# PROMis for quality care:

## Augmenting the value of Patient Reported Outcome Measures for people living with HIV

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**Master Thesis**

# Acknowledgement

**PROMis for quality care:**
**Augmenting the value of PROMs for people living with HIV**

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# Executive Summary

This report outlines a project that aimed to increase engagement with patient reported outcome measures (PROMs) for patients at an outpatient clinic. The target group was people living with HIV (PLHIV). This study was made possible thanks to the client, Amsterdam UMC, who are undertaking a larger research project that aims to improve the quality of life (QoL) of PLHIV.

The project included a comprehensive literature review and user research that involved shadowing of nurses in order to explore the clinic's context. At this point PROMs started being introduced at the outpatient clinic. To identify design opportunities, attitudes toward PROMs, and initial impressions of PROMs, semi-structured interviews were done with patients and nurses. To further the discussion of PROMs three provotypes were made and presented to participants during the interviews. The main takeaways related to patients not knowing the value or purpose of PROMs or lacking the motivation to complete them. From these takeaways design criteria were identified by making the design goal and interaction vision, which led to the development of four concepts by research through design, brainstorming, and role-playing.

A Harris profile was done on the four concepts and one of them was selected to move forward to design and implementation. The concept was a card game, and it was further iterated on by using accessibility guidelines and persuasive game design. The objective was to make a game that, while being accessible, would help change patient behavior regarding PROMs. A lo-fi mock-up was created for the game to test the different game elements with people, leading to refinement of the concept and turning it into a high-fi prototype that was tested with the target group, PLHIV.

The results were positive, with patients showing enthusiasm for the game, but with some room for improvement. Patients found the game to be compassionate and useful in learning about PROMs. The game was also tested with a peer navigator who offered many insights from the perspective of patients who are not open about their diagnosis and on how the card game could be used in relation to their role at the outpatient clinic. These findings highlight the potential of using gamification to create inclusive learning tools (i.e. the card game) in the health sector to increase engagement with other health tools (i.e. PROMs) and the importance of continued work to optimize these tools for patients with chronic illnesses such as HIV.

# Abbreviations

| | |
|---|---|
| AIDS | Acquired immunodeficiency syndrome |
| AMC | Academisch Medisch Centrum |
| Amsterdam UMC | Amsterdam Universitair Medische Centra |
| HCPs | Healthcare professionals |
| HIV | Human immunodeficiency virus |
| PLHIV | People living with Human immunodeficiency virus |
| PROMs | Person-reported outcome measures also knows as Patient-reported outcome measures |
| RQ | Research Question |
| QoL | Quality of life |

# Table of Contents

**Chapter 1**

# INTRODUCTION

This chapter introduces the topic, project aim and background. It introduces the scope of the project based on the problem and solution scope. The chapter concludes with the approaches explored throughout the project.

## 1.1 Project aim and background

This project strived to aid people living with human immunodeficiency virus (HIV) to fill out patient reported outcome measures (PROMs). As doing so can increase involvment in their care and consequently a higher quality of life (QoL).

PROMs are tools used to assess the health status and well-being of patients from the patient's perspective. PROMs can be used to collect data on a variety of health-related topics, including physical and mental health symptoms, functional abilities, QoL, and satisfaction with care. PROMs are an important tool for collecting patient-reported data and can help healthcare providers better understand the patient's experience, identify areas for improvement, and tailor treatment plans to meet the patient's needs and goals (Greenhalgh et al., 2018).

PROMs can also be used to assess the effectiveness of interventions, track patient progress over time, and inform policy and practice. This allows patients and healthcare professionals (HCP) to have a better overview of the patient's health and it can act as an early signalling system that HCPs can use to adjust individualized care (EATG, 2021).

In Figure 1, the process of how PROMs are ideally utilized in care is visualized, where after filling in the PROMs the patients discuss them with the HCP, who adjusts their health plan accordingly. In practice, however, PROMs are only filled by a minority of patients due to lack of understanding of what they are, lack of motivation, required time and effort, or questions seeming confronting. Additionally, PROMs are not always discussed in consultations which can further demotivate patients to fill them in (Van Muilekom et al., 2021). Chapter 2 provides more information on HIV and PROMs.
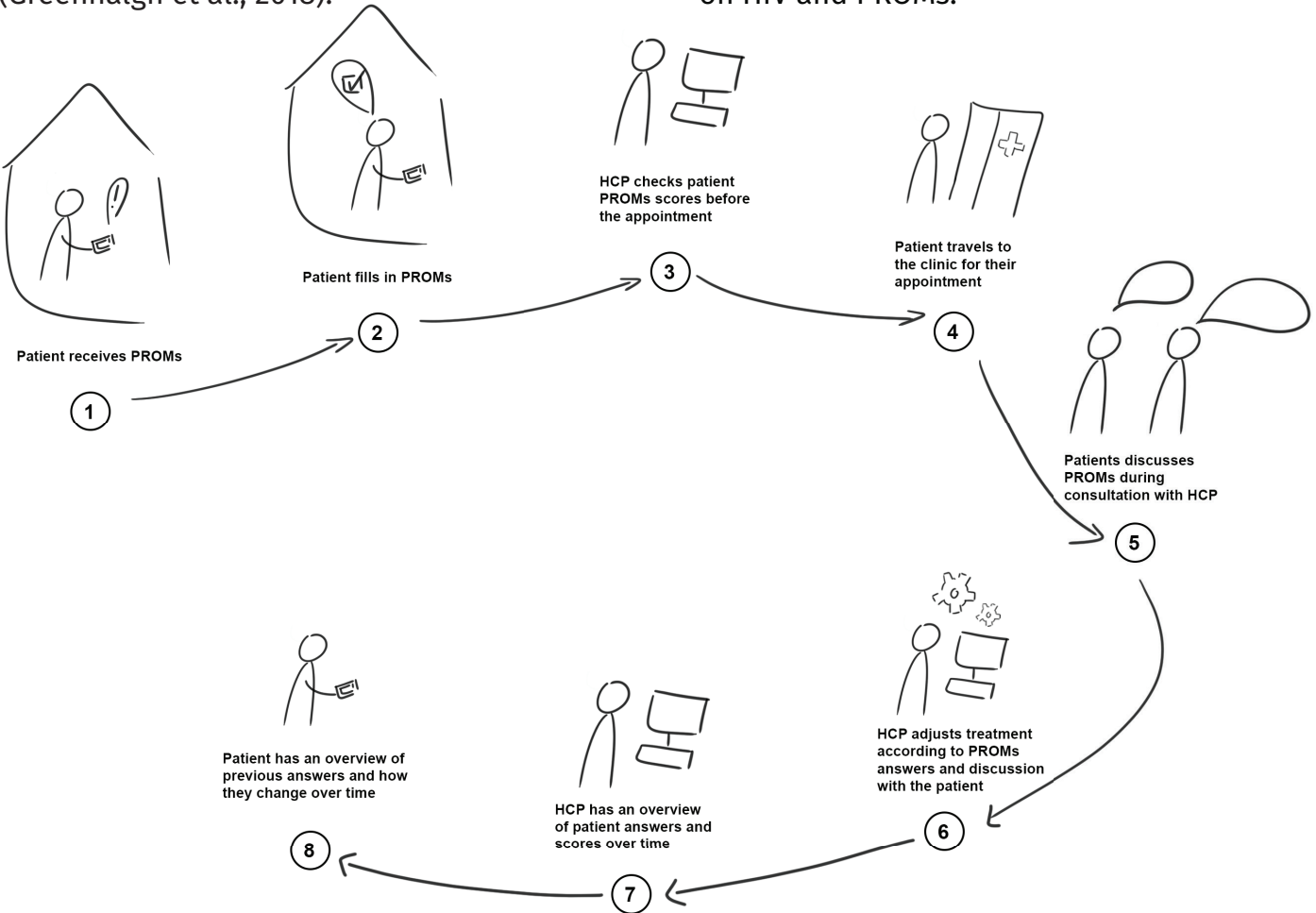


Figure 1: Simplified visual of how PROMs are ideally integrated in care.

This project is done in collaboration with the HIV outpatient clinic at Amsterdam UMC, which treats people living with human immunodeficiency virus (PLHIV). One of the client's points of departure is on improving the QoL of PLHIV, with the intent of providing small-scale and personal treatment for patients. They expressed that their goal is to give an as healthy and ordinary life as possible while having a broad focus on somatic elements, mental conditions, and social problems that correspond with HIV.

*"Everybody with HIV in Netherlands deserves a good QoL." – Client*

As part of achieving this goal, Amsterdam UMC recently introduced PROMs as part of the treatment received at the HIV outpatient clinic. The purpose of introducing this reporting tool is for patients to have a better overview of their own health and provide the clinic with the possibility to provide help when needed in a timely manner. The implementation of PROMs occurred while this project was ongoing.

The project aim was to develop a design intervention that increases the use of PROMs throughout a patient's care path.

## 1.2 Problem

The clients' aim is for the patients to fill out the PROMs at home before their appointments. During their appointments at the outpatient clinic, their scores will be shared and discussed with healthcare professionals (HCPs).

When patients do not understand the value of PROMs and do not engage in the conversation about PROMs during consultations, it could lead to sub-optimal treatment or starting up the correct help can take longer.

Additionally, if the patients do not fill out PROMs before appointments, they have to fill them out at the clinic, which is not a desirable solution due to the available time. Moreover, patients might omit important information that can feel embarrassing or they can otherwise forget the struggles they may have had since their last appointment.

Research has shown that patients often do not see PROMs' long-term value in helping them in their care. One of the reasons could be that PROMs do not have an immediate impact on the patient. This lack of short-term payoff can lead to a lack of motivation in completing PROMs. Other factors, such as the under-utilization of PROMs by clinicians during patient appointments, patients feeling that completing PROMs takes up too much of their time or being concerned about the privacy of their personal health information and how it will be used, can contribute to non-completion of PROMs (Van Muilekom et al., 2021).

The above concerns have also been expressed by the client. The client conducted a pilot study at the HIV outpatient clinic, where they introduced PROMs to several patients. They studied the discussions between nurses and patients caused by PROMs to guide the co-creation of a clinical protocol to address the outcomes of PROMs. Based on the pilot study and research of previous PROM implementations, the client expects that integrating PROMs might therefore face difficulties.

*"Everybody needs to understand the link between PROMs and a good QOL." – Client*

This project will look into addressing these concerns and look into how design can make patients at the outpatient clinic understand the link between PROMs and a good QoL. This may involve providing clear instructions, addressing privacy concerns, and highlighting the benefits of PROMs for the patient and their care.

## 1.3 Solution Scope

### Target Group

This project is focused on the context of the HIV outpatient clinic at Amsterdam UMC, location AMC, and the patient group belonging to this clinic. This is a large and diverse target group to design for, and consequently, their needs and goals can vary. The client expressed wanting to introduce PROMs to all the patients, which is why this project looked into the different types of patients at the clinic and how to design an intervention that includes as many as possible.

When discussing this with the client, they described four types of patients that they have observed. These observations are derived from multiple interactions and discussions with the HCPs at the clinic, who use informal classifications to describe the patient population. The types of patients described were: on top of everything, do not care, tell me what to do and too busy. These groupings are visualized and described in Figure 2.

### Integrity of PROMs

Changing the current PROMs contents and the way it is designed to address different types of patients' needs is not possible because PROMs need to meet 'psychometric integrity'. Any alteration to the PROMs would require it to go through validation again (Moody & EATG PROMise Task group, 2021). For the same reason making different PROM questionnaires for different types of patients is also not desirable.

### Exposure of PROMs to target group

As mentioned in the previous section, PROMs were implemented while this project was ongoing. As a result, the studies conducted during this project had a segmentation of participants: participants that were not introduced to PROMs, participants that were introduced to PROMs, participants that completed PROMs and participants that participated in the pilot study at the HIV outpatient clinic about PROMS. This can be seen in Figure 2. The size of these segmentations can fluctuate due to new patients at the clinic that have not been introduced yet to PROMs, or patients that do not have access to PROMs.

### Accessibility

Currently, at Amsterdam UMC PROMs are handled by the software EPIC. They are made available through the patient portal called MyChart, also known as Mijn Dossier. PROMs are available in both English and Dutch, however, MyChart is only available in Dutch. This excludes any patients that do not speak those languages. At Amsterdam UMC, location AMC, 67.9% of patients have MyChart. However, this also includes people that made an account with MyChart and forgot about it or decided not to use it anymore.

MyChart being the only access point for PROMs excludes people with low digital literacy and people who do not have access to smart devices that MyChart supports. While MyChart can not be changed under the scope of this project, the solution should have all these in mind.



**Types of patients at Amsterdam UMC outpatient HIV clinic:**

*based on observations from staff at Amsterdam UMC HIV outpatient clinic

Patients who are very involved in their health. They are curious and ask questions during their appointments.

Patients who do not care to learn more about their health. They will not ask questions during their appointments.

Patients who want health professionals to tell them what to do. They do not want to reflect on their own health,.

Patients who are too busy with other things in their life. They do not have the time to reflect on their health.

On top of everything

Do not care

Tell me what to do

Too busy

Figure 2: Types of patients based on client observations at Amsterdam UMC outpatient HIV clinic



Not introduced to PROMs

Introduced to PROMs

Completed PROMs

Participated in pilot study about PROMS
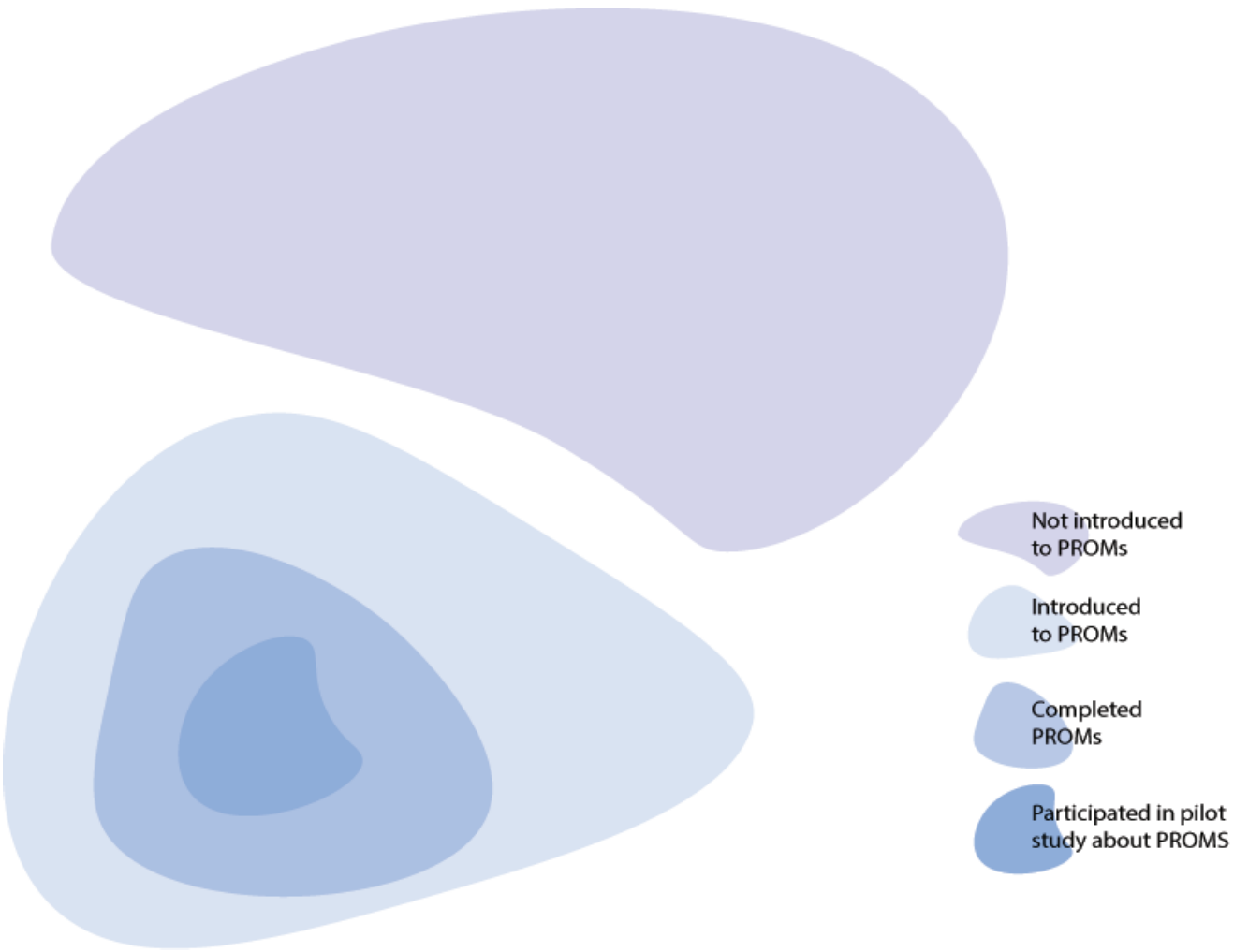
Figure 3: Segmentation of patients based on PROMs exposure

## 1.4    Approach

Throughout this project, a research and design approach is applied. Having both research and design working together allows us to tackle a complex problem to create a solution that meets the needs and goals of the target users. Research helps designers understand the needs and preferences of their users, while design uses this information to create and refine a solution that addresses the defined problem.

**Double Diamond**

The double diamond approach, seen in Figure 4, was used throughout this project and divides the project into four phases, with each phase represented by one side of the diamond. The four phases are:

- Discover: The first phase of the double diamond method is the discovery phase, in which information is gathered about the problem, the users, and the context in which the design will be used. In this project, qualitative methods were used such as literature research, shadowing and interviews. Additionally, research through design was used by including provotypes in interviews to spark discussion.

- Define: The second phase of the double diamond method is the define phase, in which the focus is narrowed down, and the scope of the project is defined more clearly. This phase involves analysing the information that has been gathered and identifying the key issues and challenges that the design will need to address. During this phase, a journey map and personas were developed to help inform the design.

- Develop: The third phase of the double diamond method is the develop phase, in which the focus broadens again through ideating and exploring different concepts. In this phase storyboards and role-playing were used to explore different ideas.

- Deliver: The fourth and final phase of the double diamond method is the deliver phase, in which the focus narrows down again by choosing a concept, designing it and testing it. In this phase, the Harris profile method was used to help choose a concept. After choosing a concept prototyping and testing were done before evaluating it with the target group.

**DISCOVER**
Study the topic, context and target group

Exploration
Literature research
Shadowing nurses
Interviews
Provotypes
Worksheets

**RESEARCH**

**DEFINE**
Structure findings and define design criteria

Analysis
Journey Map
Personas
Design Goal
Interaction Vision

**DEVELOP**
Generate potential solutions

Ideation
Brainstorming
Role Playing
Sroyboards

**DESIGN**

**DELIVER**
Implement, evaluate and detail

Harris Profile
Prototyping
Game Design
Lo-Fi Testing
Questionnaire
Evaluation
Detailing

Figure 4: Double Diamond

Chapter 2

# LITERATURE RESEARCH

This chapter goes through literature research relevant to the topic and context of the project. This includes literature about HIV and what influences patients to adhere to treatment; PROMs, their value, and current barriers patients face regarding PROMs; the implementation of PROMs at Amsterdam UMC; and finally patient-centered healthcare.

## 2.1 Introduction

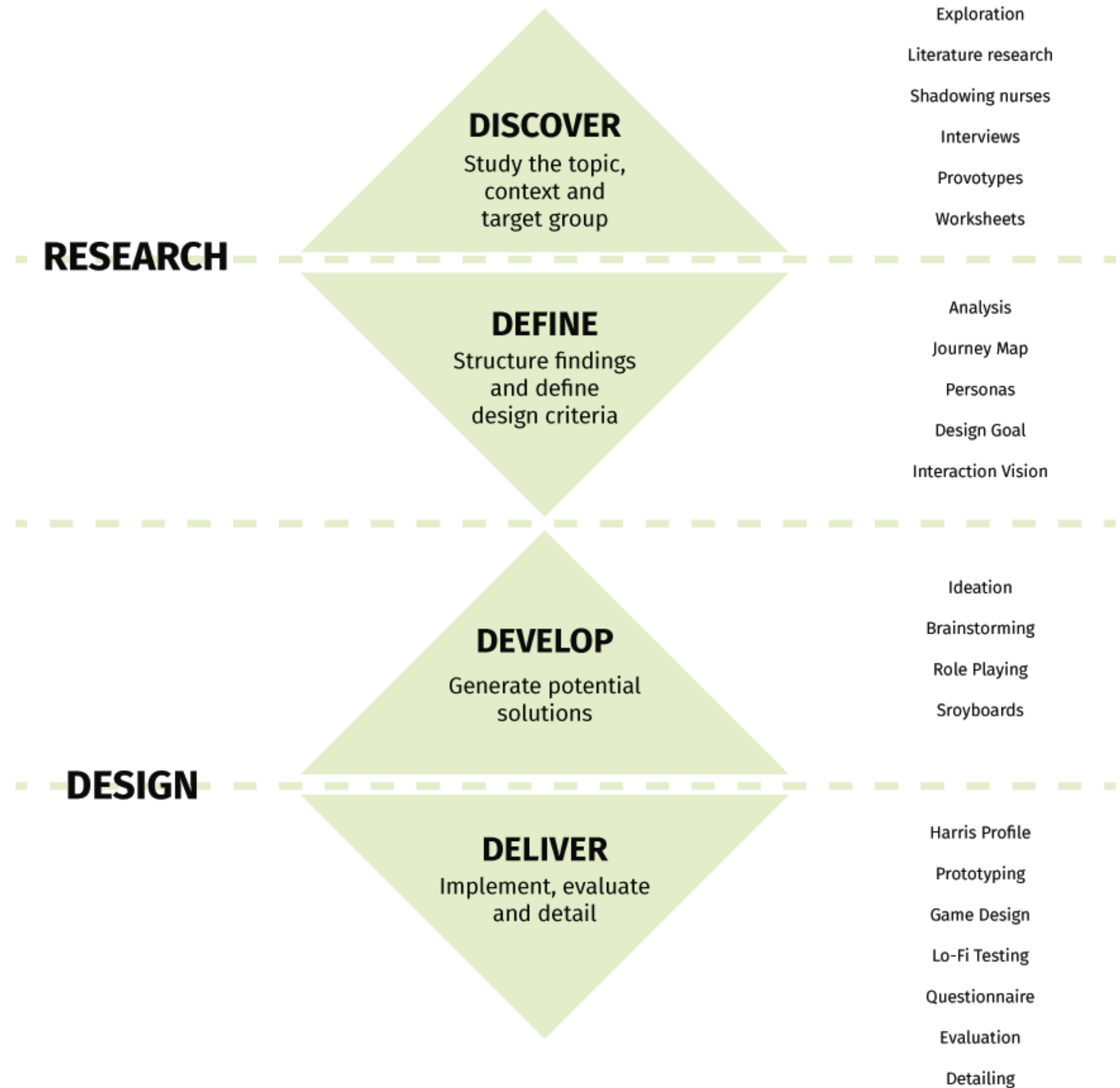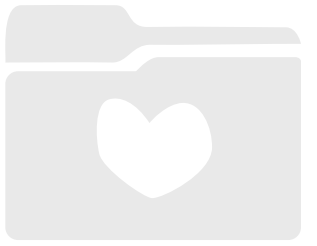The purpose of this chapter is to explore existing literature on the topic and synthesize the findings in order to provide an overview of the current state of knowledge and understanding of the use of PROMs with HIV patients. The literature review will include both primary and secondary sources, including peer-reviewed journal articles, books, and online sources. The chapter will conclude with takeaways from the findings and an outline of the implications for future research and design.

An assumption map has been developed to have a visual representation of the relationships and interconnections between the various contextual factors and any assumptions made at the beginning of this project. The map was made based on initial meetings with the clients and initial research from the Introduction Chapter. It was used to formulate initial research questions to guide the literature review. The map can be found in Appendix 2.

The initial research questions for this study were:

1. What is HIV and how does it link to QoL?

2. What HIV related factors affect PLHIVs QoL?

3. What are PROMs and what is the value of PROMs?

4. What are current barriers patients encounter regarding PROMs?

5. How is Amsterdam UMC implementing PROMs and what type of PROMs are they?

6. How does MyChart affect the implementation of PROMs?

7. What is patient involvement in care and how are patients getting involved in their care?

## 2.2 HIV

HIV stands for Human Immunodeficiency Virus and is a virus that attacks the immune system, specifically the CD4 cells, which are important for fighting off infections and diseases (CDC, ). If left untreated, HIV can lead to acquired immunodeficiency syndrome (AIDS), which is the final stage of the infection.

HIV can lead to a range of health problems, including opportunistic infections and cancers, and can also increase the risk of heart disease and liver disease. However, with access to effective antiretroviral therapy (ART), people with HIV can now live long and healthy lives. ART works by suppressing the virus, allowing the immune system to recover and reducing the risk of progression to AIDS (Kumarasamy et al. 2005; CDC, 2022).

Living with HIV creates a demand for self-management, health literacy, and treatment participation of patients for the rest of their lives. This is because HIV is a chronic condition that requires lifelong treatment (Chesney et al., 1999; Kumarasamy et al. 2005).

### 2.2.1 Health Literacy

Health literacy is the ability to understand and use health-related information to make informed decisions about one's health (van der Heide, 2015).

It is especially important for PLHIV, as managing the virus requires a good understanding of the disease and its treatment, as well as the ability to effectively communicate with healthcare providers and navigate the healthcare system (Edwards et al., 2012). For example, it is important for PLHIV to know what their medications do, how to take them correctly, and how to manage any side effects. Otherwise, they risk the medication not being as effective, putting their health at risk and risking the transmission of the virus to others.

Additionally, low health literacy can contribute to stigma and discrimination towards PLHIV, as individuals may not have the knowledge or skills to advocate for themselves (Palumbo, 2015).

Improving health literacy among PLHIV is therefore an important step in ensuring that they have access to the information and care they need to manage their disease and live healthy lives. This can be achieved through a range of strategies, including providing clear and easy-to-understand health information, involving PLHIV in the design and delivery of health services, and providing education and training for healthcare providers on the importance of health literacy and how to effectively communicate with individuals with low health literacy (Wawrzyniak et al., 2013).

### 2.2.2 Stigma

Despite the strides in HIV treatment, stigma and discrimination towards PLHIV remain a barrier to treatment.

HIV stigma refers to negative attitudes, beliefs, and behaviors directed at PLHIV.

Fear of stigma and discrimination may discourage people from disclosing their HIV status to others, including healthcare providers, which can lead to prevention or delays in seeking care and treatment (Kumar et al., 2015). This can have serious consequences, as HIV treatment is most effective when it is started early. Additionally, PLHIV who experience stigma may be less likely to adhere to their HIV treatment plan by not taking medication as prescribed, which can lead to treatment failure and the development of drug-resistant strains of HIV. (Chesney et al., 1999; Kumarasamy et al., 2005, Rao et al., 2011, Ware et al., 2006)

Another way stigma affects PLHIV is by causing social isolation. PLHIV may experience discrimination, rejection, and exclusion from social, work, and educational settings due to their HIV status. This can lead to feelings of loneliness, depression, and low self-esteem. (Chesney & Folkman, 1994; Logie et al., 2013; Vb, 1993) Internalizing stigma can have PLHIV avoid behaviors that can help them improve their QoL. Similarly, this can cause PLHIV to end up with depression or anxiety, which also leads to poor QoL. (Lee et al., 2002)

As stigma can have such a big impact on PLHIV, their privacy should be a priority when involving them in research.

### 2.2.3 QoL

Quality of life (QoL) is a term that refers to an individual's overall well-being and satisfaction with their life. It is a subjective concept that can be influenced by a variety of factors, including aphysical, psychological, social, and environmental factors.

