A design approach to improve the bridge between hospital and rehabilitation for patients with joint complaints.

Master thesis

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Design forms the bridge between hospital and rehabilitation for patients with joint complaints.

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Acknowledgement

Dear reader,

Thank you for taking the time to read my graduation thesis. This project has been the most important and extensive part of my academic journey, and I'm proud to finally share it with you. When I started, I wasn't sure where the process would take me or what the outcome would be. Now, after six months of hard work, I'm pleased with the results and everything I've learned, both about the healthcare field and new design approaches.

I'm very grateful to everyone who contributed to this project. I would like to thank my supervisors, **Jos and Peter**, for your guidance and valuable feedback throughout the process. **Petra**, your weekly support and positive attitude helped me find my way in the complex healthcare setting, thank you for that.

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With this thesis, my time as a student comes to an end. I'm proud to present the outcome of this journey and hope it offers you the same curiosity, inspiration, and reflection that it brought me throughout the process.

Throughout the writing process of this thesis, I used ChatGPT as a tool to help refine the language and improve clarity in my self-written texts. The content, research, and ideas presented are entirely my own.

Kind regards,

Kim Gaus

Executive summary

The healthcare sector is under pressure due to the aging population and a growing number of chronic musculoskeletal disorders, which are driving up healthcare demand. One of the key challenges within this system is the **transition between hospital care to rehabilitation.** This stage can be characterized by a lack of transparency, guidance and long waiting periods. Because of this, many people define it as a **"black hole"** in their care pathway. This project aims to improve this "black hole" period, with an emphasis on patients with joint complaints.

The goal of this graduation project is to **improve the healthcare experience for patients with joint complaints from the initial hospital appointment to the the start of rehabilitation.** Focusing on the context of Basalt rehabilitation and Reinier de Graaf Hospital.

Using a user-centered design approach supported by the Double Diamond model, the project involved extensive literature research, context mapping, interviews, and observational studies with both patients and healthcare professionals. The insights revealed four major challenges:

- Insufficient and unclear communication from healthcare providers in the hospital to patients.
- Late or missing information during hospital appointments for patients.
- Unrealistic expectations about rehabilitation due to misunderstandings by healthcare providers.
- A lack of resources for patients to treat chronic pain before the start of rehabilitation.

The patient interviews showed that patients gain valuable knowledge and skills, such as energy management and understanding of the pain system, during rehabilitation. While this information and tools could have helped many patients much earlier. Delayed access to such insights can lead to a lower quality of life.

These insights shaped the final design, **the Pacewise app.** This app is an useful tool meant to give patients a **timely and easily way to better manage their energy levels** before they require rehabilitation.

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01

Introduction

In this chapter, the assignment is explained. It outlines the context of the project, its scope, and focus. Additionally, relevant stakeholders and actors are discussed. Finally, the project approach is presented, including a description of the used methods.

This chapter answers the following questions:

- What is the project assignment and scope?
- Who are the relevant stakeholders?
- What is the project approach?

1. Introduction

1.1 Project assignment

1.1.1 The context around the referral to rehabilitation

Healthcare consumption is expected to increase exponentially in the coming years, leading to a growing shortage of human resources and rising costs (VWS, 2023) (Sterenborg, 2023). To ensure that patients continue to receive appropriate care throughout their health journey while keeping the healthcare accessible and affordable, significant changes are needed.

Chronic musculoskeletal conditions (pain perceived in musculoskeletal structures, such as pain in the muscles, tendons, and joints) are a major contributor to functional limitations in developed countries, impacting between 13.5% and 47% of the population (Cimmino et al., 2011). These conditions often lead to reduced productivity, loss of economic independence, and, in many cases, early workforce exit. As a result, these conditions impose a significant financial burden on both individuals and society (March et all, 2014).

Several studies have shown that patients with chronic musculoskeletal conditions benefit from rehabilitation as it equips them with the necessary resources to enhance independence (Kjeken et al., 2014). This program is often an intense period with many new experiences to take in.

The referral from the hospital to rehabilitation takes place within a complex system. This calls for research focused on mapping out the entire process, analyzing bottlenecks and risks, and identifying opportunities to better meet patients' needs.

One of the problems patients experience is a period of uncertainty between being discharged from the hospital and the start of rehabilitation. This phase is often referred to as the 'black hole' period, as many people do not know what to expect and miss relevant information during this time. To identify key bottlenecks in this phase, a context analysis, thematic analysis, interviews, and desk research need to be conducted. The scope of this project is further explained in the next paragraphs.

1.1.2 Scope and focus of the project

This project focuses on optimizing the healthcare journey from the first hospital appointment to the start of rehabilitation for people with joint complaints. There are multiple periods within this journey during which patients have to wait for an appointment with a healthcare professional. During these periods, patients often do not receive the appropriate support they need. To gain a complete understanding of the patient journey all waiting periods until the start of rehabilitation are included within the scope.

Rheumatism is a broad term encompassing more than 100 different disorders affecting the joints, muscles, and tendons. Osteoarthritis is the most common rheumatic disorder impacting the musculoskeletal system. In the Netherlands alone, nearly 1.5 million people live with osteoarthritis, experiencing its impact on their daily lives (Artrose|ReumaNederland, z.d). By 2040, this number is expected to rise to 2.5 to 3 million, and the actual figures may be even higher (Artrosecijfers Nog Erger Dan We Denken | ReumaNederland, z.d.).

In this project, I will begin by mapping the current rheumatological care process to identify bottlenecks and understand patient needs. Based on these insights, a design direction will be formulated, leading to the development of a final concept. The project will conclude with a comprehensive design proposal.

Design aim:

"Design a tool that improves the healthcare experience for patients with joint complaints from the initial hospital appointment to the the start of rehabilitation."

1.1.3 Relevant stakeholders

Several stakeholders play crucial roles within this complex healthcare ecosystem. Reinier de Graaf Hospital and its employees are essential, since they are directly involved in providing care to patients. Specifically the healthcare providers who are involved with the care for people with joint complaints, such as the rheumatologist and the rheumatology nurse.

Patients themselves are also key stakeholders, as any future changes to the system will significantly affect their experiences. Besides the patients themselves and employees from Reinier de Graaf hospital, also the rehabilitation staff play an important role, as they contribute directly to the care and recovery of patients. From the desk research a stakeholder map is made and shown in figure 1. The most important stakeholder is placed in the inner circle. Each surrounding ring represents a different level of importance within the system, with the inner ring indicating the highest importance and the outer ring the lowest.

The patient stands in the middle of the stakeholder map, as the health journey is centered around the patient. In the next level up, actors who come into direct contact with the patient for treatments are displayed. This includes for example their General Practitioner (GP), rehabilitation physician and rheumatologist. The next circle includes people that indirectly influence the health journey of the patients for example family and friends. In addition to healthcare providers and institutions, there are various other people and entities that can have a significant influence on a patient's life when dealing with severe joint complaints; these actors are included in the outer circle. These are for example support groups, public health authorities and fitness centers.

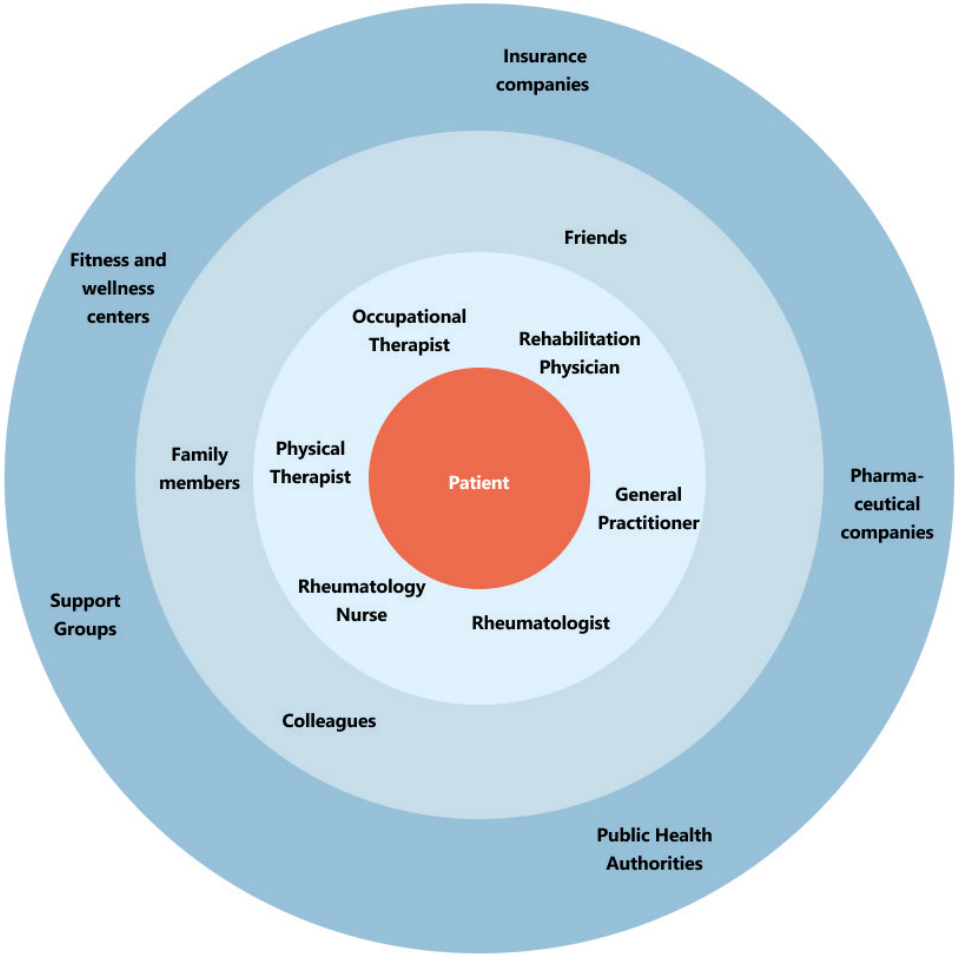

Figure 1: Stakeholder map based on desk research, indicating most important stakeholder (inner circle) to less important stakeholders (outer circles)

2.1.2 Double Diamond Model

The Double Diamond Model (DDM) is used as the starting point of this project. The DDM is a visual representation of the design and innovation process. It consists out of four stages of design; discover, define, develop and deliver. And is split into two phases, the first is the problem phase and the second is the solution phase.

Within the first diamond, the context and problem are first further discovered to widen the scope. The results of these processes are summarized to define a final design direction. Research and activities conducted during this diamond are literature study, observations and interviews with patients and relevant healthcare workers. This diamond will result in a journey map highlighting key bottlenecks. These insights will support decision-making in the next phase by identifying which design solutions are most valuable and how they align with the identified problems.

The second diamond focuses on the solution directions. The new design direction will lead to different concept directions. The insights and user interviews will leading towards one final design. The design activities planned for this diamond are idea generation, prototyping and concept testing. This phase will end with an evaluation to test the final design and a discussion and conclusion of the full project.

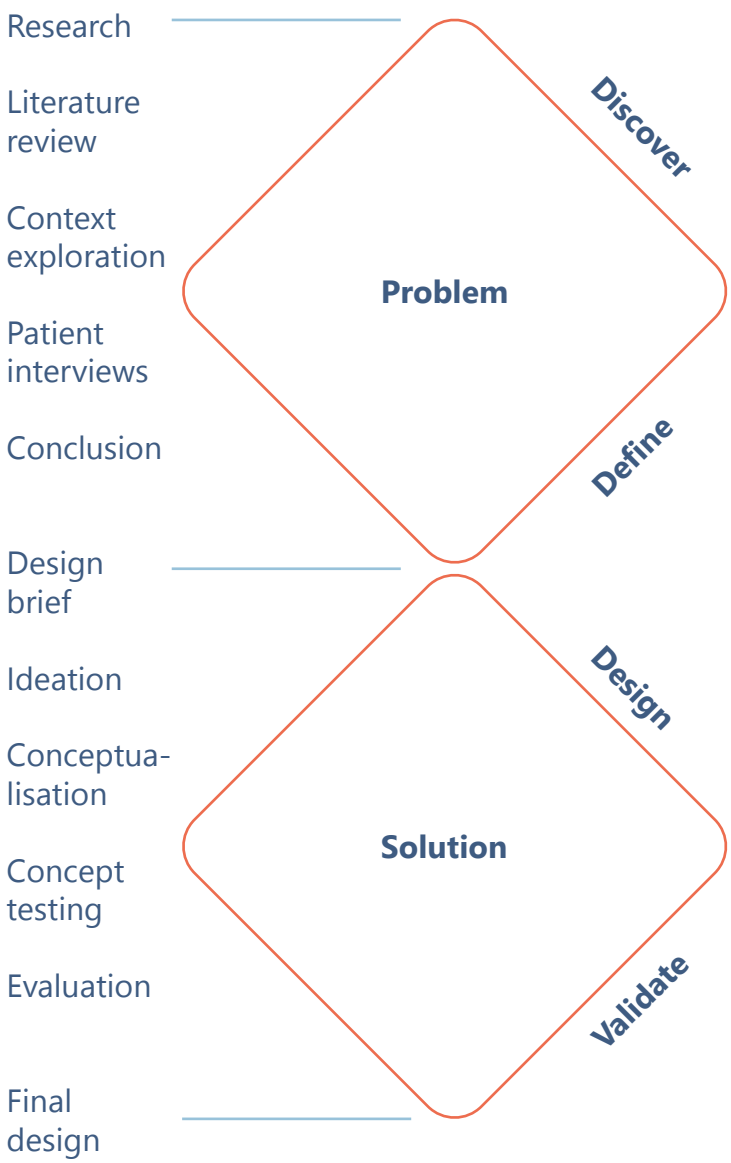

Figure 2: Double Diamond Model with relevant activities and stages

2.1 Project approach

2.1.1 Patient journey mapping and context mapping

Through observations, interviews, journey mapping, and context mapping, I will identify key pain points. Based on these insights, I will formulate a design goal, which will guide the design direction and ultimately lead to a final design concept.

The design method '***patient journey mapping***' will be used to gain an overview and insight into this "black hole" period. The patient journey helps identify bottlenecks, risks, and necessary changes within the healthcare process. This study focuses on the period from hospital appointments till the start of rehabilitation. A journey map clarifies the steps involved in this process and will help with showing what happens at each stage.

'***Context mapping***' is another method that helps uncover patients' emotions, which are often difficult to capture. This research explores the experiences, wishes, and needs of patients. By doing so, care can be better tailored to meet these needs, ultimately improving the quality of healthcare.

02

Literature review

This chapter consists of a literature review on rheumatism and rehabilitation. All information was obtained from academic papers. It begins with general information about joint complaints, followed by an exploration of the pain system. Additionally, the impact on mental health is described. The importance of rehabilitation is then discussed, and the chapter concludes by examining the gap between hospital care and rehabilitation. A brief summary wraps up the chapter.

This chapter aims to answer the following research questions:

- What types of joint complaints are there?
- What factors influence rheumatism?
- What treatment options are available for rheumatism?

2. Literature review

Joint complaints are common and can vary greatly in severity and cause. This paragraph introduces what joints are and explains the different types of joint-related issues people may experience.

2.1 Joint complaints

2.1.1 Background information about joint complaints

The joint serves as a hinge allowing the bones to move. A person has larger joints and smaller joints. (Ik Heb Last van Mijn Gewrichten. Wat Kan het Zijn? | Thuisarts.nl, 2023). Joint pain is a common issue that can affect all people. It can be mild, causing only a bit of discomfort. However in some cases it can cause severe pain which can significantly impact someone's daily life (Van Beek, 2024).

Joint pain can have multiple causes and varies from person to person. Joints are made up of several components, including cartilage, ligaments, membranes, fluids, and tissue. There are different types of joint complaints, which will be explained in more detail in the following paragraph.

Figure 3: Joint pain in the knee (AHC Fysiotherapie, 2025)

2.1.2 Types of joint pain and rheumatism

Joint complaints can have various causes. For example, the joints may be overstrained, or they may hurt due to an injury. It is also possible that an infection caused by bacteria in the joint leads to severe joint pain, a condition known as septic arthritis (Gewrichtsontsteking door Bacteriën) | LUMC, z.d.). Additionally, some people experience joint pain that is not caused by bacteria but by another underlying disease, such as Crohn's disease or ulcerative colitis. One of the most common causes of joint pain is rheumatism.

Rheumatism is a permanent disease of muscles, joints or tendons (Reuma Nederland, 2024). Almost 2 million Dutch people have a form of rheumatism, this is equal to 1 in 9 Dutch people (Reuma Nederland, 2024). There are dozens of forms of rheumatism, which can be categorized into five major groups:

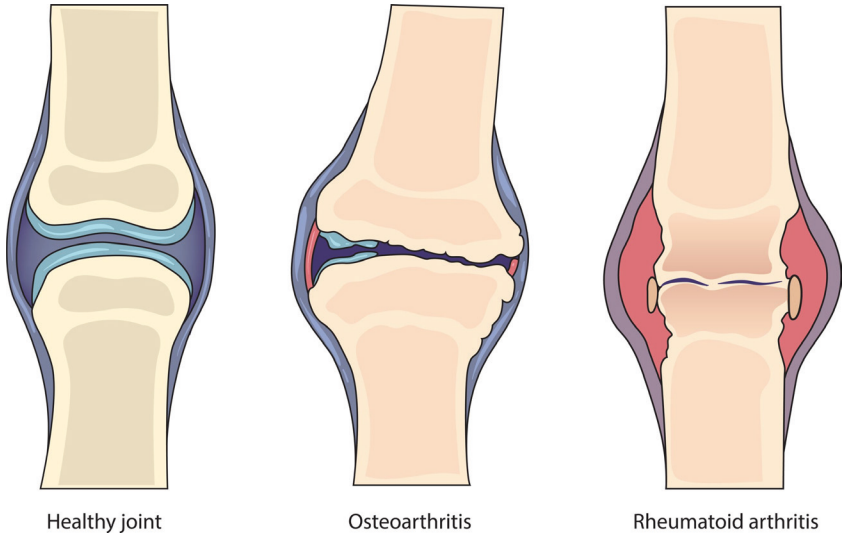

Figure 4: Healthy joint (left), joint with Osteoarthritis (middle), joint with Rheumatoid Arthritis (right) (Arthritis - Symptoms And Causes, z.d.)

1. **Inflammatory rheumatic diseases:** In this condition, the joints remain inflamed for a long period. Rheumatoid Arthritis (RA): is one of the most common forms of inflammatory rheumatism. In rheumatoid arthritis, the body's immune system is disrupted, leading to chronic inflammation in the joints. It is an autoimmune disease in which the immune system attacks the body's own tissues (Umcu, z.d.). In the Netherlands, approximately 260.000 people have rheumatoid arthritis.
2. **Osteoarthritis:** This disease involves damage to the cartilage around the ends of the bones. Osteoarthritis (OA): is the most common form of arthritis (arthritis is an inflammation of the joint or joint capsule). It occurs when the protective cartilage that cushions the ends of the bones wears down over time (Osteoarthritis - Symptoms & Causes - Mayo Clinic, 2021). Therefore, some people also call it the wear and tear disease. But besides the breakdown of cartilage, osteoarthritis affects the entire joint. In the Netherlands nearly 1.5 million persons suffer from it, especially in the hands and knees. The prevalence is expected to rise to over 2.3 million persons in 2040 (Towards New Treatments For Osteoarthritis | LUMC, z.d.).
3. **Soft tissue rheumatism:** The pain is not in the joints themselves but in the surrounding areas. The best-known soft tissue rheumatism is fibromyalgia. Fibromyalgia is a condition that causes long-term (chronic) pain in your muscles and connective tissue (Reuma Nederland, 2024).
4. **Crystal arthropathies:** is caused by the deposit of crystals in and around the joints. These crystals can lead to inflammation, pain and joint damage. One of the most common types is gout. Gout mostly affects the joint at the base of the big toe. It results from an excess buildup of uric acid in the body, leading to the formation of crystals in the joints. These crystals cause inflammation and severe pain (Reuma Nederland, 2024). In 2024, approximately 350,000 people in the Netherlands suffered from gout (Borsje, 2024).

2.1.3 Treatment of rheumatism, treat to target

Most forms of rheumatism can be treated in an effective way. The treatment is depended on the condition and the person. Rheumatism treatment often includes medication and advice on physical activity and lifestyle changes. However, rheumatism itself is not curable yet. Most people with rheumatism stay under the care of their healthcare provider, who monitors how things are going and whether the symptoms are improving or worsening.

Rheumatism is treated according to the “treat-to-target” approach, meaning that the treatment is adjusted based on the patient’s condition (specifically their flare-ups). The goal is to achieve remission, with as little medication as possible. The rheumatologist assesses whether the treatment needs to be adjusted. The European Alliance of Associations for Rheumatology (EULAR) guidelines help healthcare professionals in diagnosing, managing, and treating rheumatic diseases (Recommendations Management | EULAR, z.d.). However, not all types of rheumatism can be treated with medication.

When pain persists for more than three months, it is often called chronic pain. In that case, people need to learn how to live with their pain rather than focusing on pain reduction throug medication. About 3 million people in the Netherlands have chronic pain (Ministerie van Volksgezondheid, Welzijn en Sport, 2024).

The following paragraph will explain how the pain system works and what factors influence the pain perception of individuals experiencing chronic pain.

2.2 The working of the pain system

2.1.1 Influences on the pain system

To identify the influences on the pain system, research from the books '***Pijn & het brein***' and '***Verklein je pijn***', as well as findings from literature research, were used. The following key points emerged:

- **Why do we experience pain?** Pain exists to protect the body from threats. There are three protective systems in the body: the pain system, the immune system, and the stress system. All three work together to protect the body from danger. However, sometimes these systems remain 'active' even after the threat has passed. This overprotection is often the cause of chronic pain. It can lead to changes in the pain system, making pain feel more intense. This happens because pain signals are transmitted differently due to altered neurotransmitter activity.

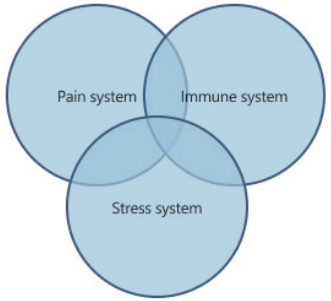

Figure 5: Protective systems in the body

Damping and amplifying effects: All parts of the pain network can have both a dampening and an amplifying effect on how pain is experienced. Even just thinking about pain can make a particular area feel more sensitive. It's important to note tha pain itself is never transmitted to the brain, only "pain signals" (nociception) are. The brain is constantly scanning for potential danger. When many pain signals reach the brain at once, they can be interpreted as a pain experience. In this sense, pain is a product of the brain. When danger is spotted, the body gives a signal. The sensors send these signals through the nervous system toward the brain. This process is not direct. The signals pass through several relay stations in the spinal cord and brain. At each station, it is determined whether a signal should be passed on to the brain. Each relay station forwards the signal to the next nerve, which then passes through another station, and so on. The stations can block, weaken, or amplify a signal.
The stations act as gatekeepers, they decide how many signals are allowed going through. The more open the gate, the more signals pass to the brain. This explains why the amount of physical damage someone has, does not necessarily correspond to the amount of pain someone feels.

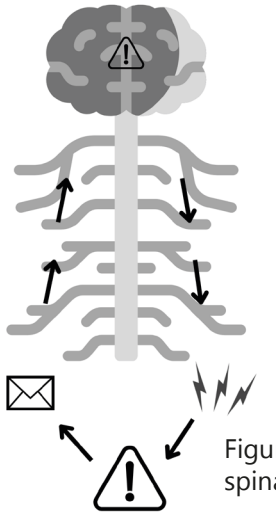

Figure 6: Pain as message through spinal cord to brain and back

Chronic vs acute pain: There is a difference between chronic pain and acute pain. Acute pain is a warning signal from the body. It often comes suddenly, usually caused from an injury. This type of pain typically decreases once the underlying cause has been healed. Chronic pain, on the other hand, is pain that remains for more than three months and often has no clear cause. This pain can take on a life of its own and alter the way the brain processes pain signals. People with chronic pain often become stuck in a loop of stress.

They start avoiding movement and exersice out of fear of worsening their symptoms. Unfortunately, this can actually intensify the pain experience.

There are various factors that can either amplify or reduce pain. These include: psychological insecurity (within someone's body), physical insecurity (in the body), and social insecurity (in someone's environment). When there is a sense of danger or insecurity in the body, it can intensify the way people experience pain.

These insights show that the impact of rheumatism is not only physical but also mental. The next paragraph will further explore the psychological effects of a rheumatic disease.

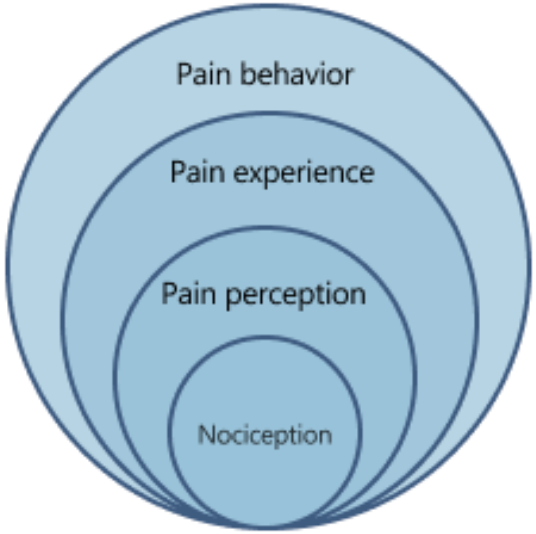

Figure 7: Model of Loeser

2.3 Mental impact of a rheumatic disease

2.3.1 The impact of rheumatic diseases on mental health

Rheumatic symptoms such as painan and fatigue can contribute to mental health issues. Anxiety and depression occur about twice as often in people with rheumatism compared to the general population (Benthemeijer, 2023). Research suggests that the same biochemical mechanisms responsible for rheumatism may also play a role in the development of mental health disorders. Inflammation in the brain that is caused by rheumatism, has been linked to depression and other psychological conditions (Benthemeijer, 2023).

Stress is also strongly connected to inflammatory processes in the body. Physical or emotional stress can act as a trigger for rheumatism (Benthemeijer, 2023). This is because stress leads to the release of cortisol and ACTH. These hormones activate the body's inflammatory response. In addition, stress increases the sympathetic nervous system activity, which stimulates the immune system even further.

Research shows that lack of understanding from the environment plays a significant role in the mental well-being of people with rheumatoid arthritis (RA). At least 50% of people with rheumatism experience a lack of understanding from those around them (Reumazorg Nederland, 2023).

This lack of support can exacerbate the emotional toll of the disease. Approximately 1 in 6 people with RA suffering from a depressive disorder as a result. A study conducted by the IGS research institute at the University of Twente reveales that a third of the patients with RA struggle to live well with the condition in the long term. These patients often experience anxiety and depressive symptoms (University of Twente, 2015). Together, these findings underscore the large impact on the mental well-being of individuals with rheumatoid arthritis.

People who experience severe pain and fatigue due to their condition often find themselves in a downward spiral. They struggle to accept the pain and try to avoid it. Which often leads to either reduced activity or pushing beyond their limits. Resulting in more pain and potentially leading to a downword spiral (see figure 8).

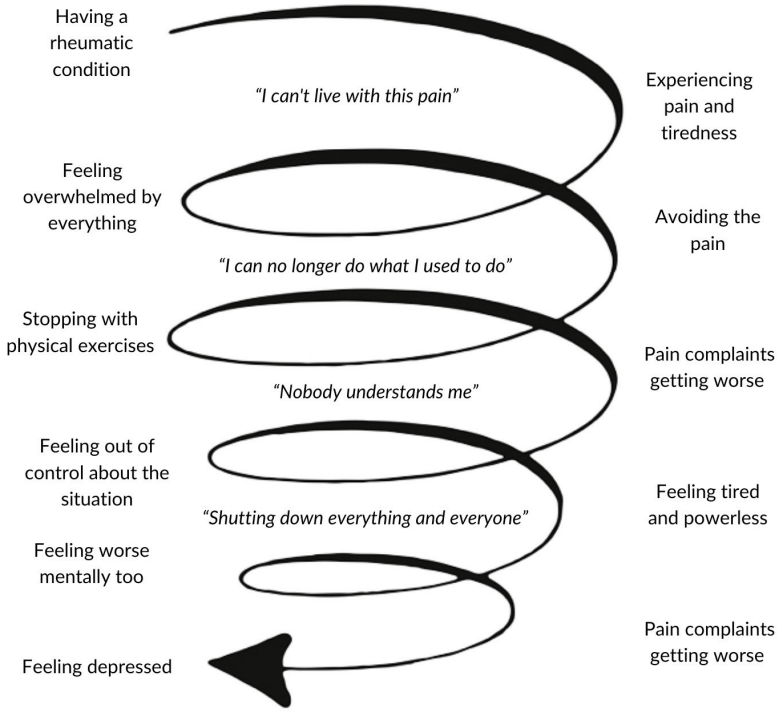

Figure 8: Downward spiral for people with chronic pain

With the right mindset and support, individuals can shift their perspective toward a more positive outlook, which often has a beneficial impact on their condition (see figure 9).

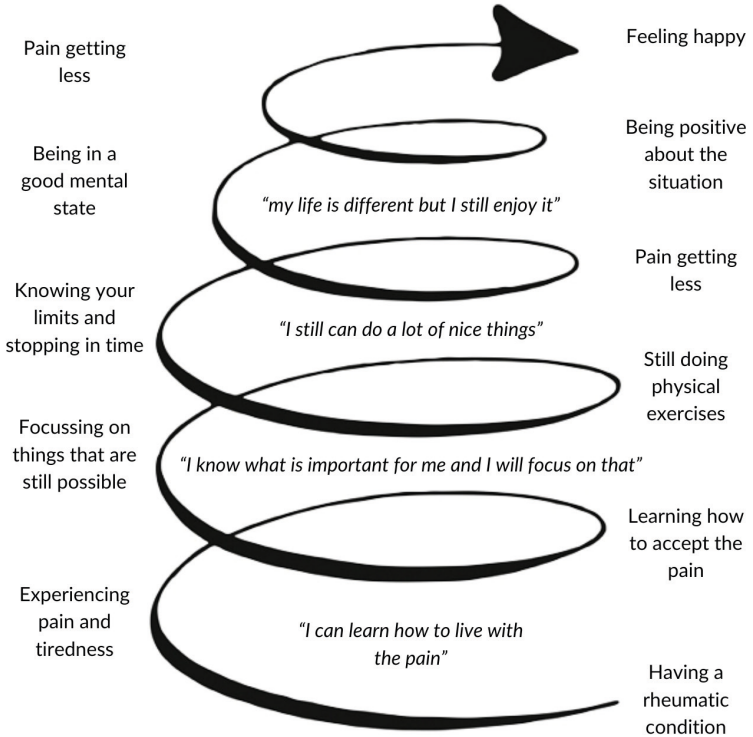

Figure 9: Upward spiral, when perspective is shifted for people with chronic pain

2.3.2 The importance of a healthy lifestyle for people with rheumatism

The ways someone lives can have a significant impact on rheumatism symptoms (Reuma Nederland, 2024). Making healthy choices can help with reducing someone's symptoms, leading to a better quality of life. A healthy lifestyle includes healthy diet, reducing stress, avoiding smoking and alcohol and staying physically active. Several studies show that Physical activity (PA) including exercise is beneficial for most chronic musculoskeletal conditions (CMC) and rank first among recommended treatment strategies (Eiseleet all, 2019). Exercising helps with keeping the joints flexible and prevents muscle weakness.

It can be challenging to make healty chooses, especially for people experiencing severe pain caused by their symptoms. Luckily, there are various specialists in the treatment team who support patients in making certain decisions. For example, a dietitian helps with making dietary choices, while an occupational therapist can assist in improving posture.

A rehabilitation team consists of a multidisciplinary team who together help patients with making lifestyle desicions. The next section will elaborate on this.

2.4 The importance of rehabilitation for people with a rheumatic diseases

2.4.1 Rehabilitation as treatment

Rheumatic diseases are characterized by emerging inflammation that can lead to joint damage and various levels of disability. Several studies have shown that patients with rheumatic diseases benefit greatly from rehabilitation (Kjeken et al., 2014). The World Health Organization (WHO) describes rehabilitation as ‘a process designed to help people with disabilities achieve and maintain their highest possible level of physical, sensory and social functioning.’

Rehabilitation usually involves a multidisciplinary approach, with a team of professionals, such as physical therapists, occupational therapists and a psychologists. this team works together to create a personalized treatment plan. Rehabilitation often involves performing physical exercises but also includes psychological and social support.

A study from the Chronic Pain Expertise Center involving 2,500 people shows that most people who have undergone a pain rehabilitation program at ‘Clinics in Rehabilitation’ (CIR) also experience positive effects in the long term. 65% of the clients experience a higher quality of life and better functioning two years after treatment. Furthermore, 70% indicate that pain has less impact on their daily lives. Even 40% report that their pain complaints have decreased (CIR: Pijnrevalidatie | >35 Jaar Expertise in Chronische Pijn, z.d.).

This research confirms that an interdisciplinary approach with a focus on both physical and mental health can yield good results.

Chapter three will provide a more detailed explanation of what rehabilitation involves and how it is structured at Basalt.

2.5 Summary literature review

This chapters aimed to answer the following questions:

- What types of joint complaints are there?
- What factors influence rheumatism?
- What treatment options are available for rheumatism?

Joint pain is a widespread problem that can significantly affect people's daily lives. Conditions such as osteoarthritis, rheumatoid arthritis, gout, and other joint disorders are examples of common rheumatic diseases. These diseases can cause pain, inflammation, and reduced mobility.

There are multiple factors that can influence the inflammation associated with rheumatism, such as diet, exercise, and weather. Research shows that someone's mental state also has a significant impact on their experience of pain caused by the disease.

Rehabilitation plays a crucial role in managing symptoms and helps improve the patient's lifestyle. Research shows that rehabilitation not only supports physical recovery, but also increases independence and self-management.

Now that these insights have been gathered, it is important to further explore the context of rehabilitation at Basalt and the workflow within the Reinier de Graaf Hospital. The next chapter provides a deep dive into these two different contexts.

Figure 10: Reinier de Graaf hospital (Reinier de Graaf, z.d.)

03

Context exploration

This chapter aims to create a better understanding in the context of rehabilitation at Basalt and the referral process at Reinier de Graaf hospital. This is done through desk research (section 3.1), followed by observations and interviews with relevant stakeholders (section 3.2).

This chapter aims to answer the following research questions:

- How does a rehabilitation program look like at Basalt?
- Which health care providers see patients before they are admitted for rehabilitation?
- What kind of challenges might patients encounter?

3. Context exploration

3.1 Rehabilitation at Basalt

3.1.1 Medical Specialist Rehabilitation at Basalt

Basalt is the renowned expertise center for medical specialist rehabilitation care in the South Holland region. Basalt Delft is a specialized rehabilitation center located next to the Reinier de Graaf hospital (Volwassenen - Basalt - de Kracht van Revalidatie, z.d.).

Basalt offers Medical Specialist Rehabilitation (MSR). This means that a patient will be treated by a team of various healthcare professionals, each with their own specialty. The team is led by a rehabilitation physician who carefully coordinates the treatment.

The practitioners at Basalt follow the ACT method, ACT stands for Acceptance and Commitment Therapy (Hayes, Wilson & Strosahl). This is a third-generation behavioral therapy that helps patients flexibly deal with the obstacles they encounter (Acceptance) so that they can continue investing in the things that truly matter to them (Commitment). ACT consists of six different processes/skills:

- Acceptance: Making space for unpleasant experiences.
- Defusion: Creating distance from your thoughts.
- Self-as-context: Adopting a flexible perspective on yourself and someone's self-image.
- Contact with the present moment: Focusing on the present moment.
- Values: Reflecting on what truly matters to someone.
- Committed action: Taking action in alignment with someone's values.

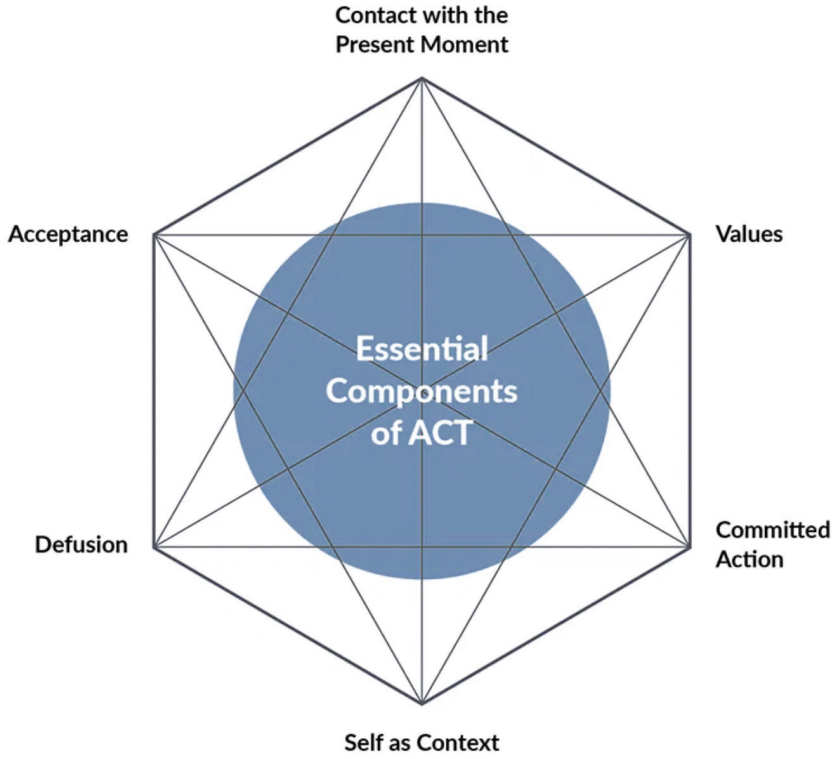

Figure 11: ACT-hexaflex with essential components (ACT in Actie - Cursus en Opleiding, 2024)

3.1.2 Rehabilitation procedure

What the rehabilitation process looks like depends on the type of complaints a person experiences. The rehabilitation physician determines the appropriate treatment and assembles the rehabilitation team. The treatment consists of multiple sessions with various professionals. During the treatment, the care team meets regularly to discuss progress. The duration of the treatment varies for each individual and depends on their condition and personal goals (Volwassenen - Basalt - de Kracht van Revalidatie, z.d.).

