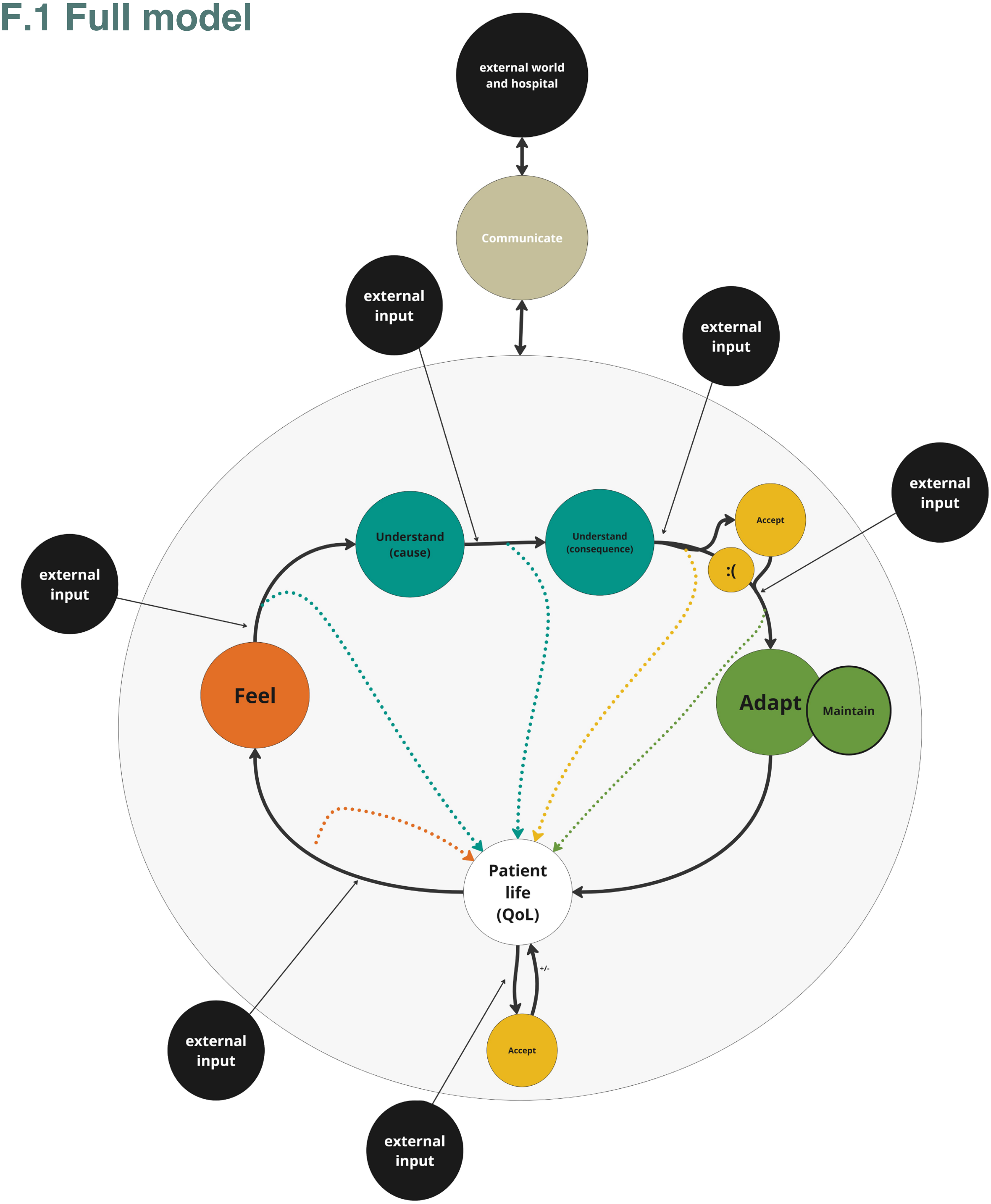
- Lower perceived necessity of adaptations during lower disease impact
- Fear for decline towards worse moments

Motivation: Forgetting to commit to adaptations when it has not become habitual yet

- Forgetting to do the movement 'the other way'
- Difficulties in making lifestyle changes (eg. food, smoking) because they have become so habitual and part of life
- Forgetting to take it slow because of disbalance between mind and body
- Medication intake becoming a habit

Appendix F - Self-management learning cycle model

F.1 Full model



F.2 Additional explanation flow failure

In the model dotted lines are given to show what happens when a patient does not succeed in the specific step and with that falls out of the loop. There are various ‘fall out’ moments:
- Feeling: When a patient does not have clarity about the symptoms to be aware of or overlooks the symptoms the can ‘forget’ to feel.
- Causal understanding: When a patient is not able to translate a felt thing into understanding about the cause.
- Consequential understanding: When a patient cannot translate the understanding about the cause in understanding about the consequential adaptation for this
- Accepting: When the patient is not accepting the needed adaptation and decides to not engage
- Adapting: When the patient does not have the capacity or opportunity to engage in the adaptation.

F.3 Additional explanation external input

In the model external input moments are shown which can create facilitators or barriers for the patient to go through the loop.

The patient can for example be reminded by their surroundings to consciously feel their symptoms or receive a diagnose from the hospital which could skip the part of needing to feel yourself to get to a cause. The patient can also receive information about adaptations that can be made such as information from the hospital and receive external input to accept this adaptation when for example surroundings motivate the patient to engage. The patient can also receive external input in establishing adaptations such as surroundings offering support in daily tasks. Finally, the patient can receive external input in accepting the influence of the adaptations on his or her life, such as friends offering mental support.

External input can also negatively influence the patient going through the loop and create a barrier, especially in the aspects of accepting and adapting. When a patient’s surroundings show grief when a planned activity has to be adapted, the patient will be less accepting towards the adaptation. Also, when a patient is willing to make an adaptation, surroundings can interfere with this. An example of this is a patient that wants to commit to his adaptation of putting less strain on his body by sitting in the bus but other people not taking this into account because of the invisibility of the disease.

External input does not necessarily have to mean that the patient will flow through to the next step in the model. For example, when receiving the diagnosis the patient still has to understand this diagnosis to really understand the cause of what he feels. The patient can thus still fall out of the flow on the causal understanding point.

Appendix G - Design guidelines from literature

Guidelines designing easy to understand materials

Sources: (Centers for Disease Control and Prevention, 2009; Pharos, 2022)

- Message: The message should be limited to three to four messages per section, making sure that the most important information is provided at the beginning of the document and action steps are clearly stated. Important information should be repeated.

- Language: Word use should be B1 level and short sentences should be used. Medical terms and metaphors should be avoided. An active tone of voice should be used to encourage the audience. Visuals and videos should be used. Visuals should be culturally appropriate. Icons should be used sparingly and the meaning should be clear.

- Visual appearance: The text should be at least 12 points, contrasting with the background and include sufficient white space. Guidelines contradict around serif or sans-serif fonds. The layout should use clear headers.