HIV is a chronic condition, which means PLHIV need to cope with symptoms related to HIV throughout their lives. They might also struggle with different social problems including stigma, depression, substance abuse, or related to their cultural beliefs. This can affect their QoL from a physical, mental, and social health point of view (Chesney & Folkman, 1994). Figure 5 shows how the impact HIV can have on QoL can be classified under four domains: Physical domain, Psychological domain, Social domain, and Environmental domain. Keeping track of these factors can help in learning what is the perceived burden of the chronic disease, tracking changes in health over time, and assessing the effects of treatment. Self-perception of QoL can be used as a screening item for assessing global QoL (Basavaraj et al., 2010).
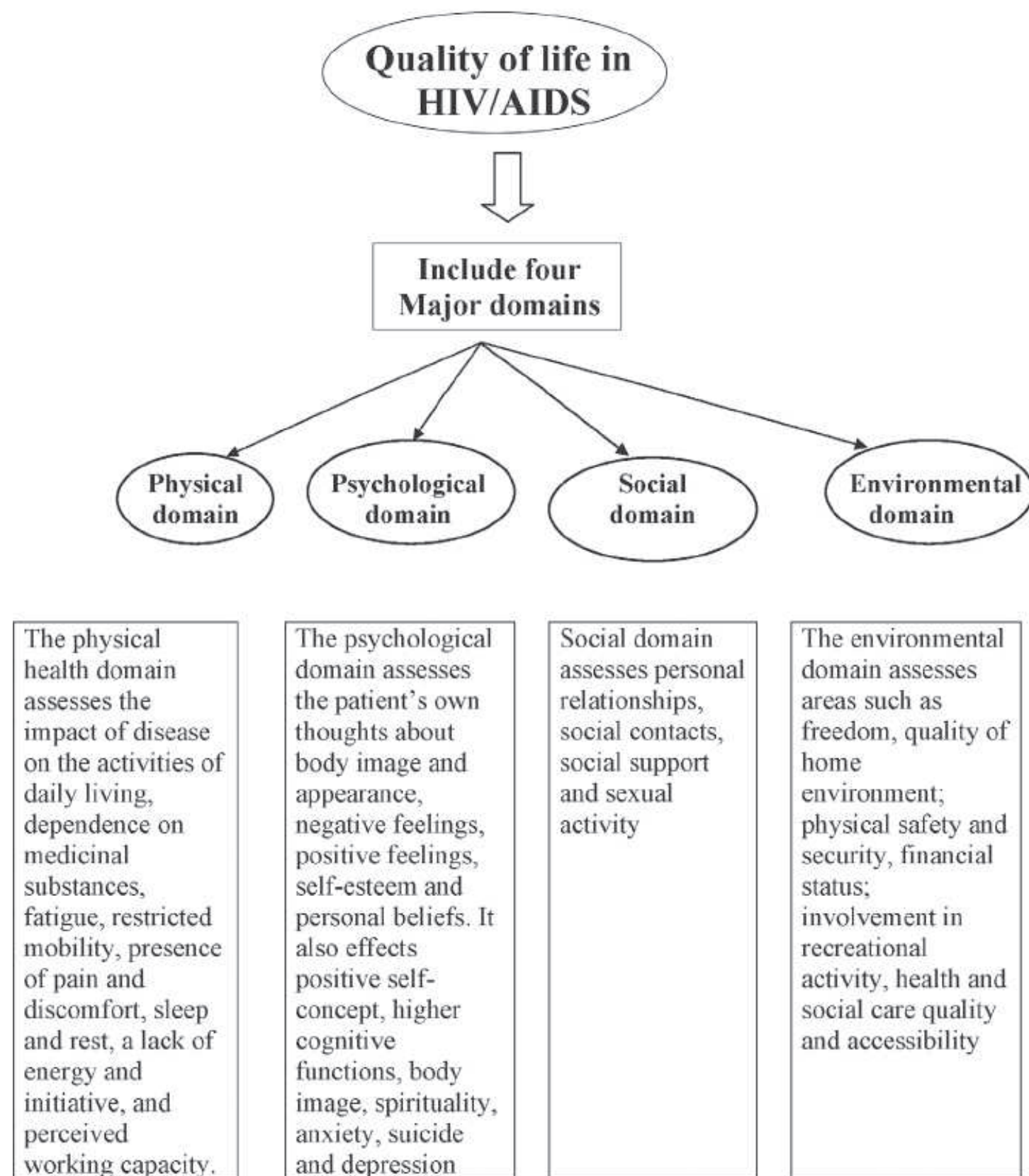
Figure 5: QoL of PLHIV falls under four different domains.

The physical health domain assesses the impact of disease on the activities of daily living, dependence on medicinal substances, fatigue, restricted mobility, presence of pain and discomfort, sleep and rest, a lack of energy and initiative, and perceived working capacity.

The psychological domain assesses the patient's own thoughts about body image and appearance, negative feelings, positive feelings, self-esteem and personal beliefs. It also effects positive self-concept, higher cognitive functions, body image, spirituality, anxiety, suicide and depression

Social domain assesses personal relationships, social contacts, social support and sexual activity

The environmental domain assesses areas such as freedom, quality of home environment; physical safety and security, financial status; involvement in recreational activity, health and social care quality and accessibility

## 2.3 PROMs

Patient-reported outcome measures (PROMs) are reporting tools that are used to gather information about patient health status, treatment outcomes, and quality of life from the patient's point of view. This information is from the patient's perspective as PROMs are designed to be completed by patients themselves, rather than being assessed by healthcare providers.

They are a tool for measurement that is scientifically validated before they are implemented for care. Scientifically validated means statistical analysis establishing the reliability and validity of their scales. This validation also means that developing and implementing PROMs is a task that cannot be done in a short time. PROMs are also generally made and validated for specific purposes (Churruca et al., 2021). They can be used to assess a wide range of health conditions.

It is vital to consider the context and data points of interest for the PROM before making a selection of a questionnaire to use. Figure 6 shows a snippet of questions taken from the WHOQOL-100 questionnaire and provides insight into how these questions are worded. The WHOQOL-100 is a questionnaire for measuring health-related QoL and was developed over several years, in 15 different cultural settings, and is available in 30 different languages (some languages have multiple versions available such as Chinese - Australia, Hong Kong - and French - France, Canada). The full questionnaire starts with an explanation of how the questions are supposed to be answered and then goes into the questions. There are 100 items spread across 6 domains and 24 facets with an additional general facet. I.e. Each facet contains 4 items. The estimated time of completion is 30 minutes (40-90 minutes for illiterate or interview-assisted completions) (THE WHOQOL GROUP, 1998).

The following questions ask about how much you have experienced certain things in the last two weeks, for example, positive feelings such as happiness or contentment. If you have experienced these things an extreme amount circle the number next to "An extreme amount". If you have not experienced these things at all, circle the number next to "Not at all". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Not at all" and "Extremely". Questions refer to the last two weeks.

F1.2  Do you worry about your pain or discomfort?

| Not at all | A little | A moderate amount | Very much | An extreme amount |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

F1.3  How difficult is it for you to handle any pain or discomfort?

| Not at all | A little | A moderate amount | Very much | An extreme amount |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

F1.4  To what extent do you feel that (physical) pain prevents you from doing what you need to do?

| Not at all | A little | A moderate amount | Very much | An extreme amount |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

F2.2  How easily do you get tired?

| Not at all | Slightly | Moderately | Very | Extremely |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

Figure 6: Snippet of questions from WHOQOL-100 that uses a 5-point scale for assessment

## 2.3.1 Value of PROMs

PROMs can be used to help healthcare providers understand the patient's perspective on their health and treatment, as well as to identify areas where patients may be experiencing difficulties or need additional support. They can also be used to assess the effectiveness of treatments and to identify areas for improvement in care. PROMs can be particularly useful for people living with chronic conditions, such as HIV, as they can help track changes in the patient's health status over time.

Research shows that PROMs facilitate these goals and much more.

- PROMs can work as an **early warning system** for issues which makes it possible to preemptively help patients, this improves their treatment outcomes and gives a higher satisfaction with their care (Greenhalgh et al. 2018; Chen et al. 2013). Clinicians experiencing this have stated *"You quickly get an impression of things that are not going well."* and *"Problems are recognized earlier."* (Teela et al. 2020).

- Patients also get a **better overview of their health,** as they are able to go back and check what they previously answered and what changed: *"provides the opportunity to compare the health situation of my child now with the situation just after diagnosis"* (Van Muilekom et al., 2021).

- PROMs **help patients prepare for their consultations** and to raise issues they have had with the HCP in their consultations: *"provides patients the opportunity to think in advance about questions and concerns. They are not confronted with these during"* (Teela et al. 2020).

- Individualized PROMs help patients to tell their stories and make them feel **heard, this in turn empowers** the patient and opens up opportunities for shared decision-making (Anthony et al. 2019; Bouazza et al, 2017).

- Patients can experience **improved communication** with their HCP (Greenhalgh et al. 2018; Bouazza et al, 2017; Chen et al. 2013). *"Completing the questions before the appointment helps you to come up with topics you want to discuss during the consultation"* or *"It helps in discussing topics that you would otherwise not think about"* are some examples of patients' and parents' experiences with the implementation of PROMs in pediatric clinical practice (Van Muilekom et al., 2021).

- PROMs can provide patients **insights into their functioning**, which can aid them in reflecting on their health. Related quotes from patients after experiencing PROMs are: "It is good that patients know what is going on" and "By completing the questionnaires you see how you are doing" (Van Muilekom et al., 2021). Clinicians also expressed that "Patients think in advance about their own functioning and request for help" (Teela et al. 2020).

- PROMs have the potential to improve the care of patients by promoting **joint-decision making** and increaseing **patient autonomy**. (Boyce et. al., 2014)

## 2.3.2 Implementation of PROMs

### Implementation of PROMs at the HIV outpatient clinic at Amsterdam UMC

Currently, PROMs at Amsterdam UMC are handled by the software EPIC. EPIC is an electronic medical record (EMR) system used by healthcare organizations to manage patient medical records and other clinical information. PROMs were made available through the patient portal called MyChart, which is run by EPIC. MyChart is an online portal that provides patients with access to their personal health information and allows them to communicate with their healthcare providers. It is a service offered by the hospital that allows patients to view their medical records, and have access to test results, immunization records, and other important health information. Patients can also request appointments and prescription refills.

Patients that have MyChart receive a reminder, to complete PROMs, seven days before their appointment. They receive a second reminder two days before their appointment if the PROMs have not been yet completed.

If PROMs are not completed before the patient's appointment, they have the opportunity to complete them at the outpatient clinic. As mentioned in the introduction Chapter, the client has expressed that this is not preferable. Based on their previous research they found that this approach gives no time for the HCPs to prepare before the appointment and the patients might not have time to reflect on their answers or might have a response bias based on what they think the HCP wants them to answer. Additionally, there might be no time to complete PROMs before or during appointments due to the short time or other topics having a higher priority at the time. Appointments take 20 minutes and the average completion time is 20 to 30 minutes.

Currently, patients receive PROMs that cover a broad range of topics, which include:
- Physical Functioning
- Fatigue
- Sleep disorders
- Social isolation
- Depression
- Anxiety
- Medication (adherence to medication)
- HIV stigma
- Substance use
- PTSD (post-traumatic stress disorder)
- Residence status and sexuality
- Alcohol consumption

Most topics are sent to the patients once a year. This can differ per topic or patient, as some topics are only sent if the HCP decides they should be sent (alcohol consumption or substance use) if the patient starts a new treatment or medication (MARS), or for some PROMs the frequency they are sent is less often (PTSD).

Figure 7: How patients see the questions from the PROM, in this case the PROM for stigma.



Figure 8: How the score of the PROM is visualized

By using the Patient-Reported Outcome Measurement Information System (PROMIS), the number of PROMs can also vary. PROMIS is a National Institute of Health initiative and the item banks have been created for adult and pediatric populations progressively. Created across physical, mental, and social health by drawing from other PROMs that have been validated (Churruca et al., 2021). They are administered using Computerized Adaptive Testing (CAT) which helps present questions to patients based on previous responses thus reducing completion time or any irrelevant questions.

A drawing of the PROM about HIV stigma is shown in Figure 7 as an example. The patient has to answer several questions on the topic by filling in a four-point Likert scale. The patient has to choose one of the following answers: strongly disagree, disagree, agree, and strongly agree.

The HCP can see if a PROM has been completed and what the patient answered to each question. The HCP can also see the score of the PROM which is visualized on a chart, as seen in Figure 8. The chart indicates to the HCP if the score is "normal" or not. The patient cannot see their score unless the HCP shows it to them while discussing PROMs during a consultation. This is done, as the score might be difficult to interpret, and having an HCP present can clear any doubts.

**Implementation of PROMs in other care**

KLIK is another software that handles PROMs at Amsterdam UMC and other hospitals in the Netherlands. Their primary target group is children under the age of 18 and their parents.

When compared to EPIC, the interface of KLIK is similar. The main difference is the layout of the interface. For example, KLIK uses a wider color selection, compared to EPIC which mostly uses different shades of blue. This can be seen in Figure 9, where the results from the PROMs are visualized using traffic colors to signify if the results are in a normal range (green), slightly out of range (yellow), and out of range (red).

The main difference between KLIK and EPIC is that KLIK has an ePROfile for the patients to have an overview of their results. The ePROfile can be seen in Figure 10. The patients can see the graphs of their results and how they can change over time. The HCPs are able to see a red line on the graphs to show where the normal range falls, seen in Figure 10, however, the patients cannot see that line for similar reasons to why EPIC does not show the score to the patients (Haverman et al., 2014).

The personalization and display of KLIK were factors that increased patient and clinician interest in PROMs *"Pediatricians/ practitioners often become more enthusiastic after they have used KLIK for a while as they experience the effect of the KLIK ePROfile first hand during the consultation."* Haverman et al. (2014).

kwaliteit van leven in kaart **klik**

PROfile

## Patient profile EMMA

| Details | CHAQ | CHAQ scores | CHAQ graphs | PEDSQL | PEDSQL graph | LTO (score) | LTO (problems) | Sessions |

☑ 04-03-2011   ☑ 05-07-2011   ☐ 07-10-2011

| Physical | 04-03-2011 | 05-07-2011 |
|---|---|---|
| 1. It is hard for me to walk more than one block | Never | Never |
| 2. It is hard for me to run | Sometimes | Often |
| 3. It is hard for me to do sports activity or exercise | Almost never | Sometimes |
| 4. It is hard for me to lift something heavy | Never | Sometimes |
| 5. It is hard for me to take a bath or shower by myself | Never | Never |
| 6. It is hard for me to do chores around the house | Never | Sometimes |
| 7. I hurt or ache | Often | Often |
| 8. I have low energy | Often | Almost always |

| Emotional | 04-03-2011 | 05-07-2011 |
|---|---|---|
| 1. I feel afraid or scared | Almost never | Almost never |
| 2. I feel sad or blue | Never | Sometimes |
| 3. I feel angry | Sometimes | Often |
| 4. I have trouble sleeping | Often | Often |
| 5. I worry about what will happen to me | Almost never | Sometimes |

| Social | 04-03-2011 | 05-07-2011 |
|---|---|---|
| 1. I have trouble getting along with other kids | Never | Never |
| 2. Other kids do not want to be my friend | Never | Never |
| 3. Other kids tease me | Never | Never |
| 4. I cannot do things that other kids my age can do | Sometimes | Often |
| 5. It is hard to keep up when I play with other kids | Sometimes | Sometimes |

| School | 04-03-2011 | 05-07-2011 |
|---|---|---|
| 1. It is hard to pay attention in class | Never | Sometimes |
| 2. I forget things | Never | Never |
| 3. I have trouble keeping up with my schoolwork | Sometimes | Sometimes |
| 4. I miss school because of not feeling well | Sometimes | Often |
| 5. I miss school to go to the doctor or hospital | Sometimes | Often |

Figure 9: Results from the PROMs are visualized using traffic colors.

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kwaliteit van leven in kaart **klik**

PROfile

## Patient profile EMMA

| Details | CHAQ | CHAQ scores | CHAQ graphs | PEDSQL | PEDSQL graph | LTO (score) | LTO (problems) | Sessions |
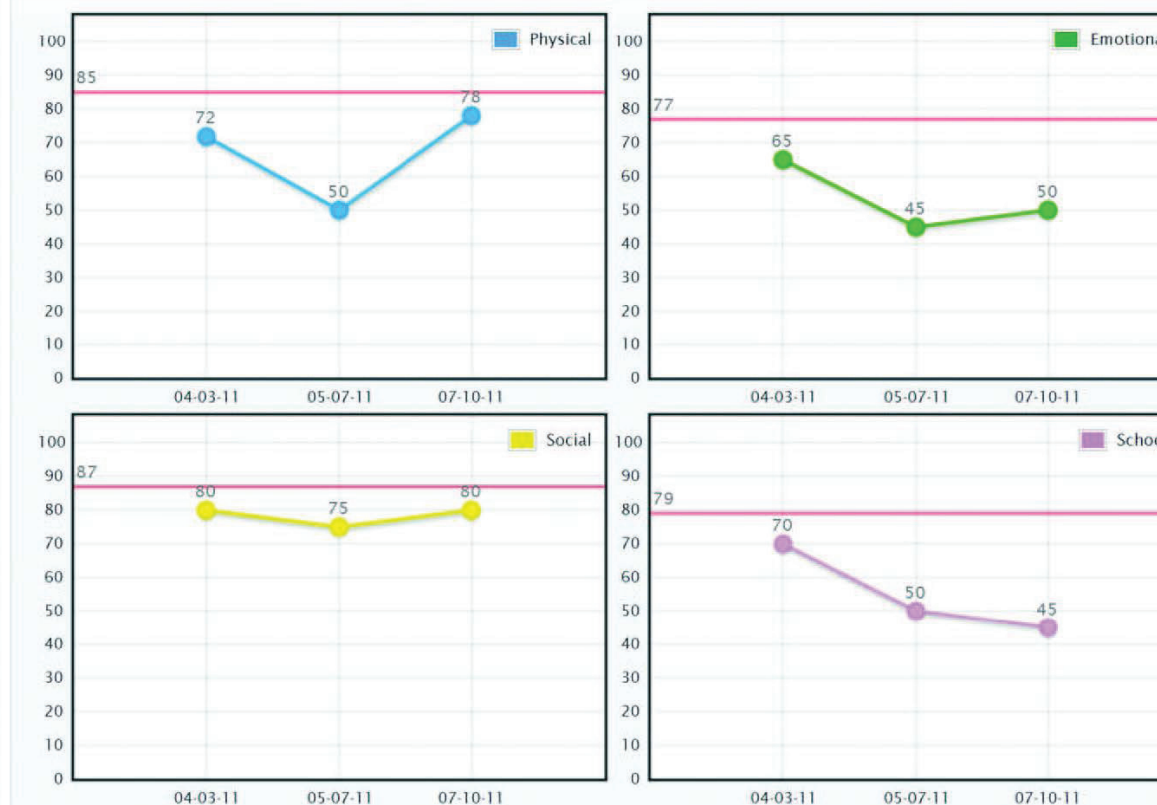


Figure 10: Graphs of their results and how the results can change over time

### 2.3.3 Current Barriers

Teela, L., et al (2020); Schepers et al. (2016); Greenhalgh et al. (2018), and Muilekom et. al. (2022) looked into the perspective of the patient on the implementation of PROMs. There were several barriers patients expressed that delayed or prevented them from filling in PROMs:

- **Purpose of PROMs is not clear:**
  Some patients felt that the purpose of PROMs was not clear, thinking that was not going to have any effect on their care. This was especially true when the healthcare provider did not discuss the PROMs during their consultation

- **Not discussed during consultations:**
  Not discussing the PROMs during their consultation, can leave the patient thinking that there was no point in filling in PROMs.

- **Lack of motivation:**
  Some patients did not see the added value PROMs could bring to care, which decreased their motivation to fill them in.

- **Lack of accesibility:**
  PROMs may not be feasible for all patients due to physical or cognitive limitations, language barriers, or lack of access to technology.

- **Confronting questions:**
  Completing PROMs felt confronting for some patients that did not want to think about their diagnosis outside appointments.

- **Lack of time and too much effort:**
  PROMs may require additional time and effort to administer.

- **Difficult, repetitive, or irrelevant:**
  Questions from PROMs were perceived as too difficult, repetitive, or irrelevant for certain patients.

Teela et. al. (2020) looked into the perspective of the HCP. The study used an online questionnaire to get the opinions of 148 HCPs on the implementation of PROMs with KLIK. With questions touching on topics such as general satisfaction, how KLIK and PROMs were used, satisfaction with PROMs and feedback on them, as well as perceived advantages and disadvantages of PROMs.

Some of the reasons given by HCPs as to why PROMs were not discussed during consultations were:
- PROMs were not completed
- No problems were found in the PROMs
- Another team member already discussed PROMs with the patient
- PROMs not being the priority
- Lack of time
- Forgetting
- Technical issues

According to the HCPs, the reasons why PROMs were not completed by a patient could be:
- Not seeing the added value of PROMs
- No motivation
- PROMs being annoying to complete
- Not having internet access
- Forgetting
- Language barrier

Although there are problems with PROMs it is still desired by the HCPs to use because, alongside other benefits, they also feel like it is a way to help empower the patients and they see this as an incentive for the patient as well, as it would involve them in their own healthcare and make it easier to request help (Teela et. al., 2020).

## 2.4    Patient-Centered Healthcare

> The Institute of Medicine defines patient-centered care (PCC) as; "Providing care that is respectful of, and responsive to, individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." (Institute of Medicine, 2001).

While this is a clear definition it does leave room for interpretation on how these are to be fulfilled. There exist different frameworks and models for defining PCC, but through a systematic review of these, some consensus does exist regarding what are definite key attributes of PCC (Shaller, 2007; Health Leads, 2019; O'Neill, 2022):
- The education and sharing of knowledge
- Information flow should be free and accessible to patients
- The involvement of friends and family
- Collaboration and team management
- Respecting the needs and preferences of the patient
- A sensitivity to spiritual and nonmedical dimensions of care

Another consensus is also found in regard to what the goal of PCC is. This goal is to empower the patient to be able to participate in their healthcare (Reynolds, 2009; O'Neill, 2022).

Greenhalgh et al. (2018) found that PROMs do not act as a neutral tool for collecting patient data, but rather causes reflection from patients about their health and permits them to raise questions with HCPs. This aligns with PCC as patients become encouraged to take a more active role in their care. Further, the paper found that individualized PROMs helped patients tell their stories, enabling dialogue between HCP and patient. This gives patients room to express needs and preferences that need to be respected by HCPs.

While the study found that it did not always seem appropriate for patients to discuss nonmedical or spiritual dimensions (health-related quality of life (HRQoL), emotional, or functional issues) with doctors (and doctors not perceiving this as being within their area of expertise), this further pushes the key attributes of PCC, namely collaboration and team management between departments and HCPs involved with the individual patients care and the care being sensitive to these dimensions. PROMs are thusly strongly positioned to assist patients in becoming more active in their own healthcare, thus empowering them.

### 2.4.1  Patient Empowerment

McAllister et al. (2012) argues that the use of PROMs is part of empowering patients. This is especially true when patients are given the possibility to track their recorded health data over time and learn from it. The paper conceptualizes empowerment as a measurable psychosocial outcome. This means that patient empowerment can change over time. So, PROMs can increase patient empowerment, even if patients are not currently empowered, as they allow patients and HCPs to collect data over time.

However, patient empowerment is complex as it has been defined differently in publications (Fumagali et al., 2014; Bravo et al., 2015), it is, therefore, necessary to get a proper definition of what patient empowerment is.

Fumagalli et al., (2014), which has also done an extensive review, of 286 articles, on more terms also defines patient empowerment. This paper defines patient empowerment in three ways. A process, an emergent state, and a behavior. They found three prerequisites for empowerment:

- **Power**
  Power refers to shared power with health care providers, so the balance of power between patient and HCP, and responsibilities for healthcare given to the patients

- **Motivation**
  Motivation refers to "a combination of attitude and self-awareness"; p 386.

- **Ability**
  Ability refers to "a combination of knowledge and skills"; p 386.

The process is the lowest level of patient empowerment as this is the process of acquiring power, motivation, and ability. The emergent state is a state of empowerment. This is when the three prerequisites have been acquired and the patient is in the state of being empowered. They share power with the HCP, they are motivated to participate in their own healthcare, and they have the ability to do so. The behavior follows the emergent state, this is the highest level of empowerment. This is when the patient has changed their behavior around their own healthcare and are fully capable of taking advantage of the care available to them and having the knowledge of what to do if their health condition changes.