3.1.3 Rehabilitation through CPAC

Patients with chronic pain can visit the Chronic Pain Advice Center (CPAC) at Basalt with a referral from a general practitioner (GP) or medical specialist, such as a surgeon, neurologist, rheumatologist or orthopedist, to receive a quick treatment recommendation. Instead of waiting several months to see a rehabilitation physician, patients can go directly to CPAC and receive advice within three weeks. Figure 12 shows the different referral pathways. This figure is a zoomed-in section of the full patient journey map, which can be found in Chapter 5.

At CPAC, patients are seen by a manual therapist who, in a sense, takes on the role of the rehabilitation physician. The manual therapist assesses whether rehabilitation is needed and whether the patient is mentally ready to begin.

Before starting pain rehabilitation (a type of rehabilitation focussed on people with chronic pain) patients must first undergo a screening. During the screening people are evaluated whether they are physically and mentally ready for the program.

Waiting times for rehabilitation vary by location: at Basalt in Delft, the wait is approximately 2 to 3 months, while at Basalt in Zoetermeer, it can take up to 5 months (De Kracht van Revalidatie, n.d.).

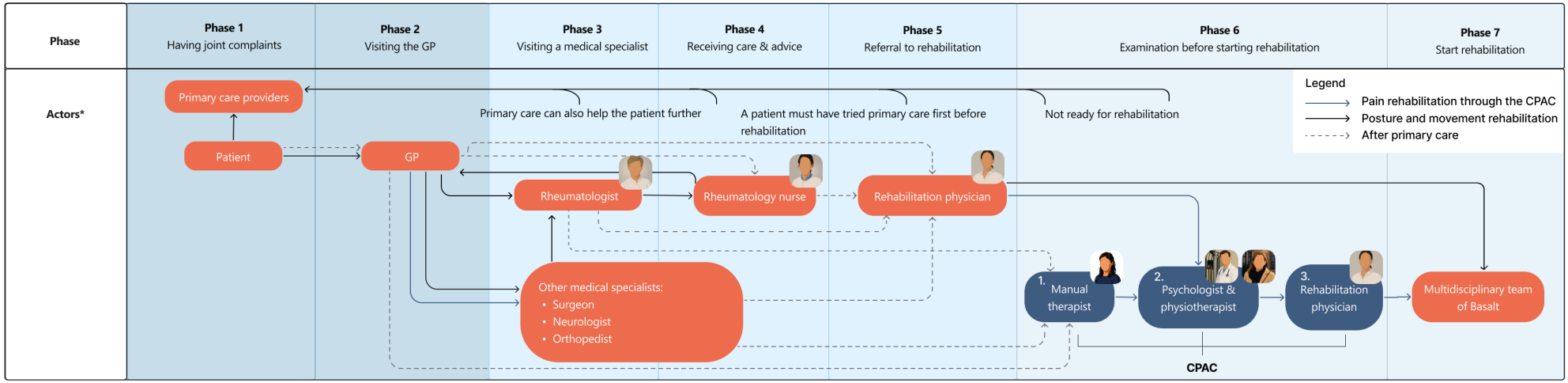

Figure 12: Zoom in patient journey map from chapter 5

3.2 Observational research and informal interviews

To gain a deeper understanding of the actual experiences at RdGG and Basalt, informal interviews and observations were conducted at both locations.

3.2.1 Short informal interviews with heathcare providers

The purpose of the interviews was to gain a better understanding of the patient referral process to rehabilitation. Patients with rheumatic diseases often see a rheumatologist, a rehabilitation physician and a rheumatologist in the hospital during the referral process. Therefore, an interview of approximately 30 minutes was conducted with each of these caregivers.

Additionally, healthcare providers from the rehabilitation clinic were interviewed to better understand what patients learn during rehabilitation and how the process is carried out in practice. These interviews included one informal 30 minute interview with an occupational therapist, a psychologist, and a manual therapist.

In total six interviews were conducted. For all interviews, pre-defined questions were determined (see Appendix A). The goal of the interviews was to understand the tasks of each healthcare provider and identify potential challenges that patients may encounter. During the interviews, notes were taken. The key takeaways from all interviews are stated below. For all interview notes, see Appendix A.

Rehabilitation physician
A rehabilitation physician serves as the link between rehabilitation at Basalt and the hospital. During the initial consultation at the hospital, typically lasting around 50 minutes, the physician assesses whether the patient requires rehabilitation. If admitted, the rehabilitation physician may act as the patient's primary point of contact. He or she is also responsible for assembling the Basalt care team.

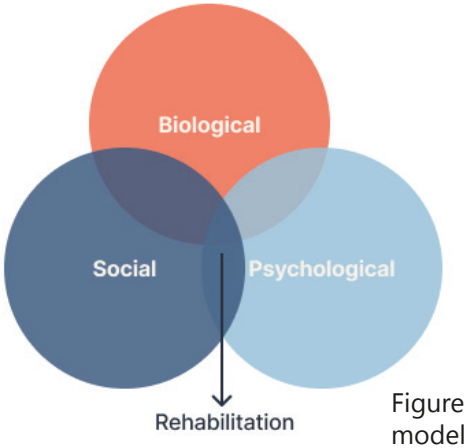

Figure 13: bio social psycho model

To determine whether a patient requires primary care or qualifies for a rehabilitation program at Basalt, three key aspects are assessed: the biological, psychological, and sociological state of the patient.

- Biological: Assesses physical limitations and pain.
- Sociological: Evaluates a person's social context, including their living environment and social network.
- Psychological: Examines the patient's mental well-being.

According to the rehabilitation physician, it is difficult to identify which group of people with joint complaints most often needs rehabilitation. Because this strongly depends on the individual. During rehabilitation, a patient not only receives physical support but also mental guidance and learns how to cope with the pain in the best possible way. People who experience only physical pain are often referred to a physiotherapist in their area. People with both physical and mental complaints are eligible for rehabilitation at Basalt.

An interesting finding from the interview was that people with fibromyalgia tend to require rehabilitation slightly more often than other rheumatic conditions. Fibromyalgia is a condition

Figure 14: Entrance Reinier de Graaf Voorburg

Figure 15: Consultant room Reinier de Graaf

characterized by persistent chronic pain in the muscles and connective tissue. The pain is often accompanied by stiffness, fatigue, sleep disorders, and mood swings (Fibromyalgia - Symptoms & Causes - Mayo Clinic, 2021). There is no medication to cure this condition, which means many people with this condition struggle not only with physical pain (biological aspect) but also with mental and social challenges (psychological and social aspect). Therefore, this rheumatic condition most often requires (pain) rehabilitation.

Another interesting finding was that there are two different approaches within rehabilitation at Basalt: pain rehabilitation and posture and movement rehabilitation.

- Approach 1: Pain rehabilitation

This approach focuses on learning to manage the pain, rather than getting physically stronger and reducing the pain. Patients in this program often experience chronic pain and struggle with effectively managing it. The rehabilitation process helps them understand how to live with the consequences of pain. Additionally, attention is given to the patient's mental well-being.

- Approach 2: Posture and movement rehabilitation

This approach aims to reduce pain and build strength through specific exercises, combined with a focus on the patient's mental well-being.

Aside from the rehabilitation physician, another member of the treatment team can act as the patient's primary contact person (PCP) during rehabilitation. This person communicates the results of team discussions to the patient and serves as a point of contact for any questions or concerns.

Quote rehabilitation physician

"There are quite a few different factors that influence how people experience pain. For people with chronic pain, the pain system is often out of balance. Pain rehabilitation helps them learn how to live with the pain."

Figure 20a: persona rehabilitation physician

Rheumatology nurse

A rheumatology nurse typically has around one hour, with the patient to provide an in-depth explanation of their diagnosis. Most patients referred to a rheumatology nurse do not yet fully understand their disease, as they have only recently been diagnosed by the rheumatologist. The nurse discusses the condition with the patient and explains not only what the disease entails but also what additional steps, beyond medication, can help with managing it. This includes recommending useful products and introducing other healthcare professionals who might be beneficial. For example, a rheumatology nurse can refer a patient to primary care services such as an occupational therapist or a physiotherapist in their area.

One important takeaway from the interview is that patients who have never tried primary care are never referred to rehabilitation. This is because health insurance will not reimburse rehabilitation unless the patient has first attempted primary care treatment. As a result, only patients who have already progressed further in their treatment journey, are eligible for rehabilitation at Basalt.

Another key insight is that patients typically visit the rheumatology nurse only once, right after their diagnosis. A follow-up appointment is scheduled only if a patient has many additional questions after the initial consultation. Otherwise, the rheumatology nurse does not maintain ongoing contact with the patient after the consultation.

Figure 16: Consultant room Basalt

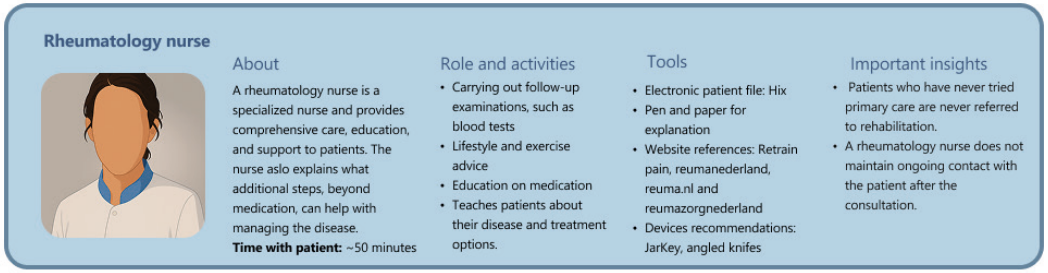

Figure 20b: persona rheumatology nurse

Psychologist (Basalt)
The psychologist has one hour to talk with the patient. Not every patient at Basalt requires psychological support. Therefore, during the initial intake conversation, it is determined whether a patient would benefit from seeing a psychologist. This decision is made by the psychologist in collaboration with the rest of the rehabilitation team.

The Basalt team holds team meetings almost every week to discuss patients' progress. All involved disciplines participate in these discussions. According to the psychologist, many patients appreciate this interdisciplinary collaboration, as they felt it was missing in primary care.

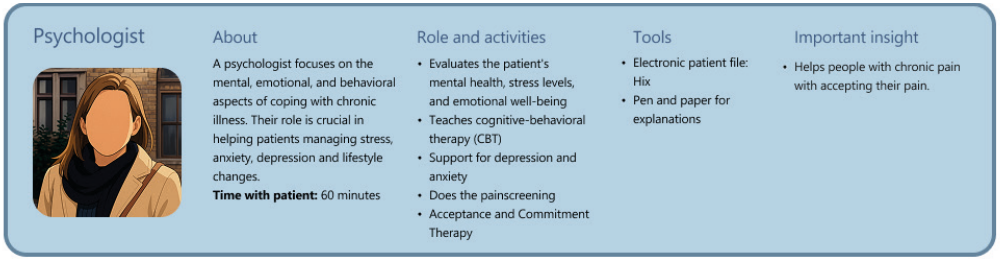

Figure 20c: persona psychologist

Occupational therapist (Basalt)
An occupational therapist has around an hour with the patient. The goal of an occupational therapist is to help individuals become as independent as possible. This includes assisting with energy management. People with chronic pain often experience fatigue, and an occupational therapist helps them better structure their daily energy levels.

Additionally, an occupational therapist focuses on ergonomics, such as improving sitting posture or optimizing posture during household tasks like cooking and vacuuming. They have extensive knowledge of adjustments and assistive devices that can support patients in their daily activities, see appendix B for an overview of different devices.

One important takeaway from this interview was that patients' expectations do not always align with what actually happens during rehabilitation, especially for those undergoing pain rehabilitation. Patients often expect pain reduction as an outcome; however, this is usually not the case. Instead, they learn how to live with the pain.

Quote occupational therapist
"Rehabilitation is a lot like getting your driver's license. Only after you've passed people start adapting all the tips they have learned to their own driving style. It's the same with rehabilitation, during the process, you learn all kinds of new tips and tricks. But it's only after the program ends that you can start applying what works best for your own lifestyle."

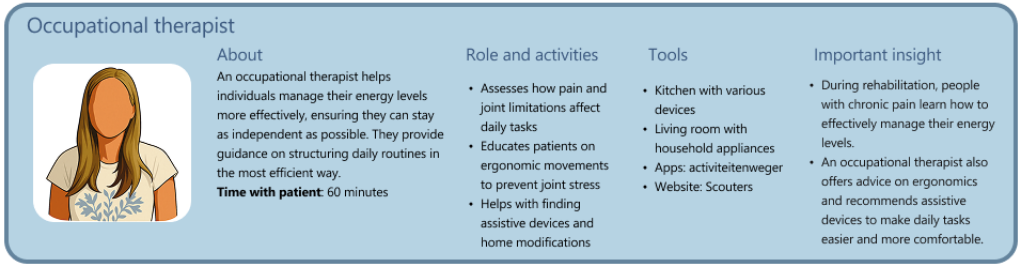

Figure 20d: persona occupational therapist

Manual therapist (and physiotherapist)
A manual therapist examines where the pain originates and uses clinical reasoning to understand the underlying cause. At Basalt, a manual therapist can also determine whether someone can be admitted to a rehabilitation program when referred through the CPAC. The therapist has approximately one hour to determine this with the patient.

A physiotherapist in posture and movement rehabilitation provides exercises to help patients become stronger, ultimately reducing pain. In pain rehabilitation, however, the focus is on teaching patients the best way to live with their pain.

There are two ways patients can enter pain rehabilitation: through the CPAC (70%) or via a rehabilitation physician (30%). The healthcare team indicates that patients referred by a medical specialist often have incorrect expectations (too focussed on pain reduction). This is a problem, as it affects the effectiveness of the rehabilitation process. Patients who are referred to a rehabilitation program by a GP or medical specialist don't always see a rehabilitation physician, sometimes they are sent to the CPAC. There, they meet with a manual therapist who assesses whether rehabilitation is the best option for the patient. However, this intermediate step is not always clearly explained to the patient. As a result, patients often expect to begin their rehabilitation during this first appointment with the manual therapist, while in reality, it is only an intake session. This miscommunication can lead to confusion and unrealistic expectations. In fact, not all healthcare professionals are even aware of the CPAC's existence, which further contributes to the confusion and misunderstandings experienced by patients.

Another interesting take-away from this interview is that many patients feel frustrated and not taken seriously when doctors bring up the social and psychological influences on pain. They fear that no one believes they are truly in pain, it feels as if they are being told, "It's all in your head." Therefore, using the right words plays a crucial role in effectively communicating with patients. Different healthcare providers even told me that patients that are not open for help, will never be referred to rehabilitation. Even Though these patients could benefit from rehabilitation, because they struggle with physical, social and mental problems. If a patient is not open to the idea, they are generally not admitted into a rehabilitation program.

Quote manual therapist
"Some people with chronic pain have become afraid of the pain, but this often ends up making the pain even worse. During rehabilitation, people learn how to cope with this in a better way, which can lead to a reduction in pain, although this is not guaranteed."

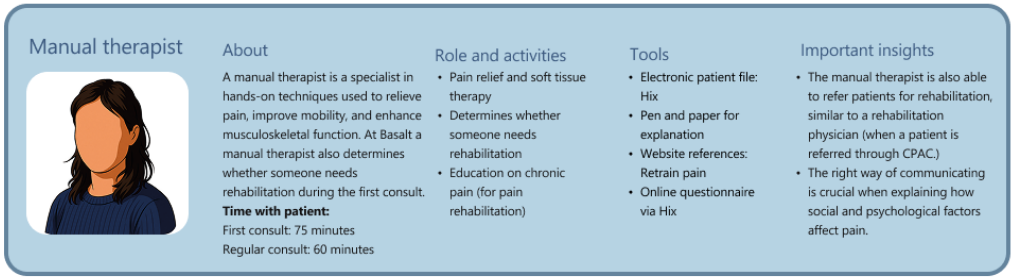

Figure 20e: persona manual therapist

3.2.2 Walk-along days with heathcare providers

Besides the interviews, several walk-along days with healthcare providers were conducted in the hospital and at Basalt. This helped in gaining a better understanding of the current context in practise.

Rheumatologist
The most important takeaway from this day is that a rheumatologist has limited time. A rheumatologist has around fifteen minutes per patient. Therefore, during appointments, there was little to no time to go in depth about the well-being of the patient.

One noticeable observation was that patients experiencing high levels of stress due to external factors, such as moving or sudden job loss, reported significantly more pain than those with little to no stress.

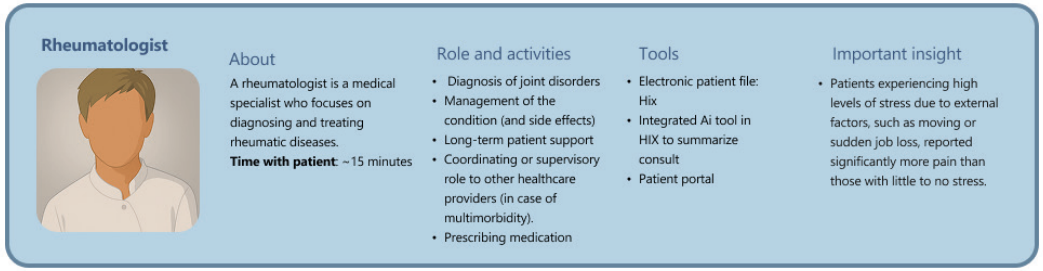

Figure 20f: persona reumatologist

Rehabilitation physician
During the consultation, the rehabilitation physician makes sure that both the patient and the physician have a shared understanding of the patient's symptoms and how these symptoms limit the patient in performing certain tasks and activities. To assess this, the rehabilitation physician uses the online patient platform (Hix) with predefined topics and carefully records which symptoms affect which activities.

Next, the rehabilitation physician explains the different referral options. Together with the patient, they determine which option is the best choice at that moment. The rehabilitation physician takes the time to clearly explain all options, including rehabilitation when applicable. Often, the physician makes a few notes on paper. The consultation concludes with a referral and advice, and the patient receives the notes to take home.

Occupational therapist
During a consultation, the occupational therapist explains how to distribute energy throughout the day using various models and tools (see figures 17, 18 and 19). Below, three important tools from the occupational therapist are explained; see Appendix B for the original visualizations provided by the occupational therapist.

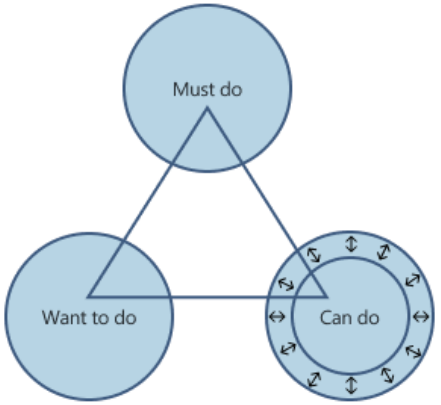

Figure 17: Can do, must do and want to do triangle

The can do, must do and want to do triangle represents the need for balance between these three aspects. The "can do" circle contains arrows, symbolizing that a person's capacity can vary from day to day. On a good day, someone might be able to do more, but that doesn't mean all their energy should be spent only on the tasks they feel they must do. If that happens, there may be no energy left for the things they actually want to do. Skipping those enjoyable activities over time can lead to feelings of depression. That's why maintaining balance is so important.

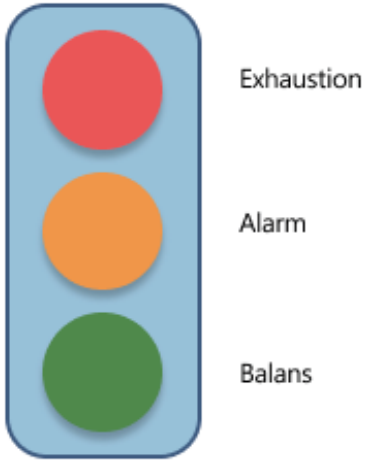

Figure 18: Traffic light visual

The traffic light method aims to create awareness about stopping in time. It shows people when they are approaching their limit (the orange and red phase). This visual representation of a traffic light helps people understand that they should stop an activity at the alarming phase, rather than pushing beyond their own boundaries (the red phase).
By clearly recognizing which phase they are in, they can learn to stop in time. In the long run, this has a positive effect on their symptoms.

The last method is a representation of a person's energy level in the form of a battery. The battery shows the difference in energy level between someone who is healthy and someone with chronic pain. A healthy person generally has enough energy to do all the activities they want, and still has some reserve energy left. After sleeping, their "battery" is fully recharged for the next day.

For someone with chronic pain, it's a very different story. They often wake up with less energy because of poor sleep. On top of that, every activity they do, consumes more energy than it would for a healthy person. As a result, their "battery" runs out much faster, and by the evening, there is usually no energy left. They then have to push through on their reserves. During the night, their battery doesn't recharge fully, so it's not at full capacity the next day. That's why maintaining a good energy balance is so important for people with chronic pain.

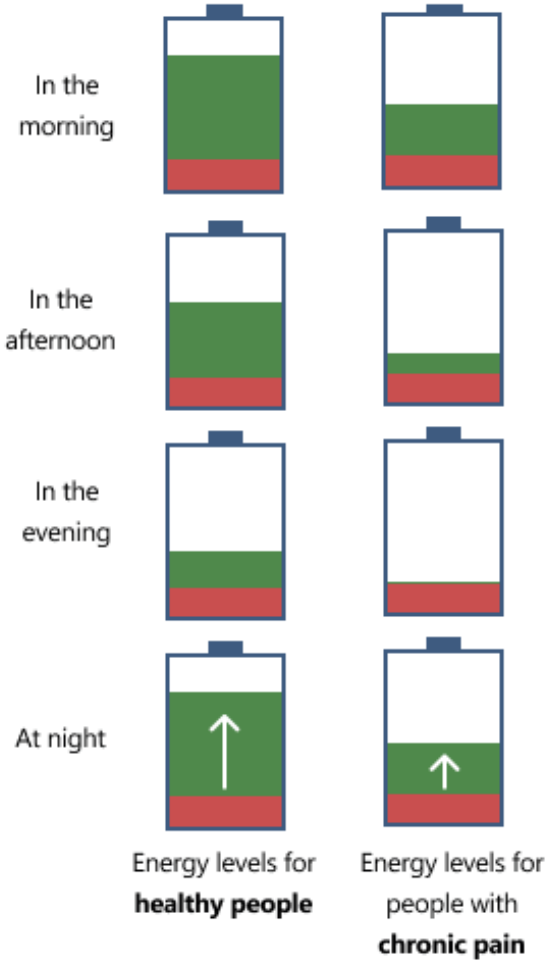

Figure 19: Battery as a visual representation of energy levels of healthy people (left) and people with chronic pain (right)

These insights are very valuable for people struggling with chronic pain. They explain in a simple way how their energy is affected (battery) and shows how to manage it (traffic light). These tools are simple yet highly effective in creating understanding. For me, this information was a crucial trigger moment.

In addition to conversational consultations, practical activities can also be part of a sessions with an occupational therapist. These may include tasks like making the bed, cutting fruit, or getting dressed. The occupational therapist provides tools and assistive devices to help with these activities (see appendix B). Patients can try them out during the sessions and, in some cases, take them home to try out.

Another important role of the occupational therapist is to administer the Canadian Occupational Performance Measure (COPM). This requires the patient to rate their goals (activities they would ideally like to do) on two main scoring catecories which include performance and satisfaction, both are out of 10 points. The patient must rate their goals during the first week of rehabilitation and again after completing rehabilitation.

Manual therapist (at CPAC Delft)
A manual therapist working at CPAC has a role similar to that of a rehabilitation physician, assessing whether a patient needs and is ready for rehabilitation. The manual therapist has one hour and fifteen minutes to consult with the patient. During this time, they discuss the patient's complaints as well as their biological, social, and psychological state.

Before the intake, the patient must complete a questionnaire covering these aspects. The answers from the tests provide the manual therapist with valuable insights into the patient's well-being and needs.

If a patient is referred to pain rehabilitation, they receive a video explaining what pain rehabilitation entails and what to expect from the rehabilitation.

3.3 Personas and stakeholder relationships

3.3.1 Personas

With the insights of the interviews and observations, a number of personas have been created of the various care providers involved in the care process of patients with joint complaints. All personas are stated below.

Hospital

Rheumatologist

About
A rheumatologist is a medical specialist who focuses on diagnosing and treating rheumatic diseases.
Time with patient: ~15 minutes

Role and activities
- Diagnosis of joint disorders
- Management of the condition (and side effects)
- Long-term patient support
- Coordinating or supervisory role to other healthcare providers (in case of multimorbidity).
- Prescribing medication

Tools
- Electronic patient file: Hix
- Integrated Ai tool in HIX to summarize consult
- Patient portal

Important insight
- Patients experiencing high levels of stress due to external factors, such as moving or sudden job loss, reported significantly more pain than those with little to no stress.

Rheumatology nurse

About
A rheumatology nurse is a specialized nurse and provides comprehensive care, education, and support to patients. The nurse aslo explains what additional steps, beyond medication, can help with managing the disease.
Time with patient: ~50 minutes

Role and activities
- Carrying out follow-up examinations, such as blood tests
- Lifestyle and exercise advice
- Education on medication
- Teaches patients about their disease and treatment options.

Tools
- Electronic patient file: Hix
- Pen and paper for explanation
- Website references: Retrain pain, reumanederland, reuma.nl and reumazorgnederland
- Devices recommendations: JarKey, angled knifes

Important insights
- Patients who have never tried primary care are never referred to rehabilitation.
- A rheumatology nurse does not maintain ongoing contact with the patient after the consultation.

Rehabilitation physician

About
A rehabilitation physician address the outcome of the condition. Focussing on improving function, reducing pain, and improving quality of life through non-surgical approaches. The physician leads the rehabilitation team.
Time wih patient:
First consult: 40 minutes
At Basalt: 30 minutes

Role and activities
- Determine whether someone should be referred to a rehabilitation program
- Coordination of multidisciplinary care
- Patient guidance (contact person)

Tools
- Electronic patient file: Hix
- Pen and paper for explanation
- Website references: Retrain pain, Pijn patiënten naar 1 stem

Important insight
- People with fibromyalgia tend to require rehabilitation slightly more often than other rheumatic conditions.
- There are two different approaches within rehabilitation at Basalt: pain rehabilitation and posture and movement rehabilitation.

Basalt care team

The Basalt care team among others consists out of:

Manual therapist

About
A manual therapist is a specialist in hands-on techniques used to relieve pain, improve mobility, and enhance musculoskeletal function. At Basalt a manual therapist also determines whether someone needs rehabilitation during the first consult.
Time with patient:
First consult: 75 minutes
Regular consult: 60 minutes

Role and activities
- Pain relief and soft tissue therapy
- Determines whether someone needs rehabilitation
- Education on chronic pain (for pain rehabilitation)

Tools
- Electronic patient file: Hix
- Pen and paper for explanation
- Website references: Retrain pain
- Online questionnaire via Hix

Important insights
- The manual therapist is also able to refer patients for rehabilitation, similar to a rehabilitation physician (when a patient is referred through CPAC.)
- The right way of communicating is crucial when explaining how social and psychological factors affect pain.

Physiotherapist

About
A physiotherapist plays a crucial role for people doing posture and movement rehabilitation. They help with improving mobility, reducing pain, and enhancing overall function. Their goal is to help patients manage symptoms and maintain independence.
Time with patient: 60 minutes

Role and activities
- Designs personalized stretching exercises to maintain joint range of motion
- Guides passive and active movement therapy
- Enhancing balance and coordination
- Supporting long-term self management
- Does the painscreening

Tools
- Electronic patient file: Hix
- Gym
- Swimming pool

Important insight
- Despite chronic pain, it is important that people continue to exercise within their own capabilities.

Occupational therapist

About
An occupational therapist helps individuals manage their energy levels more effectively, ensuring they can stay as independent as possible. They provide guidance on structuring daily routines in the most efficient way.
Time with patient: 60 minutes

Role and activities
- Assesses how pain and joint limitations affect daily tasks
- Educates patients on ergonomic movements to prevent joint stress
- Helps with finding assistive devices and home modifications

Tools
- Kitchen with various devices
- Living room with household appliances
- Apps: activiteitenweger
- Website: Scouters

Important insight
- During rehabilitation, people with chronic pain learn how to effectively manage their energy levels.
- An occupational therapist also offers advice on ergonomics and recommends assistive devices to make daily tasks easier and more comfortable.

Psychologist

About
A psychologist focuses on the mental, emotional, and behavioral aspects of coping with chronic illness. Their role is crucial in helping patients managing stress, anxiety, depression and lifestyle changes.
Time with patient: 60 minutes

Role and activities
- Evaluates the patient's mental health, stress levels, and emotional well-being
- Teaches cognitive-behavioral therapy (CBT)
- Support for depression and anxiety
- Does the painscreening
- Acceptance and Commitment Therapy

Tools
- Electronic patient file: Hix
- Pen and paper for explanations

Important insight
- Helps people with chronic pain with accepting their pain.

Figure 20: Personas of heath-care providers

3.3.2 Stakeholder relationships

Between each involved stakeholder, there are multiple connections. For example, the rheumatology nurse is most of the time in contact with the rheumatologist. The map of figure 21 shows the various connections and how they are linked to each other. Each healthcare provider typically sees the patient at least once during the healthcare journey towards rehabilitation.

The process starts with the **patient,** who often visits their general practitioner (**GP**) when experiencing joint complaints. The GP can refer the patient to **primary care providers**, such as a local occupational therapist or physiotherapist. The patient may also choose to contact these primary care professionals directly.

When symptoms persist for a longer period, the GP can refer the patient to a **rheumatologist**. The rheumatologist can make the correct diagnosis and, if necessary, prescribe appropriate medication. Additionally, the rheumatologist may refer the patient to a **rheumatology nurse**, where the patient can receive additional information about the disease.
If the patient continues to experience social or psychological issues, a medical specialist, such as a rheumatologist or neurologist, can refer the patient to a **rehabilitation physician.** The rehabilitation physician will then explore suitable treatment options. If appropriate, the patient will be referred to a rehabilitation program, where a **multidisciplinary team from Basalt** will provide guidance and support.

As shown in the map, the patient can be referred to primary care at any point. This type of care must always be tried before the patient can begin a rehabilitation program.

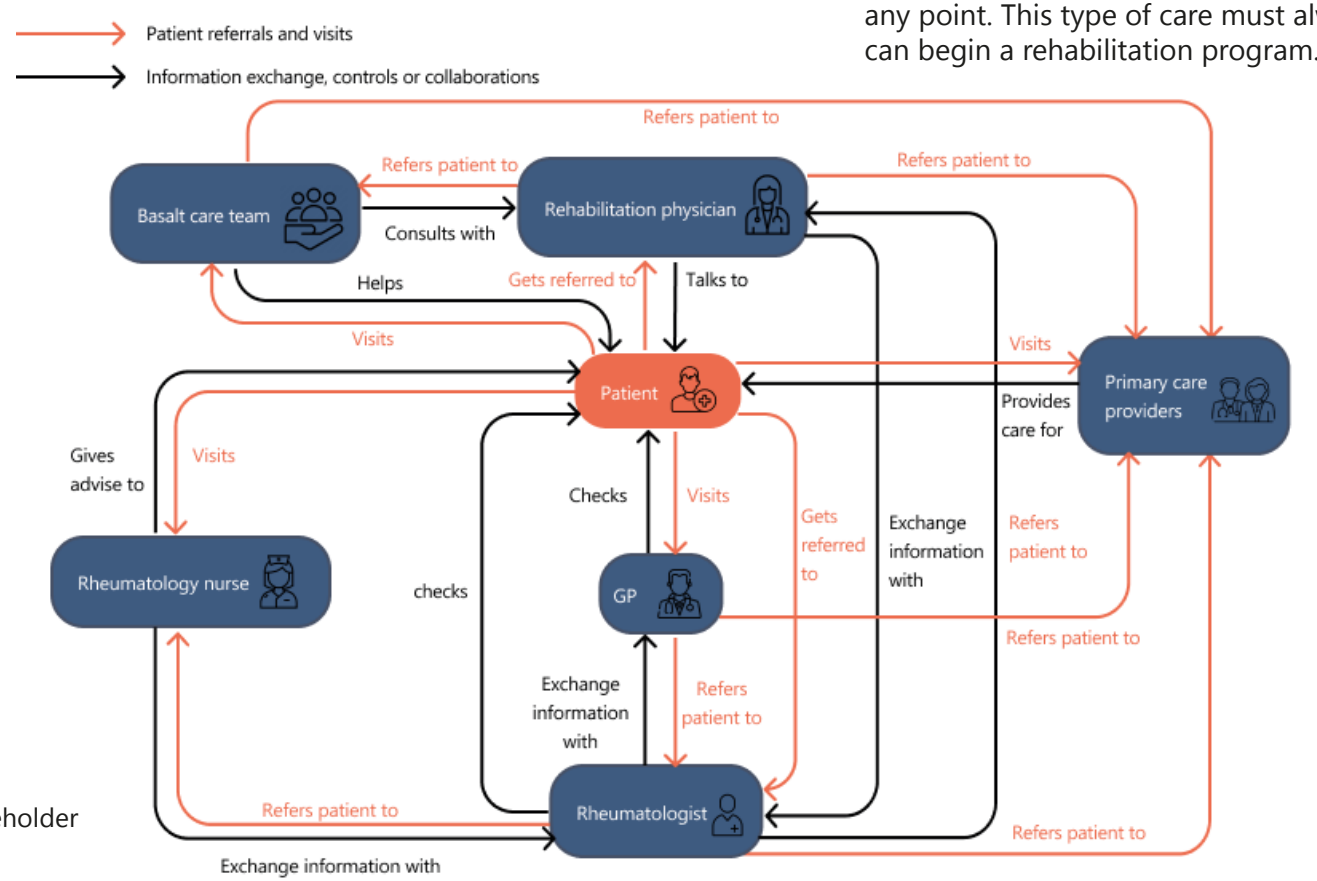

Figure 21: Stakeholder relationships

3.4 Important take-aways

This chapter aimed at answering the following questions:

- How does a rehabilitation program look like at Basalt?
- Which health care providers see patients before they are admitted for rehabilitation?
- What kind of challenges might patients encounter?

The insights gained from observations and informal interviews give a clear picture of what the rehabilitation program looks like at Basalt. At Basalt, during pain rehabilitation patients learn how to live with their pain, and they get useful tools on how to manage their energy levels.

Patients can see different healthcare providers before getting referred to rehabilitation. It is important to note that all patients first have to try primary care help before getting referred to rehabilitation. Most patients with joint complaints see a rheumatologist, rheumatology nurse, and rehabilitation physician in the hospital during their referral journey to rehabilitation.

There are several challenges patients may encounter that emerged during the observations and interviews with the healthcare providers:

1. **Mismatched patient expectations:** According to multiple healthcare providers, many patients, particularly those entering pain rehabilitation, expect pain reduction as an outcome, while the focus is actually on learning to live with pain. Misalignment in expectations negatively impacts the rehabilitation process
2. **Biopsychosocial approach in rehabilitation:** Rehabilitation at Basalt follows a biopsychosocial model, considering biological, psychological, and social factors. However, according to heathcare providers, some patients feel frustrated when psychological and social aspects are discussed, fearing that their pain is not being taken seriously. The way healthcare professionals communicate about these factors is crucial in managing patient perceptions.
3. **Exclusion of rehabilitation:** Whether or not someone is admitted to a rehabilitation program often depends on how open they are to receiving help. Several healthcare providers have mentioned that patients who aren't open to it are typically not referred, even though they could benefit from rehabilitation due to physical, mental, or social issues. This highlights how important motivation and willingness are, but also raises the question of whether some people are unintentionally excluded because of this. It also suggests the need for a better explanation of what rehabilitation entails for these people.

In addition to the perspective of healthcare providers, it is important to include the perspective of patients themselves. The next chapter covers this.

04

Defining the current experience

During the research, insights were gained about the stakeholders' experiences in the current situation. This chapter describes the current situation from the patients' perspective. It describes their current experience around the rehabilitation journey and the difficulties they may encounter during this period.

This chapter aims to find insights to answer the following research question:

- What are the positive and negative factors that influence the rehabilitation journey of patients with joint complaints?

4. Defining the current experience

4.1 Research around patients' perspective

During the interviews and observations with the healthcare providers, several important factors emerged may influence the experiences of the referral process for patients. These experiences, however, were only captured from the perspective of the healthcare providers. In this chapter, I aim to identify which factors play a positive or negative role in the referral process according to the patients themselves.

It is essential that patients carefully reflect on how they experienced this process and what emotions it evoked. Because this can be difficult to articulate, a sensitizing booklet was used. This method helps participants to reflect on their own experiences and feelings, providing insight into how they feel in certain situations.

4.1.1 Participants from my research

During the research, five participants were interviewed, each in a different phase of the rehabilitation trajectory.

- One participant had seen a rehabilitation physician but was not referred for rehabilitation; instead, he was referred to primary care.
- Two participants had received a referral for rehabilitation but had not yet begun.
- Two participants had already started their rehabilitation process.

All participants were asked to discuss their interactions with various healthcare providers and share their experiences. The complete list of interview questions can be found in Appendix D. The study was approved by the hospital's ethics committee (with study number 2025-024). All participants signed an informed consent form prior to the start of the interview (see Appendix C).

4.1.2 Set up for sensitising booklet

The exercises in the sensitizing booklet focused on participants' experiences with daily activities, healthcare professionals, and questions about assistive tools or devices. These exercises were designed to trigger memories through self-reflection tasks. Sensitizing helps participants gain insight into their own experiences, preparing them to discuss these during the interview (Sanders & Stappers, 2012).

An icebreaker exercise was included as the first task on the first day. The second day focused on participants' daily activities, where they were asked to link each activity to an emotion and a pain score. Days three and four focused on participants' recent appointments with healthcare providers.

The final day focused on the use or preferences of assistive tools. Figure 22 presents some of the exercises from the sensitizing booklet. All the pages of the sensitizing booklet can be found in Appendix E.