Guidelines designing for low digital skills

Sources: (Chaudry et al., 2012; Srivastava et al., 2021)

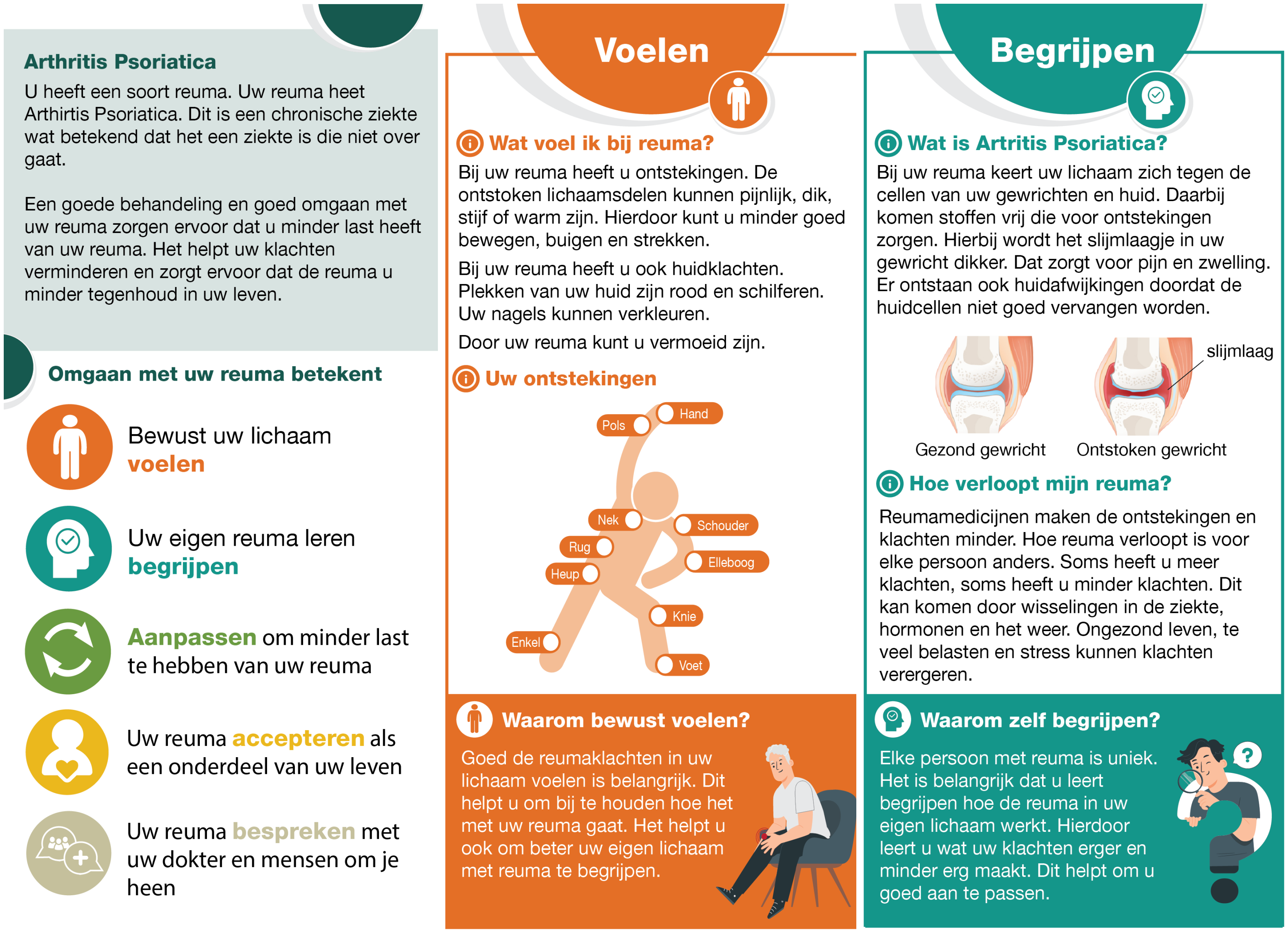
- Navigation: Choosing a mostly linear navigation system that includes a navigation bar and clear main screen for starting tasks. It's important to include a home button on every screen to allow users to easily return to the main screen.

- Language: Information should be broken down into manageable pieces, presented across multiple screens if necessary. Designers can consider offering explanatory videos to supplement text-based information. designers can consider including a read-aloud function and a speak-aloud function to help low-literate individuals better understand and interact with the digital tool. Users should also be allowed to customize the content and layout of the interface according to their individual needs, including adaptable font size.

- Visual appearance: To improve comprehensibility, the interface should incorporate visual cues such as colors, text highlighting, and icons. Widgets should be larger in size to allow for better visualization of interaction with them. The overall look of the interface should be kept minimalistic and clean.

Appendix H - GROW flyer

Front side



Arthritis Psoriatica

U heeft een soort reuma. Uw reuma heet Arthirtis Psoriatica. Dit is een chronische ziekte wat betekend dat het een ziekte is die niet over gaat.

Een goede behandeling en goed omgaan met uw reuma zorgen ervoor dat u minder last heeft van uw reuma. Het helpt uw klachten verminderen en zorgt ervoor dat de reuma u minder tegenhoud in uw leven.

Omgaan met uw reuma betekent

- Bewust uw lichaam **voelen**
- Uw eigen reuma leren **begrijpen**
- **Aanpassen** om minder last te hebben van uw reuma
- Uw reuma **accepteren** als een onderdeel van uw leven
- Uw reuma **bespreken** met uw dokter en mensen om je heen

Voelen

Wat voel ik bij reuma?

Bij uw reuma heeft u ontstekingen. De ontstoken lichaamsdelen kunnen pijnlijk, dik, stijf of warm zijn. Hierdoor kunt u minder goed bewegen, buigen en strekken.

Bij uw reuma heeft u ook huidklachten. Plekken van uw huid zijn rood en schilferen. Uw nagels kunnen verkleuren.

Door uw reuma kunt u vermoeid zijn.

Uw ontstekingen

Waarom bewust voelen?

Goed de reumaklachten in uw lichaam voelen is belangrijk. Dit helpt u om bij te houden hoe het met uw reuma gaat. Het helpt u ook om beter uw eigen lichaam met reuma te begrijpen.

Begrijpen

Wat is Artritis Psoriatica?

Bij uw reuma keert uw lichaam zich tegen de cellen van uw gewrichten en huid. Daarbij komen stoffen vrij die voor ontstekingen zorgen. Hierbij wordt het slijmlaagje in uw gewricht dikker. Dat zorgt voor pijn en zwelling. Er ontstaan ook huidafwijkingen doordat de huidcellen niet goed vervangen worden.

Gezond gewricht — Ontstoken gewricht

Hoe verloopt mijn reuma?

Reumamedicijnen maken de ontstekingen en klachten minder. Hoe reuma verloopt is voor elke persoon anders. Soms heeft u meer klachten, soms heeft u minder klachten. Dit kan komen door wisselingen in de ziekte, hormonen en het weer. Ongezond leven, te veel belasten en stress kunnen klachten verergeren.

Waarom zelf begrijpen?