Fumagalli et al., (2014) also defines that the way to increase empowerment is through patient engagement.
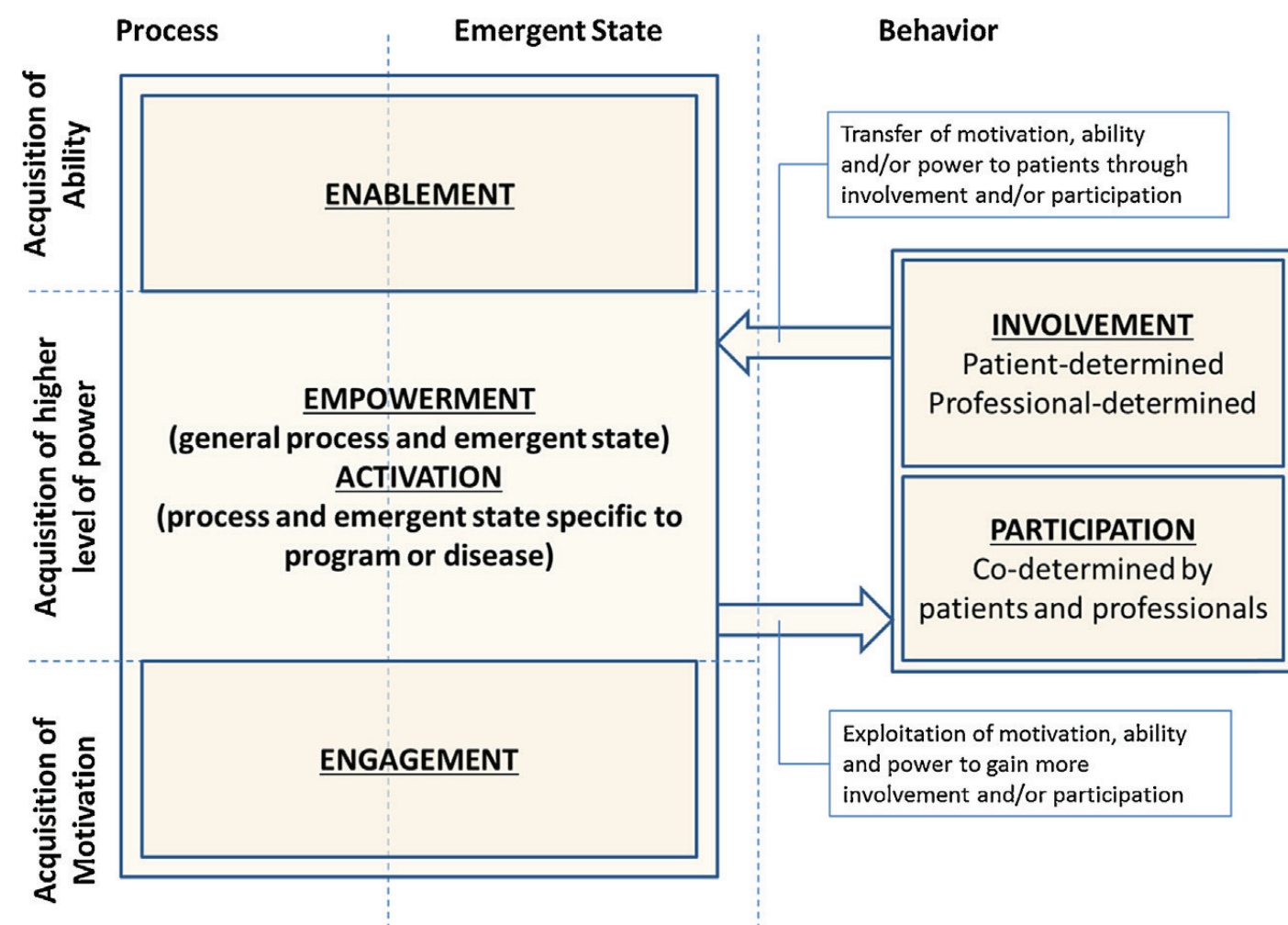


Figure 11: The unified model of patient engagement, -enablement, -empowerment and -activation by Fumagalli et al
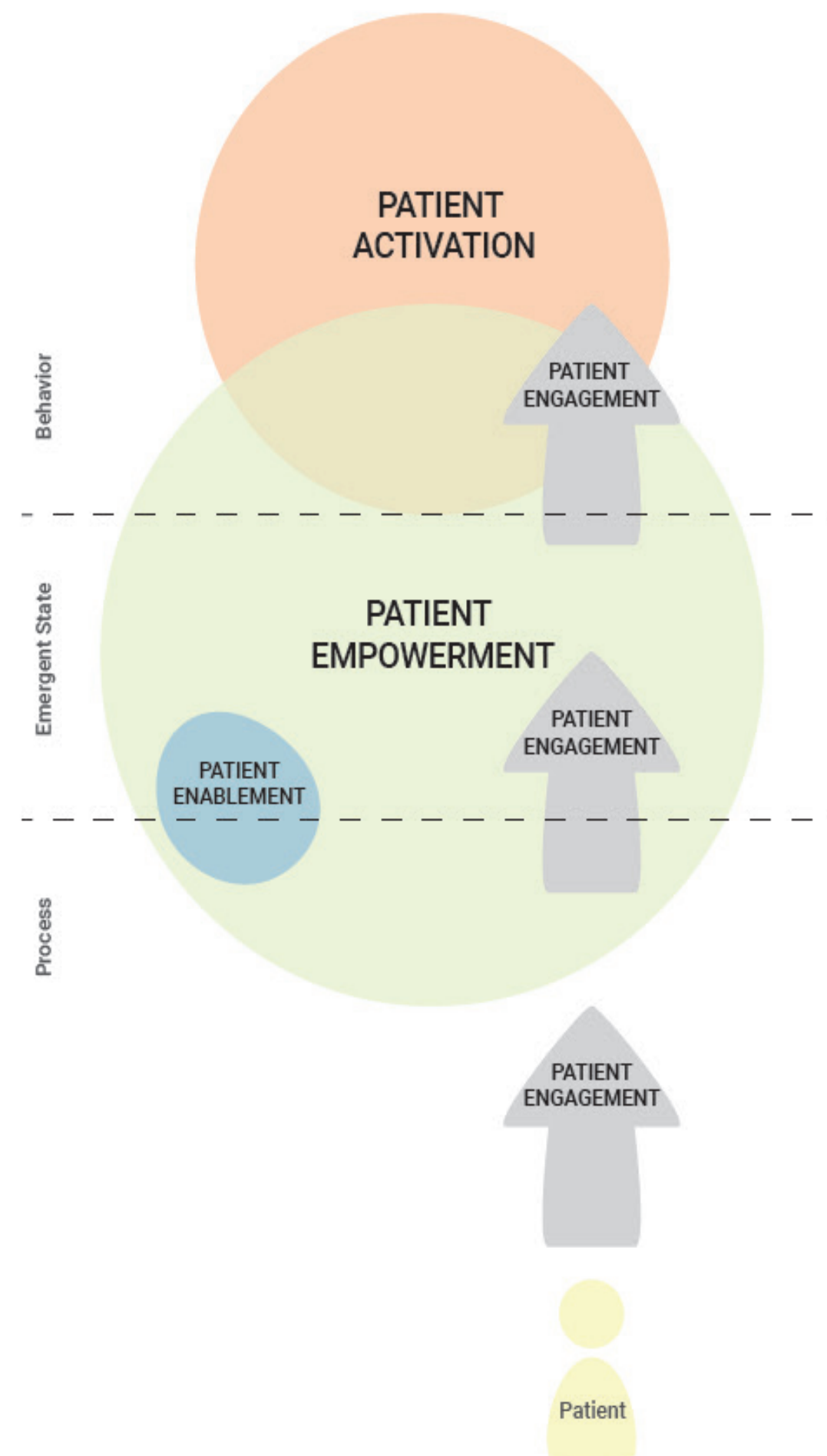


Figure 12a: Relationship between patient empowerment, engagement, activation and enablement

## 2.4.2 Patient Engagement

Research suggests that patients who are more engaged in their care have better health outcomes ("Patient Engagement," 2013). In Fumagalli et al., (2014), we see that patient engagement can both be the cause and consequence of patient empowerment, and it includes a form of participation and involvement. PROMs fit into these definitions as they can be a tool for patient engagement. Filling in PROMs could be a way for patients to participate in their own health and could lead to further involvement.

### Overlapping terminologies

The relationship between what is called patient engagement, -enablement, -empowerment, and -activation is overlapping and oftentimes wrongly synonymous, as we know from Fumagalli et al., (2014). Going by the definitions they arrive at, they create Figure 11, Figure 12a was created as a guide for the terms in this project.

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Figures 12b and 12c show the different concepts from Figure 12a in more detail.



PATIENT ENGAGEMENT

— the tool to reach patient empowerment

— the tool for turning patient empowerment into patient activation

— the tool for increasing patient empowerment

Figure 12c: Patient Engagement



PATIENT EMPOWERMENT

— Emergent state
that allows patients to have an active role in their own care

+ Ability (able)

+ Motivation (willing)

+ Power (between providers & patients)

— Process
leading to patients' acquisition of these emergent states

— Active Behaviour
through which patients participate in self-management and shared decision-making

Figure 12b: Patient Empowerment

## 2.5   Takeaways

The focus of the literature research was to clarify definitions used for this project and the context it takes place in. This is important to get a better understanding of the topic and design a suitable solution. In this section the initial RQ are adressed and key takeaways are gathered for future research and design.

- Health literacy is important for PLHIV as it enables them to effectively understand, interpret and utilize information related to their health and treatment options.

- Due to the stigmatization around HIV and the potential consequences of disclosing personal health information, the privacy of PLHIV involved with this project should be upheld as a priority.

- QoL is a multi-dimensional concept that encompasses various aspects of a person's well-being. It is essential in evaluating the impact of a disease or treatment on a person's overall life satisfaction.

- PROMs serve as a tool for enhancing patient empowerment by providing a means for patients to actively participate in their healthcare decision-making and to have their voices and experiences heard.

- The main barriers to PROMs that fall under the scope of this project are: the purpose of PROMs is unclear to patients and lack of motivation to complete them. Other barriesrs focus on accesability and content of PROMs.

- PROMs cannot be completed without an account on MyChart and interacting with the patient portal. This should be taken into consideration for the future design.

- Through a synthesized literature review we defined patient engagement as a key factor in promoting patient empowerment, as it involves involving patients in their own healthcare processes and empowering them to take an active role in their care.

**Initial RQ**

2. What HIV related factors affect PLHIVs QoL?

1. What is HIV and how does it link to QoL?

3. What are PROMs and what is the value of PROMs?

4. What are current barriers patients encounter regarding PROMs?

6. How does MyChart affect the implementation of PROMs?

7. What is patient involvement in care and how are patients getting involved in their care?
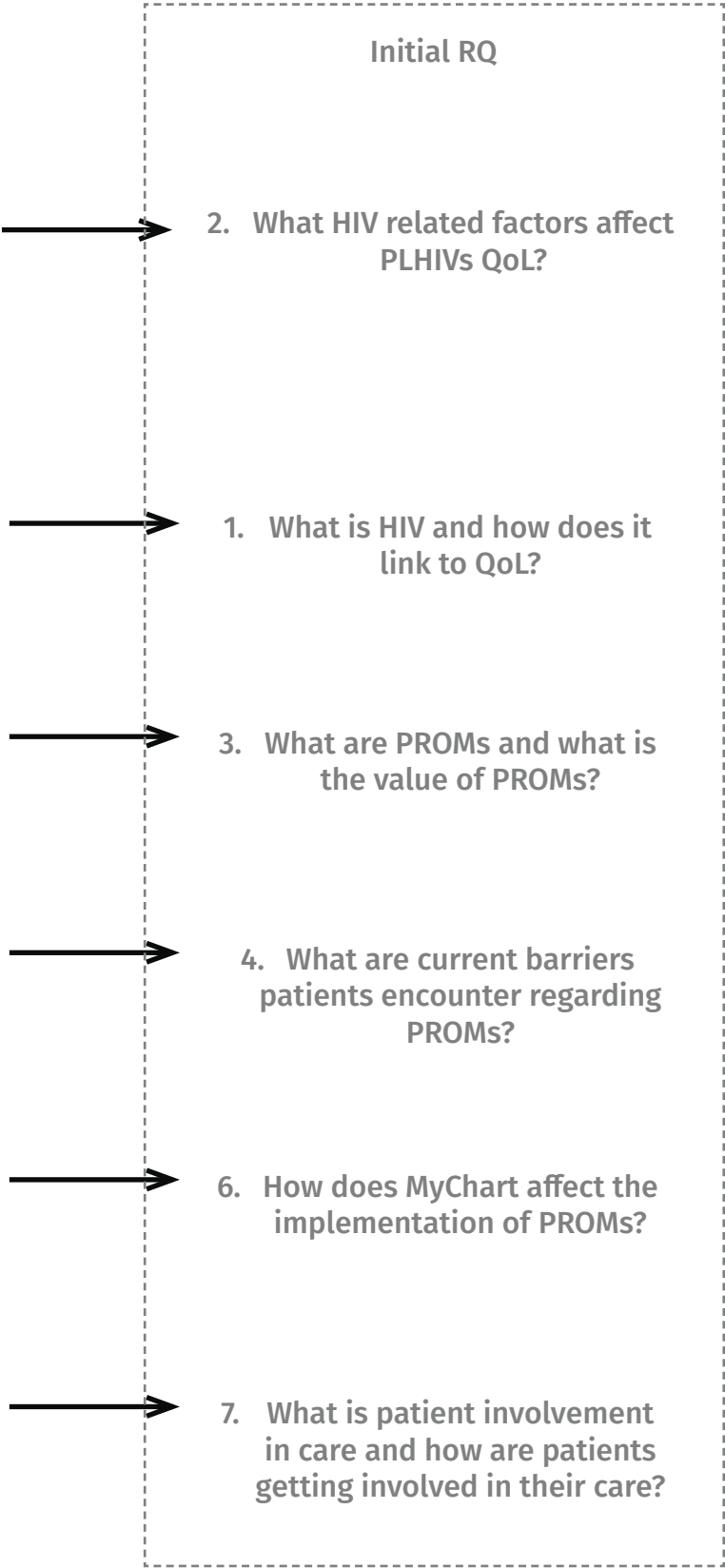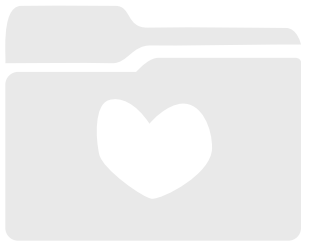
**Chapter 3**

# USER RESEARCH

This chapter aims to present the research conducted to gain insights from the patients and nurses at the outpatient clinic. These insights were gained using qualitative methods including observations and interviews. The chapter concludes by bringing all the results of the user research together to shape personas and a journey map.

## 3.1 Introduction

The purpose of this chapter is to explore the user context in-depth and gain a better understanding of the needs, motivations, and behaviors of the target group. To accomplish this a combination of shadowing HCPs and qualitative interviews were conducted, with the use of provotypes to further stimulate discussion and gather feedback. These research methods allowed for in-depth data to be gathered and analyzed, leading to the creation of personas and a journey map. The personas provide a comprehensive and human-centered representation of the target group, while the journey map offers a visual representation of their experiences, emotions, and touchpoints throughout their interactions. This user context exploration provides a foundation for informed design decisions and helps ensure that the solution meets the needs of the target group.

## 3.2 Initial field study

From previous research (reference Sharda's project) the different health deaprtemnts with different populations of patients have different contexts. In order to get familiar with the context at the outpatient clinic for PLHIV at at Amsterdam UMC, location AMC, an initail context study was conducted.

Immersion and understanding of context important before starting any design work. Getting understanding of how outpatient clinic works prior to PROMs important to understand general context of HCP and Patient relations, exploring opporetunities for design, and finding attitudes and challenges/obstacles for a new tool in that context. + User centred design approach so we must understand the context of the user and the interactions with HCP, MyChart, and the clinic.

## 3.2.1 Aim

To gain a better understanding of the context at the outpatient clinic, an initial field study was conducted. In this study nurses at the outpatient clinic would be shadowed during consultations with patients. The aim of which is to get familiar with the interactions between patients and nurses. Through this shadowing, insights were gained about the topics nurses and patients typically discuss during a consultation. The study sought to gain a general understanding of the patient experience at the outpatient clinic.

In line with this, the following themes were made to guide the study, as these themes can give an insight into the type of patient observed in the consultation:

> 1. **Current patient involvement in their care**
>    Includes the following sub-themes:
>    - *What patients want to discuss with their HCP*
>    - *What HCPs want patients to discuss during their consultation*
>
> 2. **Interactions between patients and HCPs**

Even with these themes in mind, it was important to stay open to impressions and observations during the studies, so as to avoid a cognitive bias.

## 3.2.2 Method

**Observation Study**

An observation study was used, which is a qualitative method used to study a target group in a specific context, with minimal intervention from the observer. (Muratovski, 2022)

The study happened over three weeks. During this time five consultations of 20 minutes each were observed. These consultations followed five patients during their regular appointment with their nurses. No questions were asked during the appointments to minimize observer intervention. However, in between appointments, the nurses were able to answer any clarifying questions or informal questions related to the themes of the study.

The setup of the study can be seen in Figure 13. It shows the observer taking notes, while the nurse and the patient have their usual appointment. While the observer is in the room and can observe the interaction between the nurse and patient, they are not participating in the interaction. No audio recording was taken, as the medical information discussed was not relevant to the study.

**Participants**

The nurses at the outpatient clinic are trained HIV consultants. During the study, three nurses were shadowed and five regular consultations were observed. The five patients are non-native to the Netherlands and therefore have a preference for English being used in their consultations. To ensure the privacy of the patients, no identifying information was recorded. Further, this information was irrelevant to this study.

**Analysis**

The notes from the observation study and informal interviews with the nurses were used for this analysis. Through mind-mapping and clustering of information, recurring themes were found. The themes found were used to better understand the context and find key takeaways. Those takeaways were used to inform following user research and the design process.
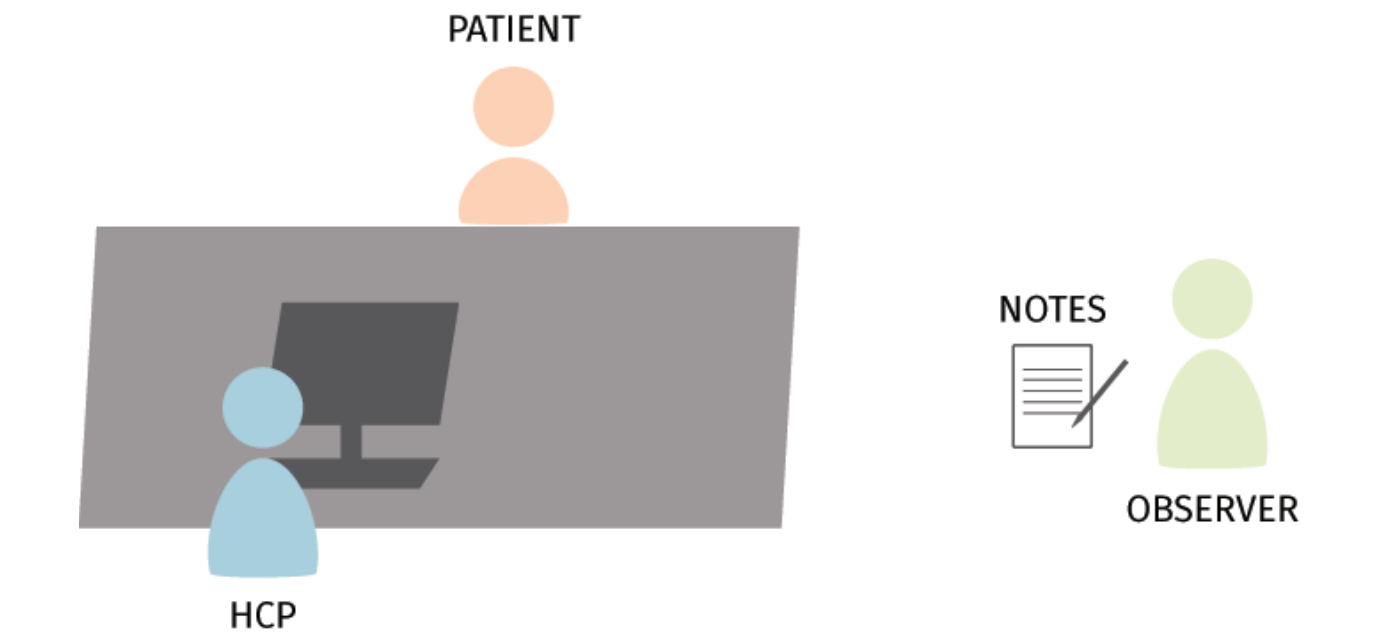


Figure 13: Observation study setup

## 3.2.5 Insights

### Theme 1: Patient involvement in their own health and the influence on the consultation

During consultations, patients portrayed various levels of involvement in the discussion with their HCP.
While most of them showed a similar level of answering questions not directly related to their health (e.g. about work or children), they displayed different engagement in regard to questions about their health (e.g. questions about medication). This can have many reasons, from patients having reflected on these questions before or being prepared for the consultation, or not really crossing their mind outside appointments. At the same time, different factors like their mood can have an influence. When asked the nurses referred to the different types of patients and how involved in their health they are.

For example, P4 showed involvement in their health by coming prepared to the appointment with questions about their health. The questions were related to their travel plans, specifically traveling while taking medication. The nurse also asked related questions:

*"Will you take enough medication with you?"* and *"Have you traveled with medication before?"*

P4 said that they thought of a plan to take 7 with them and 7 in the big luggage in case anything happens to either. Even with this information the nurse further investigated the patients' needs regarding medication by asking:

*"Maybe you should make more provisions?"* and *"I can also write you a letter for your medication, to make sure you can take it with you."*

P4 was engaged in the conversation and was asking questions in return. P4 also asked questions related to how the medication can be influenced by various health supplements as the patient works out often. Even though the nurse referred to them as an on top of everything kind of patient.

One patient showed previous reflection on their health. After being asked by the nurse if there was anything they would like to discuss, the P1 brought up wanting to see a psychologist. When the nurse asked about the reason, the patient went into detail about their thoughts.

Those patients that appeared knowledgeable about their health, had MyChart and discussed related topics with the HCP. Both P1 and P4 showed that they are using MyChart by mentioning lab results from the app or talking about how to contact the HCP through the app.

*"I am sure I will not, I am undetectable."*

Other patients, like P2, needed more encouragement from the HCP to answer questions or would often be unsure of how to answer health questions.

### Theme 2: Medication as a main topic during consultations

The topic of medication was brought up by the HCP in every consultation in the study. Medication is part of a patient's everyday life and how they take it is very important to manage the disease. Therefore, HCPs have to learn to navigate conversations to make sure the patients are taking them in the right way. For the medication to be effective it needs to be taken within 1h at the same time every day. Other medications require taking multiple a day.

*"I am very strict with patients."*

PROMs could alleviate some of the nurse's workload when it comes to finding out how to get the right information from the patient.

The nurse expressed that it is important to use a showcase that displays the different types of medication prescribed for HIV and have it on the table so the patients can understand the size and can express any concerns at the appointment. The nurse recalled some patients that got deterred by the size of the pill and stopped taking the medication without addressing it to an HCP. Having a visual display helps the patient in the conversation.

P2 switched medication about a month ago. It is important to check in with the patients after such a change and show them the showcase as a nurse explained:

*"So they are not alone and get shocked at how big it is, how and when to take it…"*

For P3 the nurse noted that their viral load was rising, even though now is better. To better understand the situation, the nurse asked some questions about medication. The nurse explained to P3 other patients train of thought on medication where they say:

*"I feel better so I don't have to take it anymore"*

P3 said they were very persistent on taking it, saying

*"It is like a vitamin now, I always take it"*

They even adjusted for when they traveled, taking the medication at 3 because in The Netherlands it was 8. The nurse asked less questions about medication after.

## Theme 3: Disordered Introduction to MyChart

The nurses introduced two of the patients to MyChart during their consultation, even though they expressed that was not part of their role. They feel they should, but a lot of patients do not have it.
When asked why they think a lot of patients do not have it, they thought that privacy is one of the main reasons patients do not get MyChart.

The nurse introduced P3 to MyChart. This was the first time the patient learned about the application in the three years they have been coming to the clinic. Despite not having been introduced to MyChart before, P3 was digitally inclined and without any assistance was able to find and install MyChart.

The nurses think only 50% of patients have MyChart and that less than that will use PROMs. When asked why, they said:

*"MyChart might feel like it is easy to hack compared to WhatsApp".*

## Theme 4: Role of the nurse

It can already be noticed in previous themes that the nurse is very involved in the consultations, even when the patient comes prepared. Nurses have knowledge about various topics outside the diagnosis, such as insurance, mental health, or traveling with medication. Additionally, they perform various tasks such as intaking data they need for the medical file, printing/sending files, introducing patients to MyChart, and supporting them with questions. A lot of departments are in contact with the HIV clinic (e.g. psychology), so if a patient has any issues they cannot resolve at the clinic, a nurse can refer the patient to a different department. When P1 asked about seeing a psychologist, the nurse informed them that if what they want to discuss with the psychologist is

HIV related, there are psychologists working with the outpatient clinic. Even though their main questions for the nurse were regarding insurance, the nurse was able to answer that.

The nurses are encouraging patients. When P5 expressed feeling surprised at their viral load being too low the nurse used words of encouragement and providing them with a positive outlook for the future.

"Now you take the right medication and you do it well! Continue!", and "It will rise over time if you continue like this."

P5 expressed gratitude:

"Thank you (name of nurse)!", and "I pray and hope so."

When P1 brought up their mental health, the nurse encouraged it by saying:

"Good that you mention it yourself"

What the nurses expressed is the most important in their role is knowing how to ask the right questions. The nurse asked P2 which medication they switched to, then proceeded to ask questions about how the patient is adjusting to the medication and about the intake (e.g. what time they take it and if they eat something with it). To make sure the patient knows what to refer to, the nurse used the showcase. The nurse also explained to the patient why they are asking these questions, as it can affect how effective it is in the end. The patient answered all these inquiries with short yes or no answers. The nurse asked again about which medication P2 switched to, to avoid any misunderstanding.

To get an elaboration on the patient answers, the nurse made small talk about work and inquired about their schedule and if it aligns with P2 taking the medication. The nurse explained after the appointment that this question is important to Figure out how they can help guide the patients regarding medication.

"Do you work?"

## Theme 5: Connection with HCP

The nurses explained that when it is about HIV it is hard to ask for help. Often patients do not share their status with their family or partners. They are afraid people will not want to have contact with them anymore or that they start to talk behind their backs. The nurse recalled different stories that exemplify that, for example, a patient being thrown out of the house with their kids or a patient being ostracized by their community after finding out about their diagnosis. This led to the nurses expressing how privacy is very important to PWHIV and that they think it will be a big deterrent from PROMs.
Due to this, some patients can see the HCPs as the only people they can talk about their diagnosis. The nurse expressed that is why they try to create a space where the patients know they can talk about a lot of subjects during their consultation. Small talk like can help find out more about their situation, such as:

"How are the children?", "How is work?"

When discussing how patients bring things up during the appointments the nurses said

"Every person is different, and I want to make them feel comfortable" and "I need to build trust between us."

This bond with the nurse could be seen throughout the consultations. For example P1 recently moved to another city permanently. The nurse asked them if they would like to move their care to that city, but the patient said:

"I would like to stay here".

One of the nurses was retiring after the study, which prompted reactions from the patients that further emphasized the bond. P3 wished the best of luck for the retiring nurse, even joking that "I am jealous". When they left the patient gave the nurse a hug. P4 told the retiring nurse that they will miss them.

"We will miss you."

When talking about medication, the nurse encouraged P5 to continue using it while showing their support.

"We are a team, if one does not work well the entire team suffers"

The nurse emphasized later how they want patients to feel like they belong and they supported in their care.

"You are one of the team members - we tell them"

## Theme 6: A lot of effort in the no-shows

The nurses experience a lot of no-shows. They think it is easy for patients as they will get another appointment. Some patients may feel confronted by this part of their lives, some oversleep. Some cannot afford public transport. For some their job or lifestyle can deter them from certain times: "If they are a sex worker 8am will not work for them".

To make sure the patients can make it to the next appointment, the nurse went through the different times with P3 and P4 until they found one that fit. "If you see in November that you cannot come, please let us know and we can change it". The patient felt comfortable to tell the nurse "I am not a morning person".

The nurses make sure the patients understand the information given to them and know how to contact them. For P3 the nurse asked if it is fine that the letter is in Dutch, even though they do not understand it. The patient said yes, to which the nurse explained that it is because the partner is Dutch. After that the nurse asked, "Do you know how to get in contact with us?" and the patient affirmed that they have the number.

Even patients that nurses think are involved in their health can accidentally miss appoints. P1 was a no-show for their previous appointment because they were on holiday. One of the first thing they did when they were back was to check when their next appointment is and that is when they realized they missed it.

## Theme 7: Privacy is very important due to stigma

Stigma can affect multiple areas in patients' lives and the nurses are trying to create a safe environment for the patient to be open about what could affect their health or general well being

P1 brought up their struggle with opening up about their HIV status to friends and family, but also how that affects them having a relationship. They expressed that they would want a relationship, but it is difficult. When the nurse asked them if they were afraid to pass it on, the patient said "I am pretty sure I will not, I am undetectable. But they still do not want to get involved". This has caused feelings of worry as they want to be upfront with people, but in their past experienced the other person disappeared because of it. "I want to be honest, I feel more comfortable with someone with the same situation, so we can support each other". To add to that, P1 recalled knowing someone who kept their HIV status a secret until marriage, which caused the couple to divorce. They also mentioned two friends that are HIV positive, and they do not want to be in a relationship anymore, because of their HIV status. They said that they gave up.

To encourage P1, when they express their worries about finding a relationship, the nurse mentions that she knows people that are HIV-positive and are in happy relationships. The nurse also brings up other options such as organizations for people with HIV where they can have contact with each other, with people that go through the same thing. P1 expressed interest in the idea, so the nurse said that they can talk about it more with another nurse that knows more about this.

When the topic of sharing the blood test results came up, the nurse went through different ways they could contact P1 and made sure P1 knows how to contact them. To nurse explained that they are reluctant to leave voicemails as they do not know who can listen to them, assuring the patient that they have their privacy in mind.

## Theme 8: Access to technology

There are many reasons patients might not have access to technology. The nurses expressed that some patients, mostly women might not be digitally inclined. For some patients, the nurses write down if they phoned or left a voice mail in case the patient cannot find it.

The nurses acknowledge that if the patient has little income or no job it can be harder to access technology. The nurses mentioned that some patients might not have phones or computers. Some do not like it and some cannot have it. There is a difference if you are undocumented and/or moving from one place to another.

## Theme 9: Potential of PROMs

Nurses think PROMs have the potential to detect problems sooner, however, the privacy concern might be a big deterrent. P1 mentioned that they wanted to bring up mental health sooner. This gave the nurse an opportunity to mention PROMs, and how these questionnaires can detect these issues sooner. At the end of the consultation the nurse mentioned that if PROMs were already out, this would have been brought to her attention sooner, especially because they believe the patient would be active on PROMs: "He is young and digitally inclined".

The nurses in the study think only 50% of patients have MyChart and that less than that will use PROMs. Additionally, they do not think PROMs will help with no-shows.

## 3.2.6 Takeaways

**Different patient involvement**
Patients engage differently with their care. E.g. Some do independent research, some interact a lot during consultations, some do exactly as the nurse tells them, and some do nothing at all. There is a lot of variation between patients.

**Nurses tailor care based on patient**
Nurses are aware that each patient engages differently. As such, they adjust how they interact with each patient. These adjustments help to inform patients or discuss how their care is going.