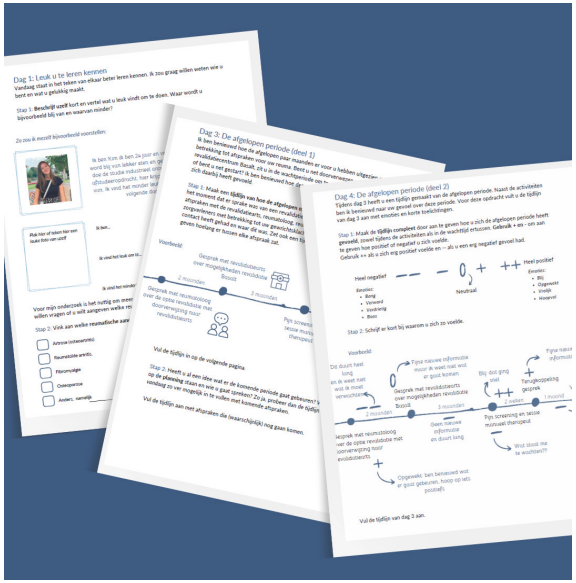

Figure 22: Pages from the sensitizing booklet

Three participants completed the sensitizing booklet, figure 23 shows some of the completed pages. Over the course of five days, participants spent five to ten minutes each day working through the exercises.

The interviews were conducted after the participants finished the sensitising booklet. Every participant was invited for a private semi-structured interview of 45 minutes. To discuss the topics mentioned in the sensitising booklet and pre-planned questions from appendix D.

The two participants that didn't complete the sensitising booklet were interviewed with similar questions.

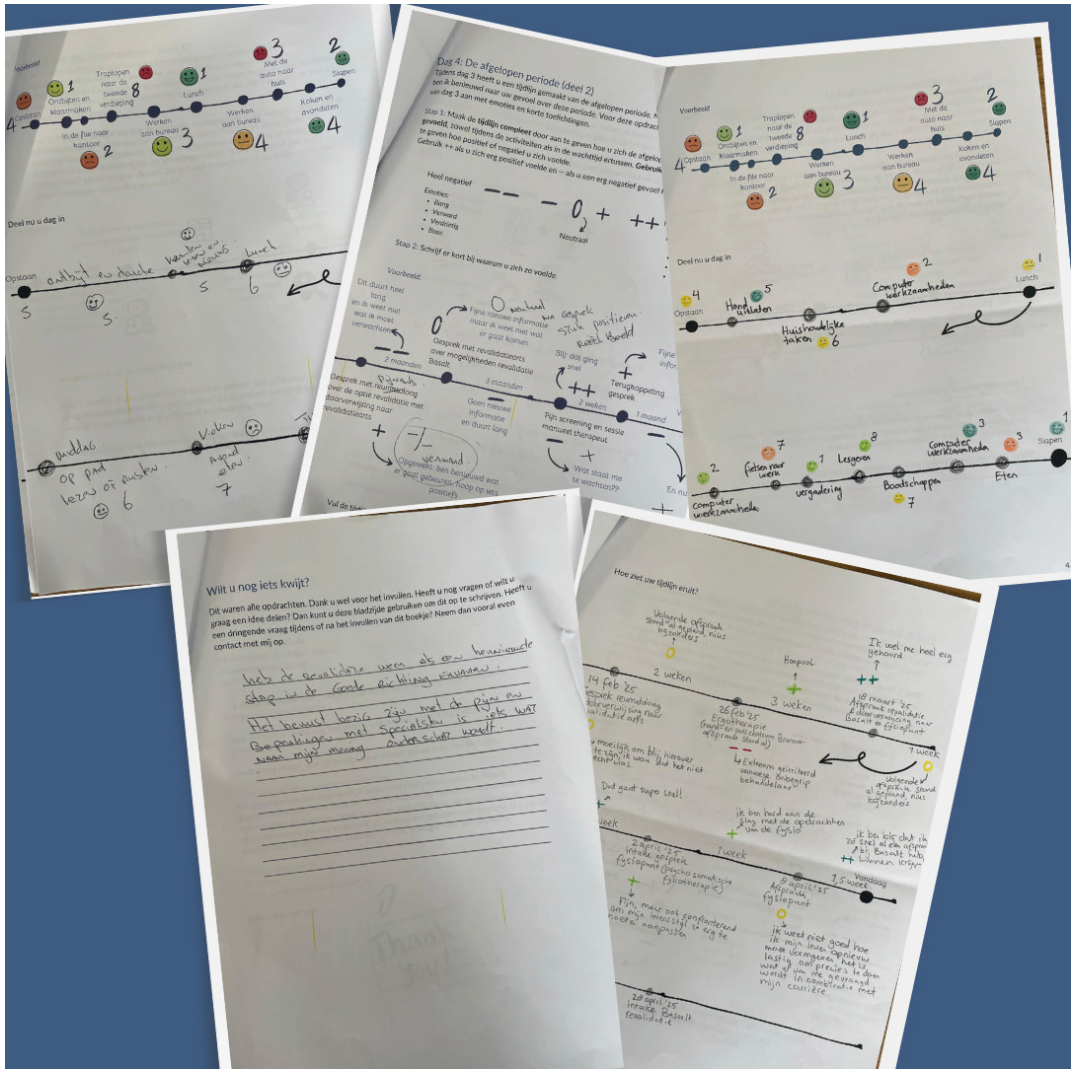

Figure 23: Some completed pages of the sensitizing booklets

4.2 Thematic analysis

4.2.1 Processing the results of the interviews

A thematic analysis has been performed (figure 25) to analyse the results of all the interviews. The thematic analysis was conducted following the process described by Braun & Clarke (2006). Qualitative research is subjective based on the researcher conducting the analysis, which makes it important to take a replicable approach to ensure the generation of insightful and trustworthy research findings (Nowell et al., 2017). The Braun & Clarke's (2006) method for thematic analysis follows six steps:

1. get familiar with the data
2. generating initial 'codes', in my case translated into statement cards
3. generating initial themes
4. revising and reviewing themes
5. defining and naming themes
6. writing down the findings in the report

From the interviews, a total of 102 quotes were collected and transformed into statement cards, see figure 24. These statement cards consist of three different parts: the original quote of the participant, an explanation of the quote's meaning, and a colour code (Sanders & Stappers, 2012). The colour code is used to distinguish the participants from each other based on which phase they are in (referral to rehabilitation, started rehabilitation or no referral to rehabilitation after appointment with rehabilitation physician) During the thematic analysis, all statement cards were clustered into different themes (Appendix F). Furthermore, connections have been made between these topics. The result of the thematic analysis is displayed in figure 26.

Participant: 3	Phase: started rehabilitation
Quote: *"Information about the pain system only came up when I saw the rehabilitation physician. Before that, I had no knowledge of it at all."*	
Meaning: Information about the pain system and its influence on pain only became clear to the patient during the first appointment with the rehabilitation physician. Yet, this information could be very useful for someone much earlier in the process.	

Figure 24 : Example of a tatement card

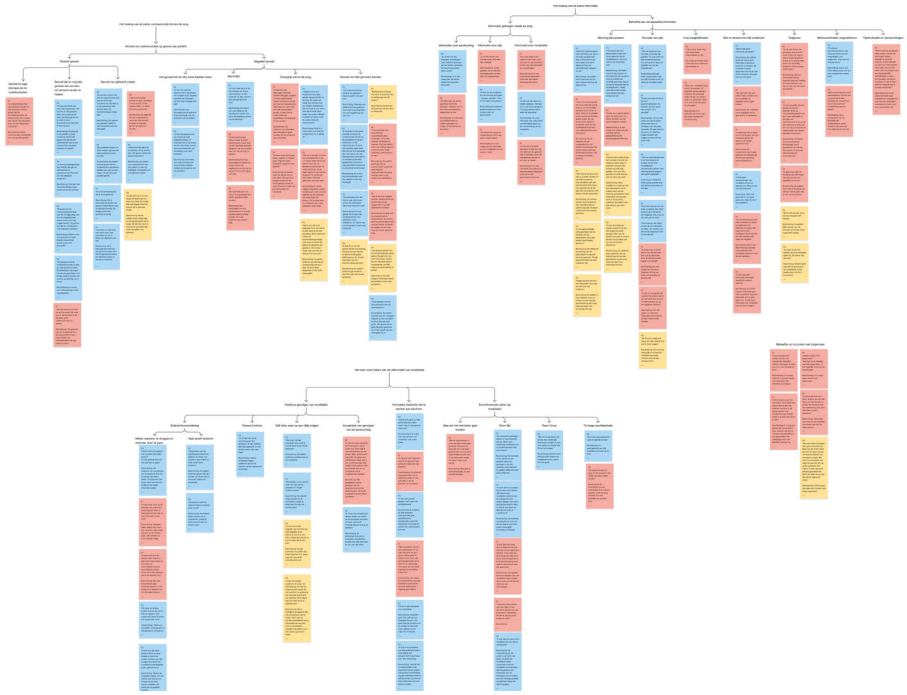

Figure 25: First version of thematic analysis

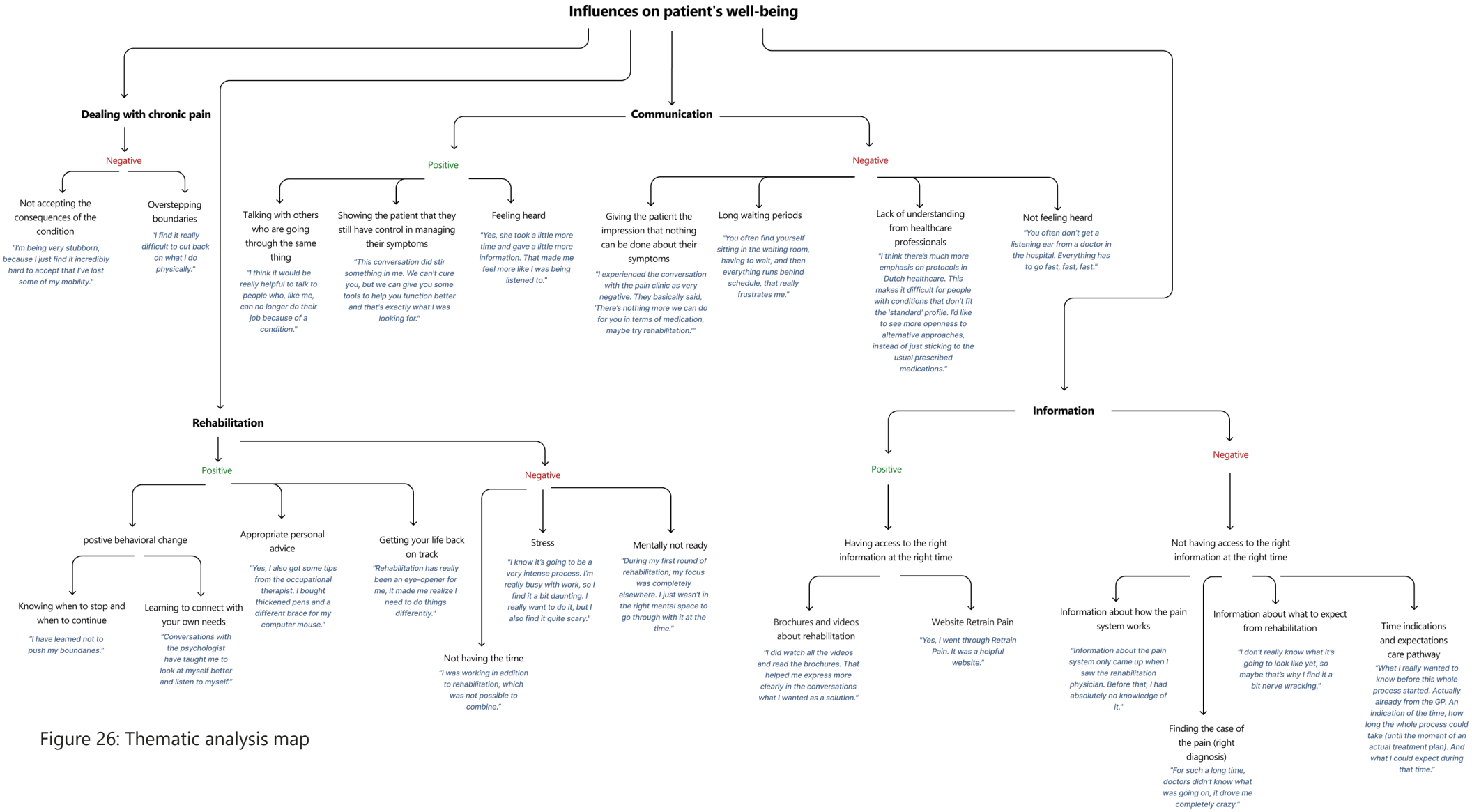

Figure 26: Thematic analysis map

From the thematic analysis, four themes were identified: communication, information, rehabilitation, and dealing with chronic pain. Each theme can influence the rehabilitation journey both positive and negative. In appendix F a full size visual of the thematic analysis map can be found. The next paragraph will explain each theme in more detail.

4.3 Results

From the thematic analysis, four main themes emerged:

- The importance of empathetic and accessible communication
- Accessibility of information
- Perceptions and expectations of rehabilitation
- Learning how to manage chronic pain

Each of these themes has a significant impact on the patient's overall experience.

1. The importance of empathetic and accessible communication to patients

This theme was mentioned repeatedly during the interviews. Participants often reported feeling unheard by their healthcare providers. Upon further probing, it became clear that this perception stemmed from the sense that providers did not take the time to explain things clearly or thoroughly. As a result, consultations were experienced as superficial and rushed. There is a strong need for longer, more in-depth conversations with care providers, which in turn fosters a greater sense of being heard and understood.

"You rarely find a listening ear with a doctor in the hospital. Everything has to go fast, fast, fast." — P3
"Had a great conversation with the rheumatology nurse. She gave just that bit more information. Unlike the appointment with the rheumatologist, which is always very superficial and brief." — P4

In contrast, communication during rehabilitation is experienced much more positively. Patients reported feeling heard and supported, which contributed to a more positive perception of care.

"I really enjoy the contact with care providers here. They truly listen. You hardly ever get that in the hospital—except maybe from the rheumatology nurse." — P3
"I found it a very positive experience. Clear communication, I can ask questions, and they take the time for you." — P5

Additionally, several patients found it difficult to understand the relationship between pain and mental health. This was especially the case among those who had not yet started rehabilitation. However, understanding how the pain system works is crucial for people with chronic pain. Currently, the way this information is communicated appears to be insufficiently clear or complete.

"I'm a bit skeptical. I feel pain all day. I don't feel like myself at all. And now they keep insisting that it's all in your head, basically. It almost makes me feel like I'm exaggerating or imagining it." — P4

2. Accessibility of information for patients

There is a noticeable disconnect between the information provided and patients' actual informational needs. Many patients indicated that information often came too late. During rehabilitation, they learned a great deal about topics such as energy management and the pain system, information they would have preferred to receive much earlier.

"Talking with the psychologist helped me learn to better listen to myself and reflect on my own needs." — P2
"I never received a clear explanation about how the pain system works; it was all quite superficial." — P4
"What I've learned now, I wish I had known when I was still working." — P2

3. Effects of rehabilitation

Rehabilitation has had a positive impact on the lives of participants who completed it. It helped them regain structure and a sense of control. However, participants who had not yet started rehabilitation expressed apprehension. They expected the process to be intense and were uncertain about what to expect or whether it would help them. This uncertainty can lead to anxiety about starting rehabilitation, even though the outcomes are often beneficial.

"What was most important for me was getting my life back on track." — P2
"Rehabilitation really was an eye-opener for me; it helped me start doing things differently." — P2
"I know it's going to be a really intense process. I'm very busy with work, so I find it a bit daunting." — P1

4. Learning to manage chronic pain effectively

One of the most valuable outcomes of rehabilitation is that patients learn how to cope with their chronic pain. Participants who had started rehabilitation repeatedly mentioned gaining awareness about their physical limits and the importance of taking rest. Exceeding their personal limits was a recurring issue mentioned during the interviews.

"I've learned not to push past my limits." — P3
"Talking with the psychologist taught me to reflect and listen to myself more closely." — P2

In contrast, participants who had not yet begun rehabilitation continued to struggle with this.

"I'm in pain every single day, it really controls my daily life. I'm not exactly getting any cheerier from it, and it affects me." — P4
"I find it really hard to cut back on what I do physically." — P1

4.4 Conclusion

Based on the interviews, the following research question can be answered:

What are the positive and negative factors that influence the rehabilitation journey of patients with joint complaints?

Four key themes influence the rehabilitation journey of patients, either positively or negatively:

- The importance of empathetic and accessible communication to patients
- Accessibility of information for patients
- Perceptions and expectations of rehabilitation
- Learning how to manage chronic pain effectively

With a clear understanding of what influences the patient's experience, a design direction can be established. There are two interesting approaches for this design direction: either improving the negative aspects or reinforcing/bringing forward the positive ones.

05

Journey map

To bundle all the information gathered from literature review, observations and interviews, a journey map is created to visually explain the current situation.

5. Patient journey

5.1 Patient journey map explained

5.1.1 General information about journey map

The patient journey map visualizes the different **phases** someone goes through before starting rehabilitation (phase 1 to 7). The map includes, among other things, the involved healthcare professionals (actors), average waiting periods, the patient's perspective, and design opportunities, see appendix O for the full size patient journey map.

The next page will explain each stage in furhter detail.

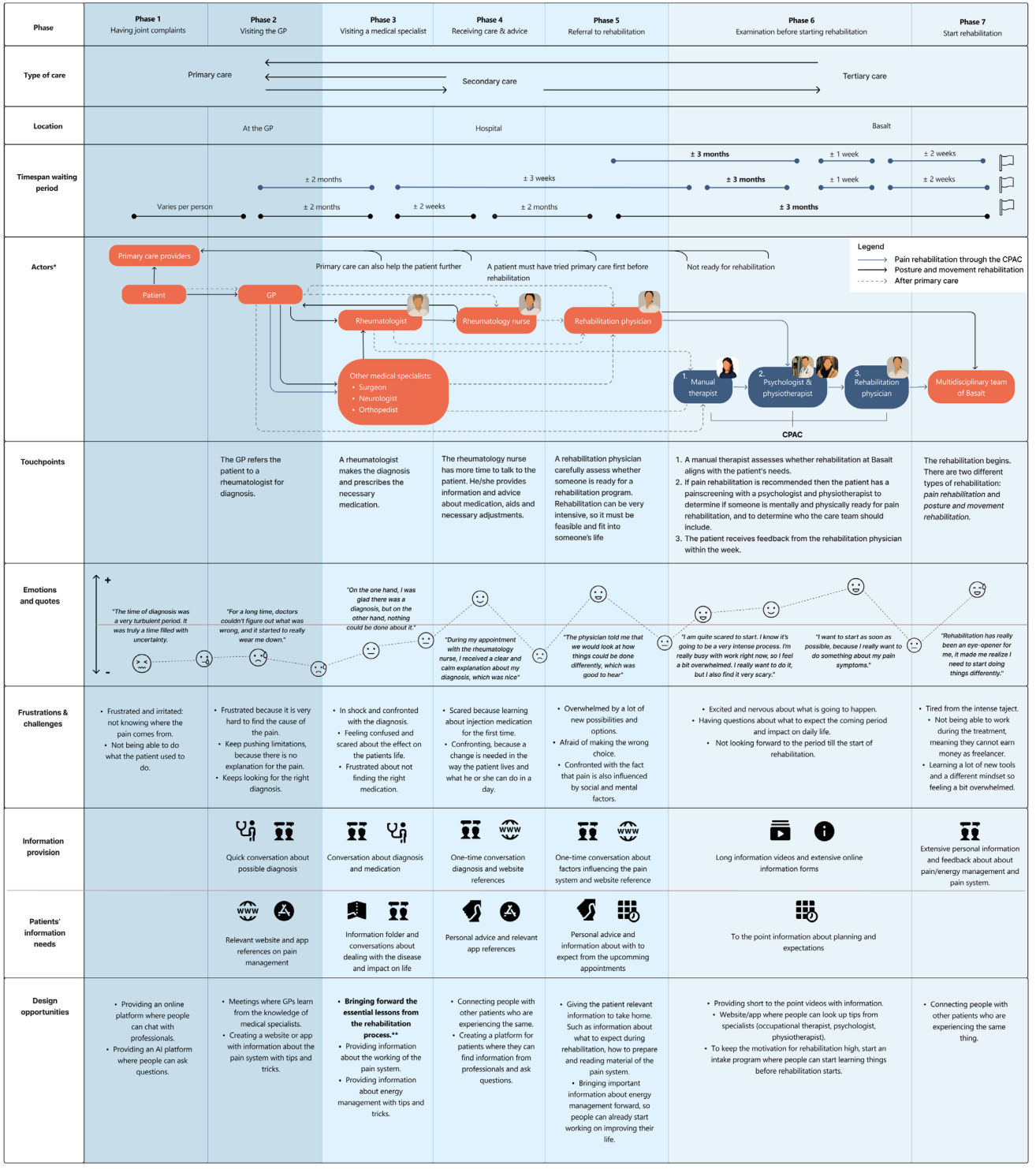

Figure 27: Patient journey map, the referral to rehabilitation for patients with joint pain

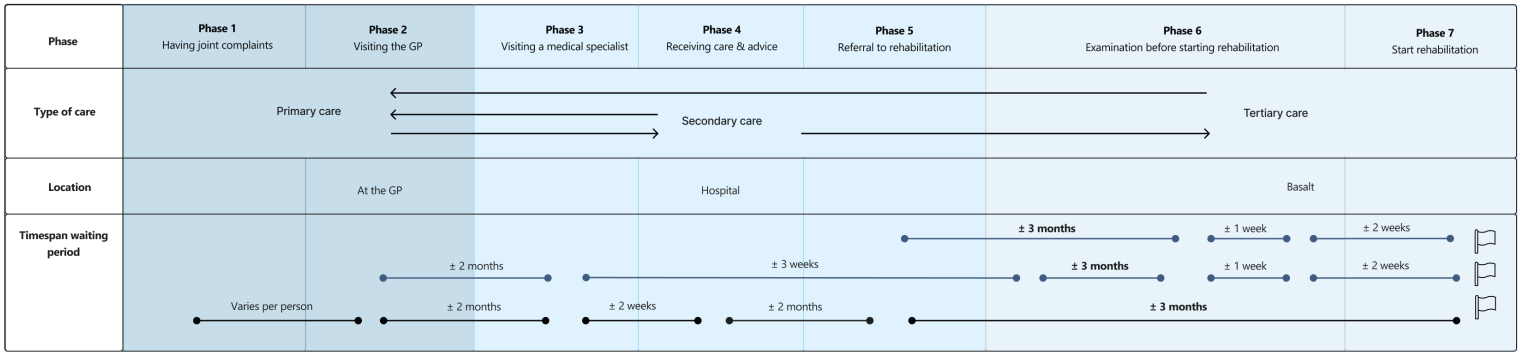

Figure 27a: Zoom in journey waiting time

The second layer of the map is organized into three **types of care**: primary, secondary and tertiary care.

Time stamps are included to indicate the average **waiting periods** for appointments with specific healthcare providers.

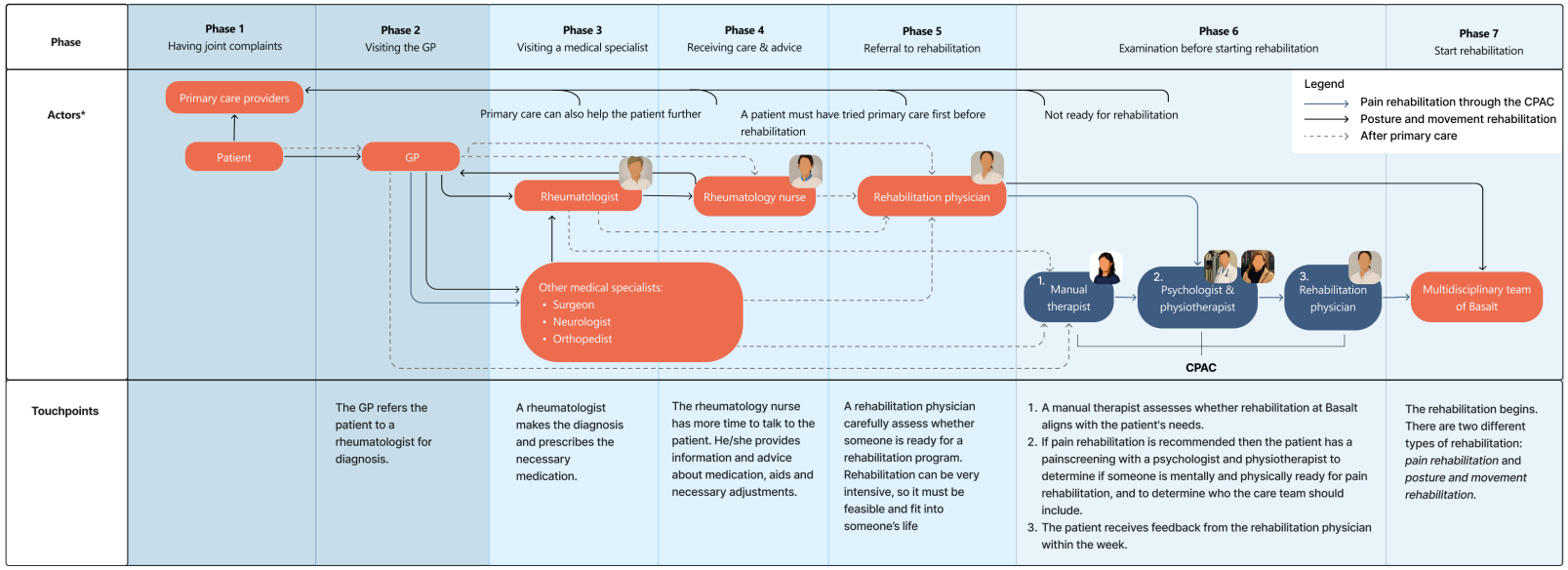

Figure 27b: Zoom in journey actors

Patients may take different routes through the system, depending on their situation, until reaching the final stage: the start of rehabilitation. There are two main types of rehabilitation included: pain rehabilitation (represented by blue arrows) and posture and movement rehabilitation (represented by black arrows). Under the heading '**Actors**', all potential referral pathways are described. A more detailed explanation of each actor can be found on page 34 of the report.

The section '**Touchpoints**' outlines the key interactions and activities that occur during that phase with the respective healthcare professionals.

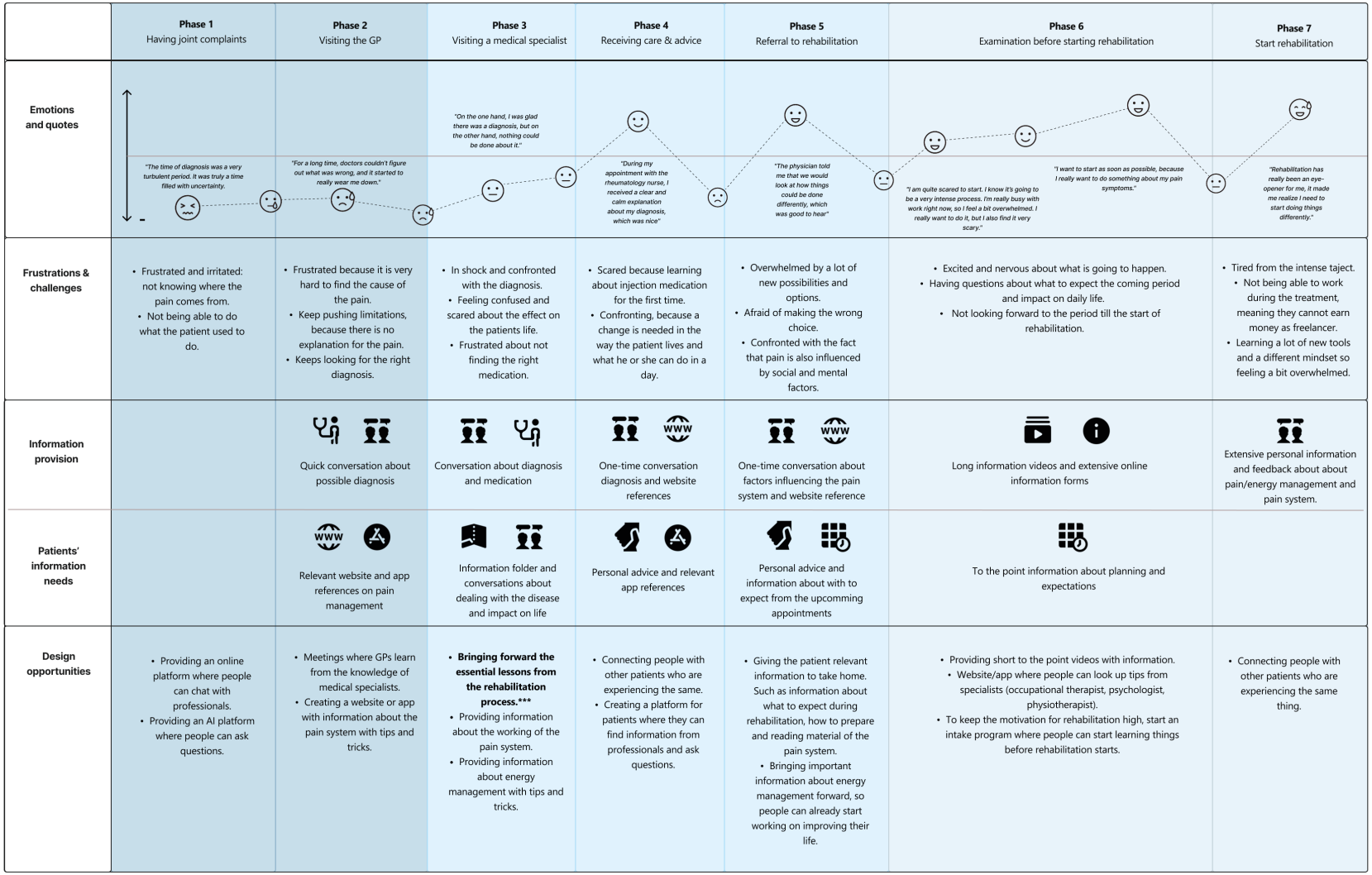

Figure 27c: Zoom in journey lower part

In addition, common **frustrations** were identified and documented through these interviews. All interview results can be found on chapter 4 of the report.

A recurring theme in the interviews was: 'a unmet need for information'. As a result, the journey map also highlights what information patients require at each stage and compares this to the information currently provided. This can be found in the section '**information provision** and '**patients' information needs**'. This data gives a clear overview of what kind of intervention in needed at what phase.

Finally, all gathered insights have been translated into concrete **design opportunities,** outlined per phase. This not only identifies which interventions are possible, but also reveals where in the journey these interventions are most needed, while taking the already existing solutions into account.

5.1.2 Additional information about actors and waiting times

Prior to being referred to rehabilitation, not every patient with joint complaints see the same medical specialist. The majority of people typically see a general practitioner (GP) for the first time when they start having joint problems. However, depending on the particular condition and the patient, determining the correct diagnosis can be difficult and time-consuming.

The final diagnosis for rheumatic diseases is made by a rheumatologist. For follow-ups on their condition and medication, patients usually visit the rheumatologist several times a year. It takes around **two months** on average to get an appointment with a rheumatologist.

The majority of patients see a rheumatology nurse once, soon after being diagnosed. It takes about **two weeks** on average to get an appointment with a rheumatology nurse.

Patients may be referred to primary care providers such as an occupational therapist, psychologist, or physiotherapist, when necessary. However, long waiting lists are common in primary care due to high demand and limited availability. This highlights the need for additional support and resources within this sector.

If a patient experiences psychological, physical, and social difficulties, they are often referred to a rehabilitation physician. A referral to rehabilitation is only possible after primary care options have been explored. The rehabilitation physician assesses whether a rehabilitation program is appropriate for the patient. The waiting time to see a rehabilitation physician is typically around **two months**, and it can take up to **three additional months** before the rehabilitation program actually begins. This means that some individuals may wait nearly **six months** before receiving the

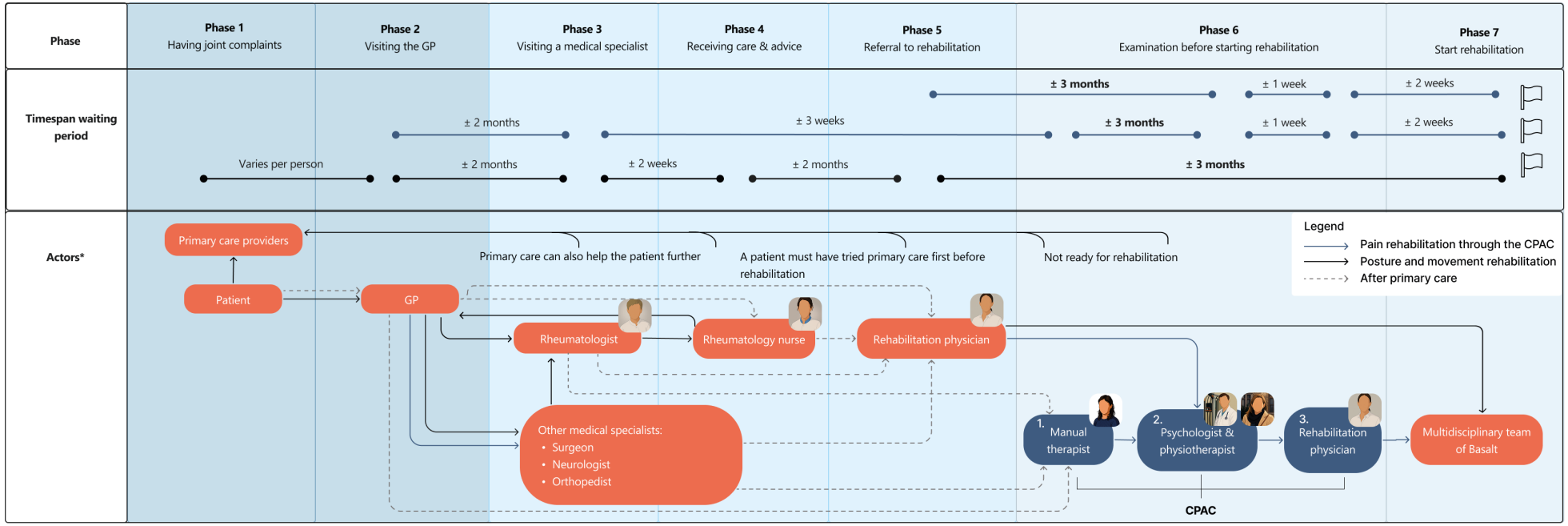

Figure 28: Inzoom of patient journey map

appropriate care they need. This insight highlights the importance of designing supportive solutions for patients in this period.

5.1.3 Take-aways from patient journey map

- Complex and variable patient pathways: The journey to rehabilitation differs per patient, with multiple possible routes and professionals involved. Diagnosis and referral processes can be lengthy and complex.
- Long waiting times: Patients face significant delays at various stages, somethimes up to 3 months, to see a professional healthcare provider. Cumulative delays can lead to a 6-month wait for proper care.
- High need for information: A key frustration among patients is a lack of clear, timely information throughout the journey. There is a mismatch between what patients want to know and what is currently provided.
- Late introduction of pain management insights: Another important takeaway is that people learn valuable strategies for managing chronic pain during rehabilitation; however, this often occurs too late in the journey, suggesting a need to introduce this knowledge earlier.

06

Design brief

In this chapter, all previous research is combined and transformed into a design brief, leading to the final design statement. This statement translates the research into a concise summary of what needs to be solved. Turning all the insights from the research into a design direction.

6. Design brief

6.1 Research combined

Over the course of my research, I identified several key themes and insights that shaped the direction of my design work. These were drawn from a thematic analysis, a detailed patient journey map, and interviews with healthcare professionals from Basalt and a hospital.

6.1.1 All take-aways

Key themes from thematic analysis:
The four overarching themes that emerged were:

- The importance of empathetic and accessible communication: Patients value healthcare professionals who communicate with clarity and compassion.
- Accessibility of information: Patients often struggle to find or understand crucial information at the right time.
- Perceptions and expectations of rehabilitation: Many patients have misunderstandings about what rehabilitation entails.
- Learning how to manage chronic pain: Patients often learn effective pain management strategies too late in their journey.

Insights from the patient journey map:
The patient journey map further highlighted that:

- Patient pathways are complex and variable, with multiple touchpoints and healthcare providers involved before reaching rehabilitation.
- Long waiting times, sometimes up to six months, delay appropriate care and support.
- Patients have a high unmet need for information, especially early in the process.
- Pain management insights are introduced late, often only during rehabilitation, when many patients have already been living with pain for years.

6.1.2 Conclusion from take-aways

The late introduction of important information regarding the management of chronic pain is a recurrent theme in all data sources. After prolonged pain and suffering, patients often reported that they learned life-changing lessons during rehabilitation, including how to manage their energy levels, how pain works, and how to shift their behavior.

- *"I have learned not to push my boundaries." (P3)*
- *"I learned one thing here that I now apply more and that is to use my energy differently. A very stupid example is the traffic light example; green, yellow and red." (P2)*
- *"Information about the pain system only came to light at the appointment with the rehabilitation physician. Before that I knew absolutely nothing about it." (P3)*

Although these insights came too late in the process, they improved the quality of life for the patients. Early access to this information could be crucial, particularly for patients with diseases like fibromyalgia who suffer from chronic pain early and for a long period of time.

6.2 Design brief

6.2.1 Final design statement

Based on these findings, I formulated the following design statement:

Design a tool that helps people with chronic pain due to a rheumatic disease effectively manage their energy levels throughout the day by supporting them to stay within their limits, to help them regain the sense of control over their pain.

- Why people with chronic pain due to a rheumatic disease

The research was conducted focusing on people with joint complaints. From the interviews with the healthcare providers, it appears that people with chronic pain, such as those with fibromyalgia, more often need rehabilitation. For this reason, this has become the focus group.

- Why manage energy levels

Learning to manage your energy levels was perceived as important and useful, as demonstrated by the patient interviews. Tools such as the traffic light serve as important starting points for this.

- Why supporting to stay within their limits

Exeding your limits is a problem that many people with chronic pain encounter. This indirectly also affects their level of pain and quality of life.

- Why regain sense of control over their pain back

People with chronic pain may feel that the illness is determining their lives. The pain determines whether they can do anything that day. This doesn't always have to be the case. When someone learns how live with the pain, the feeling of having control can return.

By providing valuable insights into managing energy levels earlier in the patient's journey, the patient experience can be improved. Over time, this may contribute to a better quality of life and could potentially ease some of the pressure on the healthcare system, allowing for more timely and targeted care for those who need it most.