Elke persoon met reuma is uniek. Het is belangrijk dat u leert begrijpen hoe de reuma in uw eigen lichaam werkt. Hierdoor leert u wat uw klachten erger en minder erg maakt. Dit helpt om u goed aan te passen.

Aanpassen

Medicatie nemen

Medicatie helpt om uw klachten te verminderen

Uw medicatie: Dosering:

☐ Tablet ☐ Prikpen ☐ Injectie ☐ Infuus

Andere aanpassingen

U blijft in beweging om uw lichaam sterk en soepel te houden. Dit vermindert stijfheid en klachten. Stress en uw lichaam teveel belasten kan klachten verergeren. U gaat zelf op zoek naar een balans tussen bewegen, belasting en rust die goed voor uw lichaam werkt.

Aanpassingen maken helpt u om met deze nieuwe balans om te gaan en minder last te hebben van uw klachten tijdens uw leven.

Waarom aanpassingen zoeken?

Uw lichaam en leven zijn uniek.
U kunt zelf zoeken en uitproberen welke aanpassingen werken voor uw lichaam. U zoekt aanpassingen die u helpen om te doen wat u belangrijk vind.

Accepteren

Reuma een plekje geven

Reuma zal dingen veranderen in uw leven. Uw lichaam voelt anders dan u gewend was. Boos, verdrietig of bezorgd worden is normaal. Dat hoort bij het hebben van een ziekte

Reuma zal altijd een onderdeel blijven van uw leven. Daarom is het belangrijk reuma een plekje te geven en hier niet tegen te vechten.

U kunt zich laten inspireren door mensen om u heen en lotgenoten die hetzelfde meemaken.

Tips bij een dip

- Krop het niet op. Praat met mensen die u vertrouwd of schrijf uw gevoel op.
- Ontspanningsoefeningen kunnen helpen om met emoties en pijn om te gaan.
- Bewegen helpt voor uw lijf en uw hoofd
- Bedenk dat u vertrouwen mag hebben in uzelf en in alles wat u kan ondanks uw reuma.

Waarom accepteren?

Uw reuma accepteren helpt om op een gelukkige manier met uw reuma om te gaan.
U kunt bedenken wat u belangrijk vind in het leven en op zoek gaan naar aanpassingen die daarbij helpen.

Bespreken

Bespreken met uw dokter

U weet het meeste over hoe de reuma in uw lichaam werkt, en welke problemen u door u reuma heeft tijdens uw leven.

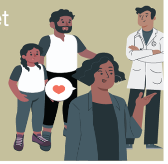
Het is belangrijk deze informatie goed met uw dokter te bespreken. Dan kan de dokter u helpen op een manier die past bij uw lichaam en leven. U kunt het hebben over dingen die u heeft geleerd of vragen die u heeft over het voelen, begrijpen, aanpassen en accepteren.

Bespreken met uw omgeving

Tijdens het omgaan met uw reuma maakt u momenten mee met de mensen om u heen. Door goed met hen te praten over uw reuma en wat u nodig heeft kunnen zij u beter begrijpen en helpen

Waarom bespreken?

U weet het beste hoe uw reuma werkt en hoe u hiermee om wil gaan.
Door dit goed te bespreken met uw omgeving en uw dokter, kunnen zij uw reuma en uw behoeften beter begrijpen en u beter helpen



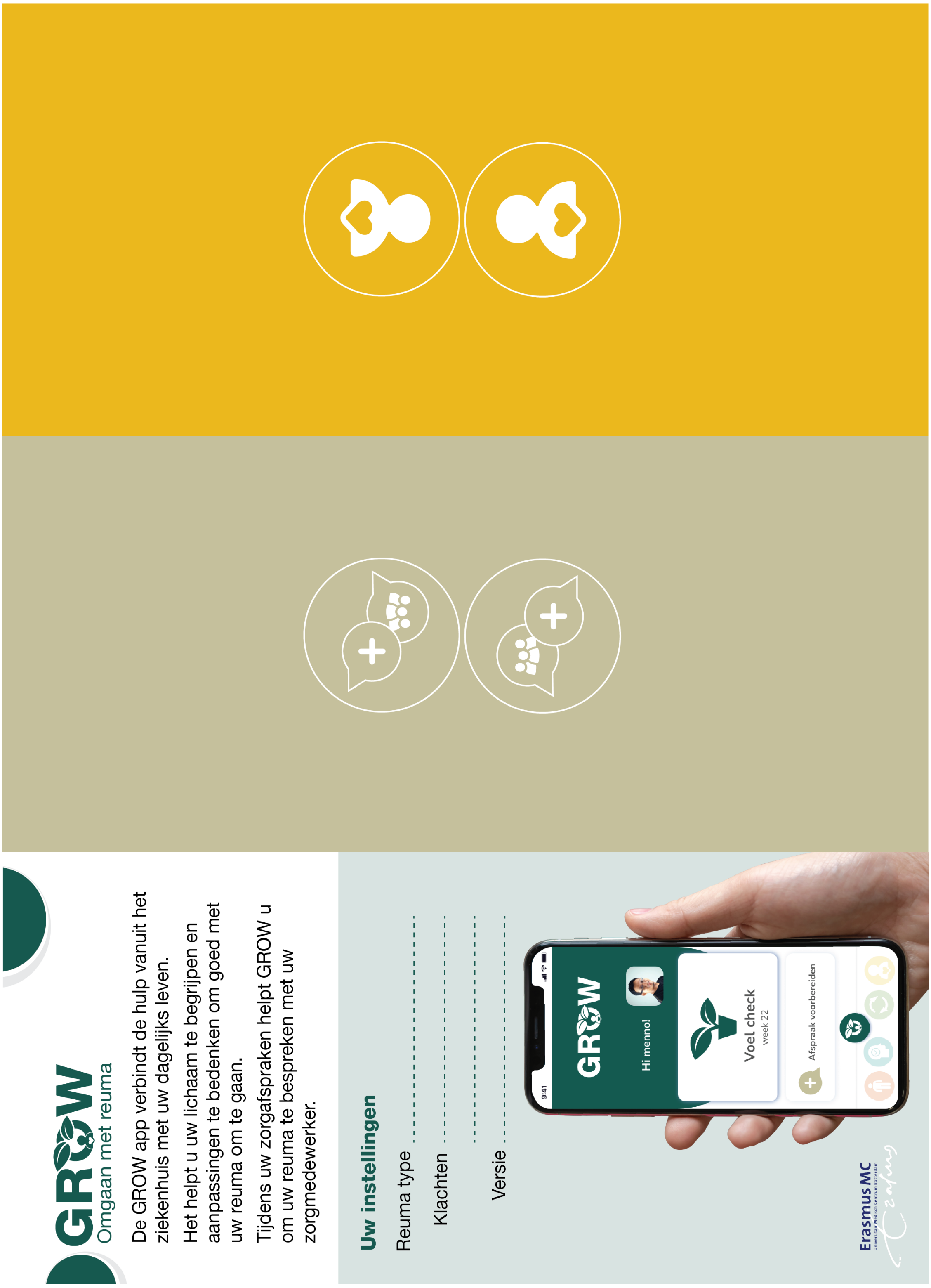
Leren omgaan met uw reuma

Elk lichaam met reuma en elk leven is anders. Het is belangrijk dat u uitzoekt hoe de reuma en medicatie in uw lichaam werkt en welke aanpassingen passen bij uw lichaam en leven.