**Unique bond between patient and nurse**
Patients and nurses at the HIV outpatient clinic have a unique bond that is built over time by creating a feeling of belonging and trust

**Privacy is a priority at the outpatient clinic**
At the HIV outpatient clinic privacy is prioritized. Due to the stigma involved with HIV, patients prioritize their privacy and HCPs are very conscious of this.

**Diverse patient population**
The outpatient clinic has a wide population of patients, which also means the patients' circumstances are very different. The patients have different levels of health literacy, different relationships with health, and in particular different cultures when it comes to HIV.

**Different capabilities for access**
A large portion of the patients do not have access to technology, I.e. no laptops or phones. This limits their access to PROMs. Additionally, a lot of patients do not speak Dutch, but MyChart is only available in Dutch.

To summarize the findings based on the themes of the observation study followed table 1 was created. Additionally, the table relates the participants to the types of patients observed by the client. This was based on their interaction during consultation and observations from the nurses.

| Participant code | Involvement in their health | What patients want to discus | What HCPs want to discuss | Interaction between patient and HCP | Type of patient |
|---|---|---|---|---|---|
| PO1 | Asking a lot of questions and being curious about what the HCP says | Their mental health and insurance, personal topics | How does it relate to HIV | Close relationship, where the patient feels they can bring up various intimate topics | On top of everything |
| PO2 | Silent most of the time | Did not bring up anything themselves | Medication and if the patient is taking it properly | Professional | Not interested |
| PO3 | Asking the HCP because they do not have time at home | Lab results | Medication and if the patient is taking it properly | Close relationship, hug at the end of the consultation | Too busy |
| PO4 | Came prepared with questions about travel, interested in other health activities too | Travelling with medication, health supplements | What to take into account when travelling with medication | Close relationship, joking throughout the appointment | On top of everything |
| PO5 | Interested in what the HCP says | What the HCP wants to talk about | Medication and if the patient is taking it properly | Close relationship, gifted the HCP a happy retirement card | Tell me what to do |

Table 1: Overview of participants from the observation study in relation to the themes established at the beginning of the study.

## 3.3 Qualitative Interviews

In the previous section, an observation study was performed in order to get familiarized with the context of the outpatient clinic. In this section, the focus will be on the target group. It was important to get a more in-depth understanding of their needs and values in relation to PROMs in order to design a suitable solution. The activities performed in this section took place after PROMs started being introduced to the patients.

To explore the needs of the target group and generate open discussion a qualitative interview was planned. At the center of those interviews were provotypes, used as a tool to spark discussion and explore possible interactions with PROMs.

### 3.3.1 Aim

The goal of the project is to develop a design intervention that increases patient engagement with PROMs, which means that the current behavior and attitudes regarding PROMs must be explored and understood. Additionally, since patients would not be able to engage with PROMs without engaging with MyChart, their current behavior and attitudes regarding MyChart must be taken into consideration as well. The aim of the qualitative interviews is to get a better understanding of this and identify the target group's needs and values to create design criteria. Based on this the following research questions and sub-questions will be addressed:

> **RQ1: What is current patient behavior regarding PROMs and what are perceived consequences?**
>
> a. What are patient attitudes toward PROMs?
>    i. What is the perceived impact on patient care caused by the introduction of PROMs?
> b. What motivates patients to interact with PROMs?
> c. What are current barriers to patient interaction with PROMs?
> d. What type of guidance do patients need when interacting with PROMs?
> e. What is the current patient behavior regarding their privacy and how does it affect their interaction with PROMs?
> f. What is the current patient digital literacy and how does it affect their interaction with PROMs?
> g. How has the introduction of PROMs affected the interactions between the patient and HCPs?
> h. How do PROMs affect patient engagement during the consults?
>
> **RQ2: What is current patient behavior regarding MyChart and what are perceived consequences?**
>
> a. What are patient attitudes toward MyChart?
> b. What motivates patients to interact with MyChart?
> c. What are current barriers to patient interaction with MyChart?
> d. What type of guidance do patients need when interacting with MyChart?
> e. What is the current patient behavior regarding their privacy and how does it affect their interaction with MyChart?
> f. What is the current patient digital literacy and how does it affect their interaction with MyChart?

### 3.3.2 Methods

**Recruiting patients**

This study was done with the target group, which consists of PLHIV that are under care at the HIV outpatient clinic at Amsterdam UMC, location AMC.

As previously discussed in literature research and initial field study, this is a vulnerable target group. Therefore, recruiting them to participate in this study should be handled with care.

Before the study, a request for an ethical approval was made at the 'Medical Ethical Research Committee' of the Amsterdam UMC. An information letter and consent were carefully made by the researcher and the supervisory team from Amsterdam UMC that were sent with the application. The information letter and consent form can be found in Appendix 7. After the application was approved the recruitment process could start.

For the privacy concerned, the target group were not approached through public spaces, including the living room or any public platform. Mostly, recruitment was done with the help of nurses. Nurses asked patients that came to the clinic for their usual appointment, if they are willing and have time after to participate in this study. Additionally, patients that participated in the previous pilot study done at the clinic and expressed interest in future research were reached through email.

A total of seven patients were recruited through this method. An informal interview hap-pened with one participant who could not read as they could not follow the provotypes. The overview of the patients that participated in the interview can be seen in table 2.

**Recruiting nurses**

The observation study showed nurses have a close relationship with patients when it comes to HIV care. This shows that nurses at the HIV outpatient clinic can have unique insights into the different types of patients at the clinic. Because this project focuses on a broad target group, and due to the short time frame of this project, it can be difficult to interview a sample of patients that represents the patient population. However, the nurses could provide a holistic view of the matter. This is especially true regarding patients who might be less engaged in their own health and therefore are less likely to participate in this kind of research.

The nurses were reached through email and were sent the same information letter as the patients. As a result, four nurses from the HIV outpatient clinic were interviewed for this study. The overview of the nurse participants can be seen in table 3.

| Code | Gender | Age | Background | PROMs | Type of patient | Notes |
|---|---|---|---|---|---|---|
| P1 | Male | 68 | Dutch | Heard of and completed PROMs before the interview | On top of everything | |
| P2 | Male | 25 | Dutch | Heard of and completed PROMs before the interview | On top of everything | |
| P3 | Male | 35 | Dutch | Heard of and completed PROMs before the interview | On top of everything | |
| P4 | Male | 31 | Dutch and Surinamese | Heard of and completed PROMs before the interview | On top of everything/Too busy | |
| P5 | Male | 52 | Ghana | Did not hear of or complete PROMs before the interview | Tell me what to do | |
| P6 | Female | 42 | Taiwanese | Did not hear of or complete PROMs before the interview | Too busy | Interviewed with her husband |
| P7 | Female | 52 | Ghana | Did not hear of or complete PROMs before the interview | Tell me what to do | Language barriers (cannot write or read in any language) |

Table 2: Overview of patients participating in the interview study.

| Code | Gender | Background | PROMs | Years at the clinic |
|---|---|---|---|---|
| N1 | Female | Dutch | Received training in PROMs | 24 years (retiring) |
| N2 | Female | Dutch | Received training in PROMs and trained other nurses | 1 year |
| N3 | Male | Dutch | Received training in PROMs | 20 years |
| N4 | Female | Dutch | Received training in PROMs | 6 years |

Table 3: Overview of nurses participating in the interview study.



What challanges have **patients** brought up regarding PROMs?

Add your answers in the empty space below. You can do that by using post-it notes or writing it directly on the empty space. Add as many answers as you want!

What do **you** think are the main challenges patients might experience with PROMs?

Add your answers in the empty space below. You can do that by using post-it notes or writing it directly on the empty space. Add as many answers as you want!

Is there anything you would like patients to discuss more?

Add your answers in the empty space below. You can do that using post-it notes or writing it directly on the empty space. Add as many answers as you want!

Figure 14: Worksheets for the nurse interviews

**Semi-structured interview**

A semi-structured interview is a qualitative research method that involves a pre-determined set of questions or topics to make sure similar questions are addressed throughout the interviews. However, unlike a structured interview, a semi-structured one is more open and has the freedom to explore any interesting topics that might come up more in-depth (Patton, 2002).

The interviews for the patients were accompanied by provotypes in order to involve the target group in the design process. The structure of the interview with the provotypes can be seen in Figure 16 and the setup of the interview can be seen in Figures 17a and 17b. The interviews were audio recorded on two separate devices and the interviewer took notes.

The interviews for the nurses consisted of two single interviews and one double interview. As the delivery of the interviews might vary due to the different number of participants, to make the data collection more reliable the interview questions and exercises stayed the same. The setup of the single interview can be seen in Figure 18 and the setup of the double interview can be seen in Figure 19.

**Interview Guides**

The themes and questions of the interviews have been formulated based on the research question introduced at the beginning of this study. The interviews for the patients were accompanied by provotypes in order to involve the target group in the design process. The structure of the interview for patients with the provotypes can be seen in Figure 21. The full interview guide for the patients can be found in Appendix 3.

The interviews for the nurses included worksheets to help generate more ideas and for the double interview to build off each other's ideas.

Those worksheets focused on questions from the interview and can be seen in Figure 14. The interview followed the themes listed below and the interview guide can be found in Appendix 4.
- Part 1: Introduction
- Part 2: Questions about the relationship between nurses and patients
- Part 3: Questions about patient involvement in their own healthcare
- Part 4: Questions about PROMs
- Part 5: Questions about MyChart

**Pilot Test**

Before conducting the interview, both interview guides went through a pilot study to test if they made sense and if it has a good flow.

**Provotypes**

Provotypes were added to patient interviews to involve them in design by engaging them to explore new directions and imagine possible scenarios.

Provotypes are "provocative prototypes" introduced in the early exploratory phases of a project, as seen in Figure 15. They are used to provoke a reaction from the target group. By creating artifacts that can be picked apart and manipulated, the target group can be included in the design process from the early stages of the project. (Haverinen, 2018).
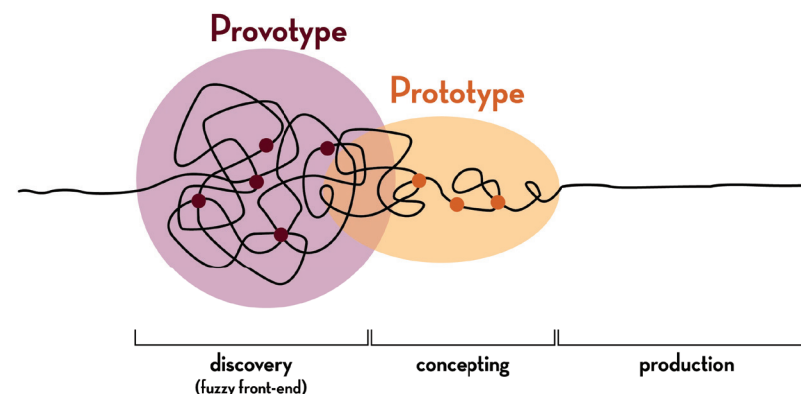


Figure 15: Design process with provotypes
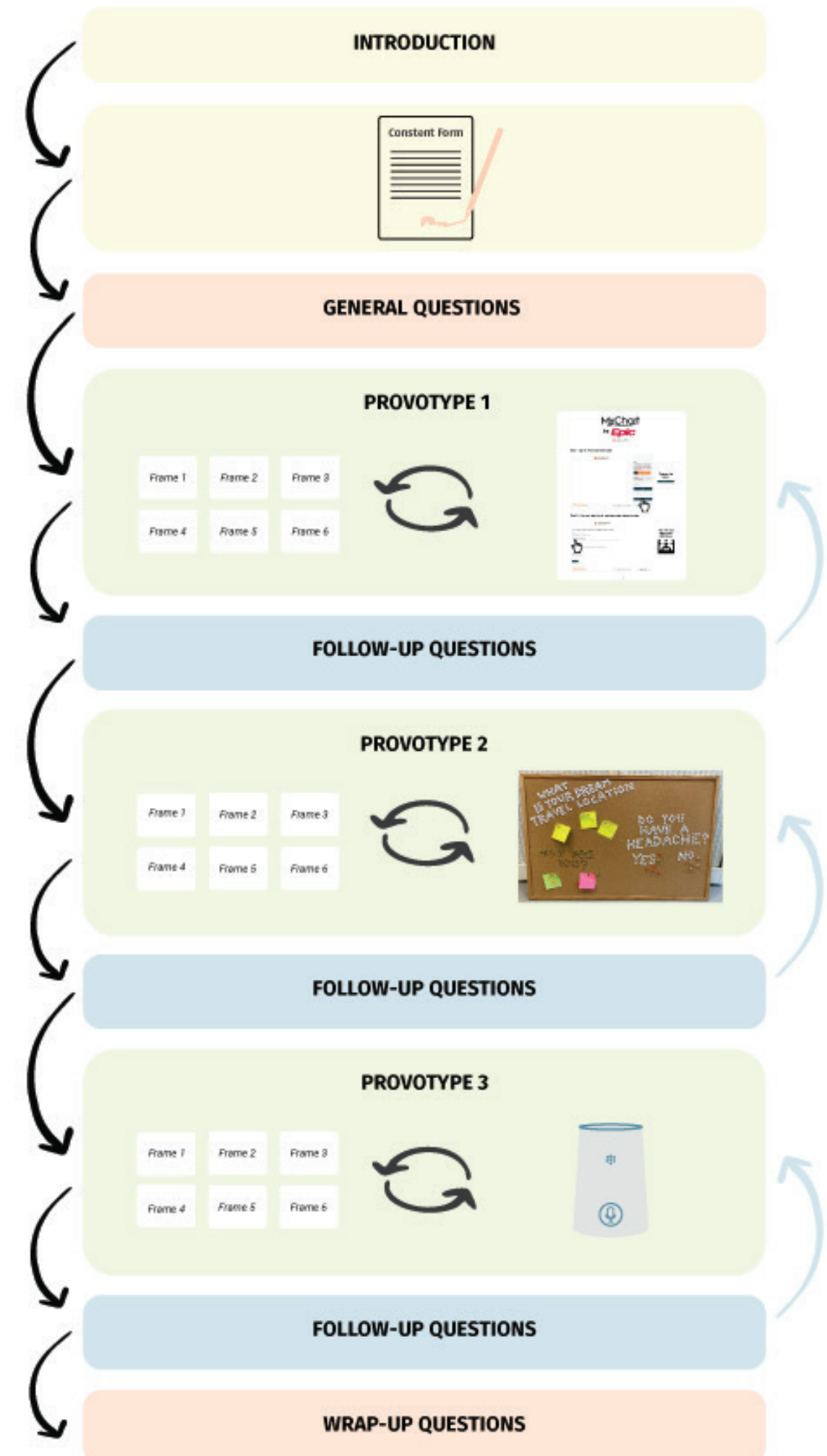


Figure 16 Interview Structure
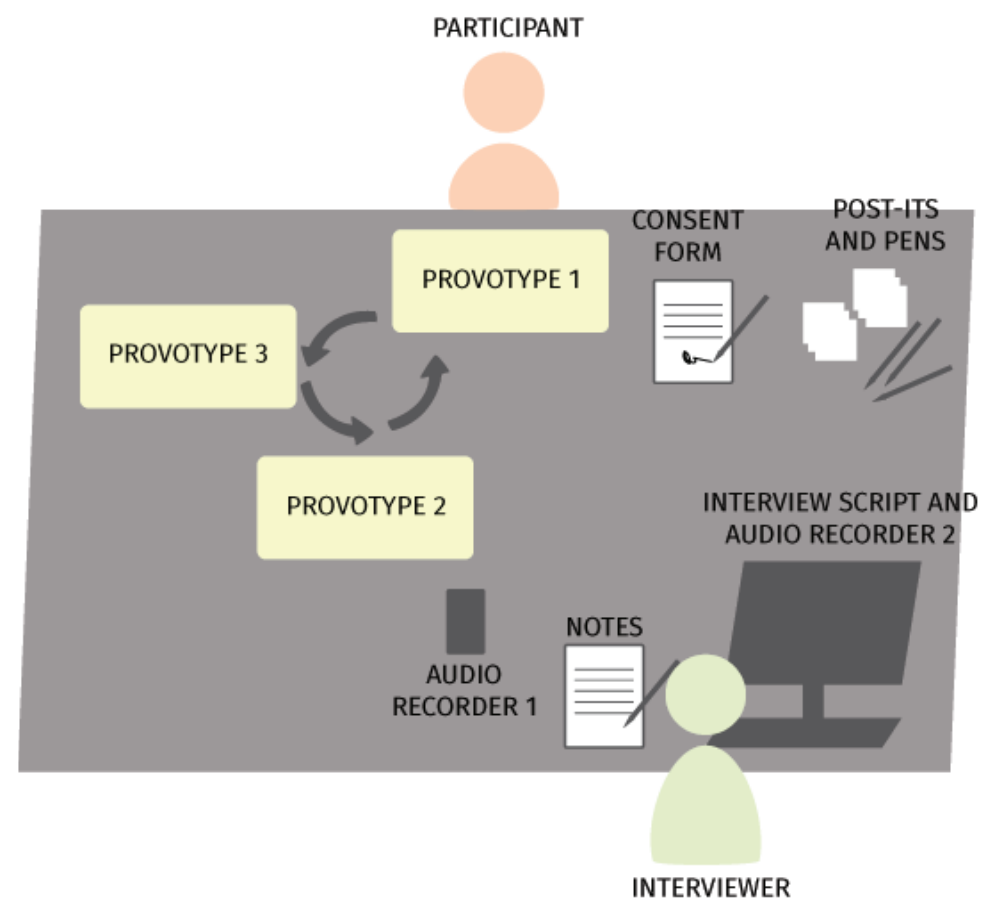
Figure 17a: Interview setup for patients



Figure 17b: Interview setup for the patients at the clicnic



Figure 18: Interview setup for nurses
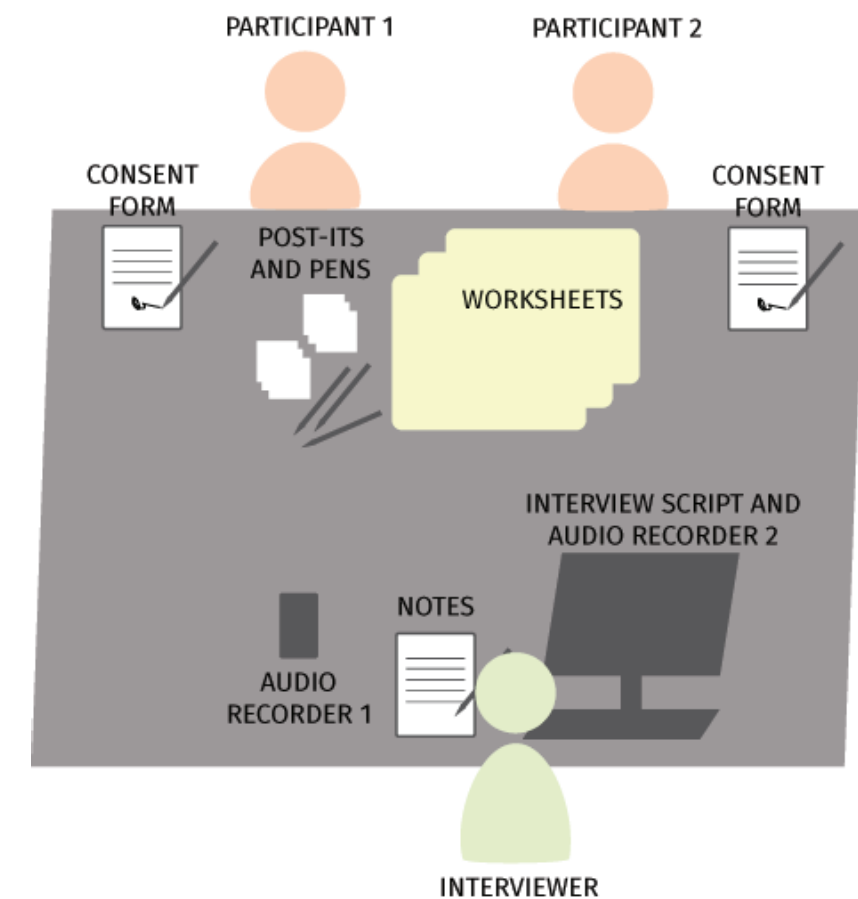


Figure 19: Interview setup for the double interview with nurses

**Provotypes used in the interview**

Three provotypes were created for the interviews with the patients. Their purpose was to start a discussion with the target group and inspire the design process. Each provotype has a scenario that illustrates the patient interacting with a future solution that is engaging them to interact with PROMs. With each scenario, the provotypes were accompanied by a prompt to help the participant immerse in the scenario. The full scenarios can be seen in appendix 5 in both English and Dutch.

Provotype 1: Waiting Room Guide

With this provotype the participant was presented with the first page of a visual guide, as seen in Figure 20, that takes them step by step through the process of creating a MyChart account, followed by how to find and complete PROMs. In the scenario, that can be seen in Figure 21, the patient is greeted by a nurse and given the visual guide. Afterward, the nurse leads the patient to a stationary computer in the waiting room where they can follow the guide.

This idea originated from talks with the client where they were thinking of providing patients with a way to do PROMs in the waiting room. By showing this scenario to the patients, it is possible to learn what are their boundaries regarding privacy but also start a discussion on how they would like to receive guidance.
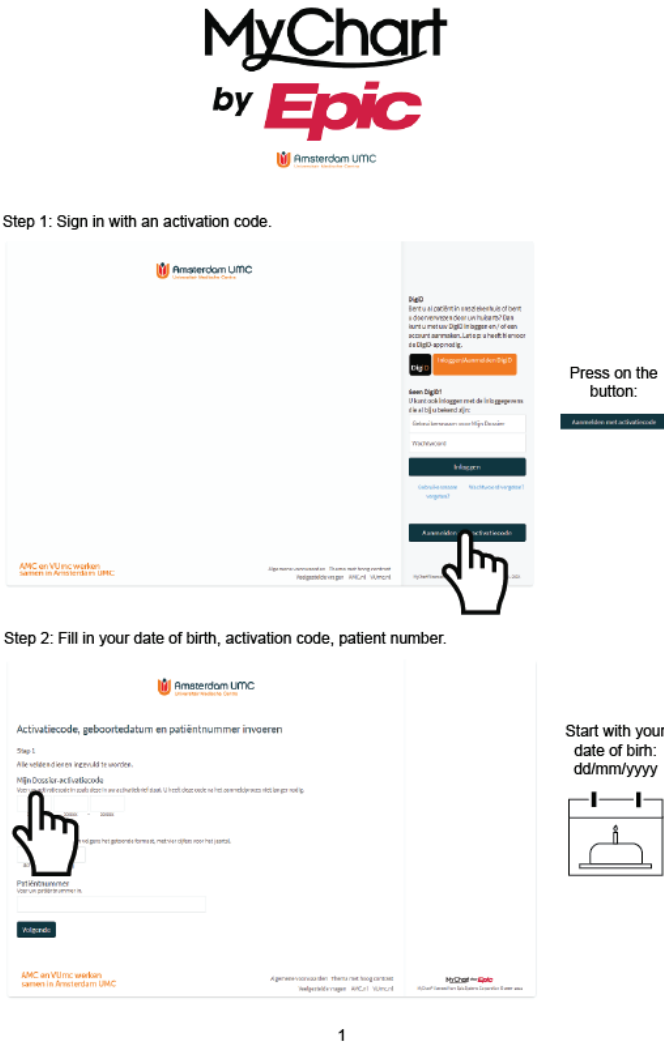


Figure 20 Provotype 1: Waiting Room Guide

Relevant RQ for this provotype:

d. *What type of guidance do patients need when interacting with PROMs?*
e. *What is the current patient behavior regarding their privacy and how does it affect their interaction with PROMs?*
f. *What is the current patient digital literacy and how does it affect their interaction with PROMs?*

**RQ2: What is current patient behavior regarding MyChart and what are perceived consequences?**

a. *What are patient attitudes toward MyChart?*
c. *What are current barriers to patient interaction with MyChart?*
d. *What type of guidance do patients need when interacting with MyChart?*
e. *What is the current patient behavior regarding their privacy and how does it affect their interaction with MyChart?*
f. *What is the current patient digital literacy and how does it affect their interaction with MyChart?*



You enter the **waiting room** passing through the reception desk. The receptionist greets you and hands you a **visual guide** on how to set up MyChart.

You are following the visual guide and set up an account with MyChart. However, you get stuck at the step where you are supposed to find the PROMs.

Figure 21: Two scenes from the scenario of the 1st provotype. On the top, the nurse gives the patient the visual guide a they enter the waiting room. In the picture below, the patient is using the guide to get MyChart on the computer available in the waiting room.

Provotype 2: Community Board

With this provotype, the participant gets to interact with a pin board filled with prompts, seen in Figure 22. The prompts on the board vary in intensity, from what is your dream travel location? to do you have a headache? In the scenario, seen in Figure 23, the patient is awarded with pins if they completed PROMs. Afterward, they can respond to one or more prompts on the board.