6.2.2 Design criteria

To create a desirable, feasible, and viable design, the intervention should meet criteria that align with the gathered insights and my personal values. These criteria will be used to evaluate the final design.

Criteria

- The design should help users manage their energy levels more effectively.
- The design should not place additional burden on healthcare capacity.
- The design should be based on scientific evidence and align with recognized rehabilitation and pain management practices.
- The design should respect patient privacy and comply with healthcare data regulations.

Wishes

- The design is scalable and adaptable for use beyond fibromyalgia or across different healthcare settings.
- The design allows for personalization based on the patient's specific needs, symptoms, or preferences.

Main target group

The design is primarily aimed at individuals living with chronic pain who struggle with the ongoing impact of their condition. This group often lacks a clear understanding of how the pain system works and how to manage their energy in a balanced way. From my interviews with care workers and patients it came forward that patients with joint complaints with the condition fibromyalgia often tick hose boxes. From the research a persona can be made that fits well with

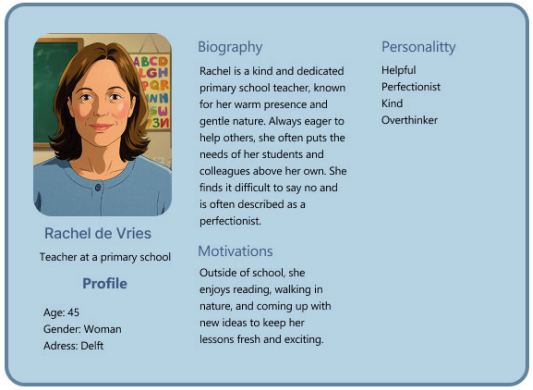

Figure 29: Persona of main target group

the target group.

Context of use
The design should be useful in all types of scenarios. It could serve as a reminder when the patient needs to slow down. This could happen at home, but also at work, during sports, or while doing groceries. The patient could receive the tool during a hospital appointment, for example, with the rheumatology nurse, as this appointment allows time for an explanation.

Analogy
Chronic pain can feel like drowning in water.
Teaching someone to swim while they're already drowning is pointless, by then, it's too late. At that moment, a quick fix like a life jacket or a lifebuoy is the best solution. Only once the person is out of immediate danger does it make sense to teach them how to swim. Ideally, you teach someone to swim before they end up in deep water.

In this project, drowning represents the overwhelming and downward spiral someone can experience when living with chronic pain. It symbolizes the physical suffering as well as the emotional and mental toll it can take. A quick fix, in this context, might be receiving verbal advice from a healthcare provider. While this can offer some direction, it will likely not be enough in the long run.

The solution I aim to create teaches people how to swim, so they never have to drown in the first place. Here, learning to swim represents the ongoing support and guidance that the tool will provide. Empowering the patients to manage their pain more effectively and sustainably.

Figure 30 : Teaching someone how to swim (Hurvitz, 2025)

6.3 Key insights from rehabilitation

6.3.1 Looking back at key insights on energy mangement from rehabilitation

The desing statement is as follows:
"Design a tool that helps people with chronic pain **effectively manage their energy levels** throughout the day by teaching them to stay within their limits, to help them regain the sense of control over their pain."

In order to develop something that helps people effectively manage their energy, it is important to reflect on the types of information and tools related to energy management that patients receive during rehabilitation. These tools appear to be helpful for most patients and can therefore be considered highly valuable.

Three important energy management tools used during occupational therapy are:

1. The balance triangle, describing the importance of balance between what someone can do and the things they want to do and must do (figure 32).
2. The visual representation of the battery of someone with chronic pain compared to someone healthy (figure 31).
3. The visual representation of a traffic light, reminding people not to go beyond their own limits (figure 33).

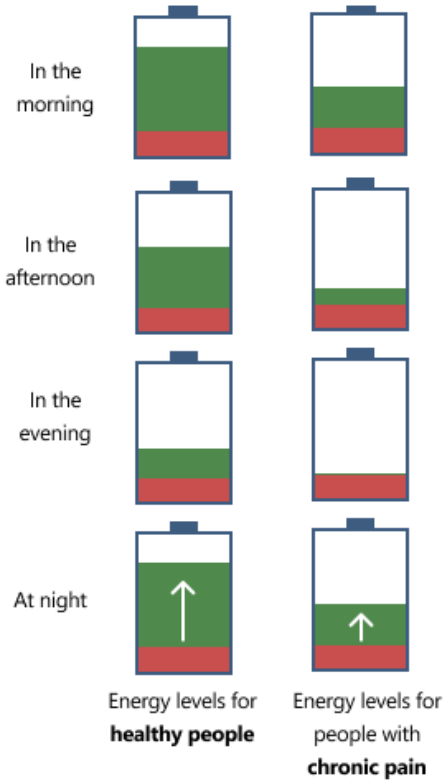

Figure 31: Battery as a visual representation of energy levels of healthy people (left) and people with chronic pain (right)

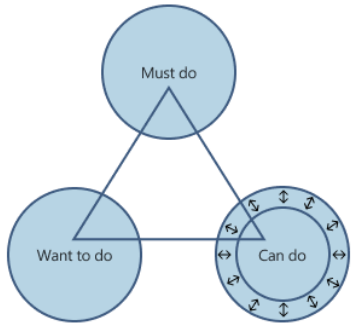

Figure 32: Can do, must do and want to do triangle

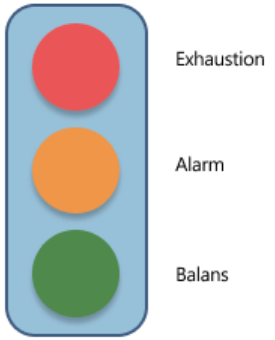

Figure 33: Trafic light visual

6.3.2 Overachring theme

Based on this information regarding energy management, an overarching theme emerges:

The importance of making patients aware of the need to stop in time and not exceeding their personal limits.

This issue was also repeatedly identified as a challenge during the interviews.

"I find it very difficult to give up what I do physically. I get a lot of comments about that from doctors. Because what I do is of course not good for my body. But what I do is very stubborn. Because I just find it very difficult to accept that I have lost mobility" (P1).

"I learned not to push my limits during rehabilitation." (P3).

"During rehabilitation I learned something that I still apply in my daily life: I learned to use my energy differently." (P2).

In conclusion, the tool should focus on making people aware of stopping in time, to avoid overpressure. The next chapter will further explore this theme.

07

Ideation

This chapter describes the ideation process that led to the development of the final concept. First, a brainstorming session was conducted to explore effective energy management tools, resulting in three distinct design concepts. Through iterative co-design with relevant stakeholders, the final concept was selected.

7. Ideation

7.2 Brainstorming ideas

7.2.1 Brainstorm around staying within your limits

To generate ideas focused on raising awareness around the topic: stopping in time to avoid overexertion, a brainstorming session was held around the central question: How can we teach people to stay within their limits?

The brainstorming session was done with two other Industrial Design students. Each time, we thought about the ***how can you*** (HKJ) question. With the first main question, how can you ensure that people stay within their limits? From this starting point a few themes emerged. For every new thema the same question was asked again, for example 'how can you create awereness?' Or 'how can you provide information?' This process took about fifteen to twenty minutes. Next, I individually further expanded the mind map with more potential solutions.

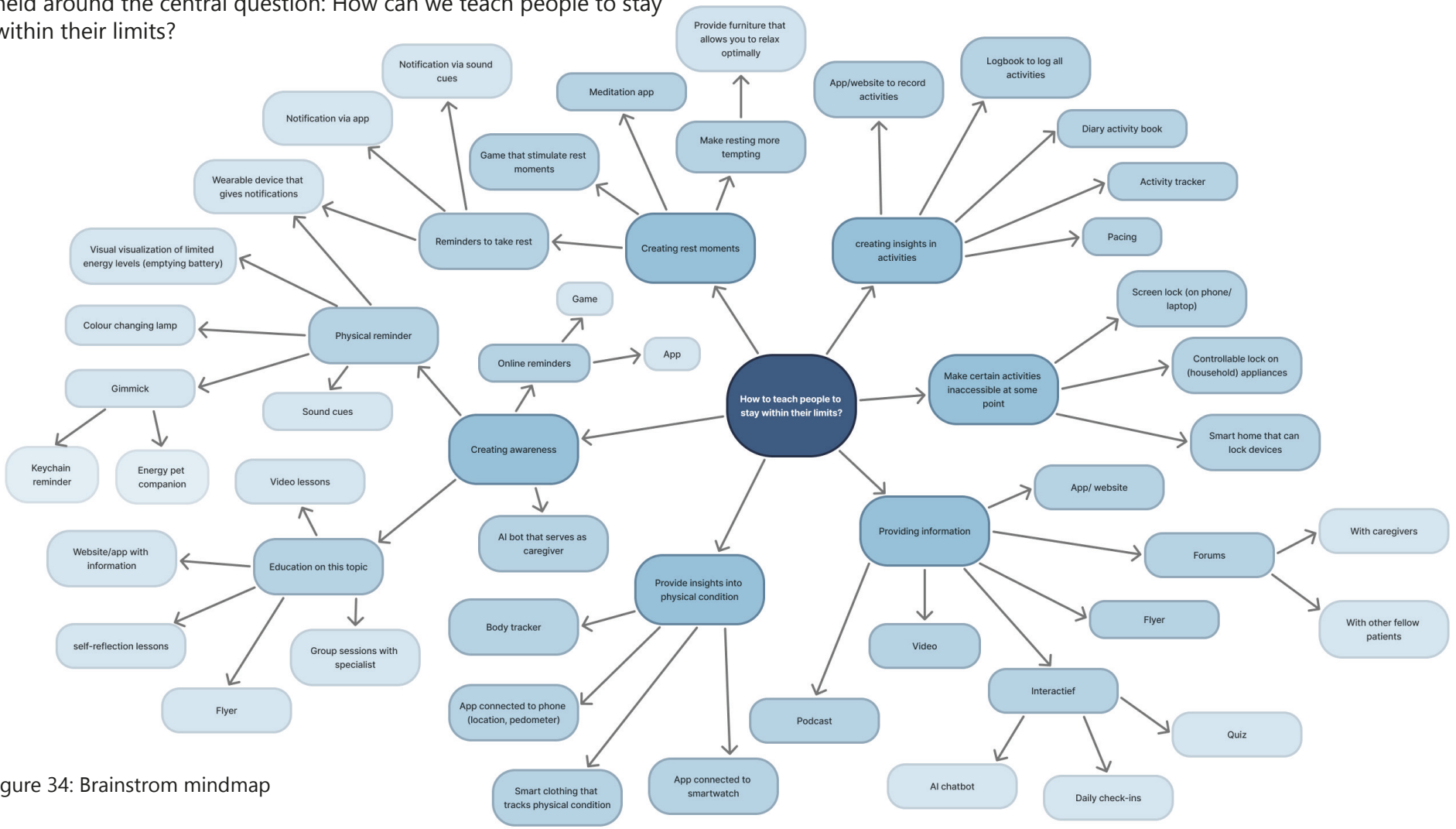

Figure 34: Brainstrom mindmap

7.2.2 Concept direction and key points

The brainstorming session generated a wide range of ideas. From there, an assessment was made to determine which ideas were the most feasible and innovative. In order to help individuals stay within their energy limits, behavioral change is needed. Merely providing information is unlikely to be a sufficient trigger. There needs to be a mechanism that continuously reminds individuals to stay within their boundaries. A digital solution can serve this purpose effectively. Today, nearly everyone carries a mobile device, research shows that 96.1% of Dutch citizens own a smartphone (This Play Media, 2023). This offers the opportunity to provide continuous access and real-time feedback.

For this reason, the decision was made to further develop a technological app solution that offers individuals insight into their energy levels.

To gain a better understanding of what the device should accomplish, a typical day in the life of a person with chronic pain was mapped out (see figure 35). The associated energy level for each activity is indicated, along with the corresponding pain level at that moment. This map is based on the answers from the second day activity from the sensitising booklet. Key challenges experienced throughout the day are also visualised. These challenges highlight important insights that can be taken into account when developing future concept directions.

The following design-relevant take-aways were identified through the creation of the 'day in the life' map, which is based on the insights from the sensitising booklets and patient interviews:

- The device should ensure that the user schedules regular rest periods.
- The device must provide timely reminders to take breaks.
- The device should help users recognize the positive impact of taking breaks in time.
- The device should enable users to engage in activities they find important without exceeding their personal limits.
- The device must help prevent users from becoming completely exhausted by the end of the day.

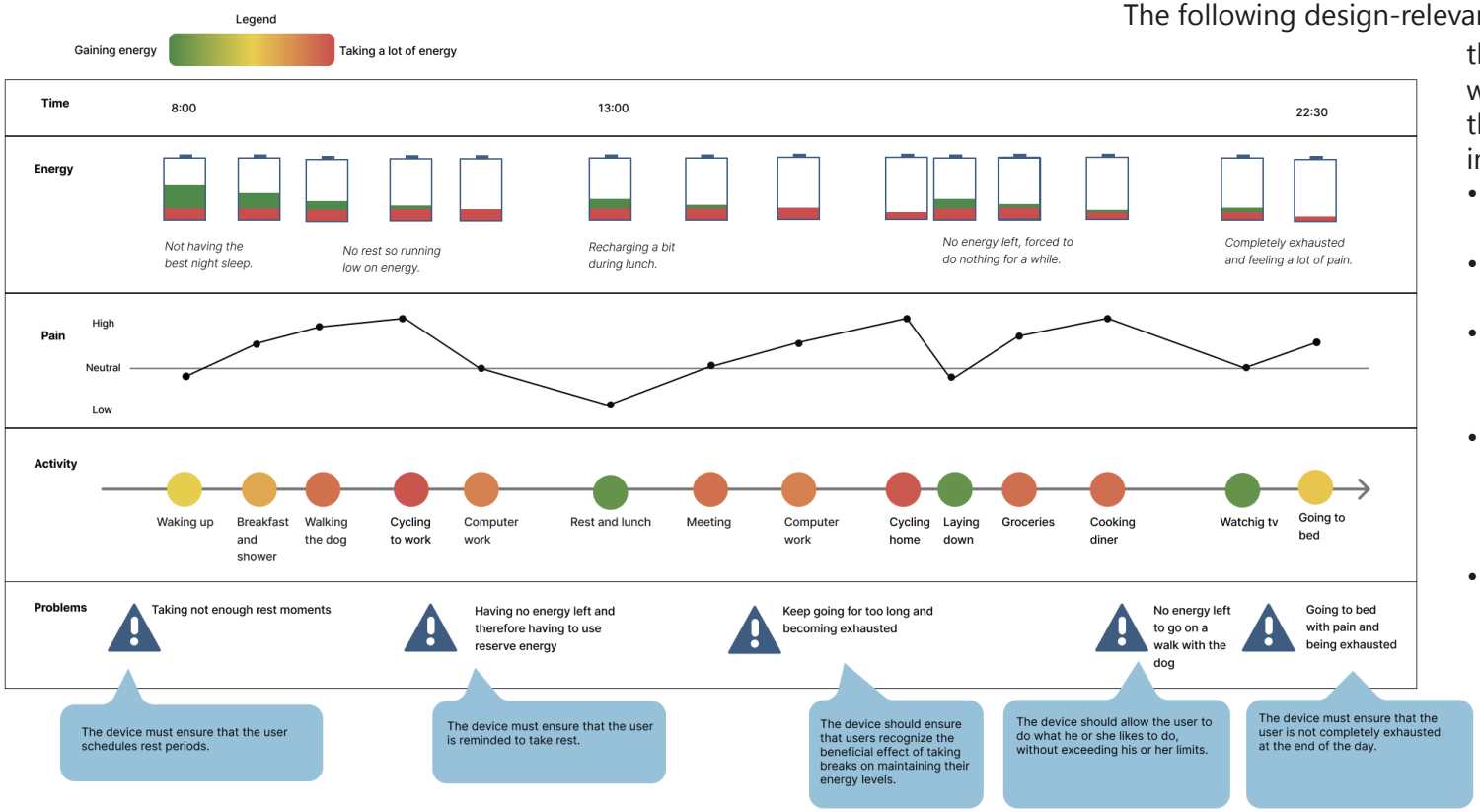

Figure 35: Day schedule with activites, energy and pain levels and related problems

7.3 Three concept ideas

From all the gathered information and insights, three different app directions emerged. All three app directions focus on stimulating users to think about and work with their energy levels. The three directions are:

- Tracking daily activities to gain insight into which tasks are most energy-consuming.
- An app focused on achieving personal goals using a pacing method.
- An app that provides visual feedback to users about their personal energy levels.

7.3.1 Track daily activities

This app direction focuses on creating insight into which activities are particularly energy-consuming for an individual. A visual representation of a battery illustrates how much energy a person has left throughout the day. This fosters awareness around the "depletion" of one's energy. The app can send notifications when a person is running low on energy, suggesting that it may be time to rest.

The advantage of this app is its ability to provide feedback on what the user can still do that day. However, a key limitation is the difficulty in accurately detecting a person's exact activities, mentally demanding tasks, for instance, are challenging to measure. As a result, the user would need to manually input a considerable amount of information before the app can provide accurate feedback.

Additional advantages and disadvantages are outlined in figure 36.

7.3.2 Achieving personal goals

This app direction is inspired by the pacing method. Pacing involves performing activities slowly and gradually increasing intensity over

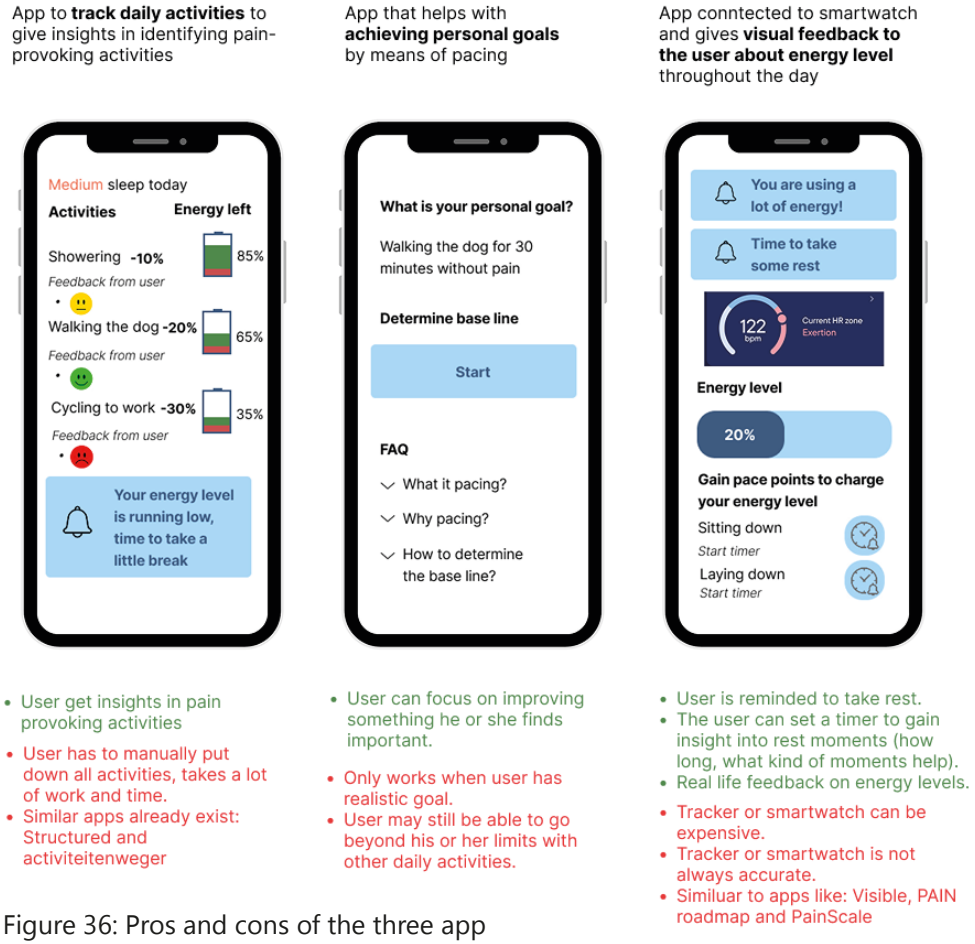

Figure 36: Pros and cons of the three app directions

time. It is considered a safe and effective strategy for managing and controlling fatigue, as well as for preventing symptom exacerbation following exertion (Hoe Pacen? – Eds.Vlaanderen, z.d.).
The app is designed to support users in achieving their personal goals. In this way, individuals can focus on what they find meaningful, something that many people with chronic pain tend to neglect due to a lack of energy.
One limitation of this approach is that users may still exceed their personal limits through other daily activities not accounted for in the

app.

7.3.3 Visual feedback on energy levels

This direction is similar to app direction 1, but in this case, the app is connected to a smartwatch or another wearable device. The device monitors various factors and provides feedback to the user about their current energy levels. Users can also “recharge” their energy in the app by taking breaks. The app offers tips on how to rest effectively.
An advantage of this concept is that users receive real-time feedback on their energy status. However, a limitation is that a smartwatch or wearable device is not always accurate and cannot measure all types of exertion. In addition, not all people have a smartwatch and purchasing one can be expensive. Also the mental aspect remains difficult to assess. As a result, it is challenging for the app to provide precise feedback.

7.4 Research into existing apps

There are already numerous healthcare apps available on the market. To avoid developing an app that duplicates existing solutions, research was conducted into current apps related to pain and energy management, figure 37 shows the results (see Appendix G for the full-size figure).

This research showed that several apps already support users in tracking their symptoms and activities. Most of these apps also receive high user ratings (ratings from the app store). However, some pacing apps got lower scores. Common reasons for these lower ratings include the app shutting down unexpectedly, being too complicated, or lacking upgrade options.

One exception is the ‘Visible’ app, which got a high app score rating. This app uses data and technology to support rest and pacing. The main downside is that it does not provide personalized advice on how to improve pacing, and it is only available in English.

The app I want to design should fill this gap. For this reason, it should not focus on just one direction. Instead, it would be better if it combines two directions.

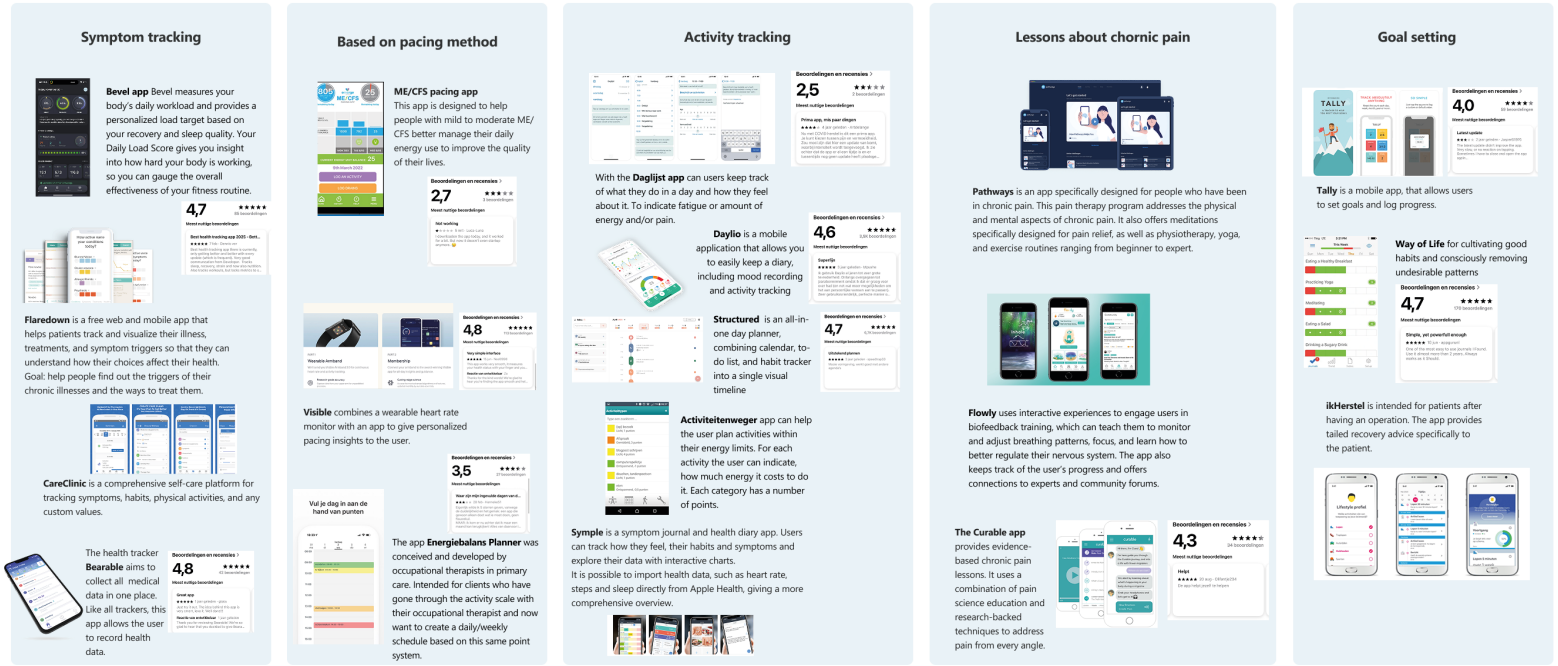

Figure 37: Market analysis of existing apps

7.5 Design direction

In order to make an informed decision regarding the three different app directions, the pros and cons of each were carefully considered. Additionally, the app directions were briefly presented to a patient with chronic pain. Based on the interview, it can be concluded that there was a stronger preference for app direction 2: goal achievement, and app direction 3: visual feedback on energy levels.

The outcome of the patient interview, combined with the pros and cons of each app direction and the research of existing app solutions, led to the final decision to proceed with a combination app that integrates concept directions 1 and 2.

The following chapter will delve further into the content and functionality of this app.

Figure 38: Combination of concepts leading to the final design

08

Final design

This chapter presents the final design of this master's thesis: the app PaceWise. First, an overview of the app is provided. This is followed by a more detailed explanation of the pacing method. In addition, key considerations for the app's effectiveness are discussed.

PaceWise

Move within your limits. Grow beyond them.

From overload to in control, support for chronic pain through pacing.

Personalized energy management, powered by insight.

8. Final concept

8.1 Introduction of the PaceWise app

Figure 39: Screen pages of the app PaceWise

PaceWise is an app designed to support individuals with chronic pain in **gaining awareness** of their energy levels by helping them achieve their personal goals. To prevent users from exceeding their physical limits, the app makes use of **pacing methods** while also providing feedback on their energy levels based on physiological measurements and user input. These measurements can be collected through a smartwatch or the user's smartphone. Paragraph 8.2 will explore this in more detail. First, the pacing method will be explained further.

8.1.1 Background information about pacing

Pacing is a self-management technique that helps people with chronic pain balance their energy and activity levels to prevent overexertion and symptom flare-ups. Rather than pushing through pain or doing too much on a "good day," which often leads to increased pain or exhaustion the next day, pacing encourages people to plan and adjust their activities in a way that respects their physical limits. It involves setting realistic goals, taking regular breaks, and gradually increasing activity levels over time (Jamieson-Lega et al., 2013).

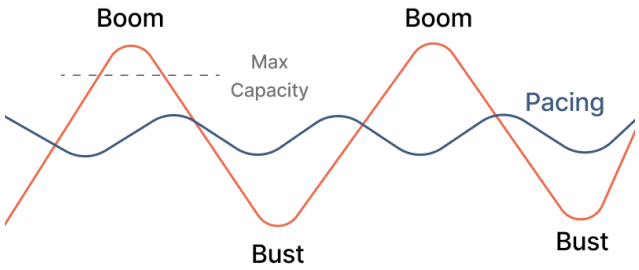

Figure 40: Boom-bust cycle

This method is especially valuable for people with chronic conditions, as it helps reduce the cycle of boom-and-bust patterns (see figure 40), improves daily functioning, and promotes a sense of control.

The boom–bust cycle is common in people with chronic pain. On a good day, people often feel better and do too much (the "boom"), which can lead to a pain flare or exhaustion in the days after (the "bust").

Pacing helps break this cycle by encouraging people to spread their energy evenly, even on good days. Instead of reacting to how they feel, they follow a planned, manageable plan. This supports steady progress without setbacks and helps maintain better control over symptoms (Holcomb et al., 2012).

Research has shown that pacing can lead to greater self-awareness of one's energy boundaries. In rehabilitation settings, patients often learn to track their activity levels and identify safe limits, which are then used to build a personal plan that supports gradual progress without worsening symptoms (Goudsmit et al., 2011).

The app takes the insights from pacing and puts it in usable practice for the user, removing the need of a healthcare professional. This way people can start pacing earlier on in their journey. Making it possible for them to keep doing the things they love the most (focusing on things people want to do, instead of must do with the energy they have, so can do). The next paragraph will explain how pacing can be used in practise.

8.1.2 Pacing in practise

The following method is based on the information leaflet created by Oxford University Hospitals NHS Trust et al. (2015b).

This leaflet outlines a method to avoid the boom-bust cycle, which over time can lead to activity avoidance. The approach involves performing specific activities for the same duration, distance, or quantity on both good and bad days, based on a personal baseline. This method requires individuals to manually track the performance of certain activities. To support this, the leaflet provides a schema (see figure 41)

Determining and monitoring one's personal limit is referred to as establishing a baseline. To calculate this baseline, individuals are advised to measure a specific activity over the course of three days,

Week 1			
Baseline	Day 1	Day 2	Day 3
Day 4	Day 5	Day 6	Day 7
Week 2			
Baseline	Day 1	Day 2	Day 3
Day 4	Day 5	Day 6	Day 7
Week 3			
Baseline	Day 1	Day 2	Day 3
Day 4	Day 5	Day 6	Day 7
Week 4			
Baseline	Day 1	Day 2	Day 3
Day 4	Day 5	Day 6	Day 7
Week 5			
Baseline	Day 1	Day 2	Day 3
Day 4	Day 5	Day 6	Day 7
Week 6			
Baseline	Day 1	Day 2	Day 3
Day 4	Day 5	Day 6	Day 7

Figure 41: Scheme to apply pacing in practise from Oxford University Hospitals NHS Trust et al. (2015)

tracking either time, distance, or quantity, without triggering a pain flare-up. Measuring over three days helps reduce the influence of daily fluctuations in symptom severity.

1. Choose a specific activity
2. Write down the time, distance or number of times that you can do the activity or task without a pain flare. Base it on the most limiting symptom associated with the activity (e.g., pain or fatigue). See appendix H for an example.
3. Record three measurements across three different days.
4. Calculate the average by adding the three values together and dividing by three.
5. To create a safety margin, reduce the result by 20% (or multiply by 0.8).

Once a baseline is established, individuals are encouraged to perform that activity up to the determined threshold for the first week. Over time, the duration, distance, or amount (Appendix H shows other ways to increase an activity) can gradually be increased, depending on how well the activity feels for the user.

However, tracking and correctly applying this method by hand can be perceived as complex and time consuming (McDuff et al., 2024). Therefore, the app aims to translate this pacing strategy into a user-friendly digital tool, allowing users to set and achieve their personal goals more effectively. Helping users to focus on things they want to do instead of only doing things they must do (balance triangle).

8.1.3 Pacing in the app

The app helps the user establish a baseline for a physical activity related to their personal goal.

It follows the five-step method outlined in the Oxford University Hospitals leaflet. The user selects a specific activity related to their goal within the app. During the first three days, the app works with the user to determine their baseline.

Once the baseline is established, the app automatically provides advice on when and for how long the user should perform the chosen activity, using the formula from step five. This means that the app only gives advice on when and for how long the user should do this specific activity, not for every activity the user performs throughout the day.

The goal of the app is explained in the next paragraph.

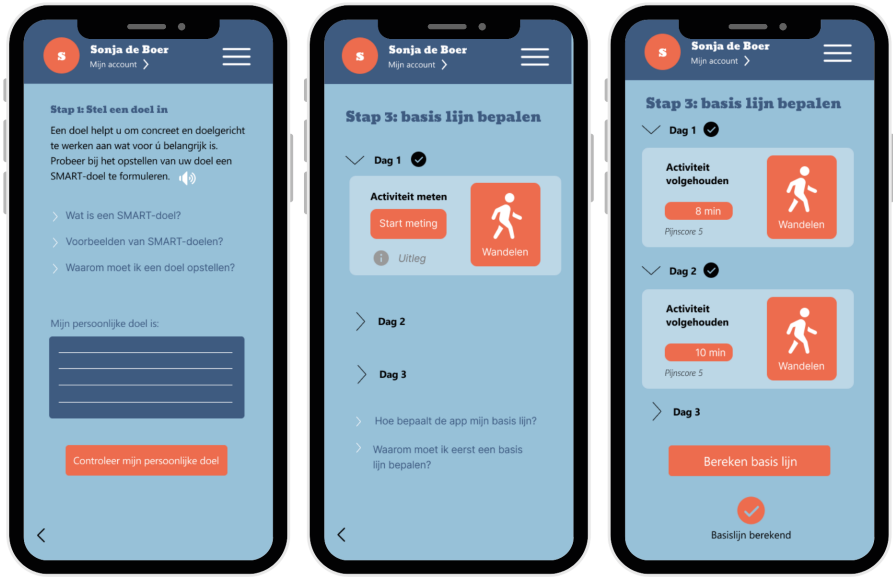

Figure 42: App screens of setting the base line

8.1.4 Goal of the app

The app is designed to help users **develop awareness** of their energy levels, while helping them **stay within their limits.** It does this by visually representing the user's estimated energy level as a battery icon that gradually depletes throughout the day, reflecting their decreasing energy.

The app estimates energy levels using an algorithm that combines various physiological and behavioral factors. This estimation process will be explained in more detail in the next paragraph. Based on these levels, the app provides personalized advice to help users make consistent progress toward their goal.

Users may spend most of their energy on daily tasks they feel like the **need to do**, which can leave little or no energy for working toward what they **really want to do** (their personal goal). To address this, the app recommends when and for how long to do physical activities aligned with the user's personal goal and applies the pacing method specifically to those activities.

The pacing approach begins with establishing a baseline for the selected activity. Based on this baseline and a predefined algorithm, combined with user input on pain and energy levels, the app generates recommended tasks. These tasks are gradually increased. This allows for steady progress while helping the user remain within their limits.

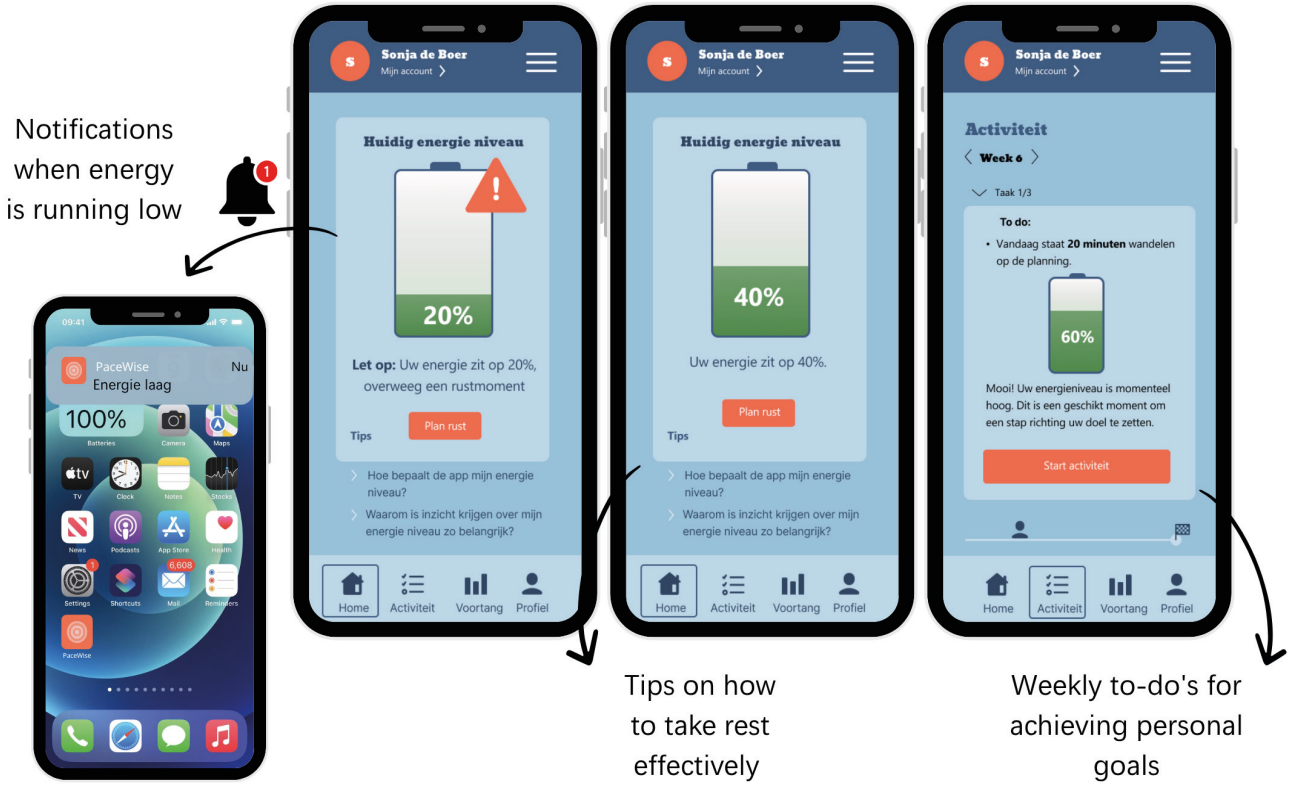

Figure 43: App screens of visual representation of the battery

8.2 Design decisions

This paragraph describes the most important design decisions that led to the final design. In addition, it explains why I chose certain elements and how they contribute to the design goal.

8.2.1 HRV and RHR as input data for the app

The app needs a variety of input data from the user in order to make tailored recommendations about someone's energy levels. Energy levels can be estimated using measurements like Heart Rate Variability (**HRV**) and Resting Heart Rate (**RHR**), which offer important insights into a person's physical health (Escorihuela et al., 2020). **RHR** indicates the number of heartbeats per minute when the body is at rest and not exercising, whereas **HRV** is the variation in time between consecutive heartbeats (Solan, 2024).

RHR is a well-known measure of cardiovascular fitness and overall health.