Door bewust uw lichaam te voelen leert u uw reuma begrijpen. Dit geeft ideeen voor aanpassingen die u kunt uitproberen.
U merkt dan of de aanpassing werkt voor uw lichaam. U merkt of de aanpassing u helpt om de reuma te accepteren en te doen wat u belangrijk vind

Door te bespreken wat u voelt, leert en wilt aanpassen kunnen anderen u hierbij helpen

Back side



GROW

Omgaan met reuma

De GROW app verbindt de hulp vanuit het ziekenhuis met uw dagelijks leven.

Het helpt u uw lichaam te begrijpen en aanpassingen te bedenken om goed met uw reuma om te gaan.

Tijdens uw zorgafspraken helpt GROW u om uw reuma te bespreken met uw zorgmedewerker.

Uw instellingen

Reuma type ....

Klachten ....

....

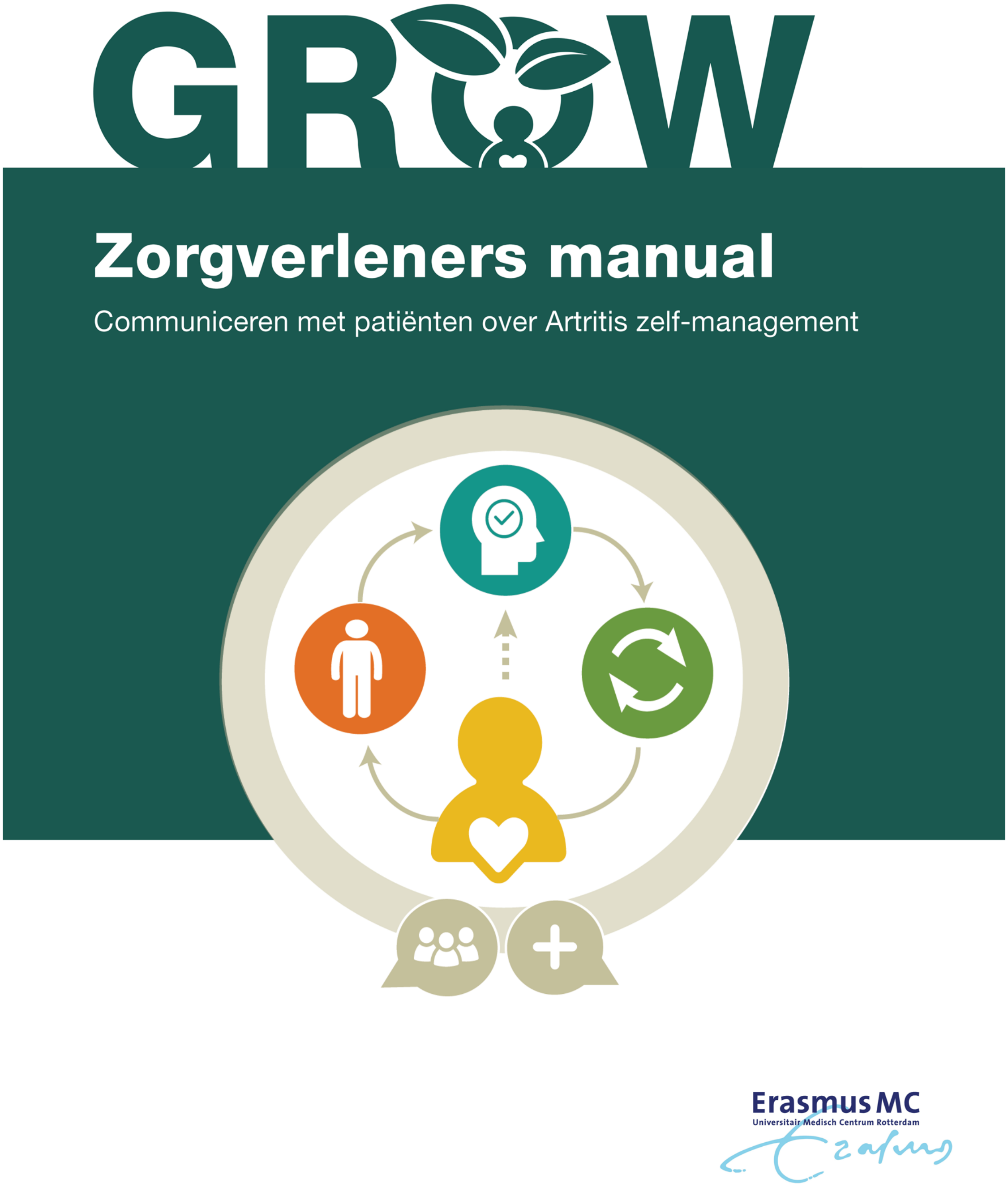
Versie ....

Omgaan met

Arthritis Psoriatica

Erasmus MC

Appendix I - Healthcare workers manual



GROW

Zorgverleners manual

Communiceren met patiënten over Artritis zelf-management

Erasmus MC
Universitair Medisch Centrum Rotterdam

Introductie: Wat is GROW?

De GROW aanpak bestaat uit een GROW communicatie aanpak en hulpmiddel voor thuis: de GROW-app. De aanpak is specifiek ontworpen om artritispatiënten met beperkte gezondheidsvaardigheden te ondersteunen bij het nemen van een actieve rol in het zelf-managen van hun ziekte. De GROW aanpak richt zich op het faciliteren van de overdracht van informatie tussen zorgverlener en patiënt en het begeleiden en motiveren van de patiënt om begrip te ontwikkelen van de ziekte en het omgaan hiermee. De aanpak wordt gestart aan het begin van het patiënten zorgpad.

De GROW-communicatie aanpak is gefocust op het opzetten van een duidelijke, consistente en stimulerende manier van communiceren over het onderwerp van zelf-management tussen zorgverleners en patiënten. De aanpak benadrukt 5 belangrijke zelf-management activiteiten: Voelen, Begrijpen, Aanpassen, Accepteren en Communiceren. Dit helpt een link te leggen tussen informatie die gecommuniceert wordt tijdens afspraken en het thuis omgaan met de ziekte door de patiënt. Door de 5 activiteiten te gebruiken als basis tijdens de communicatie ontstaat er een overzichtelijke en actie gerichte manier van indelen van informatie. Het helpt patiënten begrijpen hoe de informatie van relevantie is bij het zelf omgaan met de artritis en geeft patiënten bij vervolg afspraken houvast om zelf input te leveren tijdens het gesprek.