This provotype tests how comfortable they are to share different types of information and community-based gamification. Additionally, it can start a discussion on what would motivate them to complete PROMs in the future.
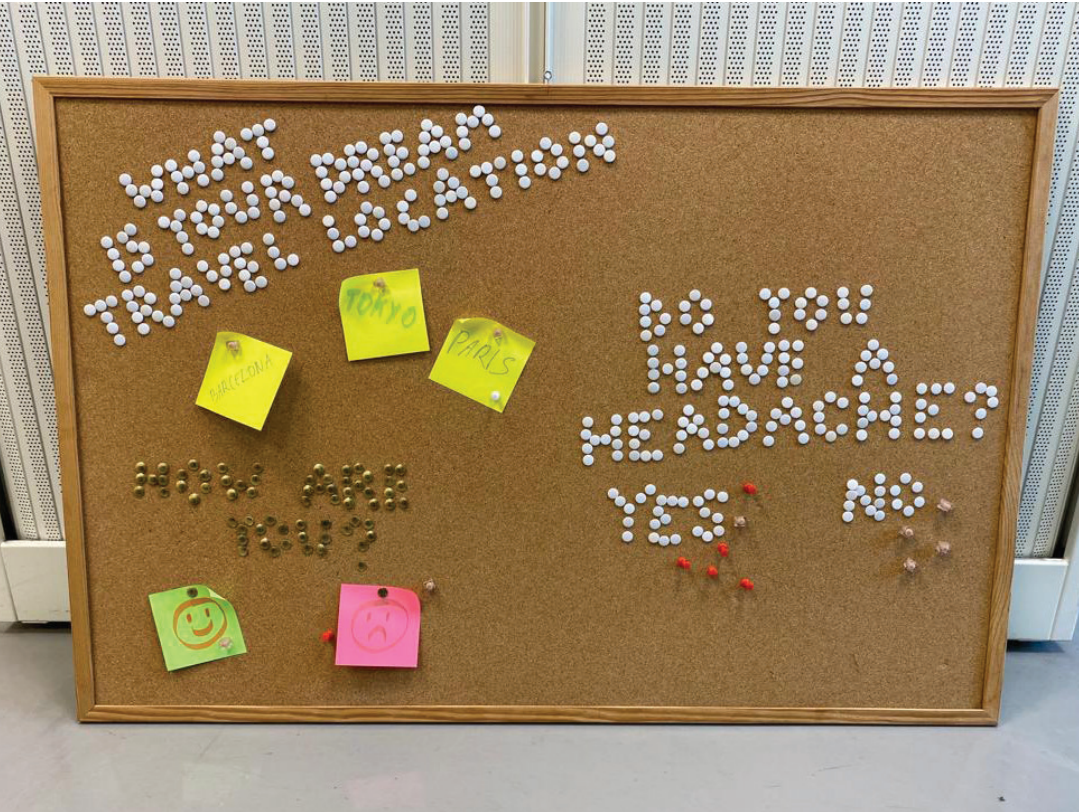


Figure 22 Provotype 2: Community Board

Relevant RQ for this provotype:

a. *What are patient attitudes toward PROMs?*
   i. *What is the perceived impact on patient care caused by the introduction of PROMs?*
b. *What motivates patients to interact with PROMs?*
e. *What is the current patient behavior regarding their privacy and how does it affect their interaction with PROMs?*

b. *What motivates patients to interact with MyChart?*
e. *What is the current patient behavior regarding their privacy and how does it affect their interaction with MyChart?*



You completed the PROMs and the receptionist gives you a **box of pins**.
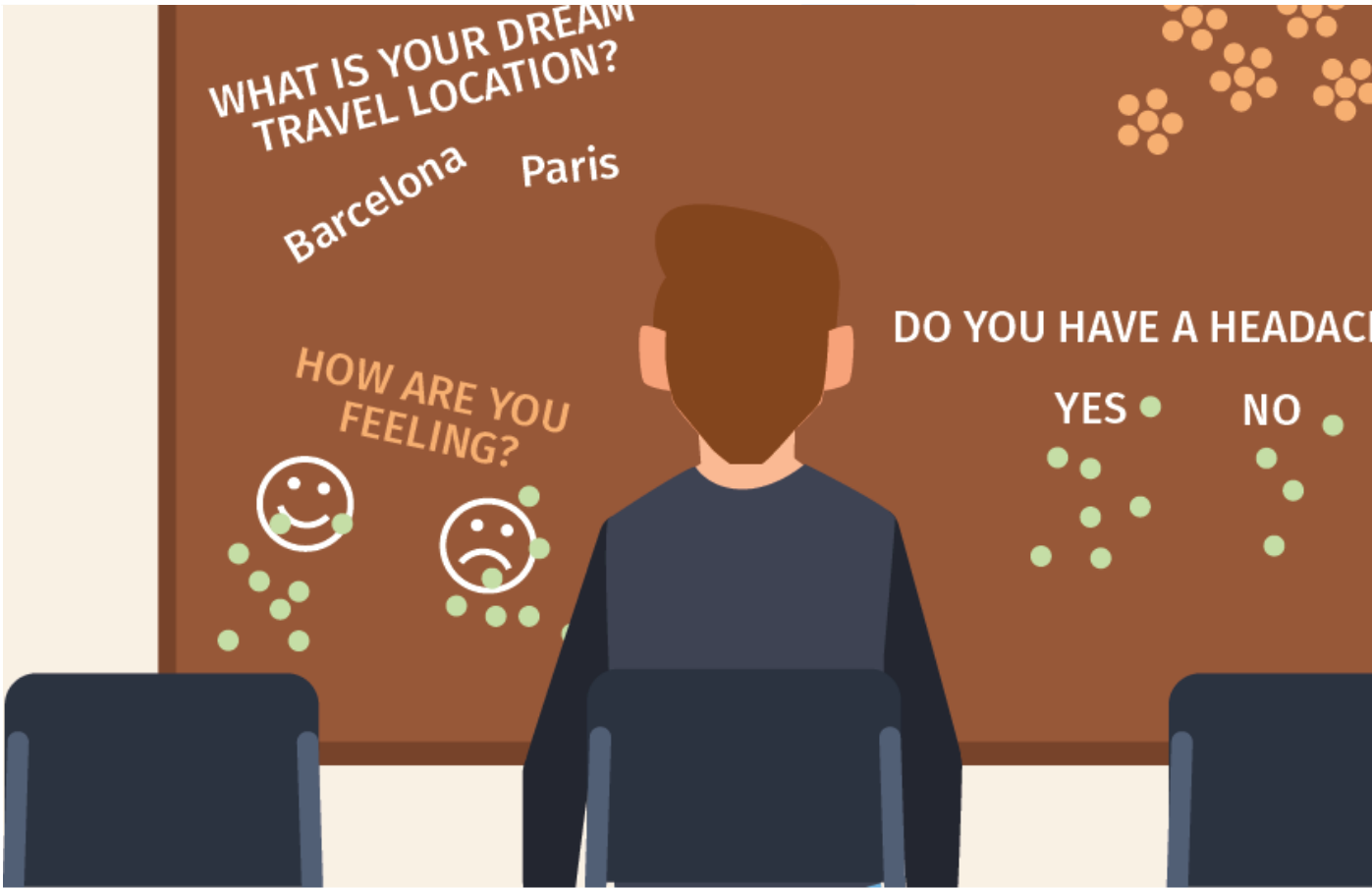
You sit down in the waiting room and see that the **wall** has some drawings and some prompts to conversation that **other patients** contributed with.

Figure 23: Two scenes from the scenario of the 2nd provotype. On the top, the nurse is giving the patient a box of pins as a reward for completing PROMs. In the picture below, the patient is reading the prompts on the board of pins in the waiting room

Provotype 3: PROMs Assistant

This provotype uses an audio prompt in form of a speaker to replicate an AI voice assistant. This can be seen in Figure 24. The purpose of the assistant is to give guidance and help the patient when navigating health with a focus on PROMs. The scenario, seen in Figure 25, is locating the patient at home. The chatbot inquires the patient if they have the time to fill in PROMs in a gentle, non-direct way. Before even mentioning PROMs the chatbot offers the patient a relaxing activity to get them in the right mindset. The participant could choose to either do a breathing exercise or listen to calming music during the interview to immerse them in the scenario. When talking about PROMs, the chatbot asked if they have any questions, so if the participants had any on the top of their head they could be noted down. If not, the chatbot provided a few common questions patients have about PROMs to spark discussion.

The purpose of this provotype was to see how comfortable they are with a different setting, how do they feel about different technology, what do they do if they have questions about health at home, but most importantly their attitudes about PROMs.



Figure 24: Provotype 3: PROMs Assistant

Relevant RQ for this provotype:

**RQ1: What is current patient behavior regarding PROMs and what are perceived consequences?**

a. *What are patient attitudes toward PROMs?*
b. *What motivates patients to interact with PROMs?*
c. *What are current barriers to patient interaction with PROMs?*
d. *What type of guidance do patients need when interacting with PROMs?*
e. *What is the current patient behavior regarding their privacy and how does it affect their interaction with PROMs?*
f. *What is the current patient digital literacy and how does it affect their interaction with PROMs?*
g. *How has the introduction of PROMs affected the interactions between the patient and HCPs?*





Figure 25: Two scenes from the scenario of the 3rd provotype. On the top, the patient is in their home when the chatbot asks them if they have time to talk about PROMs. In the picture below, the patient is asking questions about PROMs.

**Analysis**

Statement cards were used to help analyze the notes and audio files (Sanders & Stappers, 2013). These cards can be used to capture key quotes or statements from the interviewee, along with a brief summary of the context or meaning of the statement.

When creating statement cards, the first step is transcribing or summarizing the key points from each interview. Then, a card can be created for each key point or theme that emerges, capturing the quote or statement on one side of the card and a brief summary of its meaning or context on the other side. You can then review and organize the cards, grouping them by theme or topic and identifying any patterns or trends that emerge. In this case the statements cards were first clustered in different categories for each participant, then only for the interview with the patients or only the interviews with the nurses and finally all of them were grouped together to find overall takeaways.

## 3.2.3 Insights

## Theme 1: Motivation for patients to complete PROMs

The patients fall into two categories of motivation, intrinsically motivated to complete PROMs and extrinsically motivated to complete PROMs. The first category encompasses the "on top of everything" target group. They have the easiest time seeing the benefits of PROMs and the advantages PROMs can bring to their care. Four out of the six patients expressed having an intrinsic motivation. The people that get their motivation extrinsically has expressed the HCP being their main motivation either because they want to be told what to do it or because they want to do something that helps the HCPs. Five of the six patients expressed a willingness to do PROMs for the sake of the HCP. They expressed that "If the HCPs asks me to do PROMs, I will do it." and "I participate in something that's helpful to me and helpful to someone else.".

While part of the patients interviewed would be willing to do PROMs on their own (4/6), the majority expressed a willingness to do it if asked by an HCP (5/6). This can be because they trust the nurses at the outpatient clinic or because they want to do something helpful for the nurses, as they feel they are overworked or/and they feel connected to them. One of the participants expressed that "If it helps them doing their job or they actually think they need it. Because that would also benefit my health in that sense."

## Theme 2: Nurses are questioning the use of PROMs at the outpatient clinic

The HCPs have some complaints about PROMs and worry they are too time consuming or overwhelming for patients to do. Some disclosed that they most likely would not complete PROMs if they were a patient. They feel that they already put more work than other departments to get to know the patients and know how to ask the right questions, similarly to what they are trying to achieve with PROMs. However, even with these concerns they still see the value of PROMs to measure things such as the patient's psychological situation which is hugely helpful as there is not enough time in a consultation to cover everything. One nurse said: "I will be honest I don't know if I would do it if I were a patient... but I do stimulate people here to do it because I believe in it."

## Theme 3: Benefits of PROMs from the perspective of patients

Patients that have completed PROMs previously, did see benefits of doing PROMs; such as using it for self-reflection, tracking, an early help system, and wanting them to assist or guide talks during consultations. Two patients saw it as a way for HCPs to stay involved and informed about them. Five patients saw it as a way to touch on topics they did not normally discuss during consultations. One of them said: "If something would be really wrong and you are too afraid to say, and you filled it in...then it's like an easy step to say "Hey can we talk about the PROMs". I think it's an easier step than just asking directly for help if you're afraid to do it."

## Theme 4: Benefits of PROMs from the perspective of HCPs

When asked about the benefits of PROMs nurses mentioned many examples; it can work as an early signaling system, it is a good tool for self-reflection at home, and it gives patients more autonomy. The nurses also saw PROMs as a useful tool for patients that do not normally talk a lot, a tool to address topics like feelings and the sexual health of patients, and touching on topics that patients or nurses avoid. Nurses also expressed that PROMs could address topics that there was no time for during a consultation. In general nurses like PROMs because they focus on the patient's perspective.

## Theme 5: The benefits nurses see in PROMs can be reflected in the benefits patients see in PROMs

The benefits nurses see in PROMs can be reflected in the benefits patients see in PROMs. The four main benefits that they mentioned were: PROMs being an early signaling system, addressing topics that were not talked about during consultation, being able to track health over time and self-reflect, and helping HCPs stay informed. Although there is some overlap in what patients and nurses think about PROMs, the main difference is what they believe to be the purpose of PROMs. Nurses think the purpose is to benefit the patients, whereas the patients interpret the purpose based on their own values. This can be informing HCP, automating care, or finding issues early on.

## Theme 6: My privacy should be not only a given but be transparent

Patients care about their privacy and due to their diagnosis might be more careful about it. Five out of six patients expressed preferring the privacy of their home to complete PROMs, Five are also private about their diagnosis, and two are taking active steps to maintain their privacy. Two patients feel that privacy should be both guaranteed and transparent regarding how their data is handled. It is important to half of the patients that they feel in control of their technology and are not put in a compromising position. The trust put into the outpatient clinic directly affects how willing a patient is to listen and complete PROMs in between consultations.

## Theme 7: Challenges that both nurses and patients face when using PROMs

There are several challenges that both nurses and patients face when using PROMs. These include:

- Collecting and reviewing PROMs is time-consuming, especially for nurses who already have a heavy workload and limited resources. This also applies to nurses that worry about whether PROMs are too time-consuming for the patients.

- Some patients have difficulty understanding or completing PROMs due to language or cultural differences, which can affect the accuracy and usefulness of the data collected.

- PROMs are perceived as an additional burden on patients, who are already dealing with a significant amount of stress and discomfort. This leads to low participation rates.

- Some patients feel discouraged or resistant to completing PROMs, either because they do not fully understand their purpose or because they feel that their responses will not make a difference in their care.

Some patients do not want to add to the burden of the HCP, as one expressed: *I felt you really need to have a conversation to explain your answers. And I think that's probably what the questionnaire wants to avoid, it should reduce the pressure on medical staff to have a lot of conversations. The answers may raise more questions than you had before.*

## Theme 8: Patients do not want to lose touch with the HCP

Patients do not want to lose touch with their HCP. Some patients feel that answering PROMs means that it will detract from the contact they have with the HCP. They assume PROMs purpose is to make care more efficient by automating it. One of them expressed: "It's more important to talk at that moment. How are you? Is there anything different? So if you can choose, I would not answer all the PROMs questions at all."

**Insights from the worksheets**

The worksheets provided an insight into nurses' perspectives on PROMs and the interaction between patients and PROMs. In Figure 26, the worksheets can be seen after one interview.

Nurses would like patients to talk about their feelings, including feelings about HIV and sexual health. They experience these to be difficult topics for patients to bring up, especially patients that struggle with stigma. Nurses think PROMs can be used to bring up these topics in a consultation.
However, nurses think they have been trained to be able to bring up most topics from PROMs in consultations even without PROMs This is especially true due to the close relationship with the patients.

When asked about their perceived value of PROMS, most of them mentioned PROMs are a way for patients to self-reflect on their healthcare and they can give patients more autonomy during consultations.

However, some nurses mentioned that even if they see the value, they would not personally fill in PROMs.

Patients have communicated to nurses concerns about privacy in regard to PROMs and MyChart. The nurses think it would be helpful for patients to have an info point for MyChart where they can ask questions and voice any concerns.
They also mentioned that they think the questions from PROMs can be confronting to the patients and the number of questions in PROMs can be discouraging.

Nurses think explaining what PROMs are and their benefits can help patients fill in PROMsThey also think PROMs need to be more accessible for patients struggling with technology or language barriers



Figure 26: The worksheets after one of the nurse interviews.

**Insights from the provotypes**

Provotype 1: Waiting Room Guide
- Most patients asked questions if anyone was sitting behind or if there was a filter on the screen, which indicates concern for their privacy.
- Patients liked the idea of having a real person to ask questions.
- •MyChart can be difficult if you do not understand the language.

Provotype 2: Community Board
- Most participants were not interested in community-based activities in the waiting room, especially with anything related to their health
- Most patients would be curious about what information is on the board or what others had to say.
- Almost all participants would answer the questions for a reward, but they were mostly motivated by their HCP asking them to complete PROMs.

Provotype 3: PROMs Assistant
- All participants were concerned about their privacy when talking to an AI about their health.
- They also expressed not wanting to explain to other people if they have any medical device at home as that can be confrontational
- Some participants would ask the AI assistant factual information, and some thought it would be useful for people with language barriers or physical difficulties
- All patients would like to do PROMs on their own time rather than be prompted to do it

## 3.2.4 Takeaways

Patients that do not have inner motivation to complete PROMs, find motivation in doing it for the HCP.

Some nurses do not believe in PROMs. This can affect how the patient perceives PROMs due to the trust they feel towards the nurses.

The main benefit of PROMs for patients is being able to talk about topics they would normally not bring up in conversations.

The main benefit of PROMs for nurses is that it focuses on the patient's perspective.

Patients have different beliefs on what the purpose of PROMs are, that align with their values.

Privacy can be a deterrent to completing PROMs. They want to know they are safe and in control when it comes to their personal data.

Some patients fear PROMs will replace the human touch in care and lose connection with the nurses.

## 3.4 Personas

Personas are archetypical representations of the target group. They are used in user-centered design to represent the goals, behaviors, and characteristics of a particular group of users. Personas help designers and researchers understand and empathize with their users and can be used to guide decision-making about the design and development of products and services.

Based on the client observations in Figure 2 and influenced by the qualitative research from the previous sections, four personas were created: on top of everything, seen in Figure 27 too busy, seen in Figure 28, tell me what to do in Figure 29 and not involved in Figure 30.

The client observed patient of not interested was replaced with the persona not involved. This was done as our takeaways from the qualitative research indicated that it was more a lack of health literacy, or accesibility rather than a lack in the interest in other forms of care.

Each persona was given a description, an explanation of what motivates them, what are their attitudes toward PROMs and how they would like to receive information. While the names mostly stayed the same as the clients descriptions, their aspects were inspired by the participants of the observation and interview study and the descriptions of patients given by the nurses.

## On top of everything

| | |
|---|---|
| Description | This patient wants to be involved in their health. They are active during their appointments by asking questions. They already have MyChart and are curious about PROMs. They use MyChart actively to learn about their health. |
| Motivation | Still considers HCP as a professional so will be motivated to do what they say. However, they might do their own research on the topic or form their own opinion on the topic. They will discuss it with the HCP. They have an inner motivation to take control of their health. They view their health as their own responsibility. |
| PROMs | They think PROMs are a great tool for the HCP. They also appreciate the time to reflect on their health. They feel like it is too time-consuming if not discussed during appointments. |
| Information | Likes to stay informed on their own and by the HCP who can give them more sources. |

Figure 27: On top of everything persona

## Too busy

| | |
|---|---|
| Description | This patient is too busy with other things in their life. They want to be involved in their health and might download MyChart out of practicality, but they do not have time to reflect about their health. |
| Motivation | They have an inner motivation to be healthy, but it is not as pressing as other things going on in their lives. |
| PROMs | They generally do not have time for PROMs but are willing to do it if the HCP tells them to. They count on the HCP to explain what PROMs are and why they should do them. They also count on them to take over after filling them in as they do not have time. |
| Information | Likes easy and accessible ways to stay informed or be informed by the HCP. |

Figure 28: Too busy persona

## Tell me what to do

| Description | This patient wants the HCP to tell them what to do. They do not want to be involved in their own health. They might have downloaded MyChart because the HCPs told them to, but they only use it to check results or check the notifications. |
| --- | --- |
| Motivation | They are motivated by what the HCP tells them to do. They want to be healthy, but they do not view it as their job, but the HSPs job. |
| PROMs | They take on the view of the HCP. They think it is good that the HCP can keep track of their health. They do not want to think about their health outside appointments. They do not want to lose touch with HCP. |
| Information | Likes to be informed by the HCP. |

Figure 29: Tell me what to do persona

## Not involved

| Description | This patient does not have an interest at the moment in being involved in their health. They are a potential no-show, and if they show up it is because their health needs immediate attention. The nurses put more energy into contacting this patient. |
| --- | --- |
| Motivation | They lack motivation and interest in their own health. |
| PROMs | Does not want to learn or be involved with PROMs. They do not see how it could help them. |
| Information | Wants to get better quickly, does not care about other information. |

Figure 30: Not involved persona

## 3.5 Journey Map

A journey map is a visual representation of a person's experience with a product, service, or process. It is a tool used in the design process to understand and improve the experience of the target group. A journey map, seen in Figure 31 and 32, was created based on the insights gathered about the target group's interactions with PROMs and MyChart at the outpatient clinic, to help identify pain points, frustrations, and opportunities for improvement in the user experience.

A journey map typically includes a timeline of the person's experience. In this case the timeline is represented by different journey phases the patient goes through. This is done a patient that

the timeline is represented by a box on the map that outlines the patient actions on a regular visit at the clinic and the first time they would visit the clinic. Similarly other stakeholders that interact with the patient are illustrated on the map at the point of interaction. Other elements included are the barriers patients face through their journey, quotes form the qualitative interviews and opportunities together with key points that need to be addressed.

The jouney map can be seen in Figure 31, where it focuses on the patient intearctions at the clinic. Figue 32 shows the patient interactions after leaving the clinic.

An extended version of the journey map can be found in Appendix 14.

**Peer navigator**

An addition to the journey map is the peer navigator role. During the user research, the team at Amsterdam UMC added a new member. A peer navigator in a clinical setting is typically someone who has lived experience with a particular health condition and is trained to provide support and guidance to others who are going through a similar experience. They often serve as a liaison between patients and healthcare providers, helping to bridge communication gaps and connect patients with appropriate resources and services

Part of their role at the clinic is introducing new patients to PROMs and MyChart. As this is very similar to the project aim, this creates an opportunity to design a solution that can aid the peer navigator in their role.

## Journey Phases

| Preparatory steps before the consultation | Arrival at outpatient clinic | Intake (new) patient | Introduction to MyChart for not new patients | Outcome of PROMs |
|---|---|---|---|---|

## Interactions

**Reoccurring events**

- The patient receives their appointment letter
- The patient receives an appointment MyChart notification
- Patient receives PROMs on MyChart, 2 weeks before appointment
- Patient completes PROMs
- The nurse and doctor review (and discuss) patient's answers from the PROMs
- Patient goes to yearly appointment
- Patient registers at the front desk
- Front desk asks patient to have a seat in the waiting room
- Patient has a consultations with doctor and nurse
- Patient discusses PROMs with the nurse
- The nurse and doctor decide to resume/adjust treatment based on the answers from the PROMs and discussion with patient

**One-time events**

- The patient receives a referral to the outpatient clinic
- Patient receives information, at the front desk, about being a new patient
- The nurse or doctor shows the patient to the peer navigator
- Patient is introduced to MyChart
- Patient is given an activation code for MyChart
- Patient is introduced to MyChart by the nurse
- The nurse asks for an activation code for the patient
- Patient is given an activation code for MyChart

*Only one will take place if it takes place*

## Patient actions

**Patient actions**

- Saves the date
- Fills in PROMs
- Travels to the outpatient clinic
- Registers at the front desk
- Receives the activation code
- Waits to be called for
- Talks with the HCPs
- Receives the activation code
- Discusses PROMs answers/score with the nurse

## Stakeholders directly interacting with the patient

**Nurse actions**

- Checks the scores and answers from PROMs before appointment and discusses them with the doctor
- Conducts consolation with patient
- Nurse introduces MyChart to patient
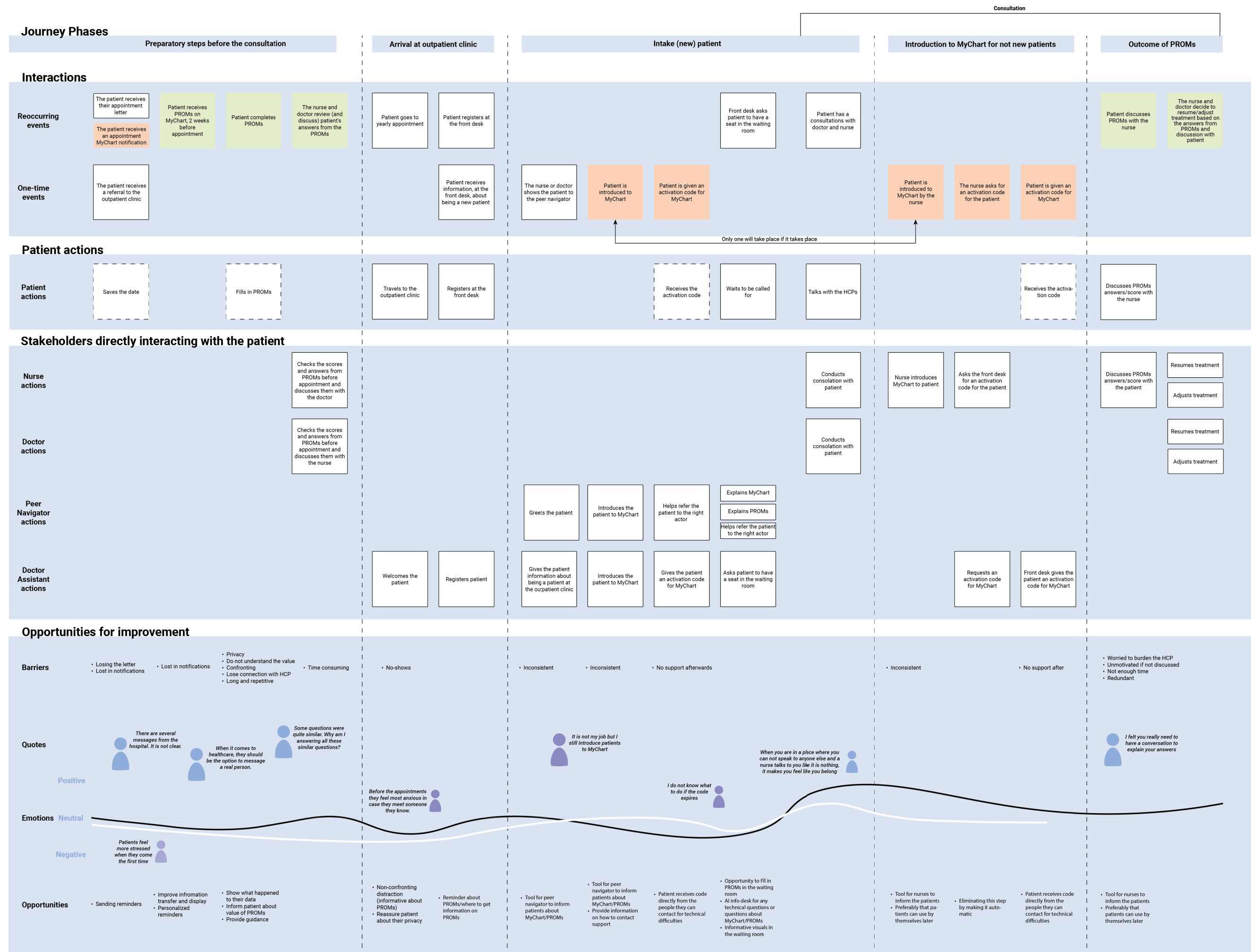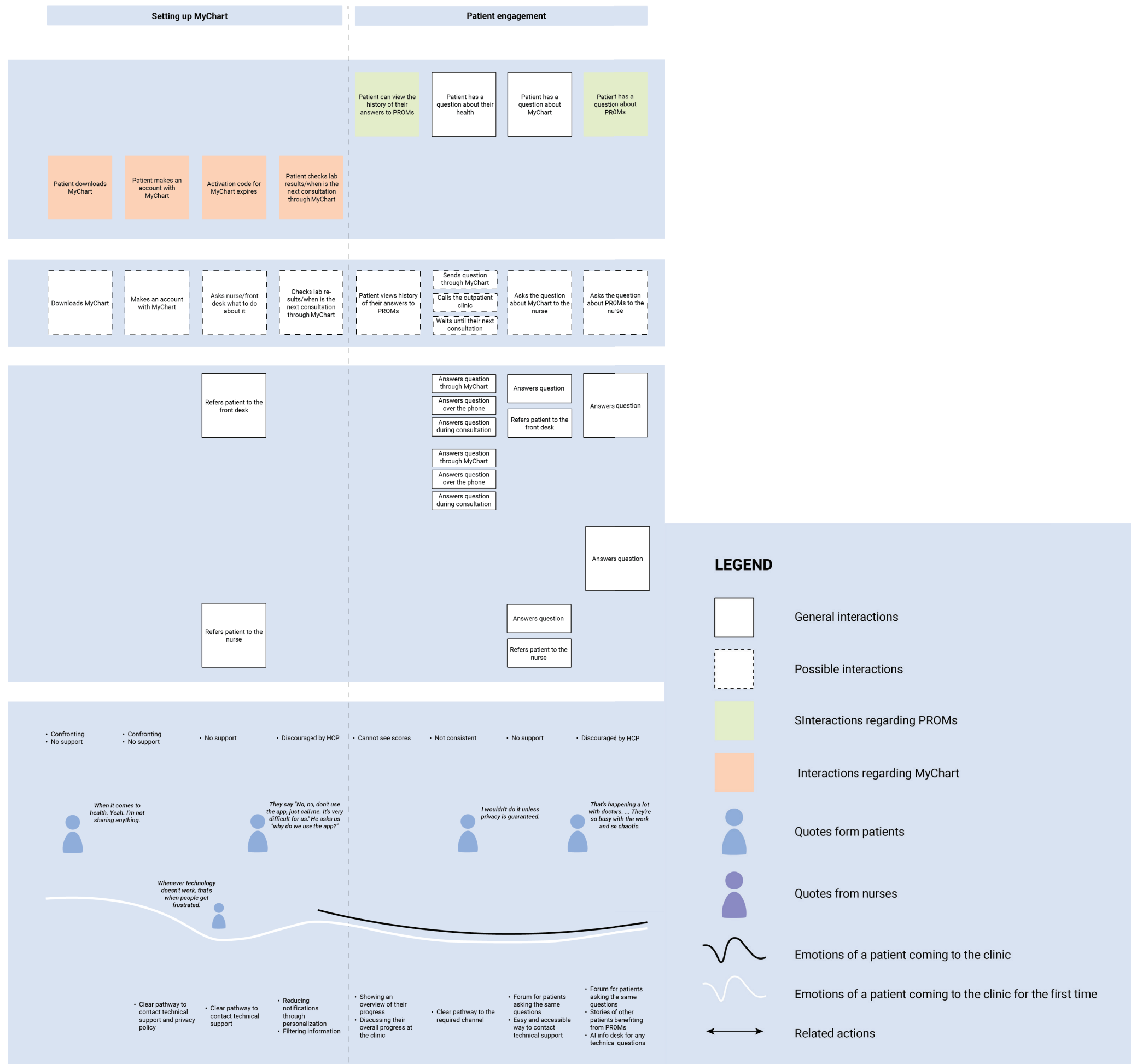- Asks the front desk for an activation code for the patient
- Discusses PROMs answers/score with the patient
- Resumes treatment
- Adjusts treatment