- **lower RHR** is generally linked to **higher levels of fitness** and greater efficiency.
- **Higher RHR** values may reflect **stress, illness, or a sedentary lifestyle.**

Numerous studies have shown that **HRV** can reveal signs of physical recovery and provide insight into the activity of the autonomic nervous system, particularly its response to stress. Chronic pain often disrupts this system, leading to an imbalance where the sympathetic nervous system (responsible for the fight-or-flight response) becomes overactive, while the parasympathetic system (which supports rest and recovery) becomes less active.

- **Lower HRV** is an indicator of an imbalance of the autonomic nervous system, what can indicate that the body is **not recovering effectively** from physical activity or other stressors (Merbler et al., 2020).
- **Higher HRV** generally indicates a **healthy and adaptable body**, particularly in relation to stress and recovery.

To support correct energy level estimation and adjust its recommendations appropriately, the app make use of the measured HRV and RHR values of the user.

Paragraph 8.3 explains how this data is measured. First, a more detailed description of how the app uses this data is given.

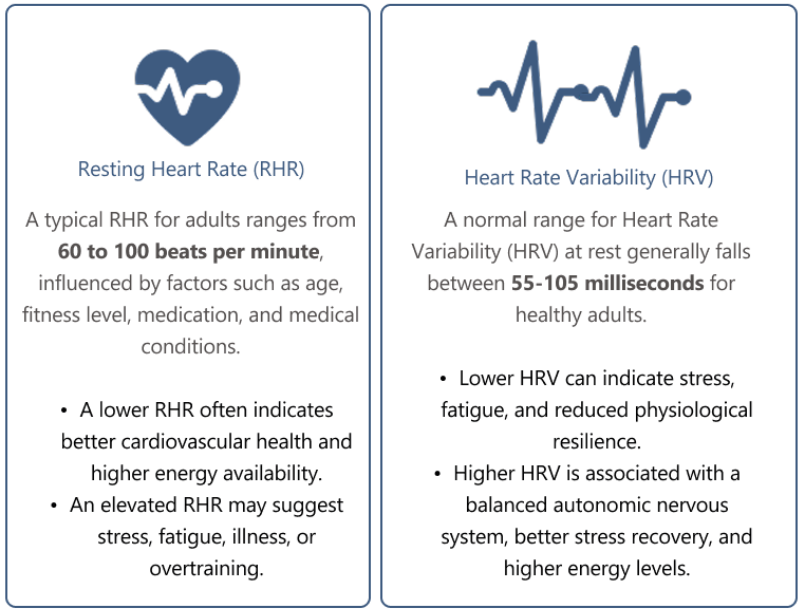

Figure 44: RHR and HRV values

8.2.2 Determining energy level from input data

As indicated in the previous paragraph, HRV and RHR values are important indicators for estimating a person's recovery. In addition to these measurements, another key indicator of recovery is sleep quality (Vyazovskiy, 2015). Sleep quality is crucial for effective recovery, both physically and mentally. During sleep, especially deep sleep, the body repairs and rebuilds tissues. This is essential for recovery and overall well-being.

To estimate the user's starting energy level each day, the app should use a combination of these physiological indicators (HRV, RHR and sleep quality). The precise weighted combination should be determined through user testing and further research.

It may be helpful for the app to compare HRV and RHR against each user's individual baseline to improve accuracy. Based on user trends, the app could dynamically adjust the weighting of each indicator over time. For example, RHR might correlate more strongly with fatigue than HRV for some users. An example calculation can be found in Appendix I.

8.2.3 Giving tailored recommendations

Depending on how much energy a user has left, the app provides tailored recommendations for achieving their personal goal. For example:

High Energy (70–100%)
"You are recovering well. Today is ideal for working on your personal goal, combined with other light to moderate activities."

Average Energy (40–69%)
"You can continue working toward your goal, but take extra rest breaks. Listen closely to your body."

Low Energy (0–39%)
"Limit activities. Schedule recovery time. Postpone non-essential goals."

This way, the user receives dynamic and personalized advice based on both objective and subjective data, making pacing tangible and no longer vague, but guided and measurable.

8.2.3 Battery discharge and recharging time

How quickly the battery depletes should be further explored and tested with users.

The app allows users to "charge" their battery by activating a rest moment. This charging function serves as a metaphor for restoring their energy. By visualizing how rest contributes to energy recovery, the app helps users become more aware that taking regular breaks can actually lead to increased energy throughout the day. The amount of energy gained from rest is another factor that should be further tested.

Even after extensive testing, the battery level shown in the app may still differ from the user's actual energy level. Therefore, the app should include a disclaimer stating that the battery provides an estimation of the user's energy and will never be a 100% accurate reflection. The battery is meant more as a tool for awareness than as a real-time, precise measure. It serves as a reminder that people with chronic pain may have a faster-draining battery, and that taking rest can help recharge it.

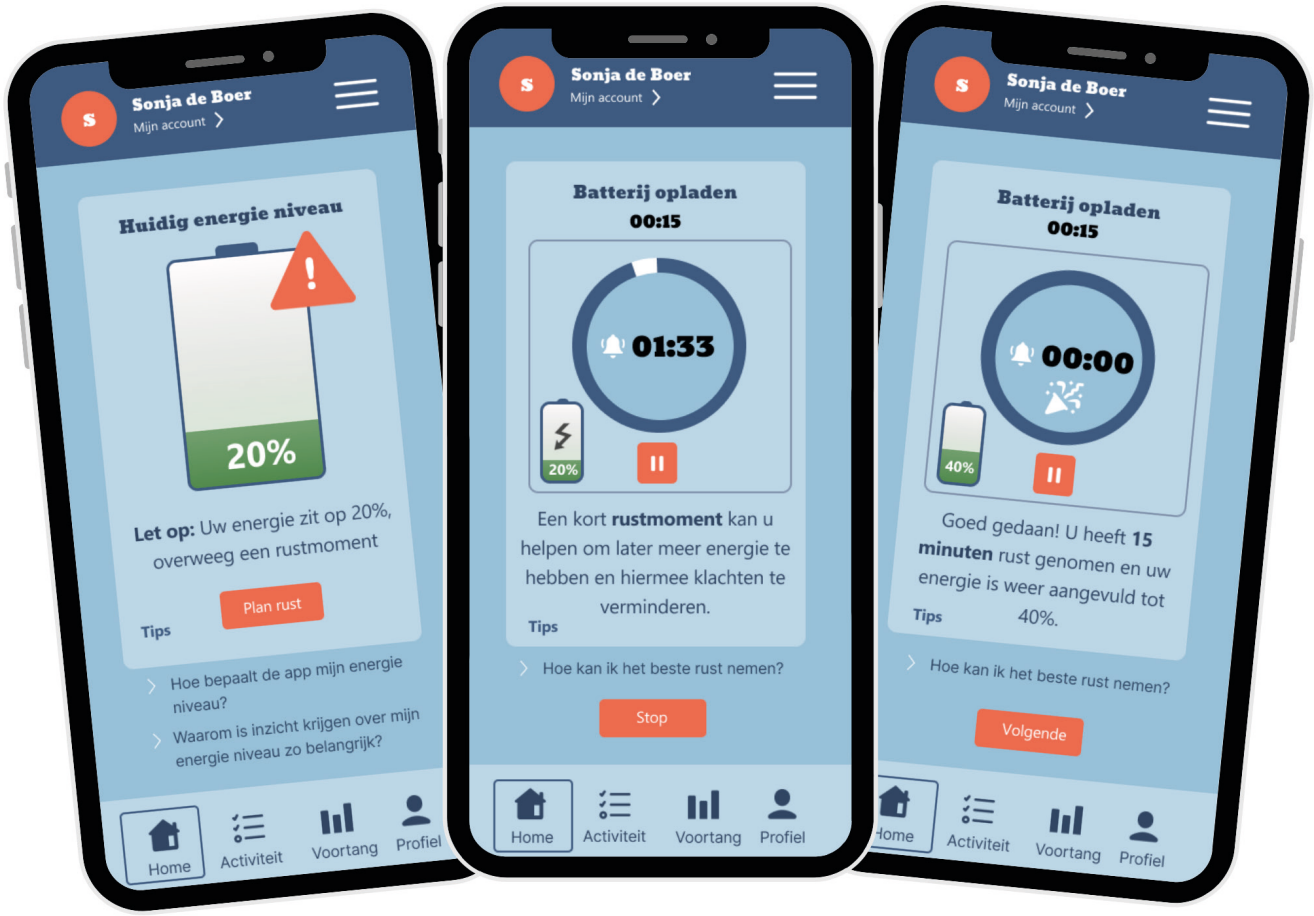

Figure 45: App screens showing battery amount (left) and timer for rest (middle and right)

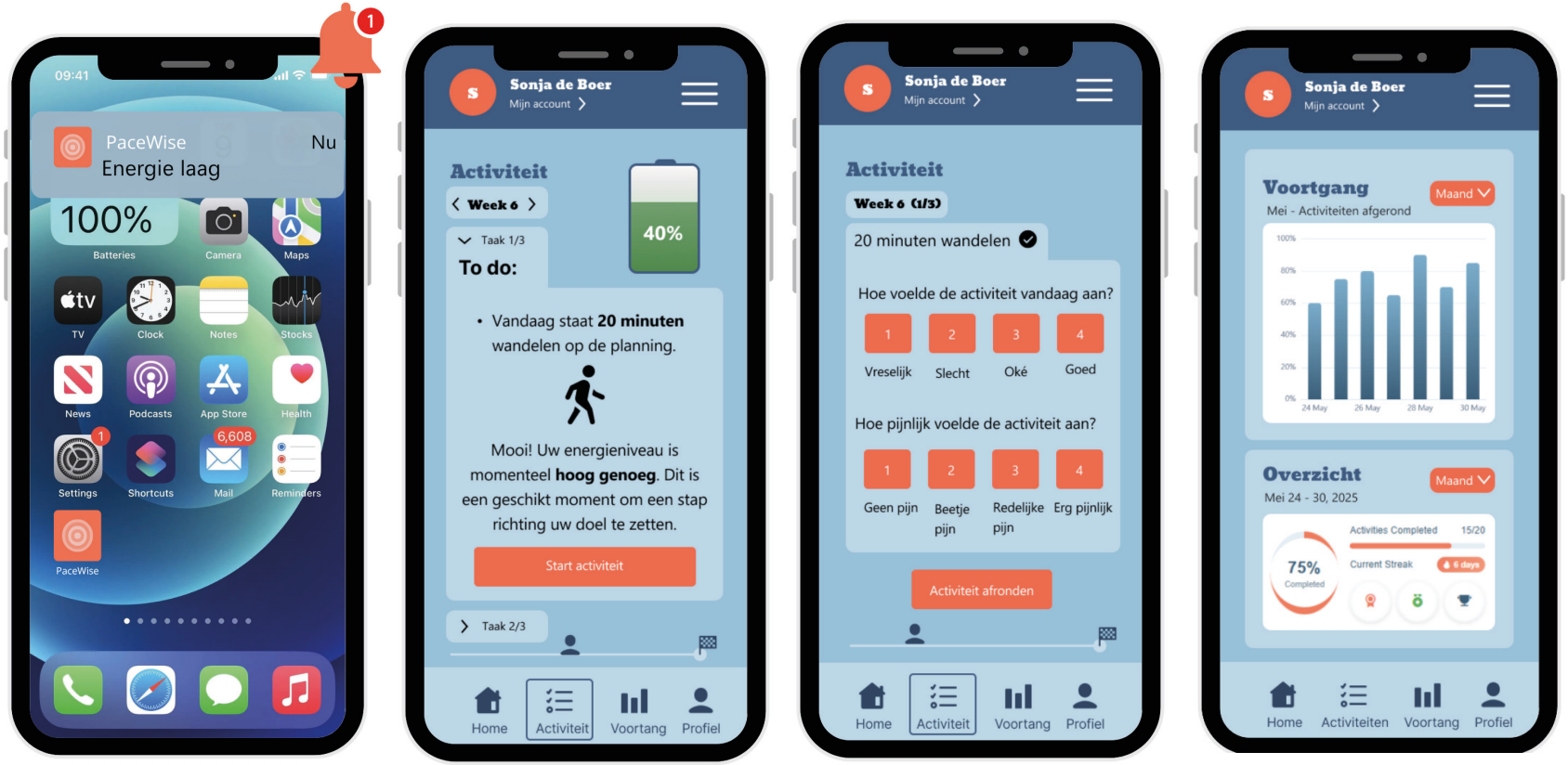

Figure 46: Examples of app screens

The user receives feedback about their energy level. When their energy is running low, the app sends a notification recommending a rest moment. Users can schedule a rest moment in the app to help recharge their energy levels.

On the activity page of the app, the user can see the recommended 'to-do'. In this example, it is a 20 minute walk. Improving walking is an activity the user wants to improve, because it helps them to get closer to their personal goal. The user can also view their current energy level according to the app. When the user starts the activity, a timer begins counting down.

After completing an activity, the user is asked to rate the activity on prefromance and pain level. The app uses this feedback to adjust the intensity of future activities accordingly.

The progress page displays how much progress the user has made toward their personal goal, along with detailed data on their HRV and RHR.

8.3 App in combination with smartphone or smartwatch

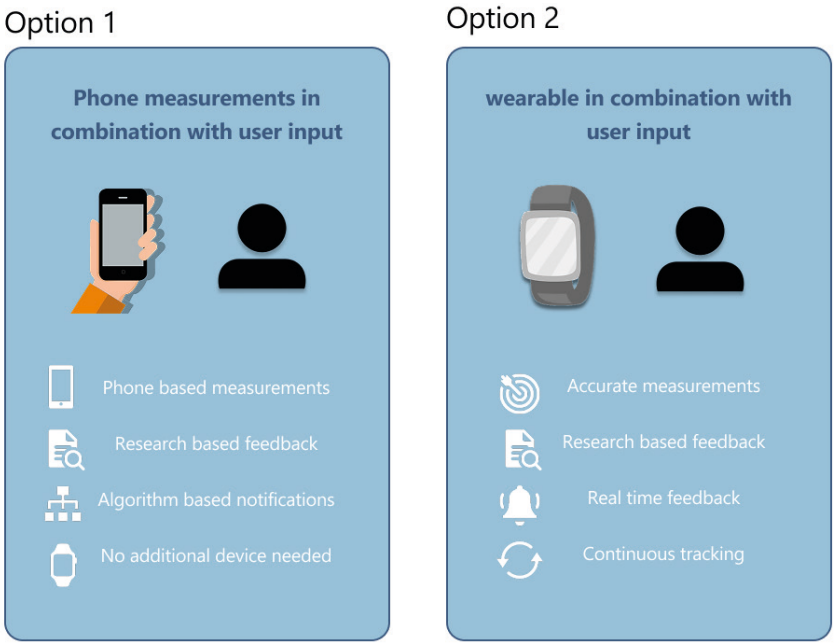

Figure 47: App combination options

To provide accurate and personalized advice, the app requires external physiological data such as Resting Heart Rate (RHR) and Heart Rate Variability (HRV). The most effective method for collecting this data is through a wearable device. Smartwatches are considered reliable for measuring Resting Heart Rate and offer good to excellent accuracy for certain HRV metrics, particularly under resting conditions and for low-frequency HRV components (Theurl et al., 2023).

However, the accuracy of short-term HRV measurements taken during movement or stress is generally moderate to low. Factors such as device type, signal quality, and environmental conditions also influence measurement accuracy (Li et al., 2023).

Alternatively, HRV and RHR can also be measured using only a smartphone. This is done via camera-based photoplethysmography (PPG), a technique that has shown results comparable to those of electrocardiograms (ECG) in research settings (Moya-Ramón et al., 2022).

Studies have demonstrated that measurements do not significantly differ from ECG results in either supine or seated positions, and they show very strong to nearly perfect correlation levels. Furthermore, no meaningful differences were found between short-duration (5-minute) and ultra-short-duration (1-minute) measurements. The intraclass correlation coefficients indicated good to excellent reliability, with a standard error of measurement below 6%.

In conclusion, seated morning smartphone-based measurements with 1 minute camera-based measurement can effectively be used to monitor HRV, offering a convenient and accessible alternative to a wearable. In order for the app to work properly, the user should take these measurements every morning. This may be inconvenient, so after a few measurements, the app will automatically standardize the data and use it as a default setting when the user forgets their morning measurement. If possible, the depletion rate of the battery should be based on a standardized algorithm when using smartphone measurements.

However, for the most accurate feedback and convenience, the user should wear a smartwatch. This also allows for real-time feedback on the user's heart rate and can send notifications when the users heart rate is too high, enabling real time feedback.

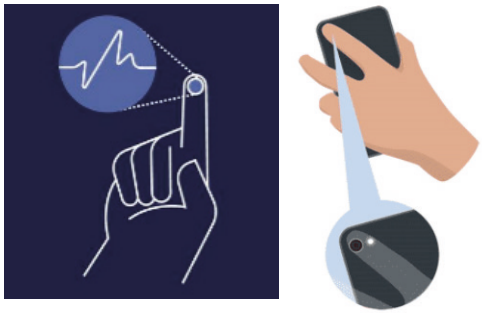

Figure 48: Camera based measurements (Sslox-ford, z.d.)

8.4 Design solution in patient journey map

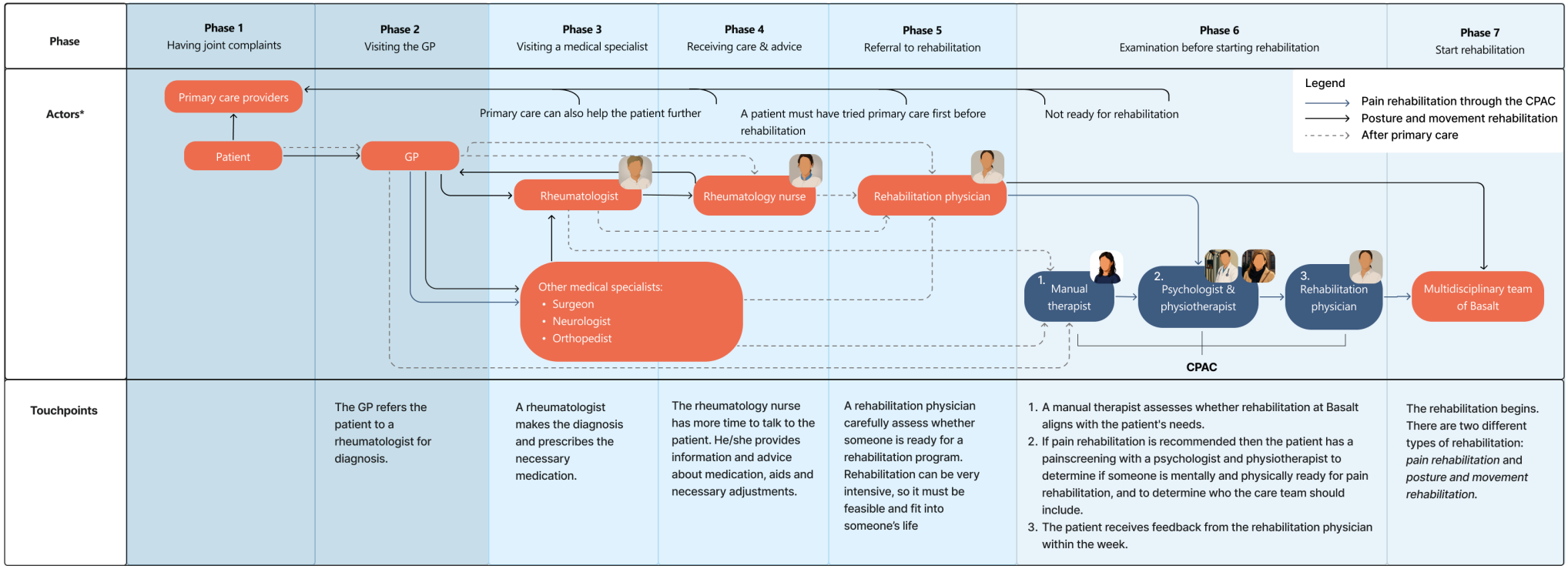

Figure 49: Zoom in of patient jourey map

The PaceWise app brings the insights form energy mangement from the occupational therapist forward in the patiet journey.

The intention is to introduce the app before the patient visits the rheumatology nurse. This way, the patient can already start with energy management before going to the appointment. During the appointment with the rheumatology nurse, the patient can ask questions about the app and about energy management to the rheumatology nurse.

09

Implementation of the app

This chapter will explain how the PaceWise app can be implemented within the healthcare environment of Reinier de Graaf, which serves as the specific context for this assignment. It outlines key considerations for integration and presents a step-by-step roadmap that the hospital can follow to successfully adopt to implement the app.

The research question this chapter aims to anwer is:

- *What steps need to be taken to effectively implement the app?*

9. Future perspective

The app cannot be immediately implemented in the hospital, as it still needs to be developed and tested. The following paragraph outlines the steps the hospital can take to eventually integrate the app into the healthcare environment.

9.1 Roadmap for implementing the app

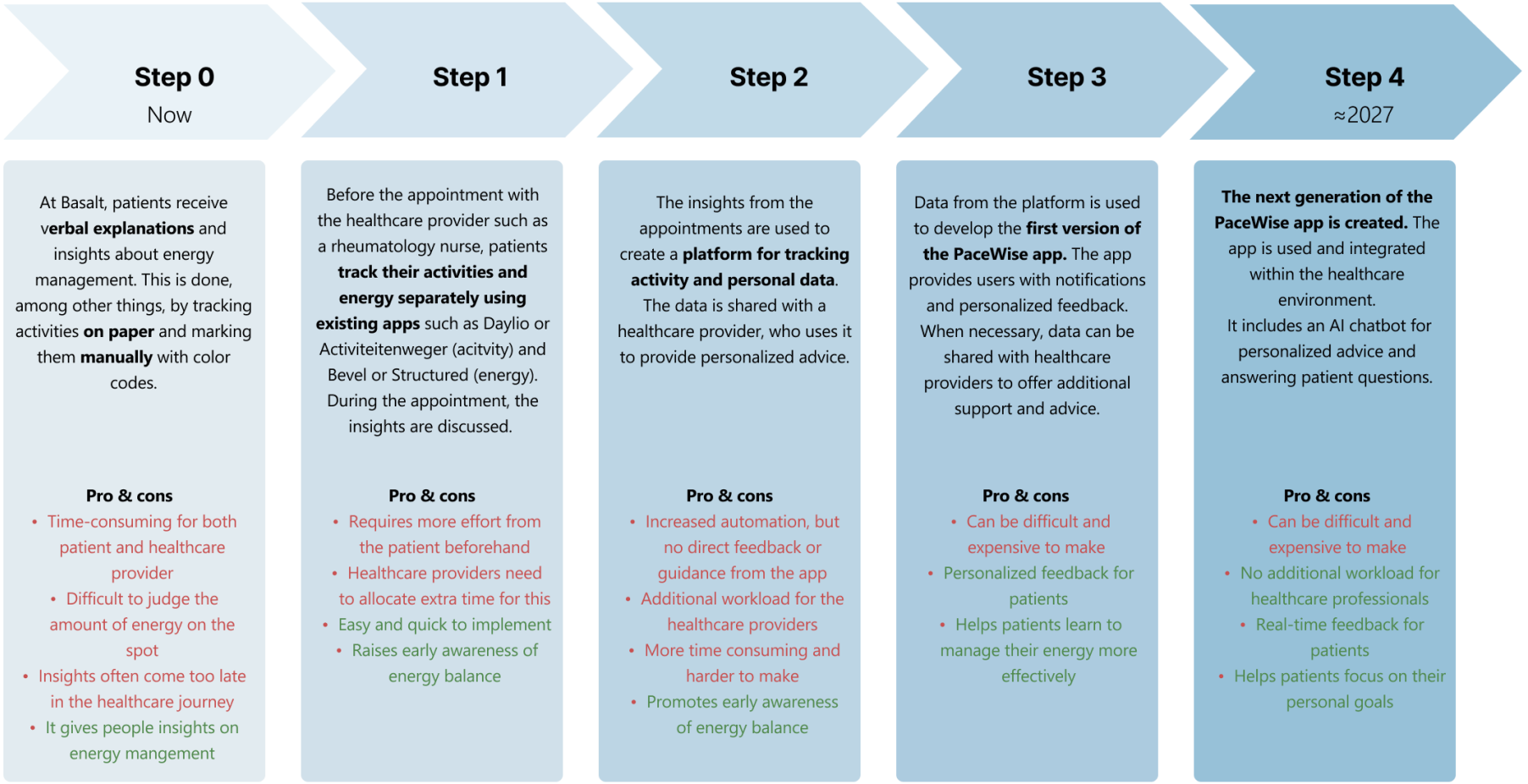

Figure 50: Roadmap for implementating the app

9.1.1 Integration steps for the app

Step 0 (now)
During occupational therapy at Basalt, patients learn to recognize their personal boundaries and how to avoid exceeding them. To help explain this concept, occupational therapists use various visual and verbal methods, such as the traffic light model, the battery metaphor, and the balance triangle. These are combined with written exercises to reinforce the learning. One such exercise involves tracking daily activities in 30-minute intervals for a week (see Appendix J). After completing this log, patients are asked to highlight each activity based on the amount of energy it costs them:

Green = energy-giving
Orange = somewhat tiring
Red = highly draining

This exercise provides valuable insights into how patients use their energy throughout the day. It helps them become more aware of their energy patterns and supports better energy management.

At the moment, during the appointment with the rheumatology nurse, patients typically receive only verbal information about their condition. As well as occasional advice on how to better manage the disease. No exercises are provided, mainly due to time constraints and the fact that this is usually a one-time consultation.

Step 1
Several apps are already available on the market to help people track their daily activities (see figure 37). Examples include '*Daylio*', '*Daglijst*' and '*Activiteitenweger*', which focus on activity tracking. Apps like '*Bevel*' and '*Structured*' support users in monitoring and analyzing their overall health and fitness levels.

Before someone can make meaningful changes to how they manage their energy, they need to understand how they are currently using it. Making people aware of their own energy distribution is therefore the first step in helping them manage their energy more effectively. A simple and effective way to do this is by providing them with personalized feedback based on their own activity patterns. A wat to do this is by sending patients a notification 1 to 2 weeks before their appointment with the rheumatology nurse, encouraging them to start using a combination of the recommended apps (one focused on tracking activities and one focused on monitoring their health). This allows patients to gather personal insights in advance. During the appointment, the nurse can review the data with the patient and provide personalized feedback. This approach offers more tailored support and helps patients better understand what energy management means in the context of their daily lives. It can also be easily implemented because no additional app needs to be created.

Additionally, a physical information flyer about the pain system can be given after the appointment (see figure 52). The rheumatology nurse can use the flyer to explain how the pain system works and emphasize the importance of energy management for people living with chronic pain.

Figure 52: Frontside flyer (final version)

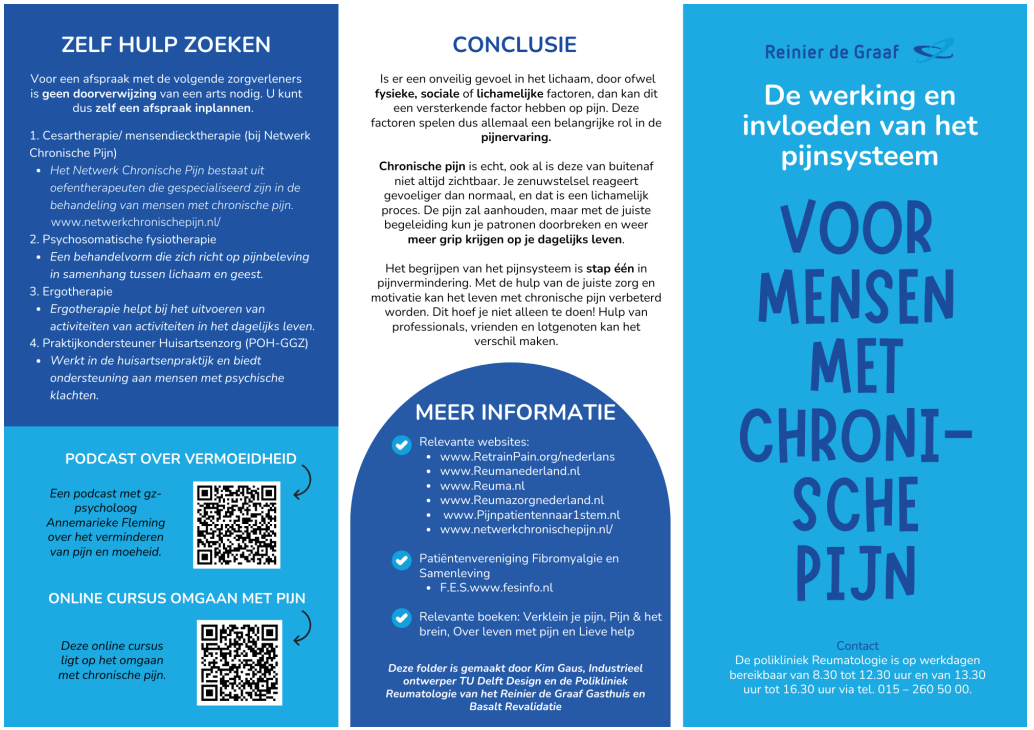

Figure 51: Backside flyer (final version)

The information in this flyer is based on the information about the pain system from chapter 2.2.

A patient was also interviewed about the content and layout of the flyer (see Appendix L for the full interview). The patient expressed that she appreciated having all the information about the pain system clearly presented on a single A4 sheet. Additionally, she preferred a physical flyer, as it is easier to read and refer back to.

However, further research is needed to determine the most effective way to convey this information to patients. See appendix L for all versions of the flyer.

To align the flyer with Reinier de Graaf's house style, the color scheme has been adapted to match the organization's official colors. In additional, extra information about options for primary care appointments are given.

Step 2
As a next step, instead of relying on a combination of external apps, Reinier de Graaf could develop an platform for tracking activities and personal data. The platform could be managed internally, this way the patient data could be shared directly with the rheumatology nurse, making it easier to provide personalized feedback. Additionally, the platform could include educational content about pain management, offering patients a more integrated and supportive experience.

Step 3
In this step, all insights gathered from the platform can be used to develop the first version of the PaceWise app. This version provides users with notifications and feedback on how to manage their energy more effectively. A detailed description of this version can be found in Chapter 8.

Step 4
In the final step, the next generation of the PaceWise app can be developed, incorporating AI technology. This would allow users to ask questions within the app about energy management and receive tailored responses. However, before this feature can be introduced, the AI must be thoroughly tested to ensure it can consistently provide accurate and helpful advice.

9.2 App requirements for a hospital integration

An app cannot be introduced into a hospital environment without careful consideration. To better understand the necessary requirements, two short online interviews were conducted with the Liaison Officer and Innovation Advisor at Reinier de Graaf Hospital. During these interviews, the concept design was briefly described. These conversations offered valuable insights into the key factors that must be taken into account when developing an app for use in healthcare settings.

9.2.1 Bringing an app to market

There are three main ways to bring a healthcare app to market:
- Outsourcing the concept to a manufacturer
- In-house development
- Collaborative development with external partners

If a manufacturer brings the app to market, the entire product file must be assessed for safety. Once it passes this assessment, the app can receive a **CE marking**, which certifies that it meets European safety, health, and environmental protection standards (CE Tool | Home, z.d.).

To determine whether the app qualifies as a medical device, and what requirements it must meet, the CE Tool can be used. This tool helps clarify the application of new medical device regulations, specifically the MDR (Medical Device Regulation) and IVDR (In Vitro Diagnostic Regulation). It also provides insight into the **risk classification** of the device.

According to a quick test conducted using the CE Tool, the app qualifies as a **medical device regulated under the MDR.**
Medical devices are classified into four categories based on risk: Class I, IIa, IIb, and III. The higher the potential risk to the patient in case of failure, the higher the classification. To determine the device's

risk class, the intended medical purpose must be defined. Based on this purpose, the applicable classification rules from the MDR can be identified.

The quick scan indicates that the app most likely falls under **Class I**, meaning it poses relatively **low risk**. However, the final classification is determined by the manufacturer. There are several steps that must be followed to receive a CE certification, these steps are described in appendix K.

9.2.2 Collaborative development with external partners

The PaceWise app's deployment is best achieved through ***collaborative development with external partners***. Since the hospital currently lacks the resources, expertise, and ability to manage such a digital product in-house effectively. If the app were to malfunction, the hospital would be responsible for resolving the issue While the hospital does not has the in-house knowledge or available personnel to address this promptly. Additionally, the hospital would not be able to provide the time and technical expertise needed for frequent app updates and maintenance.

The alternative approach, outsourcing the production to a third-party manufacturer, is also not recommended. This route carries the risk that the final product may not comply with Reinier de Graaf Hospital's privacy regulations and IT standards. Additionally, outsourcing in this way may result in an app that lacks seamless integration into the hospital's digital environment, which would reduce its usefulness and practicality for both staff and patients.

Therefore, **collaborative development with external partners** is the best option. This development would ensure that the app is professionally developed and complies with hospital requirements and current infrastructure.

9.3 Scalability of the app

Besides people with chronic pain due to joint issues, the app can also help individuals with other chronic illnesses or neuromuscular diseases, such as ALS, long COVID, or MS. The app serves as a tool to help users stay within their personal limits, making it suitable for multiple target groups.

There are also patients who are discharged from the hospital after surgery and have limited knowledge about energy balance. The app could support these individuals in regaining strength and recovering more quickly.

The hospital could recommend the app to several target groups. Since the app can be used on a broader scale than just for patients with rheumatic diseases, it becomes more valuable to invest in.

9.4 Conclusion

To come back to the initial research question of this chapter:

What steps need to be taken to effectively implement the app?

Developing an app takes time and money. Therefore, this chapter presents four steps the hospital can follow to implement the app.

1. Using existing apps to provide personal feedback to the patients
2. Create a platform for tracking activity and personal data.
3. Create the first version of the PaceWise app.
4. Create the next generation of the PaceWise app with AI technology.

In addition, I recommend having the app developed through collaborative development with external partners.

10

Evaluation

This chapter presents an evaluation of the design based on interviews with patients and two healthcare providers: a rehabilitation physician and a physiotherapist. The aim of the evaluation is to assess whether the initial design goal is achieved with the PaceWice app. The chapter concludes with an evaluation using the NASSS framework to assess the potential success of the app's implementation.

This chapter aims to answer the following research questions:

- *Does the app create awareness around energy management?*
- *Does the app support users in staying within their own limits?*
- *Does the app help the target group (people with chronic pain due to a rheumatic disease) better manage their energy levels?*
- *Is the app desirable?*
- *Does the app align with the key takeaways of energy management from rehabilitation?*
- *How easy is it to implement the app?*

10. Evaluation

10.1 Evaluation challenges and approach

With the evaluation I want to test the app on several aspects. First of all it is important to test if PaceWise, achieves the design goal from the design statement that was previously created in the project using the research insights.

10.2.1 Evaluation approach

The design statement is as follows:
Design a tool that helps people with chronic pain due to a rheumatic disease effectively manage their energy levels throughout the day by supporting them to stay within their limits, to help them regain the sense of control over their pain.

The user evaluation aims to assess whether the app effectively achieves supporting individuals in managing their energy levels throughout the day.

Since the app does not yet exist in a functional form, real-life testing in a realistic context is currently not possible. However, an alternative approach can be used: presenting the concept to users by explaining what the app would do and how it would function (with scenario sketching). This allows users to imagine its potential usefulness and provide feedback on the concept. It is important to first verify whether the core objective of the tool is being addressed before further developing and refining the idea.

The goal of the app is to raise awareness about energy management. The interviews should help determine whether the app supports this goal and should provide an initial indication of whether the concept is moving in the right direction.

10.2.2 Testing features of the app

Besides the main goal of the design, some smaller yet important aspects of the app should also be tested.

- The app is designed to prompt users to take a rest when their energy levels are running low. Therefore, it is important to test whether users actually take some rest when they receive a notification. I need to determine whether a notification from the app is a sufficient trigger to prompt rest, or if additional triggers are needed.
- The effectiveness of the weekly to-do's also needs to be evaluated. It is essential that users are motivated to engage with the activities related to their personal goals and that they actually complete them. Is simply providing a to-do list enough, or is more guidance and support required?
- Lastly, the first version of the user interface can be tested to determine whether everything is clearly communicated to the user and whether the user understands how the app works. This can be done by having participants navigate through the Figma prototype on a phone. Participants will be asked to think out loud as they interact with the app's interface.

10.2 Patient interview

Taking all the information from the previous paragraph into account, relevant interview questions were made, see appendix M for all interview questions. Also a video was made to show the participant the user context of the app.

In total, four participants were interviewed. All participants suffer from chronic pain caused by a rheumatic disease, ensuring that the desirability and opinions of the intended target group were assessed. Each interview lasted approximately 30 minutes and was recorded, with permission obtained beforehand. All participants already started a rehabilitation traject at Basalt.

The most important take-aways are stated below:

10.2.1 Improvements op the app

- Adding a page with all the tips:
  Instead of having to search for the right page for specific tips, an additional page containing all the tips could be added. Besides tips, additional information about how the pain system works could also be provided here. Opinions on whether these tips should be presented in video format or text were divided. Additional research with more patients should be conducted to make a more well-informed decision.
- Adding the option for physical or mental rest:
  The participants indicated that they would like to have the option to choose between physical and mental rest. Physical rest focuses on relaxing the body while still allowing mental stimulation, for example through reading or watching TV. In contrast, mental rest is aimed at relaxing the mind, which could be achieved through activities such as meditation.
- Give users the option to choose the amount of resting time:
  The participants also preferred having the option to choose the duration of their resting time. This allows users to adjust the rest period based on how much time they have available and how much rest they feel they need.
- Extend the three days for determining the baseline:
  All participants indicated that three days for determining the baseline is too short. Good or bad periods can sometimes last several days. To avoid measuring only during a period of either good or bad days, the baseline period should be extended to at least a minimum of one week. During this week, the app could already display the main screens, allowing the user to view their energy level. The baseline will be determined based on the user's input throughout this week. After this week, the app will unlock the personalized to-do's to help the user work toward their personal goal. Further research needs to be done to determine the optimal time to determine the baseline.