De aanpak maakt gebruikt van de GROW- kaart die op een simpele manier visualiseert hoe de 5 kern-activteiten met elkaar linken in een zelf-management leer cirkel. Deze GROW-kaart geeft de patiënten inzicht in hoe hij of zij zelf kan leren over de persoonlijke ziekte manifestaties en de strategieën die kunnen helpen om hier op een passende manier mee om te gaan. Het laat de patiënt zien dat hij of zij zelf een belangrijke rol heeft in het verminderen van de ervaren impact van de ziekte op zijn of haar leven.

De GROW app verlengd de zelf-management ondersteuning naar de thuis-situatie van de patiënt. De app stimuleert en begeleid patiënten in het leren van eigen ervaringen om meer begrip te ontwikkelen over de persoonlijke ziekte manifestaties en welke aanpassingen gemaakt kunnen worden om hier zo goed mogelijk mee om te gaan.

De GROW kern activiteiten

Bewust het lichaam **voelen.** Het is belangrijk dat patiënten voelen hoe de ziekte in hun lichaam manifesteerd, welke symptomen hier bij horen en hoe deze veranderen.

De eigen reuma **begrijpen.** Het is belangrijk dat patiënten inzicht krijgen in hoe de ziekte in hun lichaam manifesteerd en leren hoe ze hier op een bij hun lichaam en leven passende manier naar aan kunnen passen.

Aanpassingen maken om minder last van de reuma te hebben. Het is belangrijk dat patiënten aanpassingen maken, volhouden en blijven verbeteren om met de reuma symptomen om te gaan tijdens hun dagelijks leven.

Reuma **accepteren** als een onderdeel van het leven. Het is belangrijk dat patiënten om leren gaan met de reuma op een manier die hen helpt zo gelukkig mogelijk te leven.

Reuma bespreken met de dokter en omgeving. Het is belangrijk dat patiënten hun inzichten en behoeften goed bespreken zodat zorgverleners en omgeving hen kunnen begrijpen en helpen.

De GROW-kaart

Door bewust de symptomen te voelen leert de patiënt de reuma begrijpen. Dit geeft ideeën voor aanpassingen die de patiënt kan uitproberen. De patiënt merkt dat of de aanpassing werkt voor het lichaam en of het helpt om te doen wat hij of zij belangrijk vind in het leven. Goed bespreken zorgt ervoor dat anderen en de zorgmedewerkers hierbij kunnen helpen.

De zelf-management leercirkel

De GROW-kaart is gebasseerd op de zelf-management cirkel. Dit model geeft inzicht in de stappen die een patiënt doorloopt bij het leren van eigen ervaringen om zelf-management strategie op te stellen en te blijven verbeteren. Dit model geeft de zorgverlener meer inzicht in de punten waar de patiënt vast kan lopen in het leren over de ziekte en opstellen van strategieen om zijn of haar kwaliteit van leven te verhogen.

Het model uitgelegd

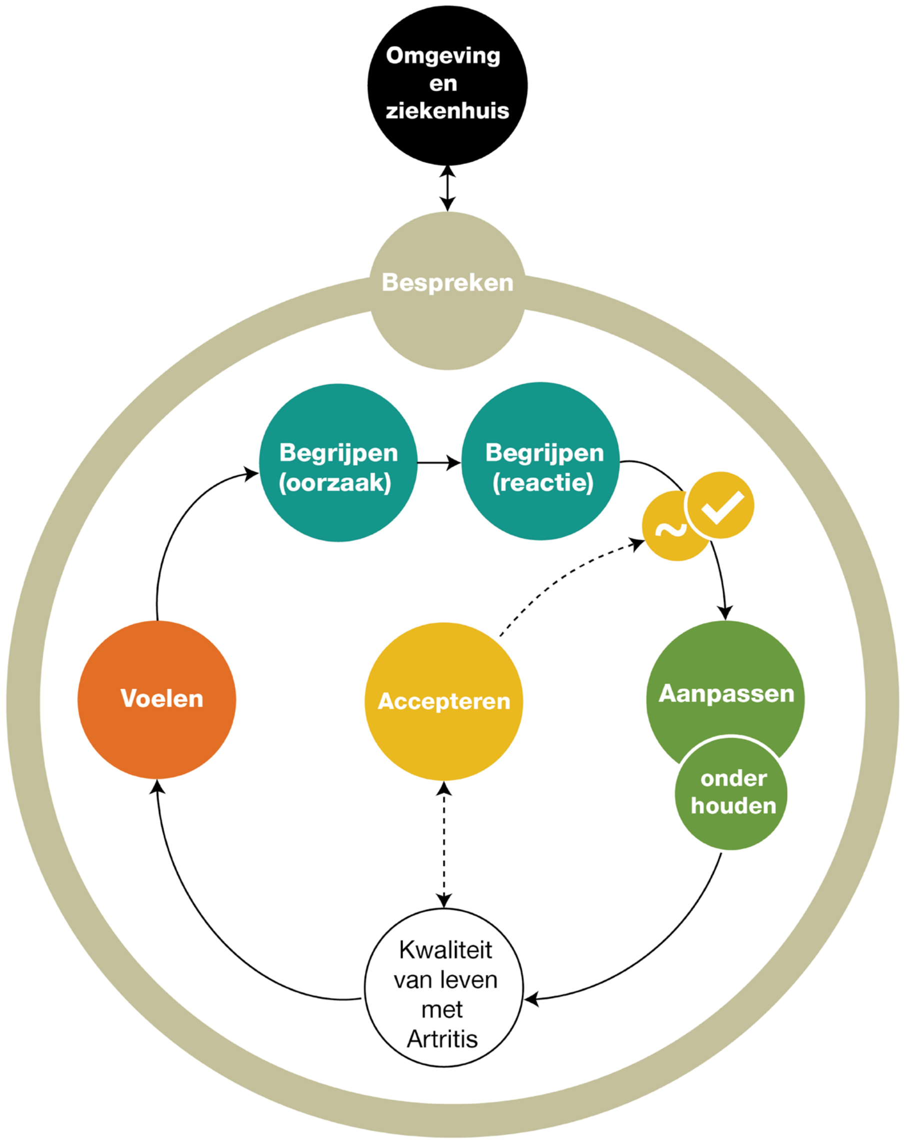
Door bewust de artritis klachten te voelen leert de patiënt zijn of haar lichaam met artritis beter begrijpen. De patiënt komt erachter wat veranderingen in symptomen veroorzaakt en welke handelingen lastig gaan.

Dit inspireert tot mogelijke aanpassingen. De patiënt bedenkt een plan en begrijpt welke aanpassing gemaakt kan worden. Vervolgens moet de patient deze aanpassing ook accepteren en willen maken om iets met dit plan te doen. Hierbij kan het zijn dat de patient de aanpassing tolereert in plaats van daadwerkelijk accepteert en een gevoel krijgt van het moeten doen in plaats van het willen doen. Doel is om aanpassingen te bedenken die de patiënt wil maken, om afwijzing van de strategie wanneer extra barrieres optreden te voorkomen.