**Doctor actions**

- Checks the scores and answers from PROMs before appointment and discusses them with the nurse
- Conducts consolation with patient
- Resumes treatment
- Adjusts treatment

**Peer Navigator actions**

- Greets the patient
- Introduces the patient to MyChart
- Helps refer the patient to the right actor
- Explains MyChart
- Explains PROMs
- Helps refer the patient to the right actor

**Doctor Assistant actions**

- Welcomes the patient
- Registers patient
- Gives the patient information about being a patient at the outpatient clinic
- Introduces the patient to MyChart
- Gives the patient an activation code for MyChart
- Asks patient to have a seat in the waiting room
- Requests an activation code for MyChart
- Front desk gives the patient an activation code for MyChart

## Opportunities for improvement

**Barriers**

- Losing the letter
- Lost in notifications
- Lost in notifications
- Privacy
- Do not understand the value
- Confronting
- Lose connection with HCP
- Long and repetitive
- Time consuming
- No-shows
- Inconsistent
- Inconsistent
- No support afterwards
- Inconsistent
- No support after
- Worried to burden the HCP
- Unmotivated if not discussed
- Not enough time
- Redundant

**Quotes**

- *There are several messages from the hospital. It is not clear.*
- *When it comes to healthcare, they should be the option to message a real person.*
- *Some questions were quite similar. Why am I answering all these similar questions?*
- *Patients feel more stressed when they come the first time*
- *Before the appointments they feel most anxious in case they meet someone they know.*
- *It is not my job but I still introduce patients to MyChart*
- *I do not know what to do if the code expires*
- *When you are in a place where you can not speak to anyone else and a nurse talks to you like it is nothing, it makes you feel like you belong*
- *I felt you really need to have a conversation to explain your answers*

**Emotions** — Positive / Neutral / Negative

**Opportunities**

- Sending reminders
- Improve infromation transfer and display
- Personalized reminders
- Show what happened to their data
- Inform patient about value of PROMs
- Provide guidance
- Non-confronting distraction (informative about PROMs)
- Reassure patient about their privacy
- Reminder about PROMs/where to get information on PROMs
- Tool for peer navigator to inform patients about MyChart/PROMs
- Tool for peer navigator to inform patients about MyChart/PROMs
- Provide information on how to contact support
- Patient receives code directly from the people they can contact for technical support
- Opportunity to fill in PROMs in the waiting room
- AI info desk for any technical questions or questions about MyChart/PROMs
- Informative visuals in the waiting room
- Tool for nurses to inform the patients
- Preferably that patients can use by themselves later
- Eliminating this step by making it automatic
- Patient receives code directly from the people they can contact for technical difficulties
- Tool for nurses to inform the patients
- Preferably that patients can use by themselves later

Figure 31: Journey Map

Figure 32: Continuation on the Journey Map and the Legend for the Journey Map

**Setting up MyChart**

- Patient downloads MyChart
- Patient makes an account with MyChart
- Activation code for MyChart expires
- Patient checks lab results/when is the next consultation through MyChart

**Patient engagement**

- Patient can view the history of their answers to PROMs
- Patient has a question about their health
- Patient has a question about MyChart
- Patient has a question about PROMs

- Downloads MyChart
- Makes an account with MyChart
- Asks nurse/front desk what to do about it
- Checks lab results/when is the next consultation through MyChart
- Patient views history of their answers to PROMs
- Sends question through MyChart
- Calls the outpatient clinic
- Waits until their next consultation
- Asks the question about MyChart to the nurse
- Asks the question about PROMs to the nurse

- Refers patient to the front desk
- Answers question through MyChart
- Answers question over the phone
- Answers question during consultation
- Answers question through MyChart
- Answers question over the phone
- Answers question during consultation
- Answers question
- Refers patient to the front desk
- Answers question

- Answers question

- Refers patient to the nurse
- Answers question
- Refers patient to the nurse

**LEGEND**

- □ General interactions
- ⬚ Possible interactions
- 🟩 SInteractions regarding PROMs
- 🟧 Interactions regarding MyChart
- 🧍 Quotes form patients
- 🧍 Quotes from nurses
- 〜 Emotions of a patient coming to the clinic
- 〜 Emotions of a patient coming to the clinic for the first time
- ↔ Related actions

- Confronting
- No support
- Confronting
- No support
- No support
- Discouraged by HCP
- Cannot see scores
- Not consistent
- No support
- Discouraged by HCP

*When it comes to health. Yeah, I'm not sharing anything.*

*They say "No, no, don't use the app, just call me. It's very difficult for us." He asks us "why do we use the app?"*

*I wouldn't do it unless privacy is guaranteed.*

*That's happening a lot with doctors. ... They're so busy with the work and so chaotic.*

*Whenever technology doesn't work, that's when people get frustrated.*

- Clear pathway to contact technical support and privacy policy
- Clear pathway to contact technical support
- Reducing notifications through personalization
- Filtering information
- Showing an overview of their progress
- Discussing their overall progress at the clinic
- Clear pathway to the required channel
- Forum for patients asking the same questions
- Easy and accessible way to contact technical support
- Forum for patients asking the same questions
- Stories of other patients benefiting from PROMs
- AI info desk for any technical questions

## 3.6 Takeaways

The project aim is to develop a design intervention that increases patient engagement with PROMs. Based on that the main takeaways should have the patient and their interaction with PROMs as a focus. Therefore, the following focus points were made based on the most common themes between participants:

**Purpose**
The patients should understand why they are answering PROMs and for whom they are answering them.

**Inner motivation**
Patients should be motivated to fill in PROMs for themselves and how PROMs can benefit them.

**Privacy**
The patient should know how their privacy is being affected by answering PROMs (and having an account on MyChart).

**Answering research questions**

RQ 1: What is current patient behavior regarding PROMs and what are perceived consequences?

Patients do not have a common understanding of what is the value of PROMs. Every participant seemed to have a different one based on what their values are or what job they have. For example, a teacher thought the main purpose of PROMs is to improve communication during consults: "I'm a teacher and when I talk to my pupils, I also send them a questionnaire first. And then when I see them face to face, we can focus on things that really strike out." Another participant who works in automation thought the purpose of PROMs is to make healthcare more efficient.

Some patients think their purpose is to help the HCP and some do it because the HCP told them to: "If the HCPs asks me to do PROMs, I will do it." Even if they think it is helpful for themselves, they are still motivated by helping the HCP: "I participate in something that's helpful to me and helpful to something else." This could result in them not continuing the behavior as they do not see the long-term value of PROMs and how it could benefit them.

a. What are patient attitudes toward PROMs?

Some participants see benefits to PROMs, such as being able to touch topics that they would normally not cover during appointments: "And I think it was about subjects that you don't really talk about with your doctor. Not that easily. So to think about it in a, yeah, what would I say to my doctor is also different, so that's nice." or taking the time to self-reflect: "Self-reflection that's just, you never make time for that. So you are in a way forced to do this."
However, they also see them as repetitive, too long, and not targeted enough towards them. 2 participants mentioned to their HCP that they did not like that there was no middle answer. And if they had to choose something they did not feel represented them there was no option to explain.

i. What is the perceived impact on patient care caused by the introduction of PROMs?

Some of the participants mentioned that they did not like not discussing the PROMs during an appointment after they took the time to complete it. This might cause them to lose interest to do them in the future since they do not see an immediate effect: "When I had my talk with (name of the clinician), we didn't really follow up on the questions. Maybe that could improve...?"

b. What motivates patients to interact with PROMs?

Some patients described an inner motivation and some said that they could be persuaded by a reward. However, all participants said that they would do it because the HCP asked them to or because they think it would make their job easier: "If the HCPs asks me to do PROMs, I will do it.", "I like the hospital here. I like the people. That's also why I participate in this interview. If I can help, if I can contribute a little bit. I like to help.", "They motivate me to come to the hospital".

c. What are current barriers to patient interaction with PROMs?

Patients can not complete PROMs if they do not have MyChart. They can experience barriers if they do not have access to technology or if they do not speak Dutch.
They might feel discouraged by the HCP if they do not think PROMs can be valuable in the context of the outpatient clinic: "I will be honest. I don't know if I would do it if I were a patient."

d. What type of guidance do patients need when interacting with PROMs?

Patients would like for information to be accessible and easy to understand. They would like to be able to contact a real person if they need help but they would not appreciate being held by the hand through every step like a child: "If you make a guide, literally everyone should be able to do it. Just gives them this click, click, click, click, and they should be able to use MyChart.", "I think it would be wonderful because we have to find out everything ourselves."

e. What is the current patient behavior regarding their privacy and how does it affect their interaction with PROMs?

The patients at the clinic value their privacy, due to stigma, past experiences but also keeping their own discretion. Privacy should be a given especially in a healthcare setting and it should be transparent to the patient. They should not have to work to find it. "I want to keep things private.", "I wouldn't do it unless privacy is guaranteed."

f. What is the current patient digital literacy and how does it affect their interaction with PROMs?

Only 67,9% of patients have MyChart, and not all have activated or used their account. Same patients do not have digital literacy to use it, some might not be able to speak the language or have access to it. Due to this not all patients can currently fill in PROMs.

g. How has the introduction of PROMs affected the interactions between the patient and HCPs?

One participant was satisfied with being able to bring up some topics they might have not been able to bring up before to their HCP. This creates an easier way for patients to bring up topics during appointments that they would not know how to before PROMs. "Sometimes it's hard subjects and you don't really have the feeling to talk about it in person. So then PROMs are really helpful with that because the questions are hard to answer."

ii. How do PROMs affect patient engagement during the consults?

PROMs can help patient think about topics they want to bring up or ask about during their appointments, by taking time before the actual appointment to self-reflect on the topic. Additionally, they might have an easier way to bring them up by talking about PROMs.

RQ 2: What is current patient behavior regarding MyChart and what are perceived consequences?

Patients use MyChart to check lab results, see when their next appointment is going to be, or contacting HCPs: "I think it's really convenient that you can see all the lab results, to order medication like new prescription for medication. And if I have like a non-urgent question then I can just send a message to (name of nurse)". Some patients may be hesitant due to privacy concerns.

h. What are patient attitudes toward MyChart?

Some participants find MyChart as an efficient way to communicate and manage your health: *"I personally, believe in efficient ways of communication and this is a way, not just aiding yourself, helping yourself, but also helping the people that work here"*. Some think it can be too complicated or overwhelming: *"An online platform, it shouldn't be too hard just to click and get a brief explanation."* And some patients prefer other ways of communication: *"It's easy to get in touch with email. Okay. Uh, the telephone, uh, also you can phone and it's always, uh, the system works basically very well."*

i. What motivates patients to interact with MyChart?

The participants that use MyChart expressed that it is an easy and accessible way to check their health and appointments. Those participants fell into on top of everything and too busy category.

j. What are current barriers to patient interaction with MyChart?

Only 67,9% of patients have MyChart, and not all have activated or used their account. Some nurses expressed that some patients have technical issues, e.g. their activation code expires, and they do not know how to help. The patients are not sure who to go to with this issue. This situation was illustrated in the journey map in section 3.2.10.
Other barriers include the digital literacy of the patient, not being able to speak the language, or not having access to technology. The nurses have expressed that some patients complain to them about the number of notifications or irrelevant questionnaires they get from MyChart.
One participant expressed being deterred by the HCP to use the app: *"He asks us 'why do we use the app?' I say, because I work all day"*.

k. What type of guidance do patients need when interacting with MyChart?

The nurses think that if patients were provided with technical support or information about who to contact, it would increase how many people use MyChart. However, the nurses have experienced enthusiastic patients and some that need to be convinced.
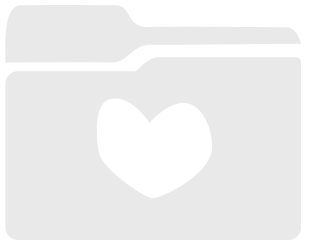Not all patients get introduced to MyChart and if they do it is after they have been a patient at the clinic for a few years.

i. What motivates patients to interact with MyChart?

All patients value their privacy and think when using any health associated device, the privacy policy should be transparent. Some put a lot of effort to remain private. "If there is an independent audit, I need to have security tested by an actual, well, what do you call these pen testers? I need to know where the server is. If the US can get the data, where the company is located that owns the server. All the legal details about it, you should just have it somewhere in to review. Instead of me doing all the research myself."

m. What is the current patient digital literacy and how does it affect their interaction with MyChart?

Only 67,9% of patients have MyChart, and not all have activated or used their account. Some patients do not have the digital literacy to use it, or the possibility to have access to technology and learn. Because of this, not all patients are able to have MyChart currently.

**Chapter 4**

# DEFINE

Based on the research this chapter will define the goal of the project by answering the research questions, creating an interaction vision and a design goal. Those will be used in the design phase of the project

## 4.1 Introduction

In this chapter, the interaction vision and design goal are presented. Based on these we arrived at the design criteria for our design intervention. The aim of which was changing patients' engagement with PROMs.
The key factors to keep in mind for this chapter is:
Patients not understanding the value and purpose of PROMs, patients not knowing the benefits of PROMs, how their data is handled, and where to go to ask for help.

## 4.2 Interaction Vision

The following interaction vision was made for this project:

> The interaction vision should feel like a personal trainer guiding you to reach your goal.

This means:
- The patient should feel they are the **focus**
- The patient should feel **guided** through the process
- Any information should be easily **accessible**
- The patient should feel in **safe** hands
- **Personalized** for the different types of patient
- Maintain and improve QoL

Another idea for the interaction vision was being guided in the classroom by a teacher. However, it did not provide a sense of focus on the patient as a teacher focuses on many students at once. A personal coach is focused on only one person during their teaching. Additionally, a personal coach gives more of a feeling of autonomy since the person being guided sets up their own goals. It also gives a sense of personalization as those goals are personalized based on the person's capabilities at the moment.

The focus on one person suits the design goal of the project, where the patient should feel in focus when filling in PROMs. A sense of autonomy is important as it was found out from the research that patients do not want to feel belittled.

The interaction vision can be seen in Figure 33.

## 4.3 Design Goal

Based on the aim of the project and the findings from the qualitative research, the following design goal was made:

> *The design goal is to increase patient engagement with PROMs by creating a clear and accessible way for them to be informed about the purpose of PROMs, how PROMs can benefit them and how their data from PROMs is being handled.*

The design goal is based on the key findings from the previous chapter which focus on three main goals.

- Accessible to different types of patients: Accessible way for patients to be informed about PROMs.
- Informative: That shows how PROMs can benefit patients.
- Transparent about their privacy: That shows how their data from PROMs is being handled.

## 4.4 Design Criteria

By defining the design goal and iteaction vison - helps focus on main design criteria

- The design should inform the patient of the **patient centered** purpose of PROMs.
- The design should inform the patient of the **benefits** of PROMs.
- The design should be transparent to the patient on how their **data is being handled**.
- The design should make the patient feel **guided**.
- The information should be easily **accessible**. accesibility
- The design shoulf be **inclusive** to different types of patients. (This includes different levels of literacy, health literacy and digital literacy.)

Design criteria derived from other takeaways in the project, that should be keept in mind during the design phase:

- The design should help **motivate** the patients to complete PROMs for themselves.
- The design should present PROMs as an addition to the patient treatment rather than a subtraction, especially regarding their **connection to the HCP**.
- The information presented should be **easily disseminated and understood**.
- The design should be **open and non-judgemental,** and not feel confronting to the patient.
- The patient should **not feel belittled**.
- The design should **not add to the role of the HCP** in a way that it becomes burden.



Figure 33: Interaction Vision

**Chapter 5**

# IDEATION AND DESIGN

This chapter different design methods were used trough research through design to generate ideas. Such methods included brainstorming, storyboarding and roleplaying. Additionally, in the chapter four concept were explored and a final concept was chosen.

## 5.1 Introduction

In this chapter, design process is delved into to explore the different stages and methods used to generate design ideas. Four design concepts are explored throug storyboarding and role playing. The use of those design methods and the Harris Profile, allowed for discussions of the different concepts. At the end of this chapter, a final concept was selected, which was deemed to be the most suitable for meeting the needs of the target group.

## 5.2 Methods

In this phase of the project Research through Design approach was used. This approach uses design practices as a method of inquiry and investigation to understand complex problems, explore new possibilities, and develop innovative solutions. It is used to generate knowledge by carrying out various design activities (Stappers & Giaccardi, 2017). The design activities performed were chosen to generate possible design directions through different iterations. At the end of this chapter, the most appropriate design direction was chosen.

### Brainstorming

Brainstorming was a method used at the beginning of the ideation process. The goal of brainstorming was to come up with a variety of ideas, rather than to evaluate or judge them. This is done to generate as many ideas as possible, without worrying about whether they are good or not. (Boeijen et al., 2010)

To come up with more targeted ideas during brainstorming, literature research on the current state of the art was conducted. This was done by searching for existing tools on how to convey information to patients in a healthcare setting.

In order to choose which ideas to focus on, they were discussed with other designers from the IDE faculty. In the end, dot voting was used to choose what ideas to develop further. Figure 34 shows the outcome of the voting session.

### Storyboarding

The storyboard method was used as the next step in the ideation phase as a visual way of communicating ideas. It involved creating a series of illustrations and sketches that tell a story or convey a concept, accompanied by notes to provide context. The storyboard is a tool used to explore and test different ideas, to help visualize the flow and experience of a design, and to facilitate communication and discussions. (Boeijen et al., 2010) This is done before proceeding to more detailed design and development. The storyboard were discussed again with designers form the IDE faculty.

### Role Playing

In order to quickly compare between the different ideas, role-playing was used. Role-playing is a technique that involves acting out a situation in order to better understand the needs, motivations, and behaviors of different groups of people. In design, role-playing can be used as a way to gather insights about user needs and behaviors and get impressions about different design ideas. (Boeijen et al., 2010)
To conduct role-playing in the design process, storyboards were created of situations that are similar to the ones that users might encounter when using the design. This was accompanied by sketches of the design to give an idea of how they might look like. This was done with design students at the IDE faculty, from different tracks.
With this, four ideas were selected to further explore in the next section.

## 5.3 Concepts

This section presents the results of the ideation and design process, which produced four distinct design concepts. In this section, each of the four concepts is presented through a storyboard and initial conceptualization.
State of the art is also presented along with the concepts to show how similar ideas work in practice.



Figure 34: Outcome of the voting session

**Idea 1 - Infographic:** *Visual Aid*

The first design idea was to make infographics about PROMs and MyChart. The goal was to inform the patients in a visual way about PROMs and how they can benefit them, and What is MyChart and how they can get it. This is in line with the main design criteria of the project.

The idea was inspired by Visual Contacts (Visual Contracts - Making Legal Content Understandable,n,d), seen in Figure 35, which is a company that uses a visual approach through design to explain complex information to users. This company's goal is to create an inclusive way for people to read information. They also do workshops on how to better visualize different specific terms in their field which could be a direction for this concept.

The infographics would hang in the waiting room so patients could read them while waiting for their appointment.

Based on the design criteria the infographic for PROMs would contain:
- What are PROMs
- What is the purpose of PROMs
- The connection between PROMs and QoL
- How PROMs can benefit the patient
- How PROMs handle privacy

The infographic for MyChart should contain:
- What is MyChart
- How to set it up
- How MyChart handless privacy
- Who to contact for support with MyChart

Figure 36 shows an example of how the first iteration of an infographic looks like and Figure 37 shows a storyboard of how a patient could interact with it.



Figure 35: Visuals from visual contracts
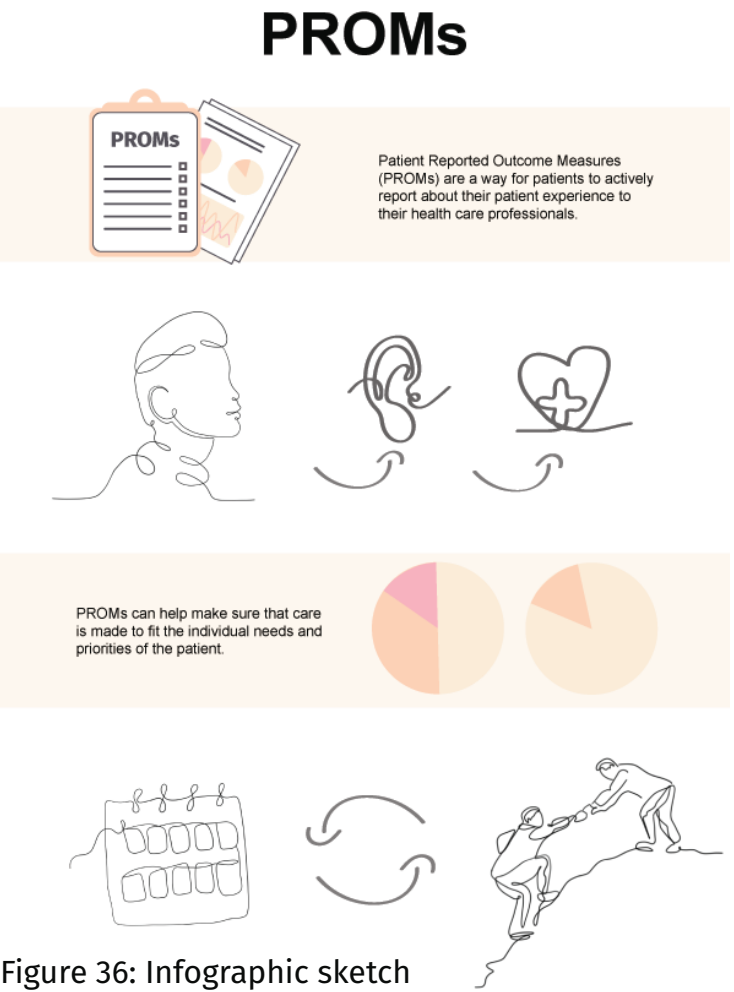


Figure 36: Infographic sketch
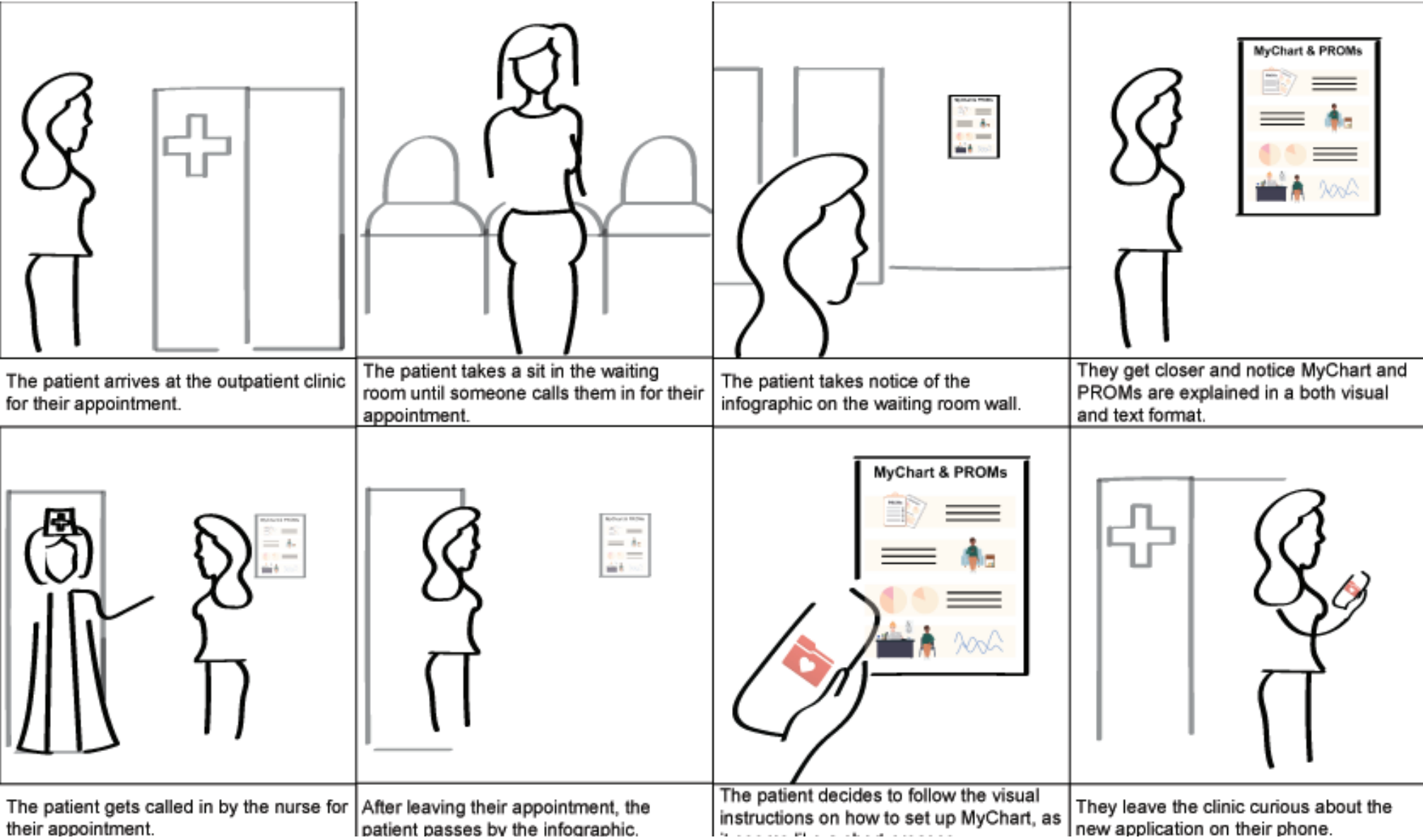


Figure 37: Storyboard of Infographic

The patient arrives at the outpatient clinic for their appointment.

The patient takes a sit in the waiting room until someone calls them in for their appointment.

The patient takes notice of the infographic on the waiting room wall.

They get closer and notice MyChart and PROMs are explained in a both visual and text format.

The patient gets called in by the nurse for their appointment.

After leaving their appointment, the patient passes by the infographic.

The patient decides to follow the visual instructions on how to set up MyChart, as it seems like a short process.

They leave the clinic curious about the new application on their phone.

## Idea 2 – Virtual Coach: *Virtual Nurse*

The second idea was to have a virtual coach, that would guide the patient through learning, without burdening the HCP at the clinic. This fits with the design criteria and the interaction vision.

Examples like The Pathmate Coach or the digital coach called Manoa (Manoa - Your coach for a healthy life, n.d.), seen in Figure 38, supports people in self-management of high blood pressure, type 2 diabetes and sleep problems in everyday life and motivates them to reduce risk factors that can be influenced. Manoa is a fully automated chatbot that responds to the individual lifestyle and needs of users and offers illness and situation-specific coaching and recommendations.
To support the user in everyday life, the app uses push notifications. In this way, Manoa can remind the user to take medication, measure blood pressure or achieve personal goals.



Figure 38: Example of virtual coach

Similarly, the Virtual Nurse could remind the patient about PROMs through notifications and support them through life time changes related to PROMs and the topics from PROMs. The virtual coach could visually and audibly go through the information about PROMs and MyChart, personalizing it based on patient needs. In order to seem more familiar to the patients, the virtual coach would be designed to look like a nurse.
Compared to Idea 1, the virtual nurse could have more interactions with the patient by answering any questions they might have.