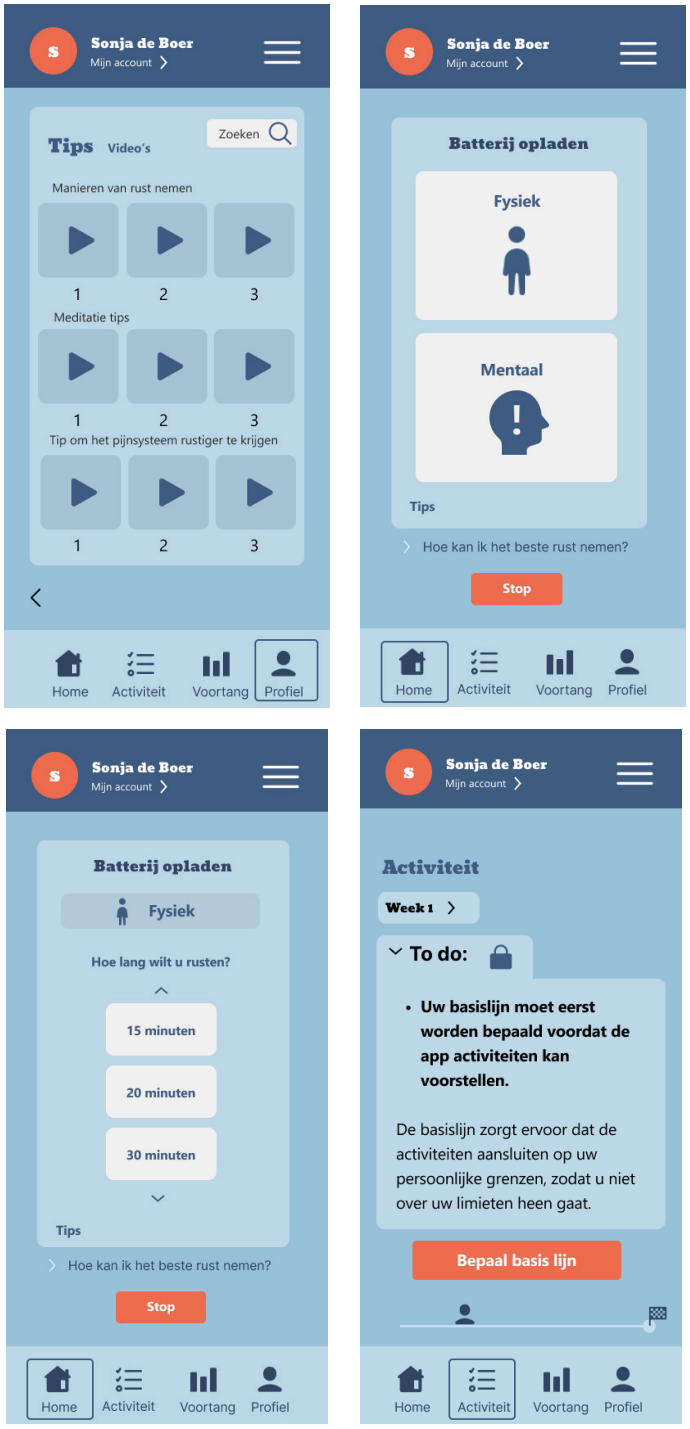

Figure 53: New app interfaces, after patient interviews

10.2.2 Answering the research questions

Through the patient interviews, I aimed to find answers to the research questions related to the goal and desirability of the app. This paragraph discusses the answers to the first four research questions.

The first research question was: "Does the app create awareness around energy management?"
Based on the interviews, it can be concluded that the app will most likely raise awareness on this topic.
All participants indicated that the app would increase the amount of awareness on a scale to one to seven, when they would start using the app.

- *"I think the app can really raise awareness." - P1*
- *"I do think it can increase your awareness, because you don't always feel how tired you really are. Your mind can also push things to the background, whereas the app can signal it."- P4*
- *"An example I currently use is the traffic light visual. I have a piece of paper from it in my drawer, and every time I see it, it makes me think about it. Your app could create that same awareness effect." - P2*

For the second question: "Does the app support users in staying within their own limits?"
Participants were not entirely certain that the app would always ensure users stay within their limits. However, they stated that it could serve as a helpful tool to raise awareness and encourage you to think about your personal limits. The app acts as a reminder to stay within those limits, which can help to prevent pain flare-ups in the future.

- *"Yes, I think a notification is enough to make someone reflect on it. It might make you think more consciously about your energy levels and how you use them." P2*
- *"I think this varies from person to person. Speaking for myself, I went over my limits a few times. I only noticed it afterward and felt the consequences. But after doing that a few times, you start to think more consciously about it and make sure that you stop in time the next time. In that case I will probably listen to the notification from the app." - P1*

The third question was: "Does the app help the target group (people with chronic pain due to a rheumatic disease) better manage their energy levels?"
Based on the patient interviews, it can be stated that this likely is the case. Since extended real-life testing with a working interactive app was not possible, participants were asked to imagine whether the app would help them manage their energy levels. All patients responded positively, indicating that they believed the app would be a helpful tool. However, the impact of the app ultimately depends on the user and how seriously they engage with it.

- *"I believe it could be helpful. Right now, you have to sense it yourself and plan things accordingly. If the app can help you with that and is very accurate, I think it could definitely offer more insight."- P4*
- *"The app increases awareness, which makes it easier to start working on it later, for example during rehabilitation or occupational therapy." – P1*
- *"It's exactly what I'm doing now in rehabilitation, and here it really helped me." - P3*

The fourth questions was: "Is the app desirable?"
To answer this question, I considered all the feedback provided. Based on the responses, I can conclude that most participants were very positive about the app. They mentioned that such an app would have been really helpful for them earlier in their journey, which is

exactly what I aimed to achieve.

- *“I really missed this kind of help earlier in my journey. This app and support from the rheumatology nurse would be very helpful. That way, I could start working on it sooner. That’s something I actually missed. It would make everything much clearer. -P1*
- *“That really hits the nail on the head. In my opinion, introducing the app before seeing the rheumatologist is an important moment, especially since scheduling an appointment can take 3 to 9 months. When you’re there as a patient, you really want to leave with a package of things to work on, knowing that your next appointment won’t be for another six months. - P2*

10.2 Interview with healthcare professional

Before the patient interviews, the app was discussed with two healthcare professionals: a physiotherapist from Basalt and a rehabilitation physician. The goal of these interviews was to further improve the app to better match the methods used at Basalt around energy management. The associated research question was:
Does the app align with the key takeaways of energy management from rehabilitation?

The first interview was conducted with a physiotherapist from Basalt who has extensive expertise in pacing and in working with patients experiencing chronic pain. The interview lasted approximately fifty minutes and focused on gaining a deeper understanding of how pacing is applied in practice during physiotherapy and how it can be translated into the app.

The interview provided valuable insights. The key takeaways are summarized below. All interview questions can be found in Appendix N.

10.2.1 Insights from physiotherapist from Basalt

Improvement point 1: The app should not aim to "solve" chronic pain
One of the main concerns was that the app may still be too focused on trying to "solve" chronic pain. While chronic pain is not something that can be cured. Instead, patients must learn to accept it as part of their lives. The idea of "achieving personal goals" within the app could unintentionally reinforce the misconception that chronic pain can be solved.

At Basalt, they use the Canadian Occupational Performance Measure (COPM) instrument, which allows patients to evaluate their goals in terms of both execution and satisfaction. This means that even if a goal is not fully achieved, a patient who feels satisfied with their progress can still rate the outcome positively.

Figure 54: App screens of the implementation of the COPM model

This principle could be integrated into the app. Users could assess their goals and activities during the initial setup. The app could then prompt monthly self-assessments, helping patients reflect on changes in execution and satisfaction. Over time, this could support the realization that while some goals may no longer be achievable, satisfaction and well-being can still improve.

Zwaarte belasting	Borgscore
	6
zeer zeer licht	7
	8
zeer licht	9
	10
tamelijk licht	11
	12
redelijk zwaar	13
	14
zwaar	15
	16
zeer zwaar	17
	18
zeer zeer zwaar	19
maximaal	20

Figure 55: The borgscore

Improvement point 2: incorporate the borg scale
The physiotherapist also emphasized the value of using the Borg rating of perceived exertion (RPE) scale, see figure 55. This tool is used to help patients become more

aware of the intensity of their activities. It teaches them that pushing to the maximum (score 20, "red zone") is excessive, and that the optimal level of exertion is around 13 ("orange zone"). This method functions as a kind of "traffic light model" for physical activity.

The app could apply this scale by asking users to rate the perceived exertion of an activity (using the Borg rating) immediately after completing it. Based on the rating, the app could provide tailored feedback on whether to reduce or increase intensity in future attempts. This would help patients understand their current exertion level relative to the ideal range and reflect more critically on how physically demanding different activities feel.

Additionally, the app could offer suggestions on how to break activities into smaller steps and incorporate rest periods more effectively. This would guide patients toward more sustainable energy management strategies and promote self-awareness in their daily routines.

Figure 56 : App screens of the implementation of the Borgscore

10.2.2 Insights from rehabilitation physician

An additional interview was conducted with a rehabilitation physician to incorporate her professional perspective. The key insights from this interview are outlined below.

During the interview, the feasibility of the app was discussed, especially regarding how realistic and attainable the user's goals are. It is possible that some patient goals may not initially appear to be linked to physical activities. For example, a patient may have the goal of being able to meet with friends for an hour. Since this is not an individual physical task, it may be challenging for the app to provide tailored and correct advice. The app is primarily designed to support function-level goals (e.g., improving mobility or endurance). Whereas rehabilitation often focuses on participation-level improvements, where the emphasis is on enabling individuals to take part in society as independently as possible.

In rehabilitation, more attention is given to exploring why a particular goal is important to a patient and what deeper needs it fulfills. The app, in its current form, cannot support patients at this level of reflection. However, it can assist users by offering guidance to improve certain functional abilities without exceeding their physical limits. Additionally, the app can raise awareness around the importance of timely rest and recognizing personal boundaries. The app should propose functional activities that are connected to a user's broader goal. For instance, in the case of wanting to meet friends for an hour, the relevant underlying functions might include sitting or walking. The app could then guide the user in managing and gradually building up these specific functional abilities.

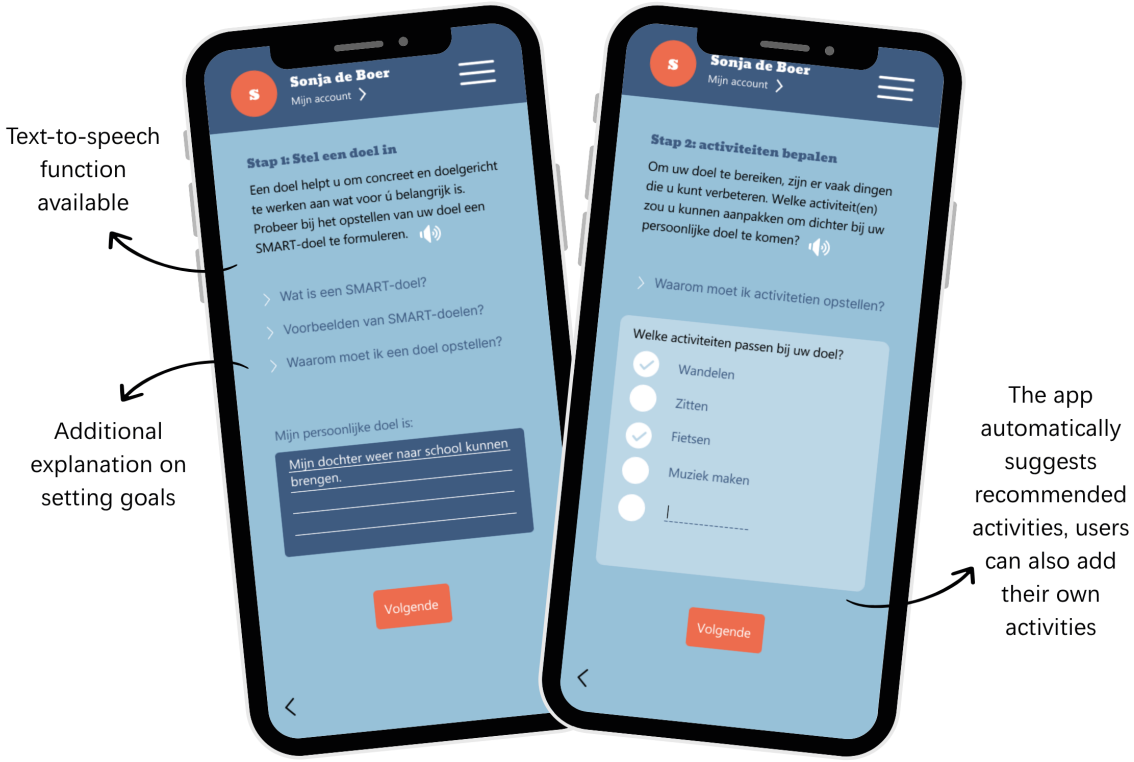

Figure 57 : App screens of setting goals and relevant activities

10.3 Nasss framework

To evaluate how easy it is to implement the app the British NASSS framework (Non-Adoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability) was used. This method helps to identify and manage the complexity associated with e-health interventions. It serves as an evaluation model consisting of seven domains that influence the success or failure of a healthcare technology. The framework was developed by Trisha Greenhalgh and Seye Abimbola (Greenhalgh & Abimbola, 2019).

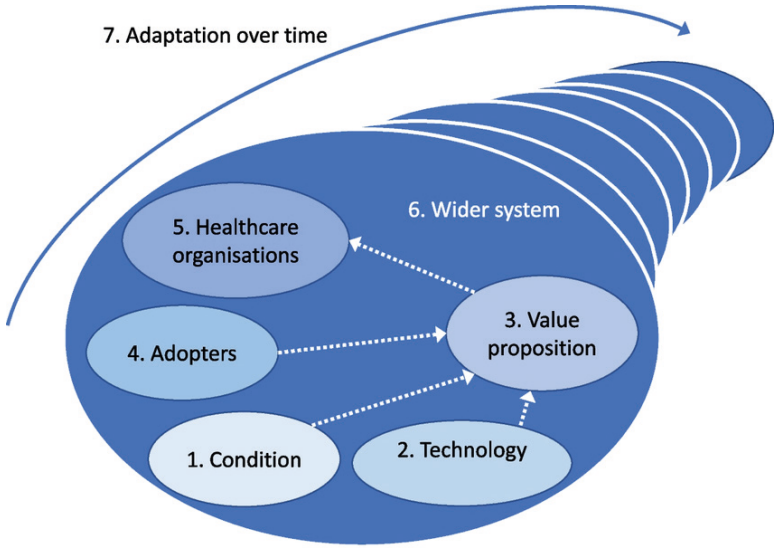

Figure 58: Nasss framework (Greenhalgh & Abimbola, 2019)

10.3.1 Evaluation on the seven domains

1. Condition

This domain concerns the illness or condition the technology is designed to address. In the case of PaceWise, the target group includes individuals with chronic pain and energy-limiting conditions. Complexity: High. These conditions are subjective, long-term, and multidimensional (biological, psychological, and social). There is no single solution that works for all; each individual requires personalized support and tailored advice.

2. Technology

This domain refers to the characteristics of the technology itself, such as usability, reliability, integration, and maintenance. PaceWise is a mobile application that may be connected to a smartwatch to collect physiological data (e.g., HRV, RHR, sleep) to assess energy levels. The measurements used are not always 100% accurate, which introduces complexity. The app is designed to be user-friendly, taking into account the needs and limitations of its target group. Data privacy and security are essential, personal health data must not be shared with third parties without consent.

Complexity: Moderate to high, due to potential sensor inaccuracies, the importance of secure data handling, and the integration of personalized feedback.

3. Value proposition

This domain focuses on the value generated by the technology and in what way. For PaceWise, the value lies in empowering patients, reducing relapses, and improving self-management. While the economic value is difficult to quantify, particularly because benefits occur mainly outside the hospital, it holds significant societal value. The app promotes proactive self-care and energy management outside hospital settings, which may help reduce the long-term burden on rehabilitation services and prevent patients from spiraling into chronic deterioration.

Complexity: Moderate to high, due to the indirect and long-term nature of the value and its limited financial relevance for hospital stakeholders.

4. Adopter system

This domain considers the users of the technology. For PaceWise, primary users are patients, but physiotherapists, rehabilitation specialists, or nurse specialists may also interact with the data to offer personalized advice. The app is designed to be intuitive, requiring minimal digital literacy, and provides feedback based on real-time data.

Complexity: Low, assuming the app remains accessible and provides meaningful feedback.

5. Health/ care organisation
This domain relates to the healthcare institutions involved in the implementation. PaceWise is used at home by patients, but is implemented by the hospital. The app aligns with broader hospital goals such as self-management, personalized care, and out-of-hospital support.

Complexity: High, as the hospital has to find a way to implement this app in the healthcare environment.

6. Wider system
This domain addresses policy, regulation, funding, privacy laws, and interoperability. For PaceWise, these aspects remain complex, particularly when the app is developed in-house. Issues around responsibility for funding, data governance, and integration with existing systems need to be carefully managed.

Complexity: High, due to regulatory and infrastructural challenges that go beyond the scope of the hospital alone.

7. Continuous embedding and adaptation over time
This domain evaluates whether the technology can adapt to changing conditions over time. PaceWise is designed to be scalable and adaptable, with potential for algorithm updates, integration of user feedback, and continuous improvement based on usage patterns.

Complexity: Moderate, depending on how flexible the system is in practice and how responsive the development team is to change.

10.3.2 Summary
The NASSS framework provides a structured approach to assess the complexity and implementation challenges of the PaceWise app across seven key domains. The analysis suggests that, in several areas, the level of complexity remains relatively high. This indicates a need for extra attention and strategic focus in these domains to support the successful implementation of the app.

10.4 Evaluation conclusion

The interviews with the patients aimed to answer the following questions:

- *Does the app create awareness around energy management?*
- *Does the app support users in staying within their own limits?*
- *Does the app help the target group (people with chronic pain due to a rheumatic disease) better manage their energy levels?*
- *Is the app desirable?*

Based on the responses received during the interviews, it can be concluded that the app will likely result in a "yes" for each question. Further research and user testing with a functional, real-life prototype should be conducted to confirm these outcomes. However, based on all the feedback, I can conclude that the app is a step in the right direction.

The interviews with the healthcare providers aimed to answer the following question:

- *Does the app align with the key takeaways of energy management from rehabilitation?*

Based on the two interviews, it can be concluded that some minor changes to the app were necessary to better align with the principles of energy management in rehabilitation. After implementing these changes, the app now reflects the key takeaways of energy management, which include becoming aware of personal limits and avoiding excessive overexertion.

The Nasss framework is a tool that helped with answering the last research question of this chapter:

- *How easy is it to implement the app?*

The app still contains some areas of relatively high complexity. These areas will require extra attention during further development to support the successful implementation of the app.

11

Project conclusion

In this chapter, a final conclusion of the project is presented. The design statement is reflected upon, and the design criteria are reviewed. A discussion is included, covering the project's limitations and recommendations for further research. The chapter concludes with reflections on the design, the process, and personal development.

11. Project conclusion

11.1 Conclusion

This project started with the following design aim:
"Design a tool that improves the healthcare experience for patients with joint complaints from the initial hospital appointment to the the start of rehabilitation."

To create a tool that enhances the healthcare experience for these patients, a patient journey map was developed. Additionally, research into the relevant context was conducted using context mapping and thematic analysis. These insights led to the following final design statement:

Who?

Design a tool that helps people with chronic pain due to a rheumatic disease effectively manage their energy levels throughout the day by supporting them to stay within their limits, to help them regain the sense of control over their pain.

How?

Why?

To evaluate whether the final design meets the goal, helping users effectively manage their energy levels throughout the day, interviews with the target group were conducted. From these interviews, it can be concluded that the PaceWise app shows potential in supporting individuals with energy management. However, as the app is not yet fully functional, real-life context testing is still needed to properly assess its effectiveness.

11.1.1 Looking back at the design criteria

Before developing the final design, several criteria were established. Below is an evaluation of whether the current design meets these criteria:

- The design should help users manage their energy levels more effectively. → Based on the user interviews, it can be concluded that the app is a step in the right direction in supporting users with managing their energy levels. While real-life testing still needs to be done, participants expressed that the app would likely help increase awareness and guide them in pacing their activities more effectively.
- The design should not place additional burden on healthcare capacity. → As described in Chapter 9, the app cannot be fully integrated into hospital systems immediately. Several preparatory steps are required, which may initially cause some additional work for healthcare providers. However, these steps are essential to support the patient in the long term. Once the AI-supported version of the app is developed, the burden on healthcare professionals is expected to decrease.
- The design should be based on scientific evidence and align with recognized rehabilitation and pain management practices. → The methods used in the app are based on rehabilitation practises and methods. For instance, the app uses pacing methods, which is a well-studied and commonly used approach during rehabilitation.
- The design should respect patient privacy and comply with healthcare data regulations. → Several interviews were conducted to gain insight into healthcare regulations. Relevant privacy laws and data protection standards, such as the GDPR and NEN 7510, were taken into account during the design process. However, this is a complex area that will require further exploration and validation during future development phases to ensure full compliance.

11.1.2 Desirability, feasibility and viability

Taking everything into account, this project has laid a solid foundation for a tool that supports individuals with chronic pain in managing their energy levels more effectively.

- The **desirability** of the PaceWise app has been validated through positive responses from patients during interviews. Participants recognized its potential to raise awareness and help them stay within their personal limits.

- In terms of **feasibility**, while the app is not yet fully functional, existing apps with similar features show that such an app is realistic to develop. Research indicates that heart rate measurements are a reliable source for assessing energy levels. However, additional research is needed to validate the accuracy of these measurements and determine the final formula for the app.
- Regarding **viability**, the PaceWise app has the potential to contribute to a more positive patient experience. Further research is required to explore the financial aspects of the app, including the cost of development and the potential for passing these costs on to users, for example through a licensing model. Additionally, the app has been designed with healthcare regulations in mind and aims to minimize the burden on healthcare providers.

The PaceWise app demonstrates a thoughtful balance between what users need, what is technically possible, and what can realistically be implemented within the healthcare system. Making it a valuable step toward improving the healthcare experience and empowering patients in their self-management journey.

11.2 Limitations

I had six months to work on this master's thesis. While this may sound like a long time, it passed quickly. Due to the limited timeframe, it was not feasible to speak with a large number of people. Although interviews with five patients already provided relevant insights, in an ideal scenario, I would have interviewed more participants to gain a broader and more diverse perspective. The same goes for the evaluation interviews in an ideal situation, I would have spoken to more patients to obtain broader feedback.

This project was carried out individually, which means that some decisions may have been influenced by my own previous experiences and personal worldview.

The context of the healthcare system is broad and complex. As a result, certain aspects may have been overlooked. This could potentially lead to unforeseen challenges during the implementation phase that were not anticipated during the research.

11.3 Recommendations

11.3.1 Improvements for the app

Further research is necessary to continue improving and finalizing the app. The following aspects need to be tested and improved:

- Tips provided in the app: These should be reviewed in consultation with healthcare professionals to ensure accuracy and relevance.
- Battery depletion formula: Additional research is needed to develop an accurate algorithm that ensures the battery level reflects the user's actual energy levels.
- User interface: The design should be further refined, and usability studies should be conducted to assess user-friendliness.
- Measured user data: Research should investigate whether data from a phone alone is sufficient to provide a reliable estimation of the user's energy level.
- Accuracy of the app: Additional testing is needed to assess how accurately the app estimates the user's energy level.

11.3.2 Regulations and legislation

A brief online interview was conducted with the ICT functional manager of Reinier de Graaf Hospital. This interview provided insight into the considerations that need to be taken into account when implementing a technical development in the hospital.

- Additional research regarding the storage of user data should be conducted, and data sharing with the hospital must be carefully evaluated and tested. The GDPR (General Data Protection Regulation) should be taken into account. This European law sets the rules for processing personal data. Similarly, NEN 7510 is a standard for information security in healthcare, specifying how healthcare organizations should organize their information security. In addition, the app must have a Dutch provider to meet the requirements of a hospital.

11.3.2 Recommendations for Reinier de Graaf Hospital

To effectively implement the design within the healthcare environment of Reinier de Graaf Hospital, several additional steps need to be taken:

- In-depth market research: Further research is required to clearly define the size and characteristics of the app's target group
- Partnership development: A company willing to develop the app in collaboration with Reinier de Graaf needs to be identified.
- Cost analysis: The overall development and implementation costs of the app should be assessed. Additionally, the potential costs passed on to users still need to be determined.

11.4 Reflection

11.4.1 Refelction on the design

Looking back, I'm proud of what I have created and accomplished within the limited time I had. I have received positive feedback on the design from several people.

If I had more time, I would have liked to develop different interface versions to test which layout and design would work best for the user. I also would have wanted to speak with more healthcare providers to further develop the tips included in the app.

My design focuses on energy management by increasing awareness of your energy levels while keeping your personal goal in mind. My design does this through an app. I do wonder whether something much simpler, like a reminder gadget/ video or paper could also help raise awareness of energy levels. However, I don't think such a gadget/ video or paper would provide enough guidance for someone.

I chose to design an app for patients rather than something that could be directly used by the hospital. I still stand behind this decision, but I am curious about what kind of design might have emerged if I had focused on creating something for healthcare providers.

11.4.2 Reflection on the process

In general, the process went smoothly. In the beginning, however, I had some difficulties finding my way in a completely new environment: the healthcare sector. Especially the strict regulations around patient contact and the process of writing the METC application were challenging. Waiting for the approval of this application slowed down my process.

However, during this waiting period, I used the time to start writing some chapters of my report. Once I received approval, I still faced more difficulty than expected in recruiting patients. My target group, patients referred to rehabilitation due to a rheumatic disease, turned out to be smaller than I had anticipated. This caused additional delays in my project. During this waiting time, I didn't know what to do, as I couldn't approach the patients myself and was completely dependent on the healthcare providers. In the end, it all worked out and I was able to speak with several patients. However, if I were to do this again, I would build in much more time for patient recruitment in my planning. I would also make sure in advance that the target group is broad enough to ensure sufficient participation.

I also learned that if you want someone to do something for you, especially in a healthcare setting, you really have to follow up consistently. At first, I found this quite difficult, but eventually, I figured out how to navigate this environment effectively. This process taught me a lot about working with external stakeholders and managing uncertainty. The project really helped me gain more confidence in approaching stakeholders and being open to a new environment.

11.4.3 Personal reflection

This project taught me a lot, not only about the topics of rehabilitation, rheumatism, and energy management, but also about managing a design project. Throughout my studies, I participated in many projects, but this was the first time I managed such a large project on my own. This experience taught me how to manage an entire project independently. Being solely responsible pushed me to be more self-reliant. At the same time, I realized the value of regularly checking in with mentors to avoid getting stuck in my own bubble.

I also learned how to communicate with stakeholders who do not respond immediately to my emails or calls. I became more resilient and proactive, learning to follow up persistently yet respectfully with

healthcare professionals. This helped me strengthen my professional communication skills.

It also learned me to improve my design skills, for example, I had never created such a large and complex patient journey map before. Context mapping was also relatively new to me. Throughout this project, I learned how to apply these methods, which will be valuable for future projects I may work on. In addition, I worked extensively on my interview skills, which will also be highly useful in future design work.

One of my goals for this project was to find out whether I would enjoy working on a complex and broad topic. I discovered that I really enjoy this type of big complex projects, especially the part that involves talking to a variety of people. I'm curious and open to learning new things, and this project gave me the perfect opportunity to do so.

This experience helped me realize that focusing only on product design might not be the best fit for me. Instead, I should look for a job where communication and working closely with people play a key role. I now realize that I enjoy working on complex, socially relevant design challenges. I want to work in a role that combines creativity with impact, ideally within healthcare or social innovation.

12

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This chapter contains all refrences used throughout this thesis.

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13

Appendix

13. Appendix

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Appendix A - Interview question for healthcare providers about their work

1. Interview met revalidatiearts

- Wat zijn de werkzaamheden van een revalidatiearts/ wat doet een revalidatie arts?
- Wat voor soort type gewrichtsklachten worden doorverwezen naar revalidatie Basalt?
- Hoelang duurt het gehele proces tot de start van revalidatie vanaf het moment van doorverwijzing uit het ziekenhuis?
- Hoe vaak komt dezelfde patiënt langs voor een afspraak?
- Komen veel mensen terug voor een tweede traject bij Basalt of zijn het voornamelijk mensen die voor de eerste keer komen?
- Hebben de meeste mensen voor het eerst gehoord dat ze bijvoorbeeld een chronische gewrichtsziekte hebben of weten de meeste mensen dit al langer?
- Wat kan een oorzaak zijn van de (lange) wachttijden voor de start van revalidatie en kan hier iets aan veranderd worden?
- Wat voor informatie krijgen de patiënten mee naar huis?
  1. Komen mensen vaak terug met vragen?
  2. Kunnen zij die ergens aan iemand stellen?
- Wordt er contact gehouden met de patiënt? Zijn er check-ins?

2. Interview met reumaverpleegkundige

- Wat zijn de werkzaamheden van een reumaverpleegkundige precies?
  1. Hoe ziet het gehele proces eruit? van eerste ontmoeting tot vervolgonderzoek naar uiteindelijk de doorverwijzing?
- Welke (groep) mensen (met welke soort reuma/klachten) worden doorverwezen naar een revalidatiecentrum en waarom?
  1. Is er verder vervolg contact met de patiënt die doorverwezen wordt?

- Wat kan er al gedaan worden in het ziekenhuis?
  1. In hoeverre worden de patiënten verder geholpen in het ziekenhuis?
- In hoeverre behoudt u het contact met de doorverwezen patiënt?
  1. Hoe ervaart u dit?
- In hoeverre is er contact met het revalidatiecentrum?
- Hoelang is de wachtperiode van reumatoloog naar een reumaverpleegkundige gemiddeld?
- Hoe vaak komen dezelfde patiënten terug bij een reumaverpleegkundige?
- Bij een doorverwijzing naar de eerstelijnszorg, dus bijvoorbeeld fysiotherapie, hoe wordt dan bepaald welke instantie hiervoor het beste is en zijn hier ook lange wachttijden? Welke informatie krijgt de patiënt dan?

3. Interview met psycholoog (bij Basalt)

- Wat zijn de taken van een psycholoog precies bij patiënten met gewrichtsklachten?
  1. Kan een patiënt altijd in contact komen met jullie voor advies als de revalidatie is gestart?
- Hoelang duurt een zorgtraject?
  1. Hoe wordt bepaald dat een behandeling is afgerond?
  2. Hoe vaak komt dezelfde patiënt langs voor een afspraak of advies?
- Hoe werkt de samenwerking tussen de verschillende zorgverleners precies?
  1. Hoe en welke informatie ontvangt de patiënt?
- Wat weet u over de wachtperiode die mensen ervaren voordat ze kunnen beginnen met revalidatie?
- Hoeveel mensen kan u tegelijkertijd behandelen?
  1. Krijgen mensen 1 op 1 advies of is dit soms ook in een groep?
- Welke (online) tools/ hulpmiddelen gebruiken jullie bij Basalt?

- Hoe werkt het CPAC?
- In hoeverre is er contact met het Reinier de Graaf ziekenhuis?

4. Interview met ergotherapeut (bij Basalt)

- Wat zijn de taken van een ergotherapeut precies bij patiënten

met gewrichtsklachten?
- Kan een patiënt altijd in contact komen met jullie voor advies als de revalidatie is gestart?
- Welke tools of hulpmiddelen gebruikt een psycholoog?
- Is er veel verschil tussen de twee type revalidatie: pijn revalidatie of houding en beweging revalidatie?
- Hoe blijft u op de hoogte van wat er bij wie gebeurt?
- Hoe en welke informatie ontvangt de patiënt?
- Wat weet u over de wachtperiode die mensen ervaren voordat ze kunnen beginnen met revalidatie?
- Hoeveel mensen kan u tegelijkertijd behandelen?
- 1. Krijgen mensen 1 op 1 advies en oefeningen of is dit in een groep?
- In hoeverre is er contact met het Reinier de Graaf ziekenhuis?
- Als je mensen in de wachtperiode iets kon meegeven als ergotherapeut, wat zou dit dan zijn?
- Krijgen jullie weleens van mensen te horen dat revalidatie goed heeft geholpen?

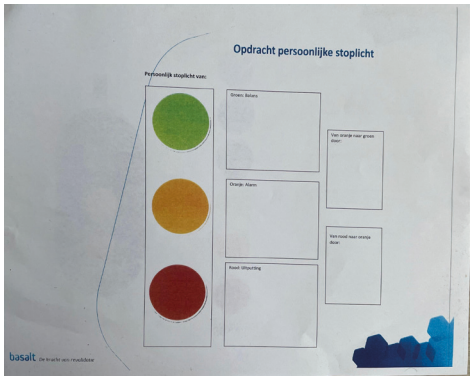
5. Interview met manueel therapeut/fysiotherapeut (bij Basalt)

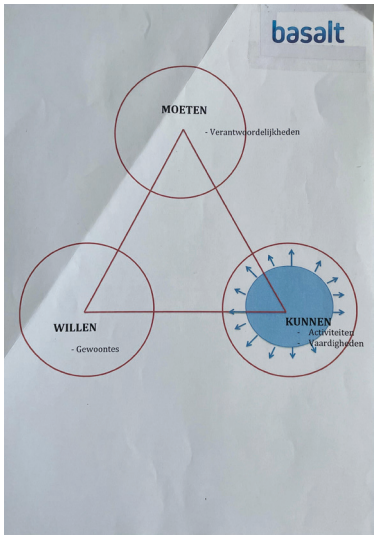
- Wat zijn de werkzaamheden van een manueel therapeut precies?
- Wat zijn de werkzaamheden van een fysiotherapeut precies?
- Wat voor of welke tool/ hulpmiddelen gebruikt een fysiotherapeut?
- Wat voor of welke tool/ hulpmiddelen gebruikt een manueel therapeut?
- Hoe en welke informatie ontvangt de patiënt voorafgaand aan het revalidatietraject?
- Wat weet u over de wachtperiode die mensen ervaren voordat ze kunnen beginnen met revalidatie?
- Als je mensen in de wachtperiode iets kon meegeven als manueel therapeut, wat zou dit dan zijn?
- In hoeverre is er contact met het ziekenhuispersoneel?

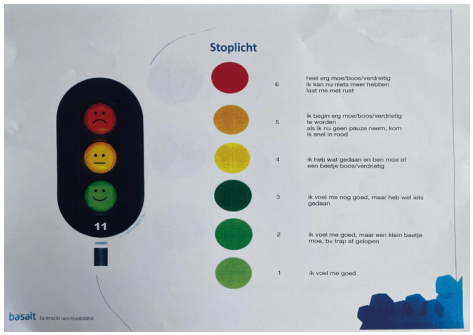
6. Interview reumatoloog

- Wat doet een reumatoloog voor mensen met gewrichtsklachten buiten het zoeken van de juiste medicatie?
- Wanneer wordt iemand doorverwezen naar een reumaverpleegkundige? (Gebeurt dit alleen als iemand net de diagnose heeft gekregen of wordt dit ook later in het zorgtraject nog gedaan?)
- Wanneer wordt iemand doorverwezen naar een revalidatiearts? Welke factoren spelen hierbij een belangrijke rol?
- Wat voor of welke tool/ hulpmiddelen gebruikt een reumatoloog?
- Hoe werkt de samenwerking tussen de verschillende zorgverleners precies?
- Hoe is het contact met de eerstelijnszorg? zoals huisarts, fysio, ergotherapeut?
- Hoe en welke informatie ontvangt de patiënt?

Appendix B - Methods and tools from occupational therapist







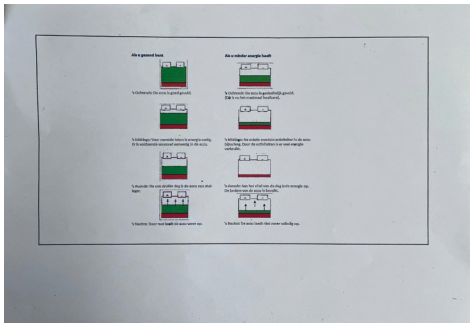


Figure 59

Figure 60

Appendix C - Patient consent form

Toestemmingsformulier proefpersoon

Design: de brug tussen ziekenhuis en revalidatie bij gewrichtsklachten.

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn goed genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen met het onderzoek. Of om ermee te stoppen. Ik hoef dan niet te zeggen waarom ik wil stoppen.
- Ik geef de onderzoekers toestemming om mijn gegevens te verzamelen en gebruiken. De onderzoekers doen dit alleen om de onderzoeksvraag van dit onderzoek te beantwoorden.
- Ik weet dat voor de controle van het onderzoek sommige mensen al mijn gegevens kunnen inzien. Die mensen staan in deze informatiebrief. Ik geef deze mensen toestemming om mijn gegevens in te zien voor deze controle.

• Wilt u in de tabel hieronder ja of nee aankruisen?

Ik geef toestemming om mijn gegevens te bewaren om dit te gebruiken voor ander onderzoek, zoals in de informatiebrief staat.	Ja ☐	Nee☐
Ik geef toestemming om mijn gegevens tot 15 jaar te bewaren op de onderzoekslocatie (het RdGG).	Ja ☐	Nee☐
Ik geef toestemming om mij eventueel na dit onderzoek te vragen of ik wil meedoen met een vervolgonderzoek.	Ja ☐	Nee☐
Ik geef toestemming voor het opnemen van het interview. De opname wordt direct na het onderzoek vernietigd.	Ja ☐	Nee☐

• Ik wil meedoen aan dit onderzoek.

Mijn naam is (proefpersoon): .....

Handtekening:..... Datum :__/__/__

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Wordt er tijdens het onderzoek informatie bekend die die de toestemming van de proefpersoon kan beïnvloeden? Dan laat ik dit op tijd weten aan deze proefpersoon.

Naam onderzoeker (of diens vertegenwoordiger):.....

Handtekening:..... Datum: __ / __ / __

Appendix D- Interview questions participants about their referral journey

Onderzoeksvraag: Welke praktische en psychologische knelpunten ervaren patiënten met gewrichtsklachten bij hun doorverwijzing naar revalidatie?