De patiënt moet vervolgens de aanpassing realiseren. Zodra dit gelukt is en de actie in werking gezet is merkt de patient effect. De patiënt voelt veranderingen in zijn of haar artritis klachten en leert zo het effect van de aanpassing begrijpen. De patient bedenkt hoe te vervolgen met de aanpassing: onderhouden, stoppen of verbeteren. De patiënt vormt ook een nieuwe acceptatie mening over de aanpassing op basis van de ervaren consequenties en voordelen tijdens het leven. Dit heeft invloed op wat de patiënt met het begrepen inzicht wil doen. Het bepaald of de patient blijft doorgaan of de aanpassing afwijst. Wanneer er verminderde acceptatie is door ervaren consequenties kan stoppen met de aanpassing soms een hogere kwaliteit van leven opleveren dan doorgaan met de aanpassing met een gevoel van moeten. Echter is het eind doel om de patiënt bij verminderde acceptatie diep genoeg te laten nadenken om tot aanpassingen te komen die hij of zij wil maken.

Het verbeteren, stoppen of doorgaan met de aanpassing zorgt weer voor nieuwe effecten. Zo blijft de patiënt de cirkel doorlopen en leert de patient steeds meer over het omgaan met zijn of haar lichaam met artritis.

Communicatie is een externe beïnvloedende factor in dit proces. Dit kan elke stap positief of negatief beinvloeden. Door inzichten en behoeften rond de 5 kern activiteiten goed te bespreken met mensen in de omgeving en de zorgverleners kan de patiënt het doorlopen van deze cirkel faciliteren en kan de omgeving en de zorgverlener de patiënt ondersteunen met informatie of andere hulp.

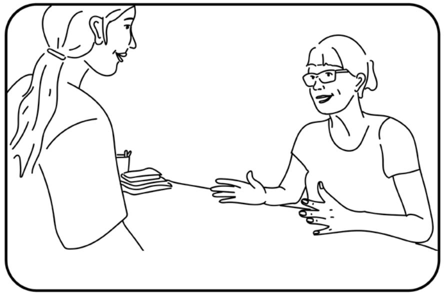


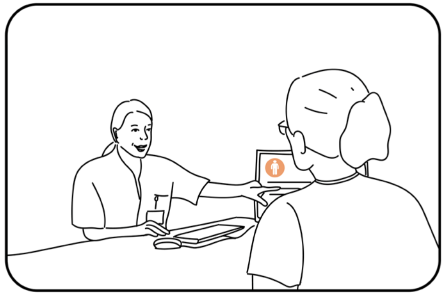
GROW communicatie toepassen

De GROW communicatie wordt gïntroduceerd in verschillende stappen tijdens de diagnositische afspraak met de consulent. Tijdens vervolg afspraken wordt de GROW communicatie gebruikt om met de patient te communiceren over het zelf-managen thuis.

Diagnostische afspraak consulent

Stap 1: Eerste ontmoeting met de patiënt en algemene uitleg





Doel
- Inschatten houding patiënt tegenover zelf-management.
- Inschatten niveau van gezondheids vaardigheden.
- De patiënt vertrouwd maken met de 5 kern-activiteiten.

Richtlijn 1

Het gesprek wordt open benaderd om de patient te leren kennen. De patiënt krijgt de ruimte om zelf het gesprek te leiden, aan tegeven wat er begrepen is en waar vragen over zijn.

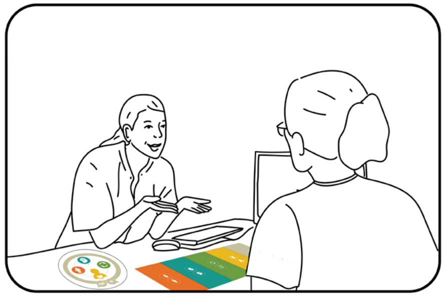
Richtlijn 2

Tijdens het gesprek worden de 5 kern-activiteiten als woorden gebruikt tijdens het uitlegen van de voor de activiteit relevante informatie. De woorden worden geintroduceerd maar nog niet expliciet uitgelegd. Zo maakt de patiënt a langzaam kennis met de 5 kern-activiteiten.

Richtlijn 3

De uitleg PowerPoint kan worden afgestemd op de communicatie aanpak. Dia's bevatten een kop icoon met de kern-activiteit en bevatten de informatie die relevant is voor die activiteit. De indeling van deze informatie is in lijn met de indeling van de informatie in de communicatie folder.

Stap 2: Introductie van de GROW activteiten en kaart



Doel
- De patiënt inzicht geven in wat zelf-management inhoud.

Richtlijn 1

De 5 kern-activiteiten worden geïntroduceert. Hierbij wordt de achterkant van de flyer gebruikt zodat de visuele taal geïntroduceerd wordt maar de patiënt nog niet overweldigd wordt door de tekst op de andere zijde.

Richtlijn 2

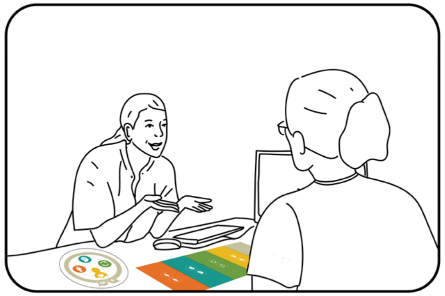
De visuele GROW-kaart wordt gebruikt om de leer cirkel van zelfmanagement te introduceren. De consulent legt uit hoe de activiteiten met elkaar verbonden zijn en samen de patiënt kunnen helpen om de arthritis in zijn of haar lichaam te begrijpen en om te gaan met de impact van arthritis op zijn of haar leven. Voorbeelden kunnen worden gebruikt om deze relatie tussen de activiteiten te verduidelijken. Een relevant voorbeeld is dat van medicatie-inname.

> *Voorbeeld medicatie-inname: De patiënt voelt nu klachten, heeft door de diagnose begrepen waar het door komt en geleerd dat de medicatie een aanpassing is om hierbij te helpen. De patiënt gaat deze aanpassing maken en zal merken dat dit invloed heeft op zijn leven (bij-effecten en regime) en op zijn ervaring van symptomen (en wellicht fysieke bijwerkingen).*

Indien het nodig lijkt kan er een metafoor worden gebruikt om de relatie tussen de aspecten op een meer alledaagse manier te beschrijven. Een voorbeeld is het verzorgen van een plant. Dit voorbeeld wordt ook gebruikt in de GROW app.

> *Voorbeeld plant: Zien dat een plant begint te hangen, weten dat de plant water nodig heeft, bedenken dat je een gieter moet pakken. De plant water geven. Wachten op het effect. Dit is een goed voorbeeld om te laten zien dat het opmerken van het effect van een aanpassing tijd kan kosten.*

Stap 3: Het doel en belang duidelijk maken



Doel

- De patiënt motiveren om met zelf-management aan de slag te gaan.

Richtlijn 1

Het belang van de patiënt zijn actieve rol wordt uitgelegd. Nadruk wordt gelegd op het feit dat elke patient een uniek lichaam en leven heeft. Het ziekenhuis kan informatie en tips geven, maar de patient zal er zelf het beste achter komen hoe de ziekte in zijn of haar lichaam werkt en welke aanpassingen binnen zijn of haar leven nodig zijn en passen. Nadruk wordt gelegd op de begeleiding die het ziekenhuis hierbij kan bieden als de patiënt hier goed over communiceerd tijdens afspraken. Dit om de patiënt en gevoel van ondersteuning te geven.