Figure 39 shows sketches of how the virtual coach could look like and Figure 40 shows a storyboard of how a patient could interact with it.
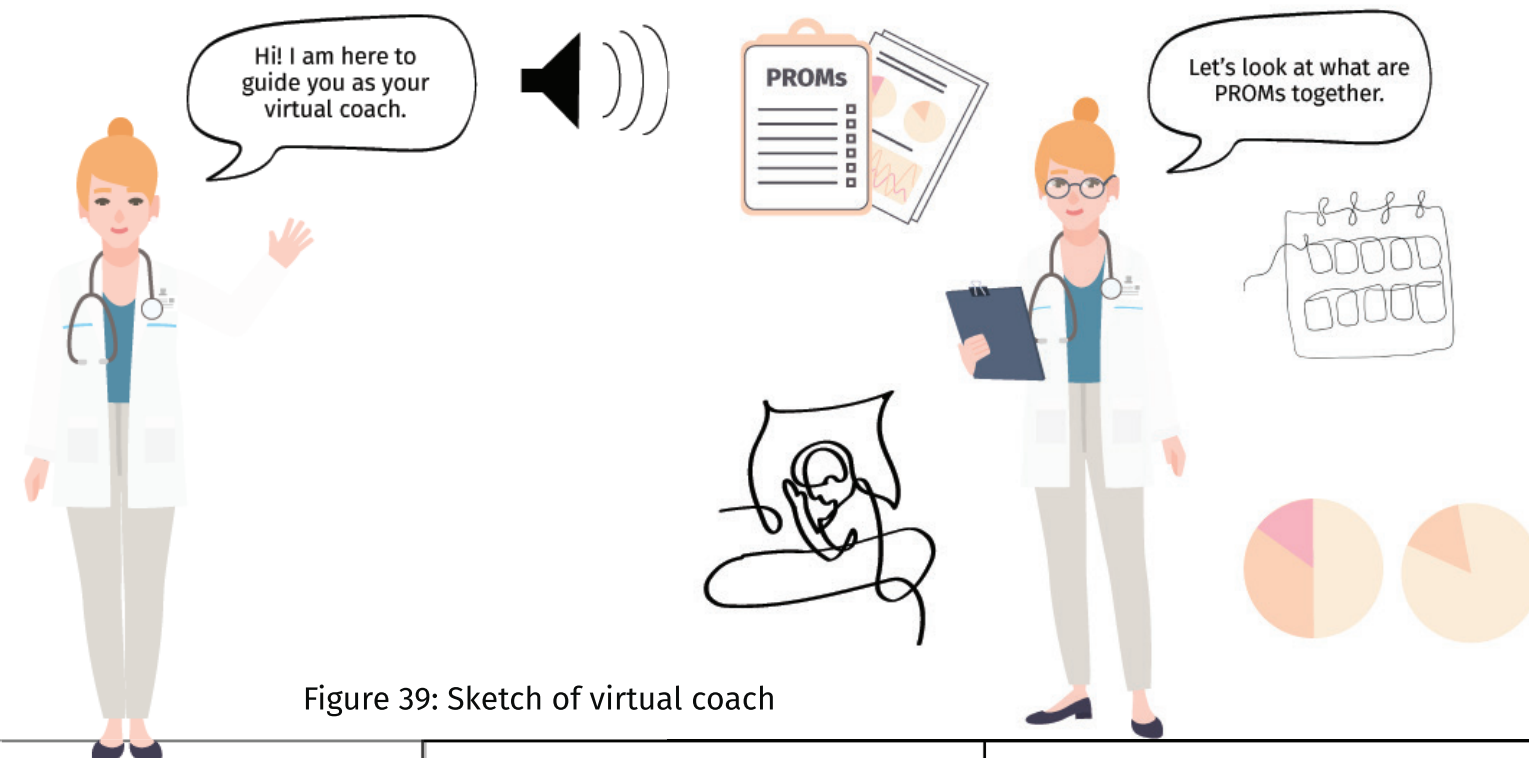


Figure 39: Sketch of virtual coach
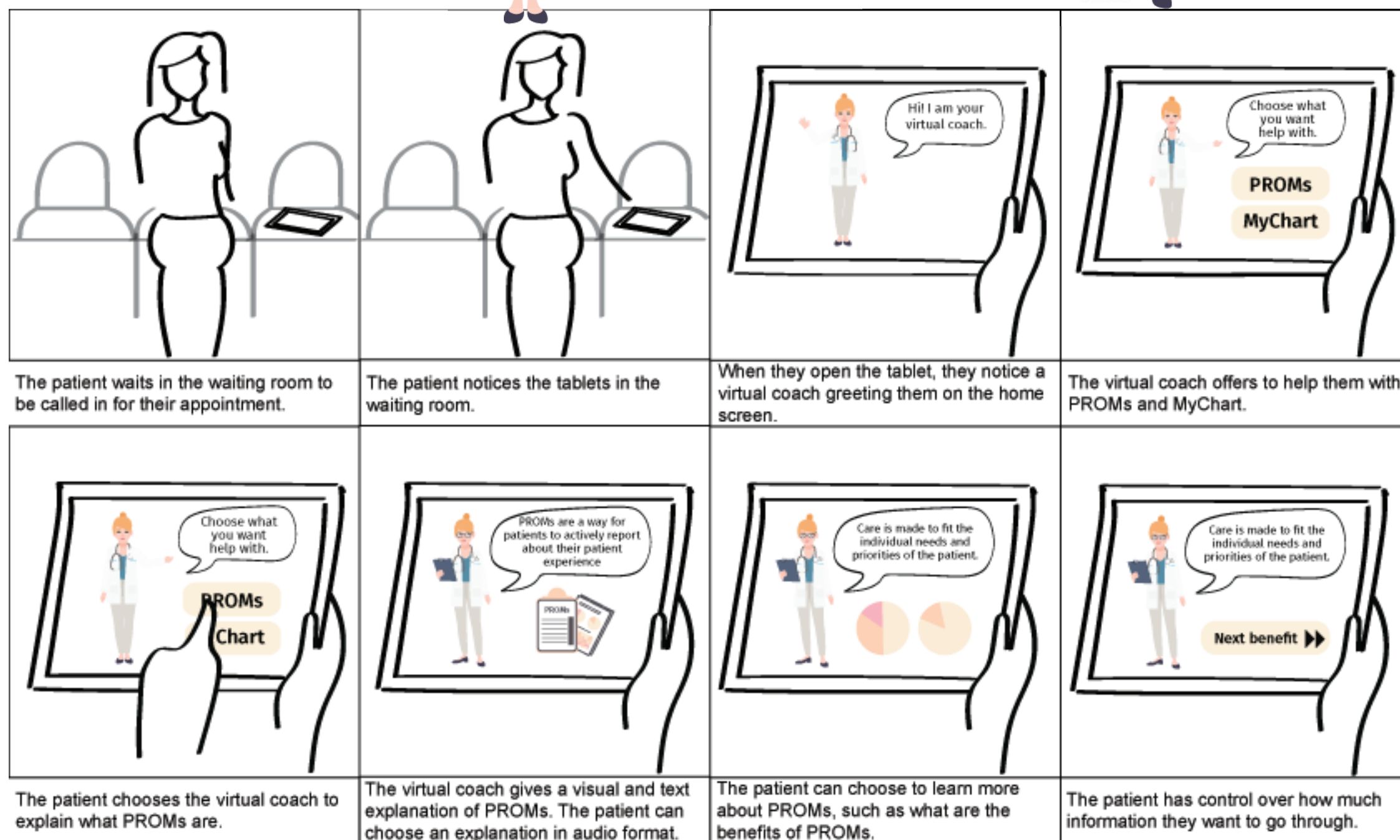


Figure 40: Storyboard of virtual coach

Figure 42: Sketch of patient platform flowchart part 1
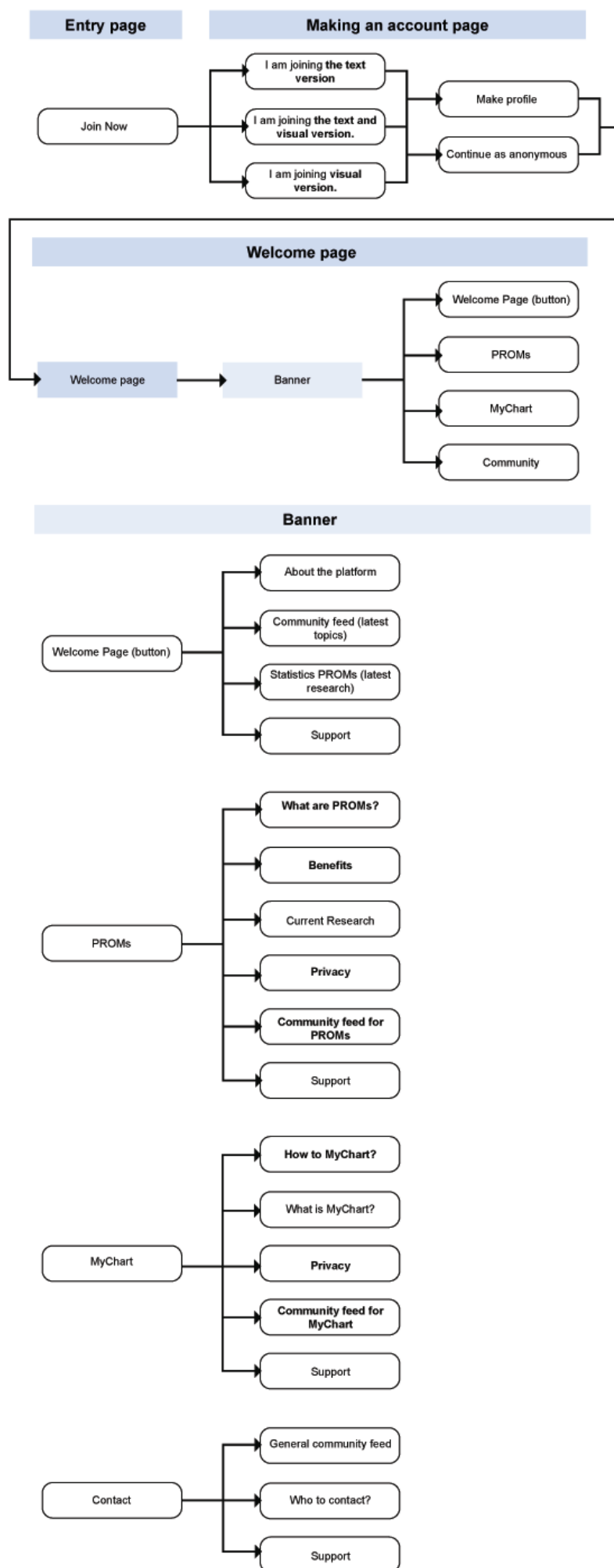
### Idea 3 - Forum for patients: *Patients with PROMs*

The third idea is to have an online community for PLHIV. This is focused on having an accessible way for patients to find information about PROMs and MyChart.

Some online communities like this already exist, such as PatientsLikeMe (Patients like me - Live better, together!, n.d.) in Figure 41.

It would be an integrated health management community, with platforms that inform patients and allows them to ask questions, see other patients' questions and discussions. It would also help patients find support and where to find support.

This platform would have three versions personalized for the patients: visual, text and visual, and only text. Due to it being online, the platform could link the patients to relevant research about PROMs to further inform them about the topic.

Figure 42 shows a flowchart of what the platform would contain and Figure 43 shows a storyboard of how a patient could interact with it.
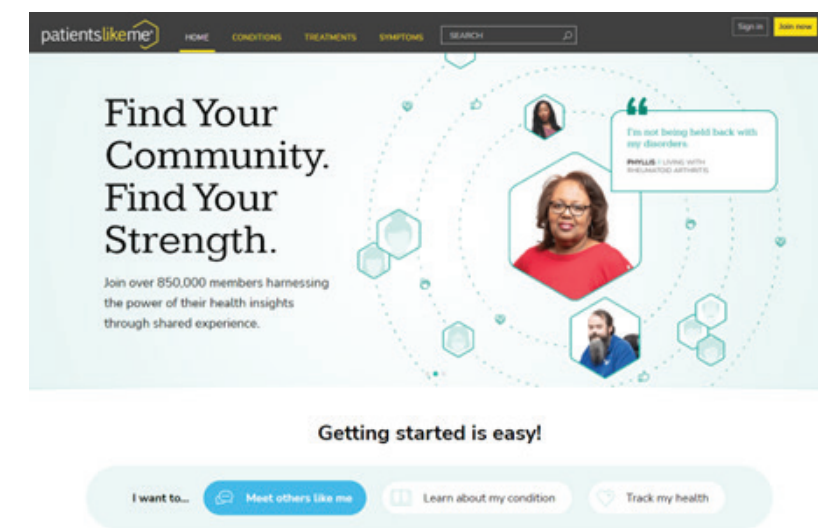


Figure 41: Examples of patient portals
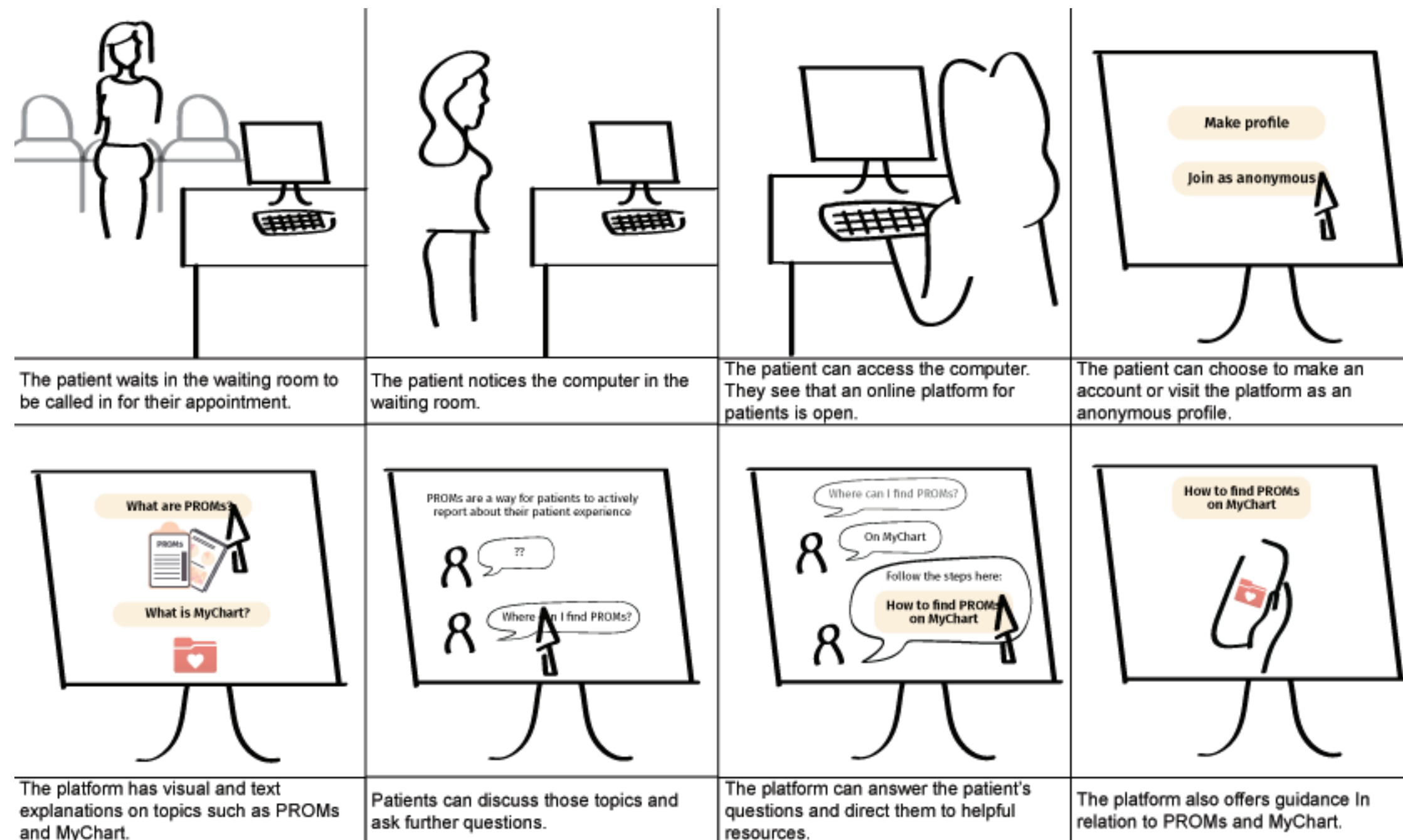


Figure 43: Storyboard of Forum for patients

## Idea 4 – Informative Card Game: *Build a patient's QOL*

The fourth idea was an informative game about PROMs. This idea related directly to the link between PROMs and QoL.

The way it would be played is by having different card types to build QoL, which is translated to points, but only being able to combine a certain number of cards.

If patients were faced with conscious choices about what makes the highest score of QOL they could relate this to their own situations.

The type of cards would be:
- Catrds about PROMs
- Cards about the benefits of PROMs
- Cards about topics from RPOMs

How to play:
- Combinations of cards amount to different points (1 point = 1 QoL)
- There is a maximum of cards you can combine
- The goal is to get the highest QoL score

To find out the results, patients can scan the cards on their phone or with available scanners in the waitig room. The scanners are available for patients that do not have or would not like to use their own phone.

There are examples of gamification being used in medical setting for the purpose of educating patients (Heller et al., 2013). Some examples can be seen in Figure 44.

Figure 45 shows a card about a benefit of PROMs in 3 versions: visual, text and visual and only text. Figure 46 shows a storyboard of how a patient could interact with the game.
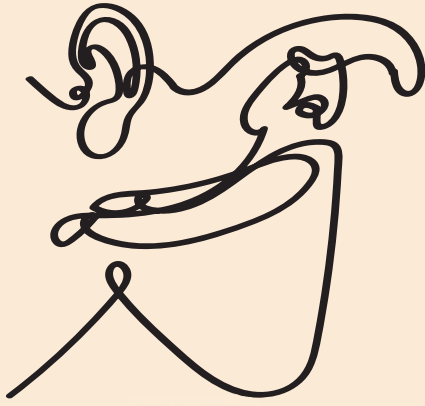


Figure: 45: card about a benefit of PROMs



Figure: 44: Examples of games in healthcare



The patient waits in the waiting room to be called in for their appointment.

The patient notices the card games in the waiting room.

The patient notices the game explains PROMs and benefits PROMs can bring to the patient.

The patient notices the game comes in 3 variations: only visual, only text and a combination between visual and text.

The patient notices other cards about topics from PROMs and MyChart.

Patients can draw a hand of cards. Each card is worth points that contribute to the patient's QoL. (e.g. 8 points = 8 QoL)

To find out how many points they got, the patient can scan the cards on their phone/on scanners in the waiting room.

The goal is for the patient is to get a higher score every time they play.

Figure: 46: Storyboard of Informative Card Game

## 5.4 Choosing a concept

**Harris Profile**

A Harris profile was made for all four ideas. A Harris profile is a graphic representation of the strength and weaknesses a design concept has in regard to predefined design criteria. (Boeijen et al., 2010) The goal is to casually and quickly see which design is better to proceed with.

To create it the design criteria of this project were taken into consideration, starting with the most relevant at the top. This method was used to help guide discussions about the different ideas with other designers and the supervisory team of the project.

**Discussion**

The profiles can be seen in Figure 47.

Concept 1, of the infographic, may seem too loud for some patients to want to read them, as due to the visuals it is a very exposing design. Additionally, while the visuals provide some level of guidance the patient would have to act mostly on their own to receive information. The Harris profile shows it as a weak idea compared to the rest, however its being analoge and personalized to different types of patients is favorable.

Concept 2, of a virtual coach or personal coach, is the most cost-consuming of the rest as it would require the waiting room to have tablets and maintain them regularly. From previous research, it seems unlikely that the patients would download it on their phones due to their distrust of technology. Additionally, patients expressed concern about PROMs replacing the contact they have with the HCPs, which this idea may trigger.

While concept 3, of an online community, might seem at a glance favorable due to the Harris profile, most patients did express a dislike for a community around their diagnosis and expressed some level of distrust towards technology. While having a computer in the waiting room and logging in as an anonymous might help with some of these concerns, the idea does not provide guidance or reason for the patient to explore it.

Concept 4 seems the most promising based on the Harris profile. However, it could draw too much attention if the patients are loudly scanning something in the waiting room. The game also feels a bit simple and allocating random points or QoL to different cards may not align with the patient's values.

This idea was also more favorable during the discussions. It might have an easier time being accepted by the patients, as it would be an analog solution and would use gamification to motivate the patients to use it. Additionally, the information in the game mechanics could be modified to address any issues, as the important thing about the game is the information on the cards.

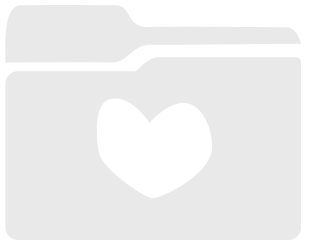With all this in mind, the single-player informative card game was chosen to move forward with.



Figure: 47 Harris profile of the four concepts, numbered after the concepts.

**Chapter 6**

# IMPLEMENTATION

The purpose of this chapter is to cover the process of implementing the concept chosen from the previous chapter and the iterations and further refinement of that concept.

## 6.1 Introduction

Since the concept chosen was a card game that strives to change patient behavior regarding PROMs, this chapter starts with research on persuasive game design. Due to the diverse target group and the design criteria, research into accessible design guidelines was conducted, to make sure the final design is inclusive to as many people as possible.

This led to the initial inception and prototype of the game, which was used for testing with people, before being iterated on and refined based on feedback. The improved design was then tested with the target group and other relevant stakeholders. Key takeaways are presented alongside an analysis of findings gained through this test phase.

## 6.2 Game Design

This section is looking into how to design a game that is accessible and able to change patient behavior.

### Accessible design guidelines:

When designing for people it is important to take into consideration the different challenges people can have in perceiving your design. There are checklists, guidelines, or similar tools to help designers ensure accessibility in their designs. One such institution is Pharos, which has compiled an Accessible Information Checklist. The checklist is meant to assist in designing patient information materials, it is based on the PEMAT (Patient Education Materials Assessment Tool) and the Health literacy Online Test and further refined in collaboration with people with low literacy.
By using this checklist as a guide we can draw some key considerations to have in mind for our game:

Content: The content of the cards should be clear, concise, and well organized, with headings and bullet points to break up the information. The language used should be easy to understand and when possible not use jargon or technical terms.

Color: The color contrast between the text and background should be sufficient to ensure that the text is easily readable by people with visual impairments.

Text size: The text size should be large enough to be easily readable.

Readability: The text should be left-aligned and not justified, with some line spacing to ensure that the text is easily readable.

Testing: The cards should ideally be tested with people who have disabilities to ensure that it is accessible and usable for everyone.

These considerations were kept in mind as the design of the game moves forward: ensuring that the cards are accessible and usable by the widest possible audience, including people with disabilities.

### Persuasive game design

Persuasive game design refers to the use of game design elements and techniques to influence players' attitudes, behaviors, and beliefs. These techniques can be used to persuade players to adopt certain behaviors, such as exercising more or to promote certain values, such as environmental conservation. Persuasive game design can also be used to educate players about a particular topic or to motivate them to act on a particular issue.

Visch et al., (2013) describe a persuasive game design model that operates on three core concepts; the gamification process, game worlds, and behavioral change design. Figure 48 shows a simplified version of the relations in this model. Transfer can happen from game world to real-world, this means the game world can motivate users to do things they otherwise find hard to do in the real-world. This can happen through for example changing the attitude of the user regarding something in the real-world.

One example is the use of "gamification," which involves adding game-like elements to non-game contexts in order to make them more engaging and motivating. Gamification can be used in a variety of settings, including education, health, and marketing.

## Defining the idea

To make the card game we must consider the persuasive game design model and the accessibility guidelines. In order for the design of the game to succeed we make the following clarifications on how to obtain the desired elements.

### Purpose of the concept

In line with the design goal, the purpose of the game is to inform patients about the benefits and patient-focused purpose PROMs serve. A change in attitude and motivation is the transfer effect we wanted to obtain.

### Transfer effect

In order to transfer this motivation we must teach users about PROMs, their purpose, and their benefits to the individual. Secondary to that is teaching about MyChart as PROMs are inaccessible without this portal.

### Game world experience

The game world experience will be to build a path of cards and obtain points from the game. In doing so the user must obtain the knowledge the cards offer.

### Real-world experience

The real-world experience is the reflection on how PROMs and MyChart are connected and how they can contribute to the users' QoL. There is also the real-world experience of doing better. The game is played solo and you are therefore fighting your own past scores.`

### Goal

The goal of the game is to stack cards out from a starting point in order to build as long a path as possible, awarding a high QoL score. This score is a measurement of how well the user did and will be affected by how well they understood the information from the cards.
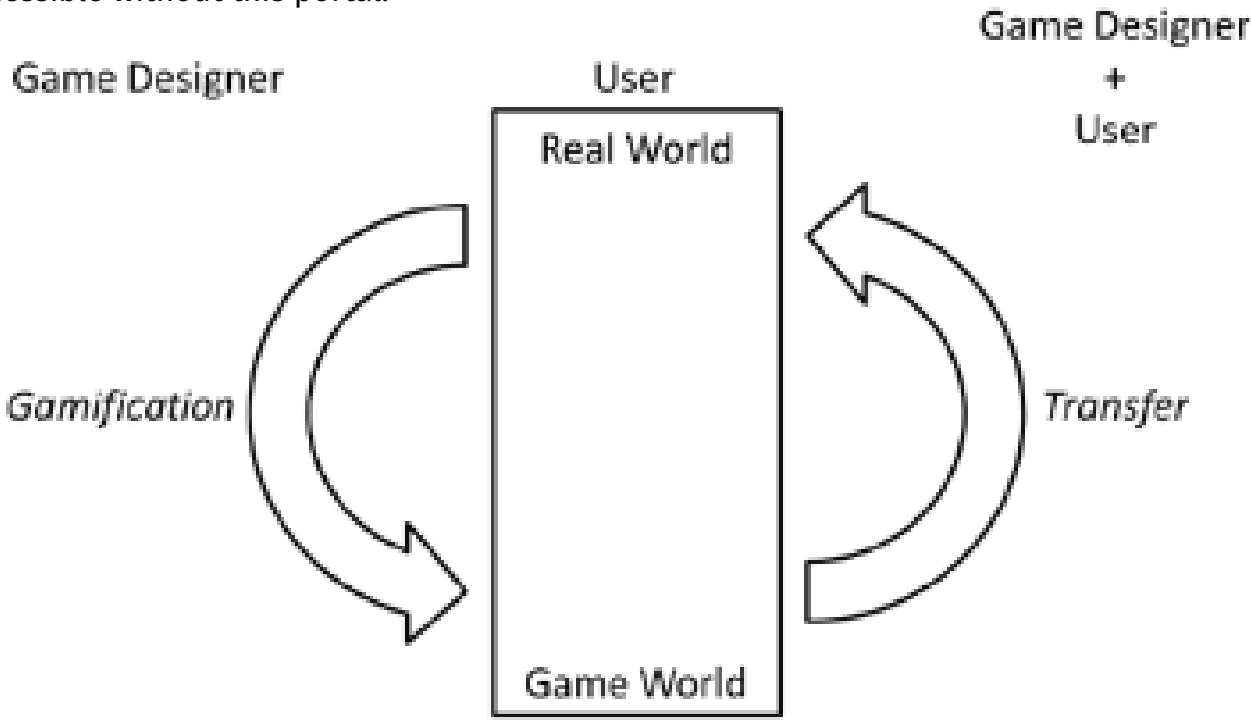


Figure 48: Simplified form of the Persuasive game design model

**Type of cards**

In order to facilitate this we need game pieces. First, a main card explaining PROMs and QoL in a general sense. We use this as the starting point for the path.

Next, we need to make the path-laying cards. Honing in on the core principles of the information we want to convey these cards should ideally fit the theme of health and have something to do with PROMs, benefits, and MyChart.

Three categories of knowledge were made, one for the Benefits of PROMs, one for MyChart, and the last one for Topics in PROMs. This can be seen in Figure 49.

**Duration**

The game should be played within 15 min as that is the duration described most often by patients that they have to wait. If the waiting time is longer or they play at home, the player should be able to play more times.

For this reason, only a limited number of cards will be played with per round.

**How to play**

First, the game must be set up, for this, the starting card is placed down in the middle of the play area, with the card side that has markings in the corners facing up. Then all remaining cards are shuffled face up. It is important the player does not look at the back of the cards.