Subvragen:
Welke informatie krijgen patiënten (over hun revalidatietraject), en sluit deze aan bij hun behoeften?
Welke emoties en ervaringen hebben patiënten tijdens het doorverwijzingsproces?
Welke verwachtingen hebben patiënten over revalidatie

Vragen aan patiënten voor de black hole periode
(de patiënten die zijn doorverwezen naar een revalidatiearts vanuit een medisch specialist)

Vragen over afgelopen periode
Om de afgelopen periode beter te begrijpen wil ik samen met de patiënt op A3 papier een tijdlijn maken met alle afspraken met zorgverleners die ze hebben gezien voorafgaand aan de revalidatie. Hierbij wil ik ook de wachtperiodes ertussen erbij zetten.

- Stap 1: Noteer samen eerst alle afspraken met medische specialisten en zorgverleners die gezien zijn de afgelopen periode.
- Stap 2: Zet de medische specialisten met korte uitleg over de afspraak in de tijdlijn met wachtperiodes tussen de afspraken.
- Stap 3: Laat de patiënt plussen en minnen zetten bij elke afspraak en de wachtperiodes. Na het invullen vraag door over waarom ze ergens een min of plus hebben ingevuld.
- Stap 4: Laat de patiënt uitleggen waarom ze ergens een min of plus hebben ingevuld.

- Welke verwachtingen had u van de afspraak met de revalidatiearts?
- Hoe is de afspraak met de revalidatiearts geweest, welke uitleg heeft u gekregen?
- Weet u waarom u niet bent doorverwezen naar revalidatie?
- Hoe heeft u de afspraken met de andere zorgverleners ervaren in uw zorgtraject?
- Heeft u de juiste zorg ontvangen op het juiste moment?
- Waar bent u op zoek gegaan naar informatie? Wat voor informatie was dit? Heeft u gevonden wat u zocht?
- Wat voor informatie heeft u gekregen vanuit de zorg, en was dit genoeg en duidelijk? (website verwijzingen bekeken, zoals retrain pain?)
- Heeft u duidelijke uitleg gekregen over de werking van het pijnsysteem?
- Hoe ervaart u de communicatie met de zorgverleners tijdens dit traject?
- Heeft u contact gehad met lotgenoten? Is hier behoefte aan?
- Wat voor hulp krijgt u nu? Bevalt dit?
- Vervolg afspraken
- Is opnieuw benaderen mogelijk?
- Staat u ervoor open om de rest van het boekje ook in te vullen?
- Ik heb alles gevraagd wat ik wilde vragen, heeft u nog toevoegingen of vragen?

Vragen aan patiënten tijdens de black hole periode
(de patiënten die worden doorverwezen naar revalidatie vanuit het ziekenhuis door een revalidatiearts)

Vragen over afgelopen periode
Boekje bespreken, ingaan op bepaalde emoties, ingaan op de waarom-vraag.
Dag 2
- Huishoudelijke taken, fietsen, boodschappen doen en lesgeven krijgen allemaal een cijfer 6 of hoger voor de pijn, waar komt dit door?
- Computerwerkzaamheden staat er een paar keer op maar met verschillende emoties, waarom zit hier verschil in?
- Zijn er bepaalde handelingen die de pijn verminderen

Dag 3 en 4
- Heeft de reumatoloog veel kunnen uitleggen over de doorverwijzing? Was alles duidelijk na deze afspraak? Was dit ook het moment van de diagnose fibromyalgie?
- Erg negatief over ergotherapie, ook bij revalidatie zit vaak ergotherapie, sta je hier alsnog voor open?
- Waar komt het hele positieve gevoel na de afspraak met de revalidatiearts vandaan?

Dag 5
- Waarom gebruikt u nog geen hulpmiddelen?

Vragen over verwachtingen
- Welke verwachtingen heeft u over de revalidatie?
- Met welke verwachtingen ging u naar de revalidatiearts?
- Wist u overal wat er ging gebeuren?

- Had u het gevoel dat u informatie miste/ niet ter beschikking had deze afgelopen periode?
- Waar bent u op zoek gegaan naar informatie? Wat voor informatie was dit? Heeft u gevonden wat u zocht?
- Wat voor informatie heeft u gekregen tijdens deze periode, en was dit genoeg en duidelijk? (website verwijzingen bekeken, zoals retrain pain?)
- Hoe ervaart u de communicatie met de zorgverleners tijdens dit traject?
- Vervolg afspraken
- Is opnieuw benaderen mogelijk?
- Ik heb alles gevraagd wat ik wilde vragen, heeft u nog toevoegingen of vragen?

Vragen aan patiënten na de black hole periode
(de patiënten die al begonnen zijn met de revalidatie bij Basalt)

Vragen over afgelopen periode
Om de afgelopen periode beter te begrijpen wil ik samen met de patiënt op A3 papier een tijdlijn maken met alle afspraken met zorgverleners die ze hebben gezien voorafgaand aan de revalidatie. Hierbij wil ik ook de wachtperiodes ertussen erbij zetten.

- Stap 1: Noteer samen eerst alle afspraken met medische specialisten en zorgverleners die gezien zijn de afgelopen periode.
- Stap 2: Zet de medische specialisten met korte uitleg over de afspraak in de tijdlijn met wachtperiodes tussen de afspraken.
- Stap 3: Laat de patiënt plussen en minnen zetten bij elke afspraak en de wachtperiodes. Na het invullen vraag door over waarom ze ergens een min of plus hebben ingevuld.
- Stap 4: Laat de patiënt uitleggen waarom ze ergens een min of plus hebben ingevuld.

Verwachtingen

- Hoe heeft u zich voorbereid op de revalidatie?
- Met welke verwachtingen ging u naar de revalidatie?
- Hoe is de eerste kennismaking verlopen met de revalidatie?
- Snapte u wat er ging gebeuren?

- Had u het gevoel dat u dingen miste/ niet ter beschikking had deze afgelopen periode?
- Waar bent u op zoek gegaan naar informatie? Wat voor informatie was dit? Heeft u gevonden wat u zocht?
- Wat voor informatie heeft u gekregen tijdens deze periode, en was dit genoeg en duidelijk? (Video over pijn revalidatie gezien? website verwijzingen bekeken zoals retrain pain?)
- Hoe ervaart u de communicatie met de zorgverleners tijdens dit traject?

Take-aways van revalidatie

- Wat heeft u geleerd bij revalidatie wat u eigenlijk eerder had willen weten?
- Als u aan zichzelf van voor de revalidatie iets kon meegeven met de kennis die u nu heeft, wat zou dat dan zijn?

Vervolg afspraken

- Is opnieuw benaderen mogelijk?

- Ik heb alles gevraagd wat ik wilde vragen, heeft u nog toevoegingen of vragen?

Appendix E - Sensitising booklet

Samen zoeken naar de beste oplossing

Een onderzoek naar de doorverwijsperiode richting de start van revalidatie

Dit boekje is van: _____

Een onderzoeken uitgevoerd door Kim Gaus in samenwerking met het Reinier de Graaf ziekenhuis

Welkom

Leuk dat u mee wilt doen aan mijn onderzoek! Mijn naam is Kim en ik ben bezig met mijn afstudeeropdracht voor de master *Integrated Product Design* aan de TU Delft. Ik doe onderzoek naar de wachtperiode vanaf het moment van doorverwijzing vanuit het ziekenhuis tot de start van revalidatie voor patiënten met gewrichtsklachten.

Bedankt dat u mee wilt werken aan dit onderzoek. Dit onderzoek bestaat uit **twee delen**. Het eerste deel bestaat uit het invullen van **dit boekje**. Via verschillende korte opdrachten in dit boekje wil ik uw ervaring met betrekking tot deze wachtperiode beter leren kennen.

Het tweede deel van dit onderzoek bestaat uit een **gesprek** waarin we kort de antwoorden uit dit boekje bespreken en waarin ik ook nieuwe vragen zal stellen.

Instructie

In dit boekje staan verschillende korte opdrachten, verdeeld over vijf dagen. Het is de bedoeling dat u de **opdrachten verspreid over vijf dagen invult**, zodat het per dag relatief **weinig tijd kost (5-10 minuten)**.

Tip: Kies een vast moment op de dag waarop u het boekje invult, bijvoorbeeld na het avondeten of bij het ontbijt.

Dag 1: Leuk u te leren kennen

Vandaag staat in het teken van elkaar beter leren kennen. Ik zou graag willen weten wie u bent en wat u gelukkig maakt.

Stap 1: **Beschrijf uzelf** kort en vertel wat u leuk vindt om te doen. Waar wordt u bijvoorbeeld blij van en waarvan minder?

Zo zou ik mezelf bijvoorbeeld voorstellen:

Ik ben Kim ik ben 24 jaar en vind het leuk om te tennissen. Ik word blij van lekker eten en gezellig afspreken met vrienden. Ik doe de studie industrieel ontwerpen en ben nu bezig met mijn afstudeeropdracht, hier krijg ik af en toe best een beetje stress van. Ik vind het minder leuk als ik tot laat moet werken en de volgende dag weer vroeg op moet.

Plak hier of teken hier een leuke foto van uzelf

Ik ben...

Ik vind het leuk om te...

Ik vind het minder leuk...

Voor mijn onderzoek is het nuttig om meer te weten over u ziektebeeld. Daarom zou ik u willen vragen of u wilt aangeven welke reumatische aandoening u heeft.

Stap 2: Vink aan welke **reumatische aandoening** u heeft (indien dit duidelijk is):

- ☐ Artrose (osteoartritis)
- ☐ Reumatoïde artritis.
- ☐ **Fibromyalgie**
- ☐ **Osteoporose**
- ☐ **Anders, namelijk** _____

2.

Dag 2: Zo ziet mijn dag er vaak uit

Welke activiteiten doet u vaak op een dag? Bestaat uw gemiddelde dag uit werken, sporten of besteed u de dag meestal anders?

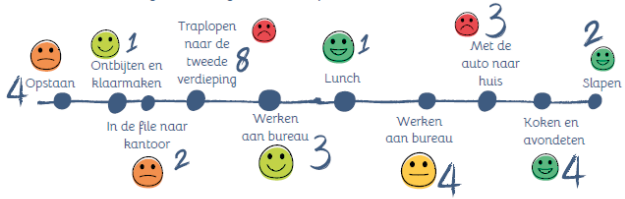
Stap 1: Ik ben benieuwd hoe **uw dag eruitziet**. Vul op de volgende pagina de tijdlijn in met al uw dagelijkse activiteiten op een **standaard doordeweekse dag**. Noteer hierbij alleen de activiteiten overdag en niet die in de nacht.

Stap 2: Teken bij elke activiteit een **emotie** (uit de emotielijn) die weergeeft hoe u zich voelt tijdens deze activiteit. Ervaart u pijn tijdens het uitvoeren van deze activiteiten? Geef elke activiteit een **cijfer** op een schaal van 1 tot 10, waarbij 1 staat voor pijnloos en 10 voor ernstige pijn.

Emotielijn: ☹ 😟 😐 🙂 😀

Pijnlijn: Geen pijn 1 → 10 Extreme pijn

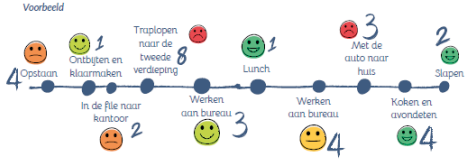
Voorbeeld: Zo zou een gemiddelde dag van een reuma patiënt eruit kunnen zien:



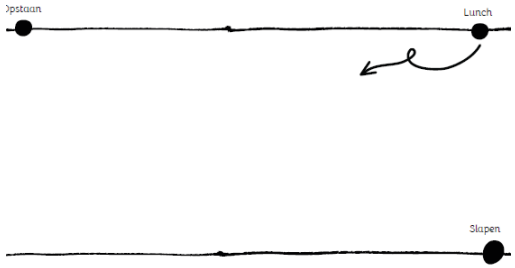
Deel nu u dag in op de volgende bladzijde

1.

Voorbeeld



Deel nu u dag in

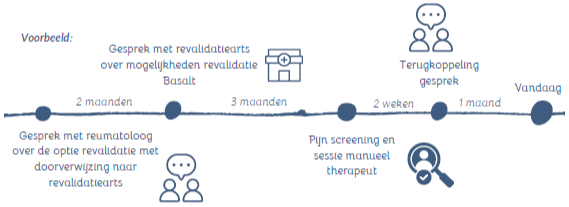


Dag 3: De afgelopen periode (deel 1)

Ik ben benieuwd hoe de afgelopen paar maanden er voor u hebben uitgezien met betrekking tot afspraken voor uw reuma. Bent u net doorverwezen naar revalidatiecentrum Basalt, zit u in de wachtperiode om te mogen beginnen met revalidatie, of bent u net gestart? Ik ben benieuwd hoe deze afgelopen periode is geweest en hoe u zich daarbij heeft gevoeld.

Stap 1: Maak een **tijdlijn van hoe de afgelopen maanden** voor u zijn verlopen. Begin vanaf het moment dat er sprake was van een revalidatietraject bij Basalt. Denk hierbij aan afspraken met de revalidatiearts, reumatoloog, reumaverpleegkundige of andere zorgverleners met betrekking tot uw gewrichtsklachten. Ik ben benieuwd met wie u contact heeft gehad en waar dit was. Zet ook een tijdsindicatie in de tijdlijn om aan te geven hoelang er tussen elke afspraak zat.

Voorbeeld:

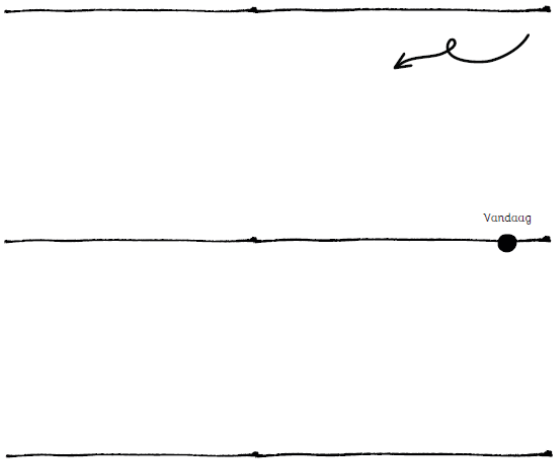


Vul de tijdlijn in op de volgende pagina.

Stap 2: Heeft u al een idee wat er de komende periode gaat gebeuren? Welke afspraken er op de **planning** staan en wie u gaat spreken? Zo ja, probeer dan de tijdlijn na het punt *vandaag* zo ver mogelijk in te vullen met komende afspraken.

Vul de tijdlijn aan met afspraken die (waarschijnlijk) nog gaan komen.

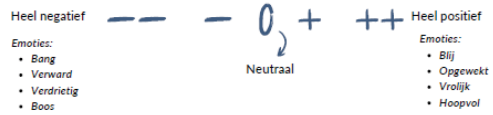
Hoe ziet uw tijdlijn eruit?



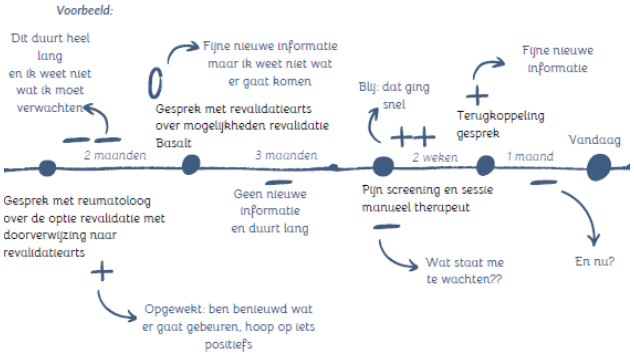
Dag 4: De afgelopen periode (deel 2)

Tijdens dag 3 heeft u een tijdlijn gemaakt van de afgelopen periode. Naast de activiteiten ben ik benieuwd naar uw gevoel over deze periode. Voor deze opdracht vult u de tijdlijn van dag 3 aan met emoties en korte toelichtingen.

Stap 1: Maak de **tijdlijn compleet** door aan te geven hoe u zich de afgelopen periode heeft **gevoeld**, zowel tijdens de activiteiten als in de wachttijd ertussen. **Gebruik + en** - om aan te geven hoe positief of negatief u zich voelde.
Gebruik ++ als u zich erg positief voelde en -- als u een erg negatief gevoel had.



Stap 2: Schrijf er kort bij waarom u zich zo voelde.



Vul de tijdlijn van dag 3 aan.

Dag 5: Ondersteuning en hulpmiddelen

Leven met gewrichtsklachten kan lastig zijn. Er zijn verschillende producten en hulpmiddelen die bepaalde activiteiten makkelijker maken. Ik ben benieuwd welke hulpmiddelen er allemaal zijn en of deze prettig in gebruik zijn of juist helemaal niet.

Stap 1: Welke producten, hulpmiddelen of apps **gebruikt u** om bepaalde activiteiten of handelingen makkelijker te maken, zodat u beter kunt omgaan met uw gewrichtsklachten? Maak of plak een foto van deze hulpmiddelen, of teken ze. Beschrijf kort waarbij ze u helpen.

Mijn hulpmiddelen/ producten/ apps:

Stap 2: Teken een + of - bij elk product om aan te geven of deze wel of niet fijn zijn om te gebruiken. Leg in een paar korte zinnen uit waarom wel of waarom niet.

Zie volgende pagina voor stap 3

Stap 3: Zijn en hulpmiddelen/apps/producten die u niet heeft, maar waar u **wel behoefte** aan heeft? Beschrijf deze kort of maak hier een tekening van:

Bijvoorbeeld

Ik moest alle informatie zelf opzoeken op het internet en er staat zoveel. Een folder vanuit het ziekenhuis zou al helpen met verwijzingen naar betrouwbare websites.

Super snelle schoenen op wieltjes zodat ik over veel sneller ben.

Wilt u nog iets kwijt?

Dit waren alle opdrachten. Dank u wel voor het invullen. Heeft u nog vragen of wilt u graag een idee delen? Dan kunt u deze bladzijde gebruiken om dit op te schrijven. Heeft u een dringende vraag tijdens of na het invullen van dit boekje? Neem dan vooral even contact met mij op.

Appendix F - Thematic analysis

phase 1

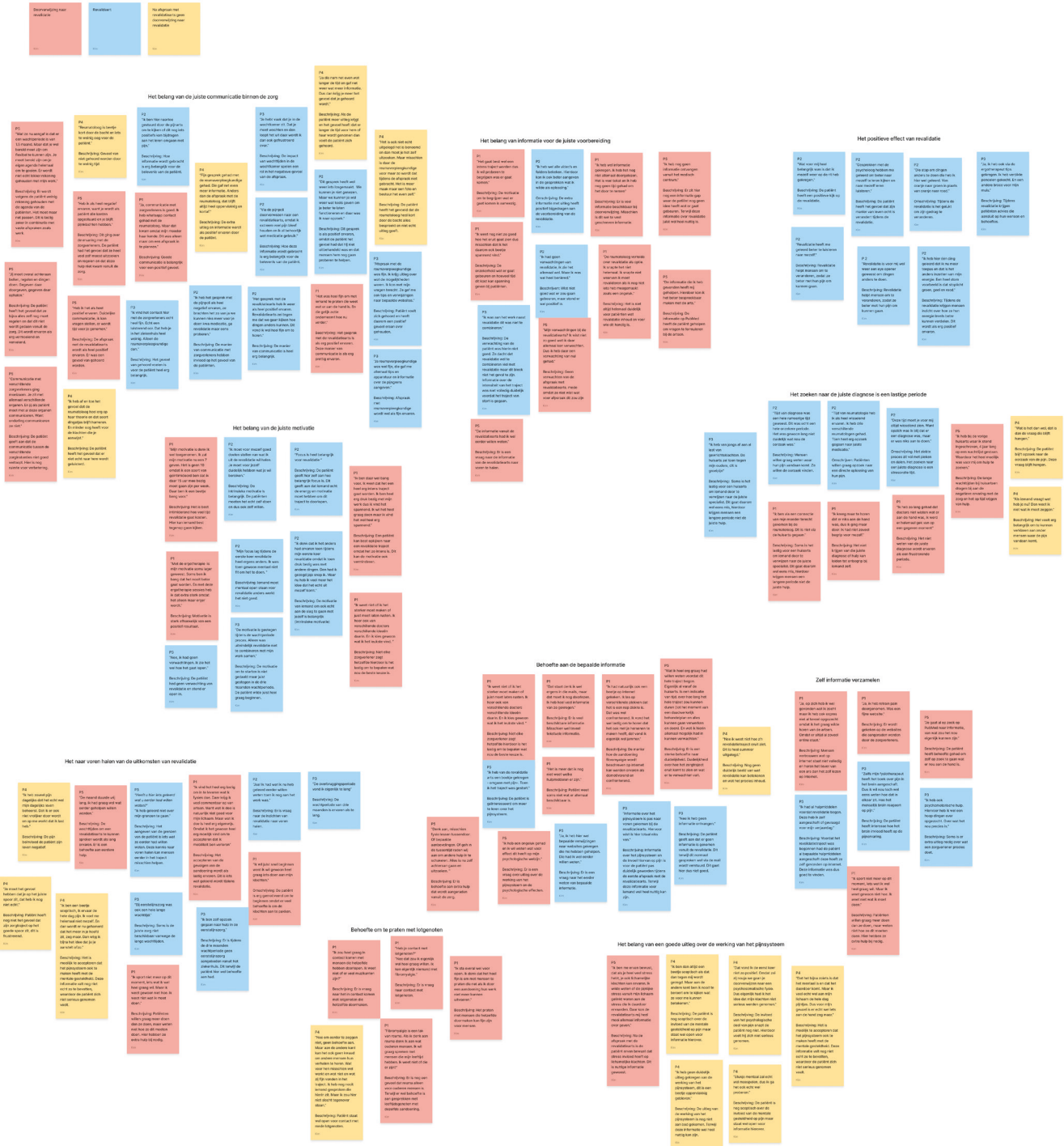
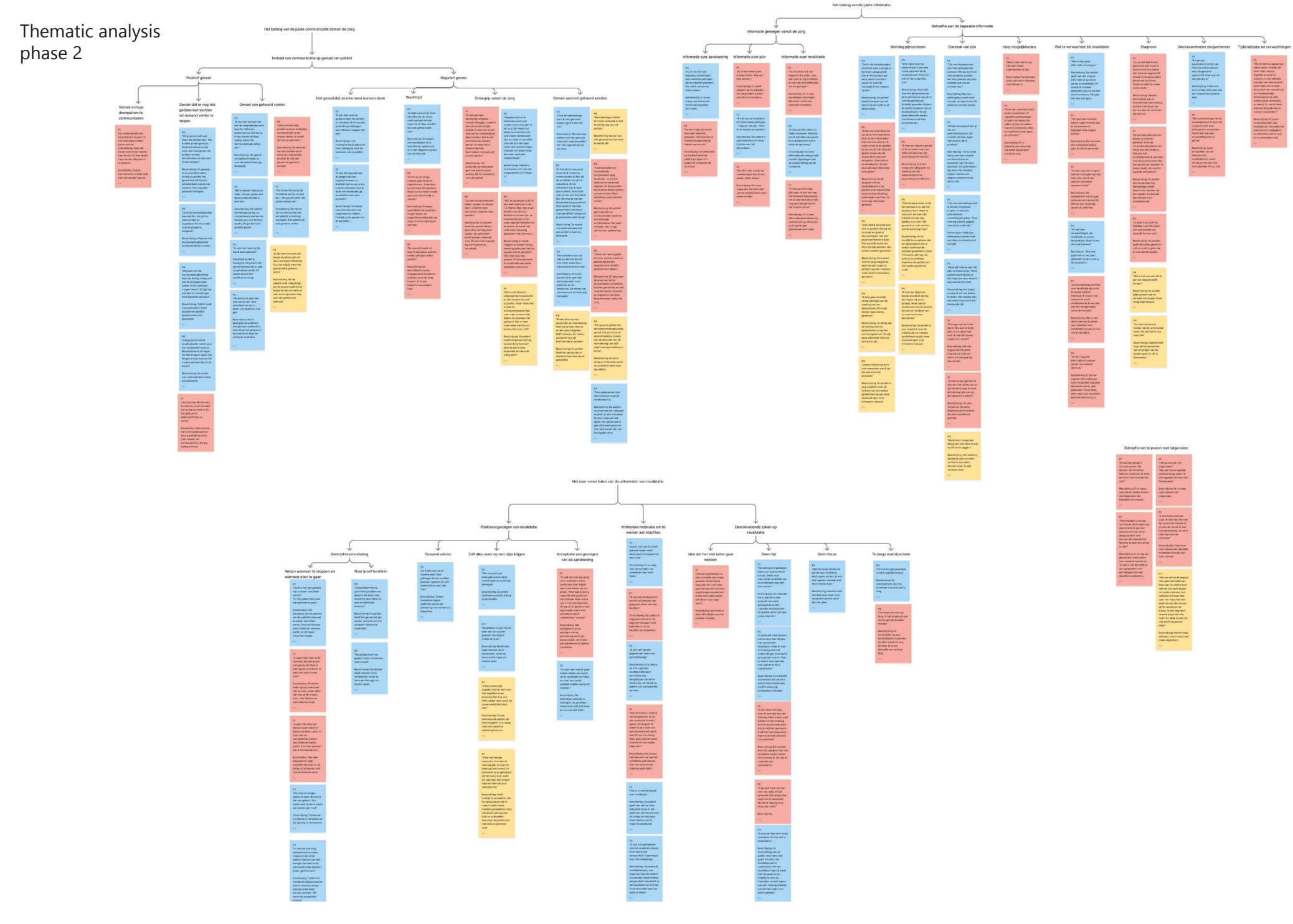
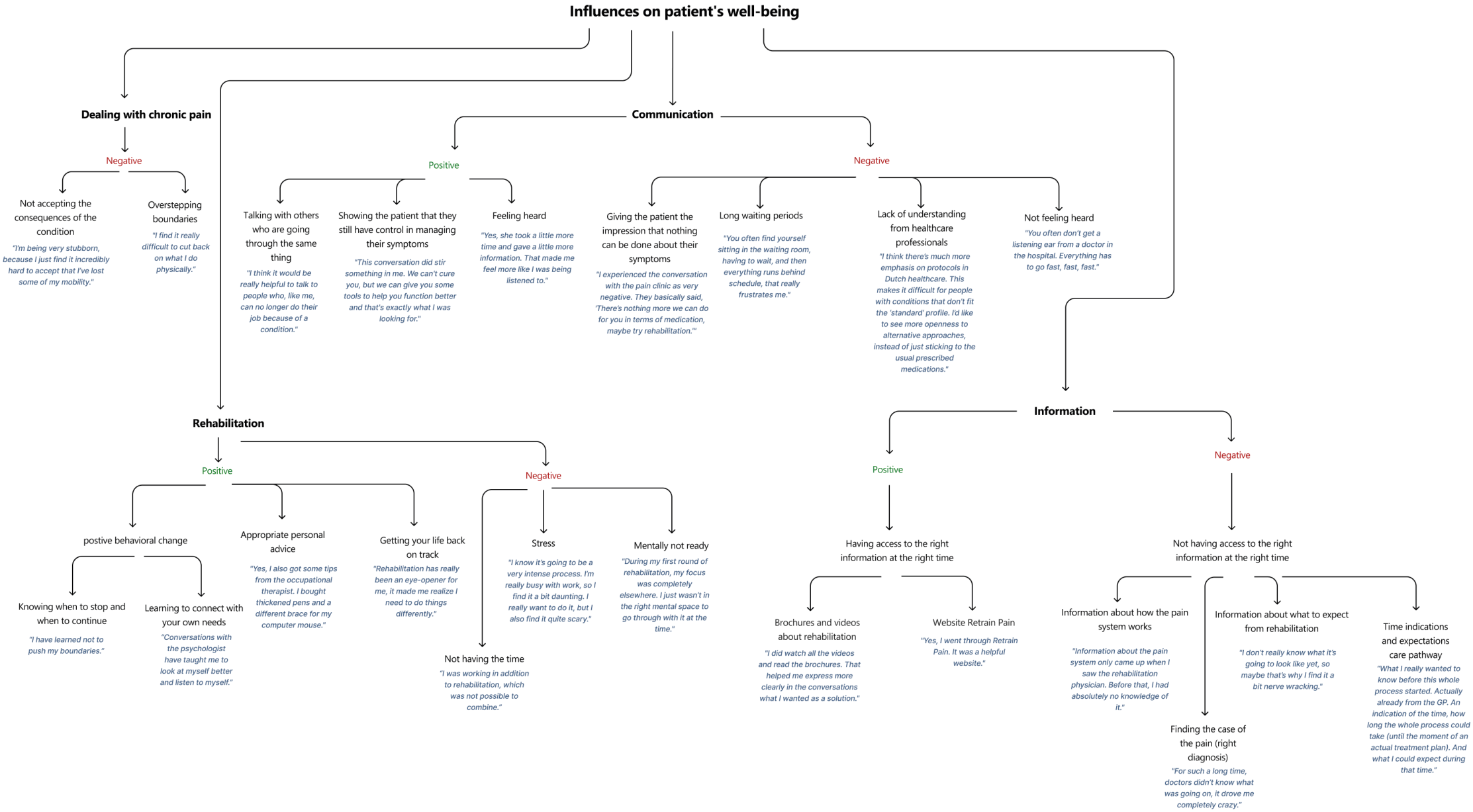


Figure 61

Thematic analysis phase 2



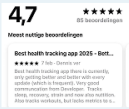
Thematic analysis final map



Appendix G - Existing app solutions on the market

Symptom tracking

Bevel app Bevel measures your body's daily workload and provides a personalized load target based on your recovery and sleep quality. Your Daily Load Score gives you insight into how hard your body is working, so you can gauge the overall effectiveness of your fitness routine.



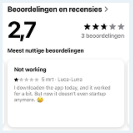
Flaredown is a free web and mobile app that helps patients track and visualize their illness, treatments, and symptom triggers so that they can understand how their choices affect their health.
Goal: help people find out the triggers of their chronic illnesses and the ways to treat them.

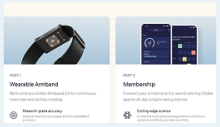
CareClinic is a comprehensive self-care platform for tracking symptoms, habits, physical activities, and any custom values.

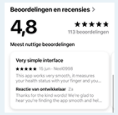
The health tracker **Bearable** aims to collect all medical data in one place. Like all trackers, this app allows the user to record health data.

Based on pacing method

ME/CFS pacing app
This app is designed to help people with mild to moderate ME/CFS better manage their daily energy use to improve the quality of their lives.







Visible combines a wearable heart rate monitor with an app to give personalized pacing insights to the user.

The app **Energiebalans Planner** was conceived and developed by occupational therapists in primary care. Intended for clients who have gone through the activity scale with their occupational therapist and now want to create a daily/weekly schedule based on this same point system.

Activity tracking

With the **Daglijst app** can users keep track of what they do in a day and how they feel about it. To indicate fatigue or amount of energy and/or pain.

Daylio is a mobile application that allows you to easily keep a diary, including mood recording and activity tracking

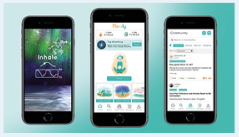
Structured is an all-in-one day planner, combining calendar, to-do list, and habit tracker into a single visual timeline

Activiteitenweger app can help the user plan activities within their energy limits. For each activity the user can indicate, how much energy it costs to do it. Each category has a number of points.

Symple is a symptom journal and health diary app. Users can track how they feel, their habits and symptoms and explore their data with interactive charts.
It is possible to import health data, such as heart rate, steps and sleep directly from Apple Health, giving a more comprehensive overview.

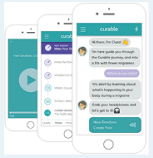
Lessons about chornic pain

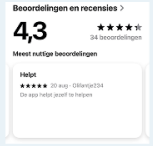
Pathways is an app specifically designed for people who have been in chronic pain. This pain therapy program addresses the physical and mental aspects of chronic pain. It also offers meditations specifically designed for pain relief, as well as physiotherapy, yoga, and exercise routines ranging from beginner to expert.



Flowly uses interactive experiences to engage users in biofeedback training, which can teach them to monitor and adjust breathing patterns, focus, and learn how to better regulate their nervous system. The app also keeps track of the user's progress and offers connections to experts and community forums.

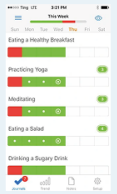
The Curable app provides evidence-based chronic pain lessons. It uses a combination of pain science education and research-backed techniques to address pain from every angle.





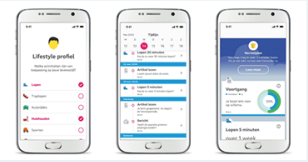
Goal setting

Tally is a mobile app, that allows users to set goals and log progress.



Way of Life for cultivating good habits and consciously removing undesirable patterns

ikHerstel is intended for patients after having an operation. The app provides tailed recovery advice specifically to the patient.



Appendix H - Example of how to find your baseline

How to find your baseline

Try to think of a few activities that could cause your symptoms to start, such as standing, cooking, driving, gardening, etc. We will use the example of gardening.

How long can I garden before I have a flare up?

I can garden for 60 minutes but I'll have a flare up for a day.

Can I garden for 40 minutes without flaring up?

Probably not, I think I will still be sore.

30 minutes of light gardening tasks?

Probably

20 minutes of light tasks?

Definitely

So for gardening your baseline would be 20 minutes of light tasks.

Think of other activities that you would like to do during your day and apply this technique to find your baseline for those tasks.

(Oxford University Hospitals NHS Trust et al., 2015b)

How to find your baseline

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Appendix I - Example energy level calculation

For standard default setting the app could use this data to estimate someone's energy level:

Score	Energy battery
4.0	100%
3.0	75%
2.0	50%
1.0	25%

For this example a man from 40 years old person is used:
Calculation Energy level:
Sleep score (25%) + HRV (50%) + resting HR (25%) = Energy level

Default setting app without taking account feedback from user:

- **Sleep score:**

Users rating: from 1 (very bad) to 4 (good)
or using data from wearable device:
To translate wearable sleep data into a 1–4 sleep score scale for a 40-year-old man, the sleep duration is important the following score ranges can be used:
Some devices also give a sleep score this can be used as well, figure FIXME.

Sleep Duration	Sleep Score
< 5.5 hours	1 = Very poor
5.5–6.5 hours	2 = Poor
6.5–7.5 hours	3 = Moderate
> 7.5 hours	4 = Good

Wearable Sleep Score	Sleep Score 1–4
0–59	1 = Very poor
60–74	2 = Poor
75–84	3 = Moderate
85–100	4 = Good

- **HRV: Measurement from wearable device or phone**

HRB below 40ms=1
HRV below 40-50 ms= 2
HRV between 51-60ms = 3
HRV between 60-80 ms = 4

- **Resting heart rate: Measurement from wearable device or phone**

RHR between 46 - 63 = 4
RHR between 64-78 = 3
RHR between 78-85 = 2
Rhr higher than 85 = 1

After using the app for a couple of days (around 3 days) the app can use the gathered data to determine the users personal baseline measurements. HRV varies a lot between individuals, the app must compare the measurements to someone's personal baseline, not absolute thresholds. A sudden or sustained drop (e.g. 20–30% below average) suggests that the body is:

- Under physical or emotional stress
- Not recovering well (e.g., poor sleep, illness, overexertion)
- In a state of sympathetic nervous system dominance (fight-or-flight mode)

Indicating that the personal has lower energy that day. The deviation scores can be found below.

Base HRV scoring on deviation from personal average:

HRV vs personal average	Score
> +15%	4
0 to +15%	3
-15% to -30%	2
> -30%	1

RHR vs personal baseline	Score
> +15%	1
+5% to +15%	2
-5% to +5%	3
< -5%	4

Appendix J - Week planning for occupational therapy

Weekschema

	Maandag	Dinsdag	Woensdag	Donderdag	Vrijdag	Zaterdag	Zondag
6.30							
7.00							
7.30							
8.00							
8.30							
9.00							
9.30							
10.00							
10.30							
11.00							
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21.30							
22.00							
22.30							
23.00							
23.30							

Appendix K - Step by step plan for CE certification

(CE Tool | Home, z.d.).

Appendix L - Interview questions about information flyer

Vragen aan patiënt over informatiefolders

- Is deze informatie naar voren gekomen tijdens de afspraak met de reumaverpleegkundige?
- Is de informatie begrijpelijk? Mist er nog informatie, of is er extra uitleg nodig ergens?
- Welke flyer sprak je het meeste aan? Waarom deze?
- Er worden soms informatiefolders doorgestuurd via het patiëntenportaal, lees je deze altijd door?
- Krijg je de flyer liever fysiek mee naar huis na de afspraak of online via het patiëntenportaal? Waarom?

Interview vragen reumaverpleegkundige over ontwerp

Tijdens de interviews die ik gehad heb met patiënten kwam naar voren dat veel mensen uitleg over de werking van het pijnsysteem vaak pas laat of soms niet kregen. Daarom wil ik deze uitleg naar voren halen. De afspraak met de reumaverpleegkundige leek me hiervoor een goed moment. Deze flyers heb ik gemaakt om de informatie op een makkelijke en overzichtelijke manier over te brengen. Het is wel de bedoeling dat de reumaverpleegkundige extra persoonlijke informatie vertelt aan de patiënt tijdens de afspraak. Over deze flyer en methode wil ik graag een aantal vragen stellen.

- Welke informatie over het pijnsysteem wordt op dit moment al besproken? Waarom die informatie wel?

- Waarom die informatie niet?

- Denkt u dat er genoeg tijd is om de informatie van de flyer tijdens de afspraak te bespreken?
- Hoofdstuk 2 (invloed energielevels) heeft extra uitleg nodig over de moeten, kunnen en willen driehoek en stoplicht methode. Wordt dit nu al besproken? Zijn jullie hier bekend mee?
- Het is de bedoeling dat de patiënten deze flyer mee naar huis nemen wna de afspraak, is deze informatie dan duidelijk genoeg denkt u? Mist er nog essentiële informatie?

Flyer version 1

4. ONTDEKKEN & VERKENNEN

Het begrijpen en in kaart brengen van waar je **oorspronkelijk pijn vandaan kwam**, kan helpen met het deactiveren van de 'actieve' stand van het pijn systeem. Het verkennen van de **diepere emoties** verbonden met die periode van pijn kan helpen met het verminderen van de pijnervaring.

Je brein heeft namelijk nieuwe (snellere) verbindingen gemaakt in deze periode voor pijn, die ervoor zorgen dat pijnsignalen makkelijker en sneller worden doorgegeven. Dit gebeurt door stoffen in je hersenen, zoals **neurotransmitters**, die de pijn kunnen versterken.