Richtlijn 2

Samen met de patiënt wordt er een duidelijk en realistisch doel opgesteld om naar te streven met het uitvoeren van de leer cirkel. Een doel omtrend: ‘inzicht krijgen in de ziekte en erachter komen hoe de invloed van de reuma op het leven te verminderen’ kan voor sommige patiënten voldoende zijn. Indien mogelijk kan het extra motiverend zijn om een concreet doel op te stellen. Hierbij wordt het algemene doel van vermindering van pijn vermeden en gezocht naar meer concrete doelen. Denk hierbij met name aan emotioneel gericht doelen met betrekking tot het kunnen ervaren van waardevolle momenten en bezigheden.

Richtlijn 3

Meer afhankelijke en volgzame patiënten hebben extra motivatie nodig om zelf een actieve rol aan te nemen in plaats van de expertise van de zorgverlener te volgen. Bij deze patiënten is het van belang te benadrukken dat het zelf opdoen van inzichten en goede communicatie hiervan naar de de zorgverlener helpt om zijn werk zo goed mogelijk te doen en inzichten van de patiënt te kunnen valideren.

Stap 4: Informatie flyer uitleggen en personaliseren

Doel

- Herhalen van informatie binnen de 5 kern-activiteiten.
- Benadrukken van medicatie en persoonlijke symptomen.

Richtlijn 1

De voorkant van de flyer wordt gebruikt om de belangrijkste informatie te herhalen ingedeeld per categorie. De flyer wordt gepersonaliseerd voor de patiënt zijn of haar symptomen en medicatie. De informatie wordt samen ingevuld zodat er een persoonlijk gevoel bij de flyer ontstaat en de belangrijkste persoonlijke informatie benadrukt wordt.

Stap 5: Introductie GROW app

Doel

- Stimuleren van de patiënt om thuis met de GROW app aan de slag te gaan.

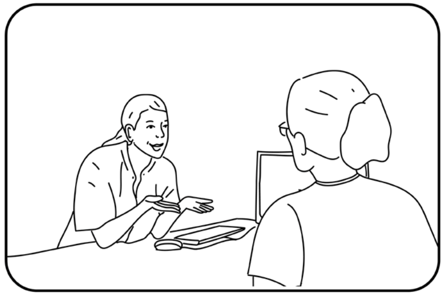
Richtlijn 1

De flyer pagina over de GROW app wordt geïntroduceerd. De voordelen van de app worden benadrukt: (1) Een handige informatie basis, (2) ondersteuning bij het voelen en begrijpen van het lichaam en het bedenken van aanpassingen, (3) een manier om gevoel en inzichten bij te houden om met de reumatoloog de bespreken. Op de flyer worden de instellingen passend bij de patiënt ingevuld: Type reuma, ontstekings locaties en de versie. De versie hangt af van de ziekte activiteit van de patiënt (1= lagere ziekte activiteit, 2=hogere ziekte activiteit).

Richtlijn 2

Bij inschatting van lage digitale vaardigheden kan de patiënt uitgenodigd worden om samen de app te downloaden en in te stellen. De Voel Check notificatie wordt samen ingesteld, zodat de patiënt thuis enkel wekelijks op de notificatie hoeft te klikken.

Stap 6: De afspraak afronden



Doel
- De patiënt bewust maken van de mogelijkheid tot communicatie vanuit huis.
- De patient voorbereieden op communicatie tijdens de volgende afspraak.

Richtlijn 1

De patiënt wordt gestimuleerd om vanuit huis contact op te nemen wanneer er afwijkende dingen gevoeld worden (bijwerkingen) of onzekerheden zijn rondom het aanpassen en nemen van medicatie.

Richtlijn 2

De patiënt wordt herinnert aan het ontwikkelen van inzichten binnen de 4 kern-activiteiten (naast bespreken) om te bespreken bij de volgende afspraak. En krijgt de flyer mee om hiermee aan de slag te gaan.

Richtlijn 3

De digitale Zorg-op-Maat kan worden gestructureerd in de 5 kern-activiteiten.
Het huidge menu staat al in de juiste volgorde. Dit houd de informatie voorziening consistent te houden en maakt het voor patiënten makkelijker om extra informatie te vinden.

Vervolg afspraken Reumatoloog / Consulent

Doel
- De patiënt stimuleren om thuis opgedane inzichten te communiceren.
- Pijn punten identificeren aan de hand van de zelf-management leer cirkel.

Richtlijn 1

De GROW-kaart wordt op tafel gelegd tijdens de afspraak. Bij de vraag hoe het omgaan met de ziekte thuis gaat wordt actief gerefereerd naar de kaart om de patiënt te inspireren en stimuleren om inzichten te delen. Zorgverlener kan het model van de zelf-management leer cirkel in gedachte houden om in te schatten waar de patiënt vastloopt in het omgaan met de ziekte en hier extra aandacht aan besteden.

Richtlijn 2

De patiënt kan worden gevraagd of hij zij de GROW app heeft gebruikt. De patiënt kan worden gevraagd of hij zij de afspraak heeft voorbereid met de app. Indien dit het geval is kan het door de app gemaakte afspraak scherm erbij gepakt worden. Als de patiënt de app wel heeft gebruikt maar niet de afspraak heeft voorbereid kan het voel menu erbij gepakt worden om samen naar de grafiek te kijken. De patiënt kan worden uitgenodigd om belangrijke opgeslagen inzichten te delen.

Richtlijn 3

Indien er een concreet doel is gesteld kan dit doel geevalueerd en eventueel gespecificeerd of aangepast worden. Indien er nog geen concreet doel gesteld was kan worden ingeschat of er een realistisch doel kan worden opgesteld samen met de patient. Denk hierbij aan het meemaken van waardevolle momenten, activiteiten of bezigheden.

Appendix J - Use cases GROW app

Installing the app

When the app is installed, the patient gets an introduction video. This video gives a visual and audio explanation of the five core activities and the GROW loop. Referring to the app name ‘GROW’, the video uses the example of growing a plant to explain the cause-consequence relation of the GROW loop.

The patient sets his profile by entering the Arthritis type and inflammation locations. Also, the patient chooses an app version (1 or 2). The version is advised by the consultant and depends on the patient’s disease activity. The patient can select a read-out-loud function.

After this, the patient gets his first Feeling Check which ends with choosing the moment to get the weekly Feeling Check reminder.

The screens during installing the app are shown in Appendix Figure 4.