Door te begrijpen hoe en waarom deze verbindingen zijn ontstaan, kun je samen met je behandelaar manieren vinden om deze pijncirkel te doorbreken en je klachten stap voor stap te verminderen.

5. FUNCTIONEREN & SOCIALE FACTOREN

Pijnbeleving wordt ook beïnvloed door **sociale factoren** zoals werk, school, vrienden en familie. Onbegrip vanuit de omgeving kan leiden tot **negatieve gedachten en verhoogde stress**. Deze factoren dragen bij aan een verhoogde activiteit in het pijnsysteem. Probeer aan je omgeving uit te leggen dat jouw lichaam anders omgaat met pijnsignalen en daar heftiger op reageert. De **lepeltheorie** kan helpen om je omgeving op een eenvoudige manier duidelijk te maken hoeveel energie en moeite het kost om met pijn te leven.

Het aanpakken van negatief gedachten kan gedaan worden met **cognitieve gedragstherapie**. Hierbij kijk je goed naar welke gedachten je hebt en welke gevoelens daarbij horen. Als je dit bewust weet kan je het ook proberen te veranderen, hierbij kan je ook hulp vragen van professionals.

CONCLUSIE

Is er een onveilig gevoel in het lichaam, door ofwel **fysieke, sociale** of **lichamelijke** factoren, dan kan dit een versterkende factor hebben op pijn. Deze factoren spelen dus allemaal een belangrijke rol in de **pijnervaring.**

Chronische pijn is echt, ook al is deze van buitenaf niet altijd zichtbaar. Je zenuwstelsel reageert gevoeliger dan normaal, en dat is een lichamelijk proces. De pijn zal aanhouden, maar met de juiste begeleiding kun je patronen doorbreken en weer **meer grip krijgen op je dagelijks leven**.

Het begrijpen van het pijnsysteem is **stap één** in pijnvermindering. Met de hulp van de juiste zorg en motivatie kan het leven met chronische pijn verbeterd worden. Dit hoef je niet alleen te doen! Hulp van professionals, vrienden en lotgenoten kan het verschil maken.

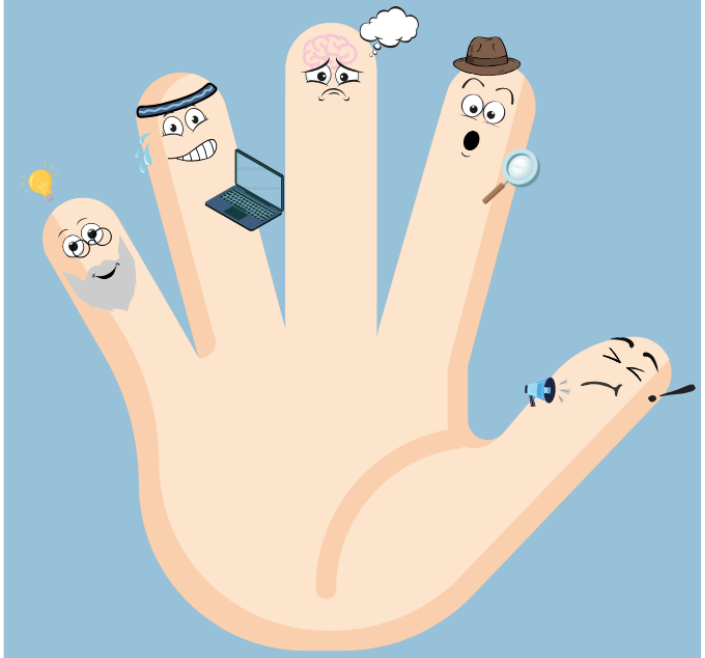
MEER INFORMATIE

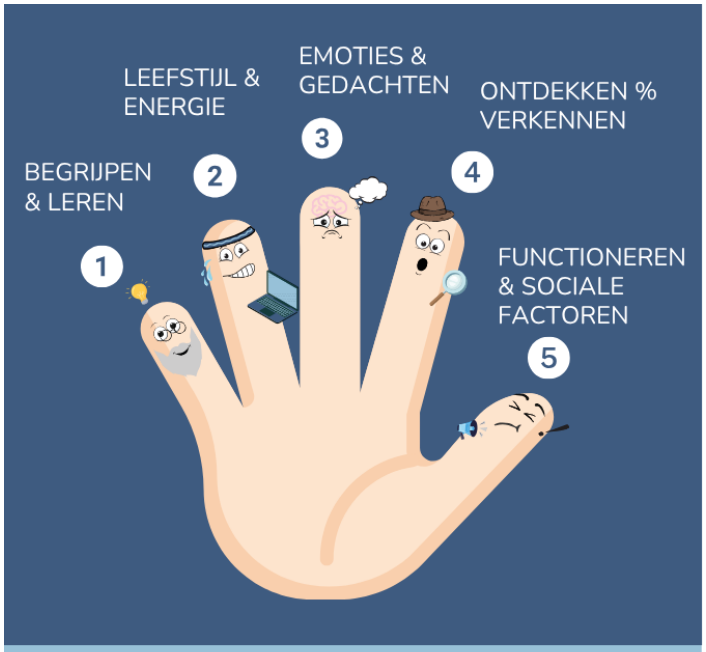
- Relevante websites: Retrain Pain, Reumanederland, Pijnpatientennaaréénstem, Agency for clinical innovation: Be Pain Smart plan
- Handige boeken over het pijnsyteem: Verklein je pijn, Pijn & het brein, Over leven met pijn en Lieve help
- Zoek hulp van zorgverleners, neem wanneer nodig op tijd contact op met bijvoorbeeld een reumaverpleegkundige, huisarts of revalidatiearts voor meer persoonlijke hulp

Deze folder is gemaakt door Kim Gaus in samenwerking met de zorgverleners van het Reinier de Graaf ziekenhuis

Laat me je een handje

HELPEN





1. **Begrijpen & leren**
   1. Wat is pijn?
   2. Acute vs chronische pijn
   3. Dempende en versterkende invloeden
2. **Leefstijl & energie**
   1. Energie verdeling bij chronische pijn
   2. Moeten, kunnen en willen
   3. Stoplicht methode
3. **Emoties & gedachten**
   1. Negatieve gedachten
   2. Vicieuze cirkel
   3. Gedachteverandering
4. **Ontdekken & verkennen**
   1. Verkennen van eerste ervaring met de pijn
   2. Ontdekken van diepere emoties
   3. Cirkel doorbreken
5. **Functioneren & sociale factoren**
   1. Invloeden van socialen factoren
   2. Pijn uitleggen aan anderen
   3. Cognitieve gedragstherapie

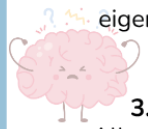
1. BEGRIJPEN & LEREN

1. Wat is pijn

Pijn is er om je lichaam te **beschermen tegen bedreigingen**. Er zijn drie beschermsystemen in het lichaam: Het pijnsysteem, immuunsysteem en stresssysteem. Alle drie de systemen zijn er om je lichaam te beschermen tegen gevaar. Maar soms blijven deze systemen op **'actief'** staan terwijl er geen gevaar meer is. Over bescherming is vaak de oorzaak van aanhoudende pijn. Dit kan leiden tot een verandering in het pijnsysteem. Pijn kan hierdoor als heftiger ervaren worden. Pijnprikkels worden namelijk heftiger doorgegeven omdat de neurotransmitters anders zijn afgesteld.

2. Acute vs chronische pijn

Er is een verschil tussen chronische pijn en acute pijn. Acute pijn is een waarschuwingssignaal van het lichaam. Het is plotseling, vaak hevig, en ontstaat bij een letsel of ziekte. Deze pijn vermindert meestal zodra de oorzaak is behandeld of genezen. **Chronische pijn** (aanhoudende pijn) daarentegen is pijn die **langer dan drie maanden aanhoudt**, vaak zonder een duidelijke oorzaak. Deze pijn kan een eigen leven gaan leiden en verandert de manier waarop het brein pijn verwerkt.



3. Dempende en versterkende invloeden

Alle onderdelen van het pijnnetwerk kunnen een dempende en een versterkende invloed hebben op de pijnbeleving. Sensoren sturen signalen via je zenuwstelsel door naar de hersenen. Dit gaat niet rechtstreeks. Het signaal passeert allerlei schakelstations in je ruggenmerg en je hersenen. Hier wordt bepaald of een signaal wel of niet naar de hersenen wordt doorgestuurd. Deze schakelstations hebben de functie om berichten tegen te houden, te verzwakken en te versterken. Schakelstations fungeren als poortwachters: ze bepalen hoeveel signalen er verder gaan. Hoe verder de poort geopend wordt, hoe meer signalen er worden doorgelaten naar je hersenen. Dit principe maakt ook duidelijk dat de mate van schade en de mate van pijn niet direct aan elkaar gekoppeld zijn.

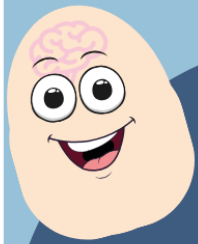
2. LEEFSTIJL & ENERGIE

Bij het ervaren van chronische pijn is het belangrijk dat je goed met **energie levels** omgaat. Veel mensen putten zichzelf te veel uit. Wat uiteindelijk resulteert in meer pijn en vermoeidheid.

Zorg ervoor dat je goed voor jezelf duidelijk hebt wat je **kan** doen en verdeel dit met gelijke hoeveelheid over wat je **moet** en vooral ook over wat je **wilt** doen.

De stoplicht methode

Probeer niet te vaak over je eigen grenzen te gaan. Stop wanneer het te veel wordt (oranje --> groen in plaats van, oranje --> rood), zorg ervoor dat je genoeg kunt opladen elke keer. Denk hierbij terug aan je mentale accu.



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De gedachten aan pijn heeft al invloed op het pijnsysteem. **Negatieve gedachten** kunnen negatieve gevoelens (zoals schuld, schaamte en verdriet) bij je opwekken die pijn verhogende neurotransmitters vrijmaken.

Dit kan leiden tot een **vicieuze cirkel**: de pijn blijft, ook al is er geen directe aanleiding meer. Je kan vast raken in een cyclus van stress en angst, minder durven bewegen, die de pijnervaring kan verergeren.

Hoe vermijd je deze vicieuze cirkel? Het doorbreken van de vicieuze cirkel begint met begrip en acceptatie. Leefstijlaanpassingen zoals regelmatige beweging (op eigen tempo), ontspanningstechnieken en sociale steun kunnen helpen. Daarnaast helpt therapie. Laat je begeleiden op maat.

Flyer version 2

4. INVLOED VAN ERVARINGEN

Het begrijpen en in kaart brengen van waar je **oorspronkelijk pijn vandaan kwam**, kan helpen met het deactiveren van de 'actieve' stand van het pijn systeem. Het verkennen van de **diepere emoties** verbonden met die periode van pijn kan helpen met het verminderen van de pijnervaring.

Je brein heeft namelijk nieuwe (snellere) verbindingen gemaakt in deze periode voor pijn, die ervoor zorgen dat pijnsignalen makkelijker en sneller worden doorgegeven. Dit gebeurt door stoffen in je hersenen, zoals **neurotransmitters**, die de pijn kunnen versterken.

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De werking en invloeden van het pijnsysteem

VOOR MENSEN MET CHRONISCHE PIJN

INHOUDSOPGAVE

1. **Leren over het pijnsysteem**
   1. Wat is pijn?
   2. Acute vs chronische pijn
   3. Dempende en versterkende invloeden

2. **Invloed energie levels**
   1. Energie verdeling bij chronische pijn
   2. Moeten, kunnen en willen
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Flyer version 3

ZELF HULP ZOEKEN

Voor een afspraak met de volgende zorgverleners is **geen doorverwijzing** van een arts nodig. U kunt dus **zelf een afspraak inplannen**.

1. Cesartherapie/ mensendiecktherapie (bij Netwerk Chronische Pijn)
   - *Het Netwerk Chronische Pijn bestaat uit oefentherapeuten die gespecialiseerd zijn in de behandeling van mensen met chronische pijn.* www.netwerkchronischepijn.nl/
2. Psychosomatische fysiotherapie
   - *Een behandelvorm die zich richt op pijnbeleving in samenhang tussen lichaam en geest.*
3. Ergotherapie
   - *Ergotherapie helpt bij het uitvoeren van activiteiten van activiteiten in het dagelijks leven.*
4. Praktijkondersteuner Huisartsenzorg (POH-GGZ)
   - *Werkt in de huisartsenpraktijk en biedt ondersteuning aan mensen met psychische klachten.*

PODCAST OVER VERMOEIDHEID

Een podcast met gz-psycholoog Annemarieke Fleming over het verminderen van pijn en moeheid.

ONLINE CURSUS OMGAAN MET PIJN

Deze online cursus ligt op het omgaan met chronische pijn.

CONCLUSIE

Is er een onveilig gevoel in het lichaam, door ofwel **fysieke, sociale** of **lichamelijke** factoren, dan kan dit een versterkende factor hebben op pijn. Deze factoren spelen dus allemaal een belangrijke rol in de **pijnervaring.**

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Het begrijpen van het pijnsysteem is **stap één** in pijnvermindering. Met de hulp van de juiste zorg en motivatie kan het leven met chronische pijn verbeterd worden. Dit hoef je niet alleen te doen! Hulp van professionals, vrienden en lotgenoten kan het verschil maken.

MEER INFORMATIE

- Relevante websites:
  - www.RetrainPain.org/nederlans
  - www.Reumanederland.nl
  - www.Reuma.nl
  - www.Reumazorgnederland.nl
  - www.Pijnpatientennaar1stem.nl
  - www.netwerkchronischepijn.nl/
- Patiëntenvereniging Fibromyalgie en Samenleving
  - F.E.S.www.fesinfo.nl
- Relevante boeken: Verklein je pijn, Pijn & het brein, Over leven met pijn en Lieve help

Deze folder is gemaakt door Kim Gaus, Industrieel ontwerper TU Delft Design en de Polikliniek Reumatologie van het Reinier de Graaf Gasthuis en Basalt Revalidatie

Reinier de Graaf

De werking en invloeden van het pijnsysteem

VOOR MENSEN MET CHRONI-SCHE PIJN

Contact
De polikliniek Reumatologie is op werkdagen bereikbaar van 8.30 tot 12.30 uur en van 13.30 uur tot 16.30 uur via tel. 015 – 260 50 00.

1. LEREN OVER HET PIJNSYSTEEM

1. Wat is pijn
Pijn is een waarschuwingssignaal dat je lichaam **beschermt** tegen gevaar. Er zijn drie belangrijke beschermsystemen in het lichaam: het pijnsysteem, het immuunsysteem en het stresssysteem. Deze systemen helpen je lichaam om te reageren op dreiging. Soms blijven deze systemen echter 'aan' staan, ook als er geen echt gevaar meer is. Die overbescherming kan zorgen voor aanhoudende pijn. Het pijnsysteem raakt dan uit balans, waardoor pijn heftiger kan worden ervaren.

2. Acute vs chronische pijn
Er is een verschil tussen acute en chronische pijn. Acute pijn is plotseling en vaak heftig. Het ontstaat bijvoorbeeld bij een verwonding of ziekte en verdwijnt meestal zodra de oorzaak is behandeld of genezen.
Chronische pijn, ook wel aanhoudende pijn genoemd, **duurt langer dan drie maanden**. Vaak is er geen duidelijke lichamelijke oorzaak meer. De pijn kan dan een eigen leven gaan leiden en het brein gaat pijn op een andere manier verwerken.

3. Dempende en versterkende invloeden
Alle onderdelen van het pijnsysteem kunnen pijn **versterken of juist dempen.** Sensoren in je lichaam sturen signalen via je zenuwstelsel naar je hersenen. Deze signalen gaan niet in één keer door, maar passeren allerlei **'schakels'** in je ruggenmerg en hersenen. Deze schakels werken als poortwachters: ze bepalen hoeveel signalen er doorgelaten worden. Hoe verder de 'poort' openstaat, hoe meer signalen de hersenen bereiken en hoe sterker de pijn kan worden ervaren. Dit laat zien dat de hoeveelheid pijn niet altijd overeenkomt met de hoeveelheid schade in het lichaam.

2. INVLOED OP JE ENERGIE

Bij chronische pijn is het belangrijk om zorgvuldig met je energie om te gaan. Veel mensen putten zichzelf ongemerkt uit, wat uiteindelijk leidt tot meer pijn en vermoeidheid.

Zorg dat je voor jezelf goed in beeld hebt wat je aankunt, en verdeel je energie evenwichtig over dingen die je moet doen en vooral ook over wat je graag wilt doen. Een ergotherapeut kan hierbij helpen.

De pacing methode
Pacing is een methode die mensen met chronische pijn helpt om hun energie beter te verdelen over de dag. Door activiteiten en rust bewust af te wisselen en op tijd te pauzeren, voorkom je overbelasting en pijnopvlammingen. Zo kun je op een stabieler tempo meer doen, zonder telkens over je grenzen te gaan.

3. INVLOED VAN EMOTIES & GEDACHTEN

Alleen al het denken aan pijn kan invloed hebben op je pijnsysteem. Negatieve gedachten kunnen gevoelens oproepen zoals schuld, schaamte of verdriet en die emoties kunnen de pijn juist versterken.

Dit kan leiden tot een vicieuze cirkel: de pijn blijft, ook al is er geen directe lichamelijke oorzaak meer. Je kunt vast komen te zitten in een patroon van stress, angst en minder bewegen. Dat maakt de pijnervaring vaak nog erger.

Hoe doorbreek je deze vicieuze cirkel?
De eerste stap is begrip en acceptatie van hoe pijn werkt. Daarna kun je, stap voor stap, dingen gaan doen die helpen: regelmatig bewegen (op je eigen tempo), ontspanningsoefeningen en steun van anderen. Ook begeleiding via therapie kan veel verschil maken. Zoek hulp die bij jou past.

4. INVLOED VAN ERVARINGEN

Ervaringen uit het verleden kunnen een grote rol spelen bij het ontstaan en blijven bestaan van chronische pijn. Bijvoorbeeld een heftige gebeurtenis, langdurige stress of het gevoel niet begrepen te worden, kan het pijnsysteem gevoeliger maken. Je lichaam onthoudt die ervaringen, en je brein reageert sneller op prikkels die onveilig of belastend aanvoelen.

Zonder dat je het doorhebt, kan je pijn daardoor sterker worden, ook als er lichamelijk niets nieuws aan de hand is. Door samen met een behandelaar naar deze ervaringen te kijken en ermee aan de slag te gaan, kun je leren hoe je lichaam en brein weer tot rust kunnen komen.

5. INVLOED VAN SOCIALE FACTOREN

Pijnbeleving wordt niet alleen beïnvloed door het lichaam, maar ook door sociale factoren zoals werk, school, vrienden en familie. Onbegrip vanuit de omgeving kan leiden tot negatieve gedachten en verhoogde stress. Dit zorgt voor extra prikkeling van het pijnsysteem, waardoor je meer pijn kunt ervaren.

Probeer aan je omgeving uit te leggen dat jouw lichaam anders omgaat met pijnsignalen en daar gevoeliger op reageert. De lepeltheorie kan helpen om op een eenvoudige manier uit te leggen hoeveel energie en moeite het kost om te leven met chronische pijn.

Cognitieve gedragstherapie kan helpen om hiermee om te gaan. Dit proces kun je samen met een professional aangaan, zodat je hier stap voor stap sterker in wordt.

Appendix M - Evaluation interview guide with patients

With patient interviews I want to test my design on several aspects. First of all it is important to test if my design, the PaceWise app, achieves the design goal from the design statement that was previously created in the project using the research insights.

The design statement is as follows: Design a tool that helps people with chronic pain due to a rheumatic disease effectively manage their energy levels throughout the day by supporting them to stay within their limits, to help them regain the sense of control over their pain.

Participants
The target group for the design is people with chronic pain caused by a rheumatic disease. Therefore, the target group for the evaluation should also consist of people with chronic pain due to a rheumatic disease.

The goal of the design is to support these individuals in managing their energy levels throughout the day by helping them stay within their personal limits. The user evaluation aims to assess whether the tool effectively achieves this goal.

Evaluation challenges and approach
Since the app does not yet exist in a functional form, real-life testing in a realistic context is currently not possible. However, an alternative approach can be used: presenting the concept to users by explaining what the app would do and how it would function (scenario sketching). This allows users to imagine its potential usefulness and provide feedback on the concept. It is important to first verify whether the core objective of the tool is being addressed before further developing and refining the idea. Once the desirability of the concept is confirmed, user testing with actual interactive interfaces can take place in a later stage.

Testing the main goal of the app, creating awareness
The goal of the app is to raise awareness around energy management. This can be evaluated by asking participants how aware they currently are of their energy levels and limits, using a scale from 1 to 7, before introducing the concept. After explaining the app through a scenario, the same question will be asked again. While this method is not fully representative of real-world use, it can provide an initial indication of whether the concept is moving in the right direction.

Testing features of the app
Besides the main goal of the app, some smaller yet important aspects of the app should also be tested. The app is designed to prompt users to take a rest when their energy levels are running low. Therefore, it is important to test whether users actually take a rest when they receive a notification. I need to determine whether a notification from the app is a sufficient trigger to prompt rest, or if additional triggers are needed.
The effectiveness of the weekly to-dos also needs to be evaluated. It is essential that users are motivated to engage with the activities related to their personal goals and that they actually complete them. Is simply providing a to-do list enough, or is more guidance and support required?

Lastly, the user interface can be tested to determine whether everything is clearly communicated to the user and whether the user understands how the app works. This can be done by having participants navigate through the Figma prototype on a phone. Participants will be asked to think out loud as they interact with the app's interface.

Interview set up
Taking all the information from the previous paragraph into account, relevant interview questions were made. Also a video was made to show the participant the user context of the app.
Vragen participanten interview

Uitleg waar ik mee bezig ben

- Hoeveel bent u nu bewust bezig met uw energie hoeveelheid op een schaal van 1 (totaal niet) tot 7 (heel veel)?
- Was dit voor revalidatie minder?
- Wat heeft ervoor gezorgd dat dit nu meer is?

Uitleg video van de app met extra uitleg vanuit mij

- Deze app is bedoeld voor mensen met chronische pijn door gewrichtsklachten om ze bewuster te maken over hun energie level. Is dit een app die u zou kunnen helpen?
- Waarom wel? Waarom niet?
- Wat kan er aan de app worden aangepast om deze wel aan te sluiten op uw behoeftes?
- Wat zijn belangrijke dingen die u heeft geleerd tijdens revalidatie die u graag zou willen terugzien in de app?
- Wat vindt u belangrijk in een app? Wat zijn dingen die ervoor kunnen zorgen dat u de app zou downloaden?
- Op advies van een zorgverlener?
- Andere dingen die ervoor zorgen dat u zo'n app blijft gebruiken?
- Hoeveel zou u bewust bezig zijn met u energie hoeveelheid op een schaal van 1 (totaal niet) tot 7 (heel veel) als u deze app zou hebben, denkt u?

Scenario
- Stel u heeft deze app en u krijgt een melding dat uw energielevel laag is. Zou een melding op uw telefoon ervoor zorgen dat u rust zou nemen?
- Of misschien bewust erover nadenken?
- Is dit niet het geval is, wat zou er dan wel voor zorgen dat u wel rustiger aan doet?
- Stel u heeft deze app en de app geeft aan dat u nu genoeg energie heeft om de activiteit die hoort bij uw doel te doen. Zou u dan getriggerd worden om deze activiteit te doen?]
- Als dit niet het geval is, wat zou er dan wel voor kunnen zorgen dat u deze activiteit wel gaat doen?

Kleine user interface test
Mijn telefoon met de app prototype geven, de deelnemer kan door het prototype heen klikken. Ik zal van te voren vragen of ze hardop willen zeggen wat ze denken terwijl ze de app gebruiken. Tijdens het klikken zal ik ook eventuele extra uitleg geven om bepaalde functies nog verder te toelichten. Ik zal ook aangeven dat dit nog geen eindontwerp is maar een prototype voor een eerste indruk.
- Wat vind u van de layout van de app?
- Was alles duidelijk? Wat was nog onduidelijk?

- Opmerkingen: Heeft u verder nog feedback voor de app/design

Appendix N - Evaluation interviews with occupational therapist about the app

Interview met ergotherapeut Basalt

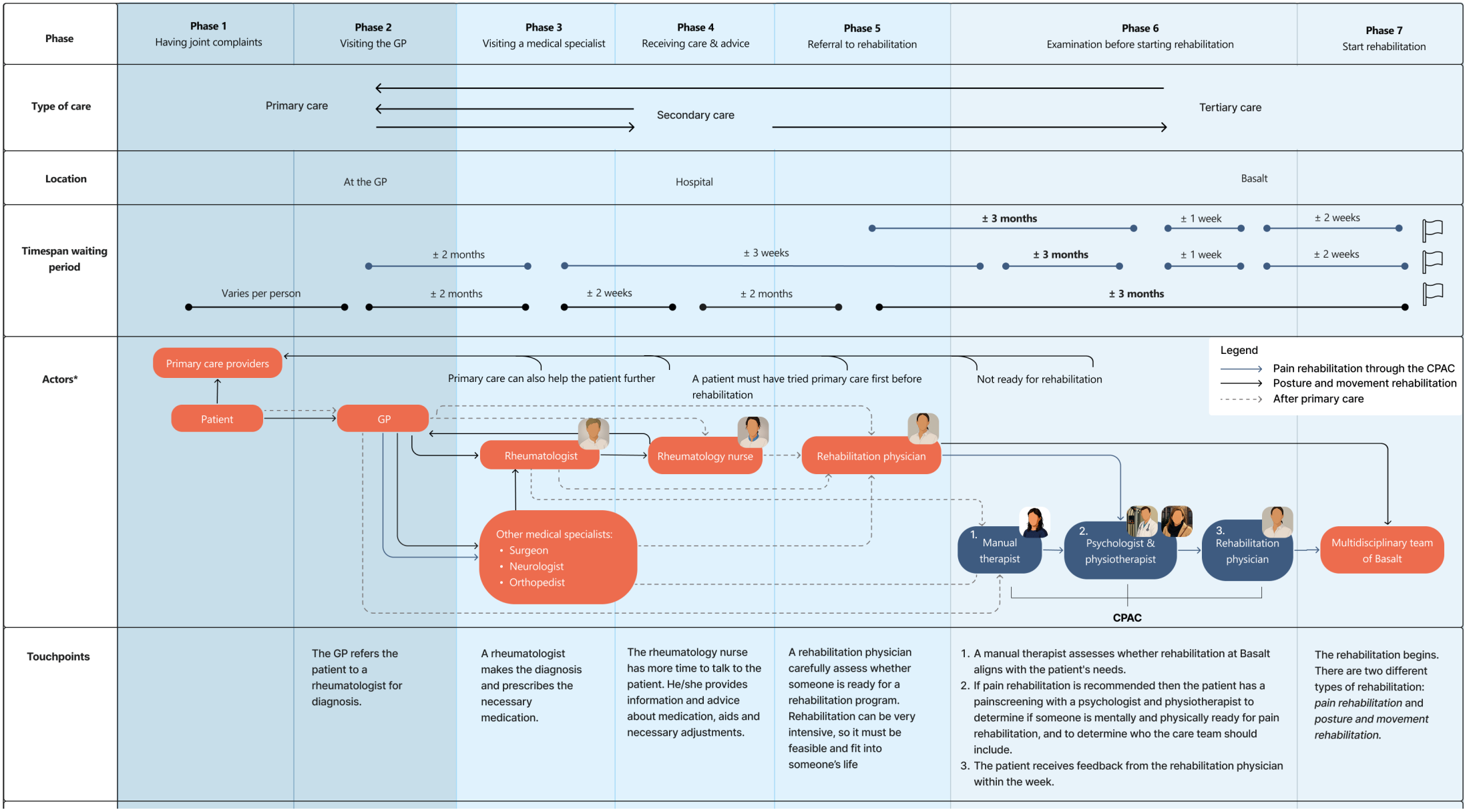
- Hoe past u de pacing methode toe in praktijk?
- Gebruikt u hiervoor bepaalde hulpmiddelen (formulieren etc)?
- Werken mensen bij u aan specifieke doelen? Zo ja, hoe worden deze doelen dan opgesteld? Hoe kan ik ervoor zorgen dat mensen in de app een goed doel opstellen?
- Wat valt onder rust nemen?

Uitleg over de app (schermen laten zien)

- Wat vind u van het idee van deze app?
- Denkt u dat deze app meerwaarde geeft aan patiënten?
- Denkt u dat de gebruiker goed zelf kan inschatten hoeveel energie hij of zij heeft gebruikt om op deze manier de app goede input te geven?

Appendix O - Full size patient journey map

Part 1



Part 2

Emotions and quotes	*"The time of diagnosis was a very turbulent period. It was truly a time filled with uncertainty."*	*"For a long time, doctors couldn't figure out what was wrong, and it started to really wear me down."*	*"On the one hand, I was glad there was a diagnosis, but on the other hand, nothing could be done about it."*	*"During my appointment with the rheumatology nurse, I received a clear and calm explanation about my diagnosis, which was nice"*	*"The physician told me that we would look at how things could be done differently, which was good to hear"*	*"I am quite scared to start. I know it's going to be a very intense process. I'm really busy with work right now, so I feel a bit overwhelmed. I really want to do it, but I also find it very scary."*	*"I want to start as soon as possible, because I really want to do something about my pain symptoms."*	*"Rehabilitation has really been an eye-opener for me, it made me realize I need to start doing things differently."*
Frustrations & challenges	• Frustrated and irritated: not knowing where the pain comes from. • Not being able to do what the patient used to do.	• Frustrated because it is very hard to find the cause of the pain. • Keep pushing limitations, because there is no explanation for the pain. • Keeps looking for the right diagnosis.	• In shock and confronted with the diagnosis. • Feeling confused and scared about the effect on the patients life. • Frustrated about not finding the right medication.	• Scared because learning about injection medication for the first time. • Confronting, because a change is needed in the way the patient lives and what he or she can do in a day.	• Overwhelmed by a lot of new possibilities and options. • Afraid of making the wrong choice. • Confronted with the fact that pain is also influenced by social and mental factors.	• Excited and nervous about what is going to happen. • Having questions about what to expect the coming period and impact on daily life. • Not looking forward to the period till the start of rehabilitation.		• Tired from the intense taject. • Not being able to work during the treatment, meaning they cannot earn money as freelancer. • Learning a lot of new tools and a different mindset so feeling a bit overwhelmed.
Information provision		Quick conversation about possible diagnosis	Conversation about diagnosis and medication	One-time conversation diagnosis and website references	One-time conversation about factors influencing the pain system and website reference	Long information videos and extensive online information forms		Extensive personal information and feedback about about pain/energy management and pain system.
Patients' information needs		Relevant website and app references on pain management	Information folder and conversations about dealing with the disease and impact on life	Personal advice and relevant app references	Personal advice and information about with to expect from the upcomming appointments	To the point information about planning and expectations		
Design opportunities	• Providing an online platform where people can chat with professionals. • Providing an AI platform where people can ask questions.	• Meetings where GPs learn from the knowledge of medical specialists. • Creating a website or app with information about the pain system with tips and tricks.	• **Bringing forward the essential lessons from the rehabilitation process.**** • Providing information about the working of the pain system. • Providing information about energy management with tips and tricks.	• Connecting people with other patients who are experiencing the same. • Creating a platform for patients where they can find information from professionals and ask questions.	• Giving the patient relevant information to take home. Such as information about what to expect during rehabilitation, how to prepare and reading material of the pain system. • Bringing important information about energy management forward, so people can already start working on improving their life.	• Providing short to the point videos with information. • Website/app where people can look up tips from specialists (occupational therapist, psychologist, physiotherapist). • To keep the motivation for rehabilitation high, start an intake program where people can start learning things before rehabilitation starts.		• Connecting people with other patients who are experiencing the same thing.

Appendix P - Project brief

DESIGN FOR our future

TUDelft

Personal Project Brief – IDE Master Graduation Project

Name student Kim Gaus **Student number** 5,264,855

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT
Complete all fields, keep information clear, specific and concise

Project title Optimizing the transition between hospital discharge to rehabilitation for patients with joint complaints.

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

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

Healthcare consumption is rising rapidly, leading to workforce shortages and increasing costs. To ensure accessible, high-quality, and affordable care, significant changes are necessary.

Rheumatic diseases, including osteoarthritis—the most common degenerative joint disease—affect millions in the Netherlands, impacting daily life (Artrose | ReumaNederland, n.d.). These conditions cause chronic inflammation, leading to joint damage and disability. Despite early diagnosis and treatment, many patients require rehabilitation at various stages. The World Health Organization emphasizes rehabilitation as key to improving independence and quality of life for those with disabilities. Research supports its benefits for rheumatic patients, enhancing self-sufficiency and overall well-being (Kjeken et al., 2014; WHO, 2023).

This project focuses on optimizing the transition from hospital discharge to rehabilitation, addressing the "black hole" period where many patients experience gaps in care. Through observations, interviews, focus groups, and system analysis, I will identify key pain points and develop a sustainable solution to improve patient experience and healthcare workflows.

The referral journey is complex, involving multiple healthcare professionals. A smoother, more efficient process benefits both patients and providers, improving care outcomes and work satisfaction. Key stakeholders include Reinier de Graaf Hospital, rehabilitation professionals, and patients, whose experiences will directly shape system improvements.

While this project presents opportunities for innovation, navigating the complexities of the healthcare system poses challenges. Stakeholder insights and further research will be crucial in identifying pain points and designing effective solutions. Given the broad scope and novelty of this topic, careful exploration and feasibility assessment are essential.

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introduction (continued): space for images

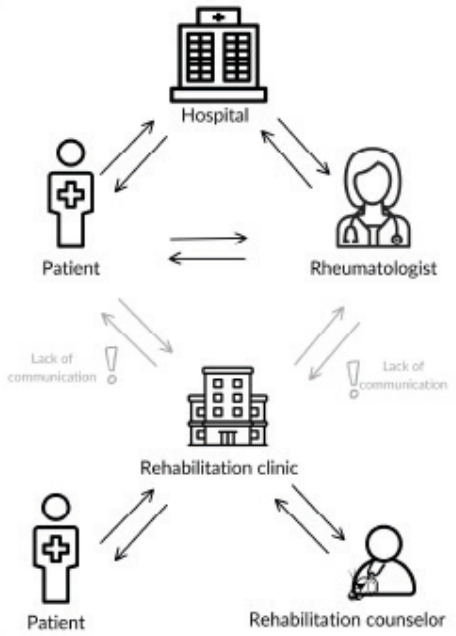
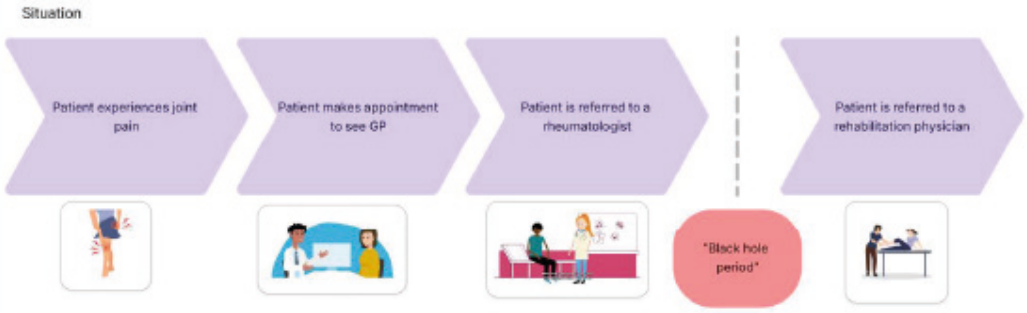


image / figure 1 Stakeholder map



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DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

After being discharged from the hospital, patients with joint complaints often face challenges such as a lack of information and communication (between the hospital and the rehabilitation clinic) while awaiting the start of their rehabilitation. Patients often face the problem of not knowing what to expect or what they should do during the long period before starting the rehabilitation process. The maximum waiting time at the rehabilitation of Reinier de Graaf (Basalt) is 4 weeks for access to the outpatient clinic and diagnostics, and 7 weeks for treatment (Wachttijden - Basalt - de Kracht van Revalidatie, z.d.).

In this project I will start with mapping the current rheumatological care process, identify bottlenecks and name the needs associated with referral to rehabilitation with regard to patients with joint complaints.

The goal of this graduation research is to conduct a qualitative and exploratory study to develop an impactful solution that helps the patients during this transitional phase.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

Design an intervention that improves the bridge between hospital and rehabilitation for patients with joint complaints.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

I will begin with desk research to gain a deeper understanding of the overall context. Following this, I will engage with stakeholders to map the entire system and create a comprehensive stakeholder map. Journey mapping will help with providing overview and conncetion and can help to gain an overview and create a shared language for change. A patient journey and context mapping can help with better understanding the patients needs and biggest painpoints. After mapping out the system I will focus on creating an intervention for the the pain points within this system.

The Double Diamond Model (DDM) guides this project through four design stages: discover, define, develop, and deliver. The first diamond explores the problem through research, including literature study, observations, and interviews, culminating in a journey map of key bottlenecks. The second diamond focuses on solutions, refining concepts through ideation, prototyping, and testing, ultimately leading to a final design concept.

Due to the sensitive information from the patients and hospital I will consistently prioritize and safeguard their privacy. I wil also do an ethical application at the hospital for this project.

Project planning and key moments

*To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting, mid-term evaluation meeting, green light meeting and graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting	19 feb 2025
Mid-term evaluation	16 apr 2025
Green light meeting	11 juni 2025
Graduation ceremony	9 juli 2025

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	
For how many project weeks	
Number of project days per week	

Comments:

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

I want to start this project because I enjoy helping people and creating designs that have a positive impact on people their lives. It aligns well with my studies in Industrial Design Engineering, where I've learned to tackle complex problems using tools like stakeholder mapping and journey mapping. My master's specialization is Integrated Product Design (IPD), which influences how I approach potential design solutions. While I have a slight preference for designing physical products, my primary goal is to create a significant positive impact with my solution. Therefore, I am open to exploring other types of solutions if they offer greater benefits for the patients.

Through this project, I hope to explore whether designing in a healthcare environment suits me. I enjoy engaging with people and considering the perspectives of various stakeholders. This project provides an opportunity for me to discover what I truly enjoy and what suits me best.