Naam Menno
Reuma type Artritis Psoriatica
Klachten
Versie 1a
Voorleesfunctie ja

Appendix Figure 4

Installing the app

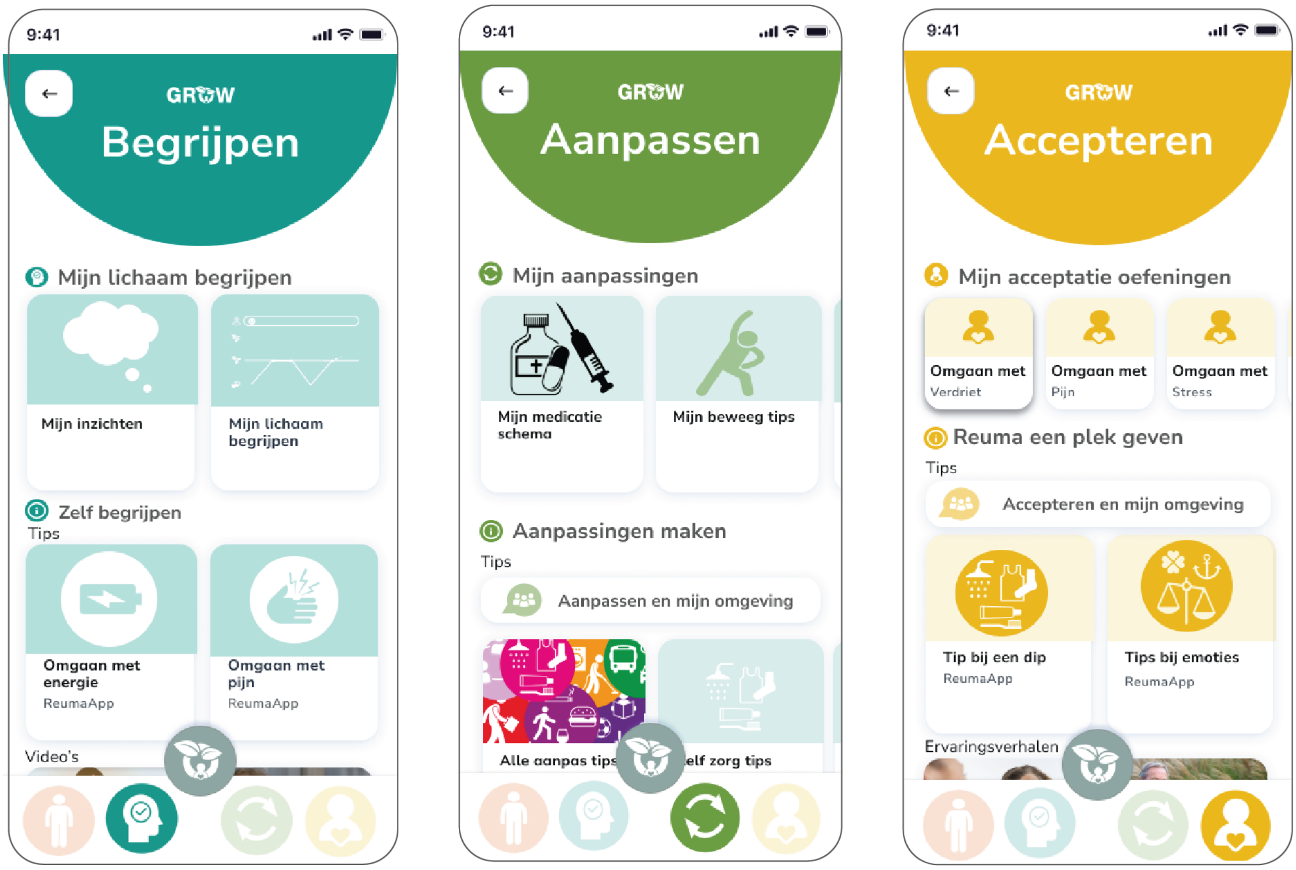
The GROW app consists of 4 menus related to the GROW core activities Feeling, Understanding, Adapting, and Accepting. Information, tips, and exercises are categorized in the core-activity menus to guide patients in understanding how to use the information in dealing with their disease.

Every menu includes a part that tailors to the patient during app use. The patient can find a graph overview of the entered Feel data in the Feel menu and revisit their saved insights in the Understand menu. The adapt menu provides personal information around adapting tailored to the patient’s entered symptom locations and disease type.

The acceptance menu highlights exercises relevant to the patient’s main feeling that month.

The acceptance menu’s are visualised in Appendix Figure 5 and 6.

Appendix Figure 5



Appendix Figure 6

Preparing appointments

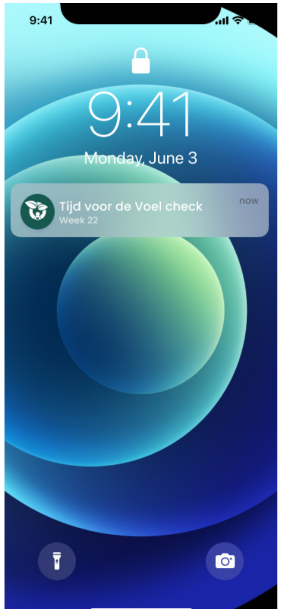
The app’s main screen contains a button inviting the patient to prepare for his appointment. The patient is stimulated to revisit the monthly feeling graphs and saved insights and asked to highlight interesting things to communicate. Triggering questions encourage the patient to decide on his goal for that appointment and what he would like to get support in. Based on this, the app generates a summary that can be revisited during the appointment.

The main screen including the preparing appointment function is shown in Appendix Figure 7.

Appendix Figure 7

Appendix K - Learning loop 2

START



Tijd voor de Voel check
Week 22

Hi !

Klik op het scherm om door te gaan

Wat fijn dat je er weer bent!

Voelen

Denkend aan je reumaklachten...

Hoe voelt je lichaam vandaag?

Bad

Ai dat is vervelend...

Misschien kan dit gevoel je helpen om te leren over het omgaan met je reuma

Begrijpen

Misschien voelt je lichaam minder goed door iets waar je zelf invloed op hebt

Als je terugdenkt aan je levenswijze de afgelopen tijd..

Kan je iets bedenken wat dit gevoel kan hebben veroorzaakt?

Yes

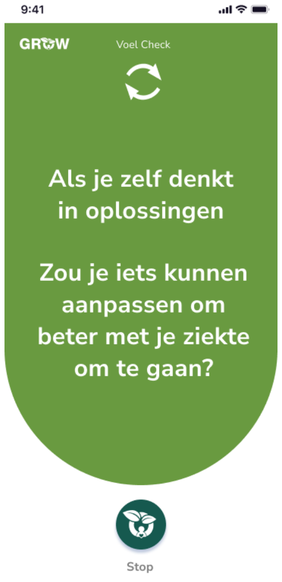
Wat goed!

wat zou dit kunnen zijn?

Bespreken

Je kunt hier bij je volgende afspraak hulp over vragen

Aanpassen



Als je zelf denkt in oplossingen

Zou je iets kunnen aanpassen om beter met je ziekte om te gaan?

Accepteren

Denk goed aan aanpassingen die je ook zou willen maken

Misschien kan je tips vinden in de app

No

Je minder voelen kan ook komen door dingen waar je zelf geen invloed op hebt

Zoals het weer, hormonen en wisselingen in de ziekte activiteit

In de app kan je meer informatie vinden over deze veranderingen en omgaan met energie en pijn

GROW