After the setup of the game is finished, play continues in three phases: a draw phase, a play phase, and a scoring phase.

In the first phase, cards are drawn to make the playing hand, still without looking at the back of the cards. The number of cards drawn is up to the player. This ensures control over how long a round will be and the amount of information presented to the player.

The second phase starts immediately after the playing hand has been drawn. In this phase the player plays a card from their hand, making sure to align one of the markings on it, with one in play, effectively making a path of cards, see Figure 50 for a possible way it could pan out. This action repeats until the player has no more cards on hand or until they can no longer match any cards in the play area.

Then begins the last phase, counting the QoL score. This is done by flipping over all the cards, now looking at the card back and counting the longest paths made with cards in the same category obtaining one point per card pairing in the path.

This means that besides matching cards players must obtain the information on the cards and reflect on what category it falls into. Only cards from the same category that connect to each other will give a point.
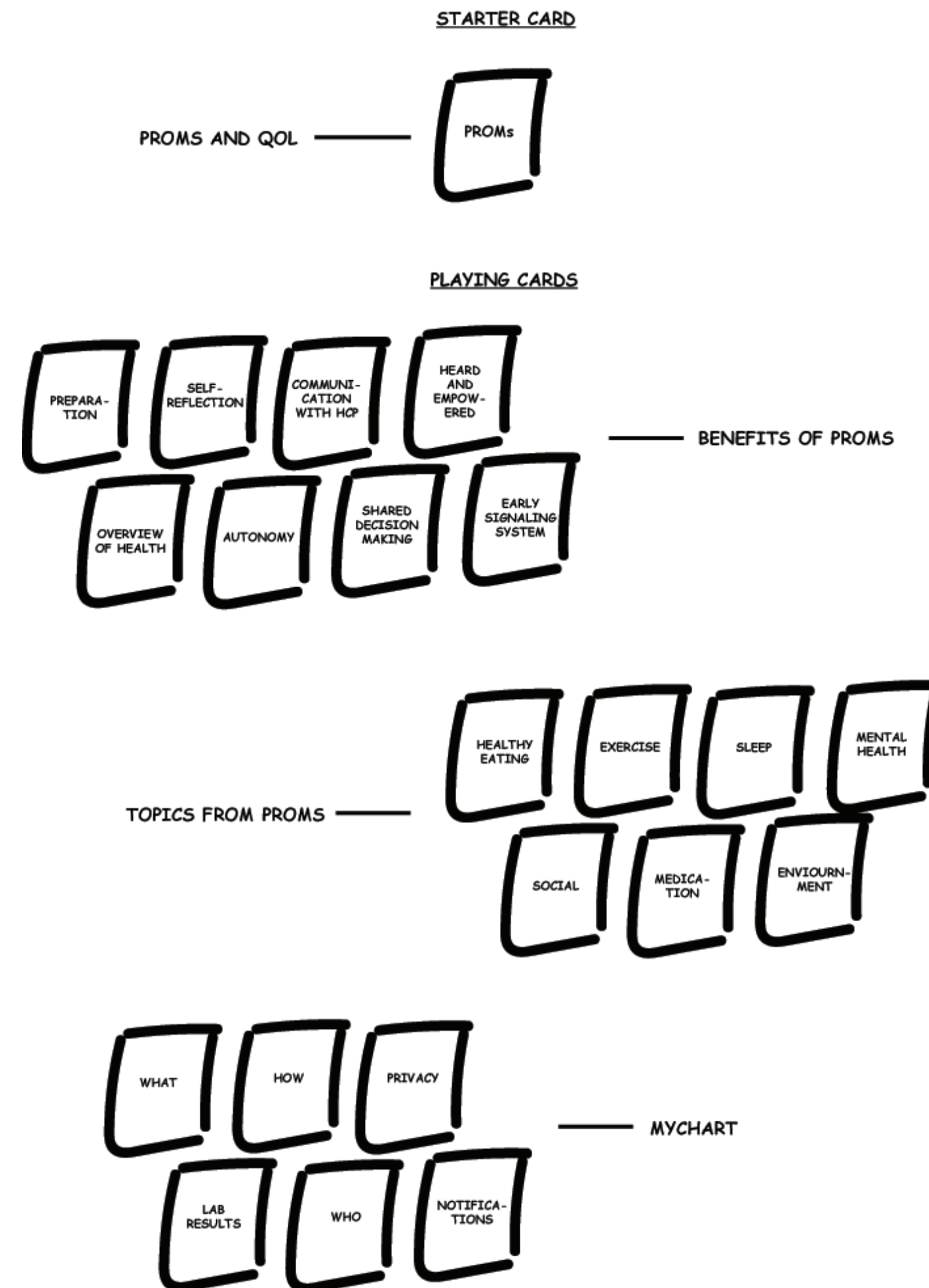


Figure 49: The different knowledge categories of cards

## 6.3 Prototyping

Prototyping is one of the co-creative design methods that advocates Human Centered Design (HCD) and is often used in the iterative design process of eHealth applications (Hochstenbach et al., 2017). HCD focuses on the needs and requirements of users, and by doing so enhances effectiveness and user satisfaction (Grimaldi et al., 2020). Therefore, a qualitative prototype test actively involves the users by letting them test and evaluate the prototype, as recommended in the data-enabled design 8-shape model of van Kollenburg & Bogers (2019).

Prototyping can thus be seen as a good way to co-create with your users. This is also important when you want to design for patient empowerment as it is part of the antecedent 'patient-centered' as described in chapter 2.4. By prototyping, you can make your idea more tangible and show it to your users for discussion. By discussing it you can together explore the value that your idea could create and what is currently still missing or should be changed.

Font
The text on the cards should keep up with the serious tone of colors, but also still convey a bit of warmth. As the cards will have rather small text, choosing a humanist typeface will be a good choice. Specifically the typeface Fira Sans, has nice and clean strokes, is easy to read, and has a vibe of seriousness with a touch of human warmth.

Colors
Color psychology can be a big aspect of design, and in the given context of this project, it is relevant as it can be used to attribute perceived values to the cards and the information they present.

Based on common values attributed to colors, three primary colors were picked for the cards; these three colors are blue, green, and orange. Each color will be representative of a category and be used in the visuals on the cards. Other colors will be used in the visuals as well, however, the three highlighted ones are of special importance as they will each represent one of three knowledge categories, Topics in PROMs, Benefits of PROMs, and MyChart.

Blue was chosen because blue is often associated with trust, stability, and professionalism. These are all important qualities to convey in a game about medical information, as patients need to feel confident in the accuracy and reliability of the information they are receiving. It aligns well with the information we want to convey to patients about the topics of PROMs.

Green was chosen because green is often associated with growth, health, and positivity, which aligns well with the benefits of PROMs topic, such as improved patient satisfaction, better outcomes, and increased engagement in their own care.

Orange was chosen because this warm color evokes feelings of optimism, energy, and excitement, which aligns with the goals of PROMs and the hope they can bring to patients and their healthcare teams. It was chosen for the third category MyChart, as that is how patients can access PROMs and it is better if they are optimistic about doing so.

Overall, the color choices for the cards should help effectively communicate the key information about PROMs and help to create an engaging and informative game that communicates the benefits of this medical tool.
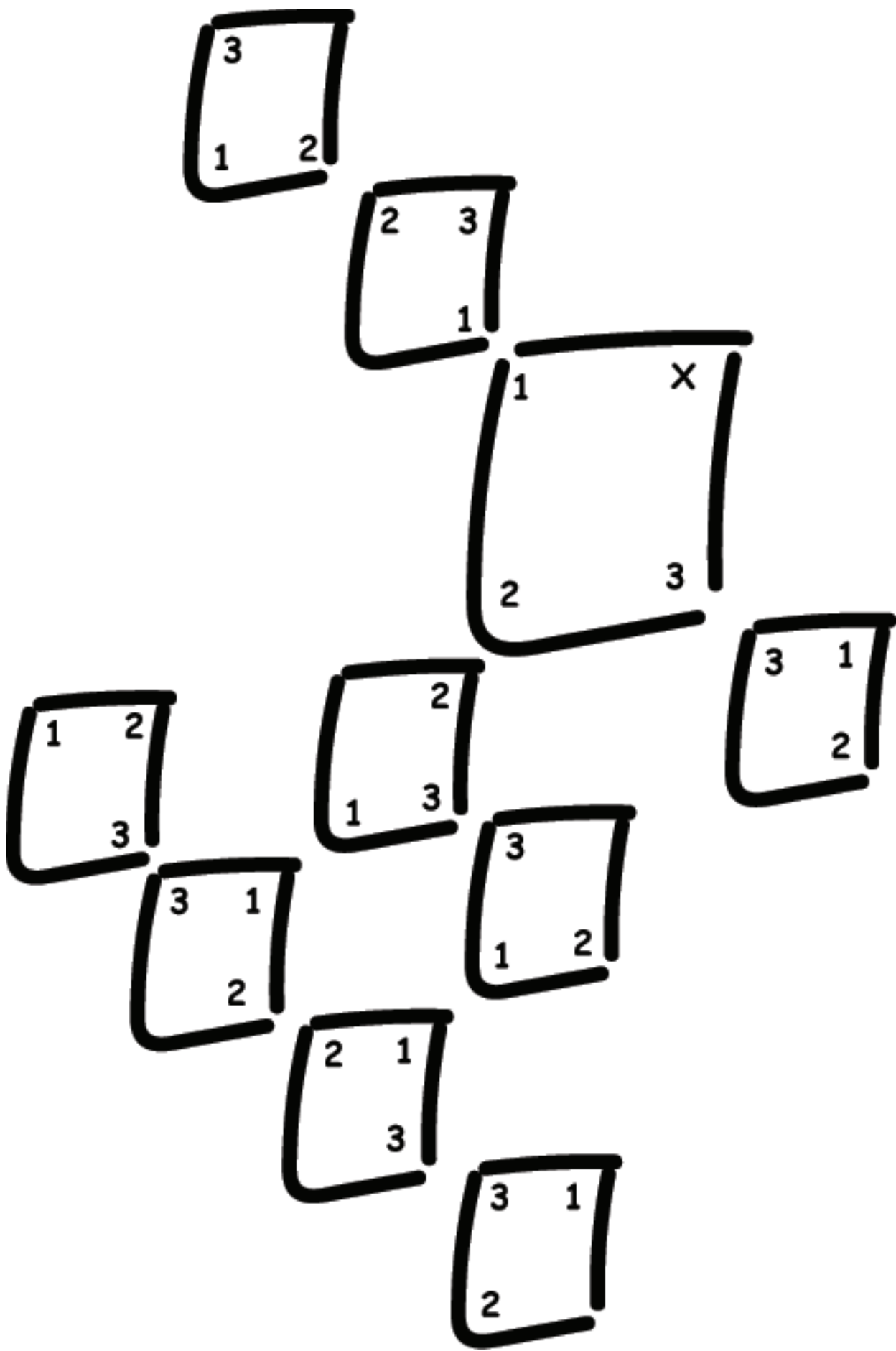


Figure 50: Concept of the path building element of the card game

## Cards

The first card that was made was the starting card. On one side it was made to contain information about PROMs. The information is general about PROMs and avoids overlap with the two knowledge categories related to PROMs. This side of the card will also contain the markings used for the path-building of the game. Learning something general about PROMs was a good entry into the game. Since we know from Figure 3 that patients are most likely to not have encountered them before. Instead of a card back for this card, another side of information is present. Information about QoL, chosen as this side of the card is revealed alongside the card back of other cards, once the player is counting their QoL score. In this way, information is presented when it is relevant and later serves as a reminder once a player has become a veteran at the game. The starting card being larger than the rest and being the only card that does not have a card back makes it easily distinguishable from the rest of the cards. This is ideal as it is the first card needed for play.

For the three knowledge decks, the first thing designed was the card back. An icon to identify each category was made and combined with the color attributed to the category. Thus, three unique card backs were made and can serve to easily distinguish between the three types of cards for the third phase of the game. A checkmark icon was made for the category of Topics from PROMs. A heart with a plus icon was made for the Benefits of PROMs category. Lastly, an icon symbolizing MyChart was made with inspiration from their official app store thumbnail for the category of MyChart. See Figure 51 to see the three icons.

Designed for different motivations

From the personas in Chapter 3, we have some insights into the diversity of the target group. In order to be as accessible as possible three different versions of the cards were made. One version of the cards containing only text, one version of cards contains only visuals, and the third was a combined version.

The text version of the cards was made with the on top of everything persona in mind, they are heavy on learning which might appeal to this archetype.

The visual version was made with the not involved persona in mind, these patients may have a lack of health literacy or a language barrier preventing them from engaging.

The combined version was made with the tell me what to do and too busy personas in mind, they were made to be easier to read than the only text version, which could lead to the tell me what to do archetype to engage with them on request from an HCP. The too busy archetype could play the game with these cards to learn from them and since the game is designed with the player in control of the playtime they could start with a small number of cards. If they like it they can come back and play again.
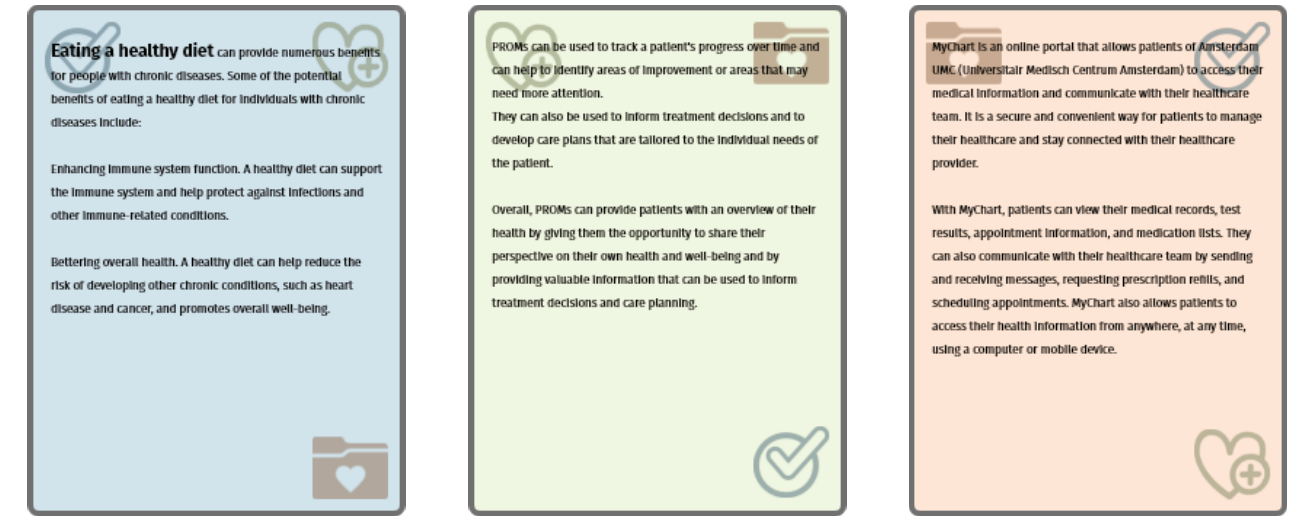


Figure 52: Some of the cards from the first lo-fi prototype



Figure 51: The different icons made for the cards



Figure 53: Some of the cards from the first high-fi prototype

## 6.4 Testing

To ensure the design concept works as intended, a series of lo-fi and high-fi tests were conducted. This allowed for testing different elements of the chosen concept and refining them before developing the final design.

## 6.4.1 Aim

The aim of the lo-fi test is to test the different elements of the concept through multiple iterations. The elements this testing focused on were:

- Text: Is the text clear? Does it convey the intended information? Is it suitable for the context of the project?
- Visuals: Are the visuals clear? Do they convey the intended information? Are they suitable for the context of the project?
- Game elements: Does the game make sense? Can people play it? Does the scoring system make sense?

Finally, the aim of the high-fidelity test is to ensure that all the above elements make sense together.

## 6.4.3 Participants

Since the aim of this testing is focused on the design of the concept, the testing was done with participants outside the target group. 9 people participated throughout the testing. While 6 of them were students at the IDE faculty, 3 of them were students from other faculties.

While the supervisory team was not part of the testing they participated in discussions about the design.

This provided a wide range of perspectives on the design.

## 6.4.2 Method

### Low Fidelity Testing

Low-fidelity testing refers to the testing of a product that is still in an early stage of development and has limited functionality or features. It is a type of testing that is usually performed with prototypes that do not accurately represent the final product. The purpose is to identify any problems with the design and user experience early on, so that they can be addressed before the product is fully developed (Muratovski, 2022), see Figure 52 for some cards from the lo-fi testing.

Pictures of the low-fidelity cards were shown to people while conducting informal interviews and discussions with different prototypes. Note taking was used to record the feedback of the participants.

### High Fidelity Testing

High-fidelity testing refers to the testing of a product or system that is near or at its final stage of development and has most of its intended functionality and features. High-fidelity testing provides a realistic simulation of the user experience, see Figure 53 for some cards from the high-fi testing.   (Muratovski, 2022)

A high-fidelity paper prototype was made to determine if people are able to use a product before testing it with the target group. Notes and video recordings were taken during this test to record the participants' impressions and feedback.

### Analysis

The analysis was done based on notes and video recordings done during the testing. Recurring themes were clustered together and in the end, pain points were gathered. Those pain points were categorized based on the elements described in the aim section. Due to the aim, the pain points are on an interaction level.

## 6.4.3 Insights

### Text Element

All participants understood the text and thought it was clear what it was supposed to convey. However, most of them thought the amount of text was intimidating and some words were too complex. The main pain points were:

- Overload of information: The amount of text is intimidating even for the only-text version of the cards. One participant mentioned that it *"Feels like I am reading a newspaper, not a game"*.
- Complexity: Some words seem too complex especially for the combined version of the cards. Another participant mentioned: *"I can see how it can feel a lot for some people, especially if they already feel anxious"*

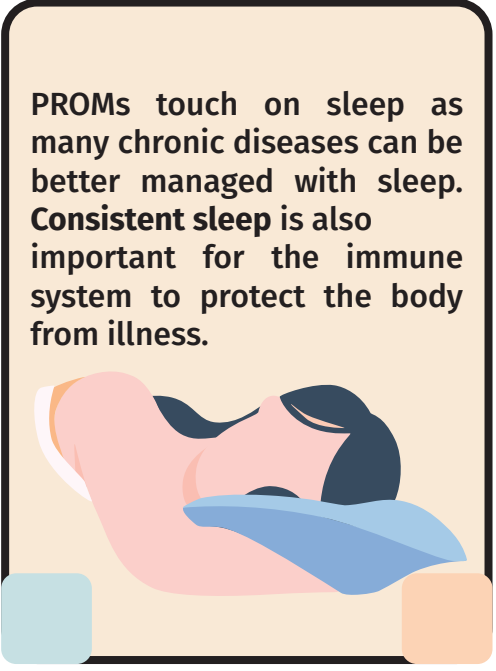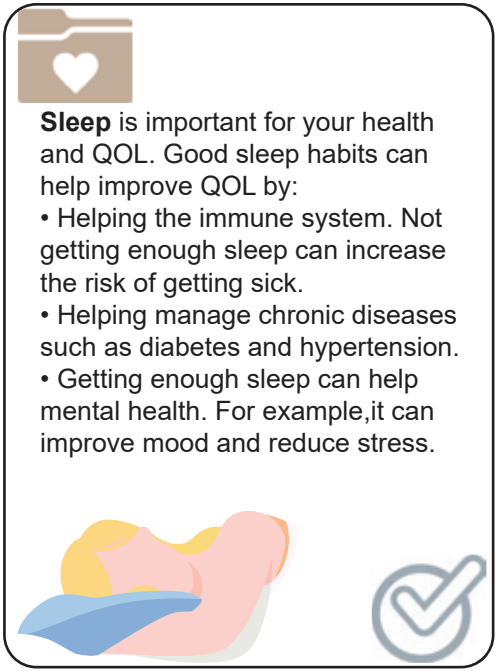Figure 54 and 55 show how these pain points were addressed.



Figure 54: Combo card used for the high-fidelity test and modified version of the same card.

PROMs allow patients to self-reflect when it comes to their health by:

Providing a structured way for patients to reflect on their health: PROMs provide a standardized set of questions that patients can use to report on their health status. This can help patients to focus on specific aspects of their health and to reflect on how these aspects are impacting their daily life.

Allowing patients to track their progress over time: PROMs can be used to track a patient's health status over time. This can help patients to see how their health has changed and to identify areas of improvement or areas that may need more attention.

---

**PROMs can help patients with self-reflection by:**

- **Providing a structured way for patients to reflect on their health. PROMs provide a standardized set of questions. This can help patients focus on specific aspects of their health and reflect on how these aspects impact their daily life.**
- **Tracking a patient's health status over time. This can help patients see how their health has changed and identify areas of improvement or that may need more attention.**

Figure 55: Text card used for the test and modified version of that card

### Visual element

In general, the participants gave positive feedback about the style of the visuals, by saying it is not too complicated or too simple. Comments included that it was not too bright, not exaggerated or belittling.

While it was easy to understand the combined verion of the cards as it provided both visual and textual aid, some illustrations from the visual cards were often misunderstood. Those illustrations are included in the following pain points:

- Starting card: 2-way thing, you tell the doctor your problems and they can help you
- Self-reflection card: person thinking about themselves, looks like you are tryng to connect with yourself,
- Heard and empowered card: hand on a patient to show empathy, looks like they are listening to other people's advice
- Shared decision making card: (asking doctor to know more, honesty between them should be hand on a patient to show listening)

- Being prepared for consultations card: not sure what it means, is the HCP explaining? Or is everything with patient neg and they are confused - minuses
- Patient autonomy card: looks like there is only one right path that you have to choose

The supervisory team and participants thought that having keywords on the cards might make it easier.

Other pain points that were repeating between participants regarding the visuals were:

- Plus seems to be a medical aid
- The plus on the cards can be confused with the icons due to the size. Additionally, some people thought it meant a benefit.
- Associating heart with health rather than a benefit of PROMs
- (should look the same for consistency and to seperate them from the rest of the visuals)

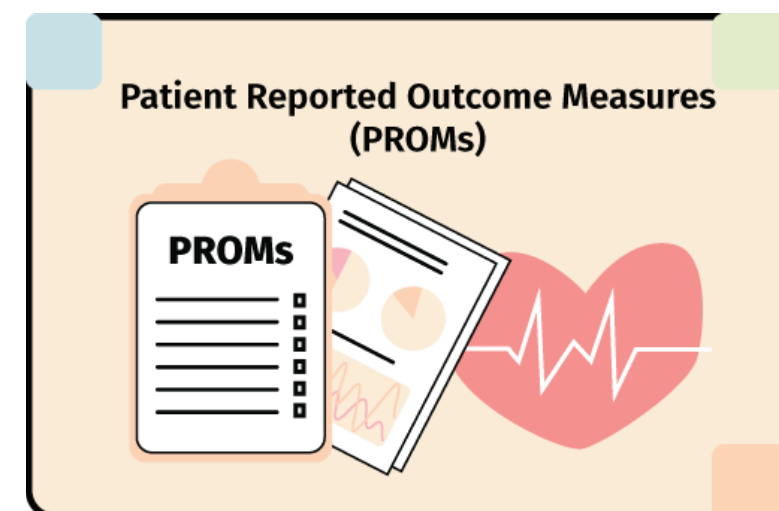Figure 56 shows how the pain points were tackled:



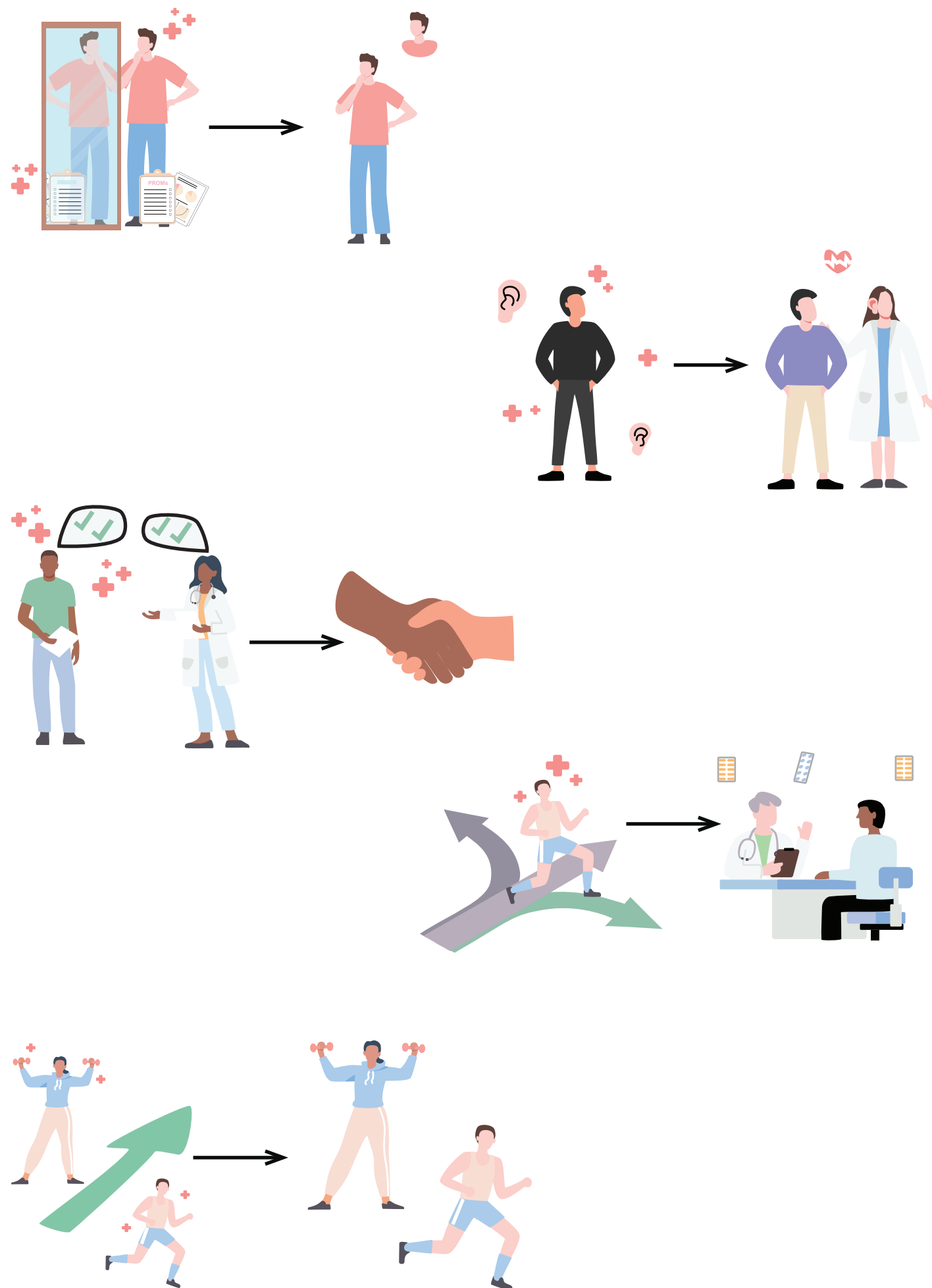Figure 56: Starting card used for the test and modified version of the card

Figure 57: Different visuals and how they were modified based on feedback

## Game Elements

After a short explanation of the game, accompanied by a guide, the participants were able to play right away and expressed thinking it was easy and clear. However, while talking out loud the following pain points were gathered:

- Easy to see the back, and easy to cheat
- People forget that only the longest line counts, as they may get more matching cards in another or they can not put them together as they want to - cause for frustration
- Some would like to play with others as they want cmpetition
- People thought the icons relate to the content on the card, when they were actually random.

One participant read the cards before but did not revisit them after finding out the score, even though they only matched 2 out of 6 cards. The majority of participants read the content before and after to see why they scored the way they did. Those participants had a better recollection of what was on the cards. One participant only focused on getting points and read the content after seeing what category the card belongs to. Then they continued playing and tried to remember the cards. One participant mentioned *"Every time I played I learned something new."* Another one said: *"I retain information quicker because it is a game."*
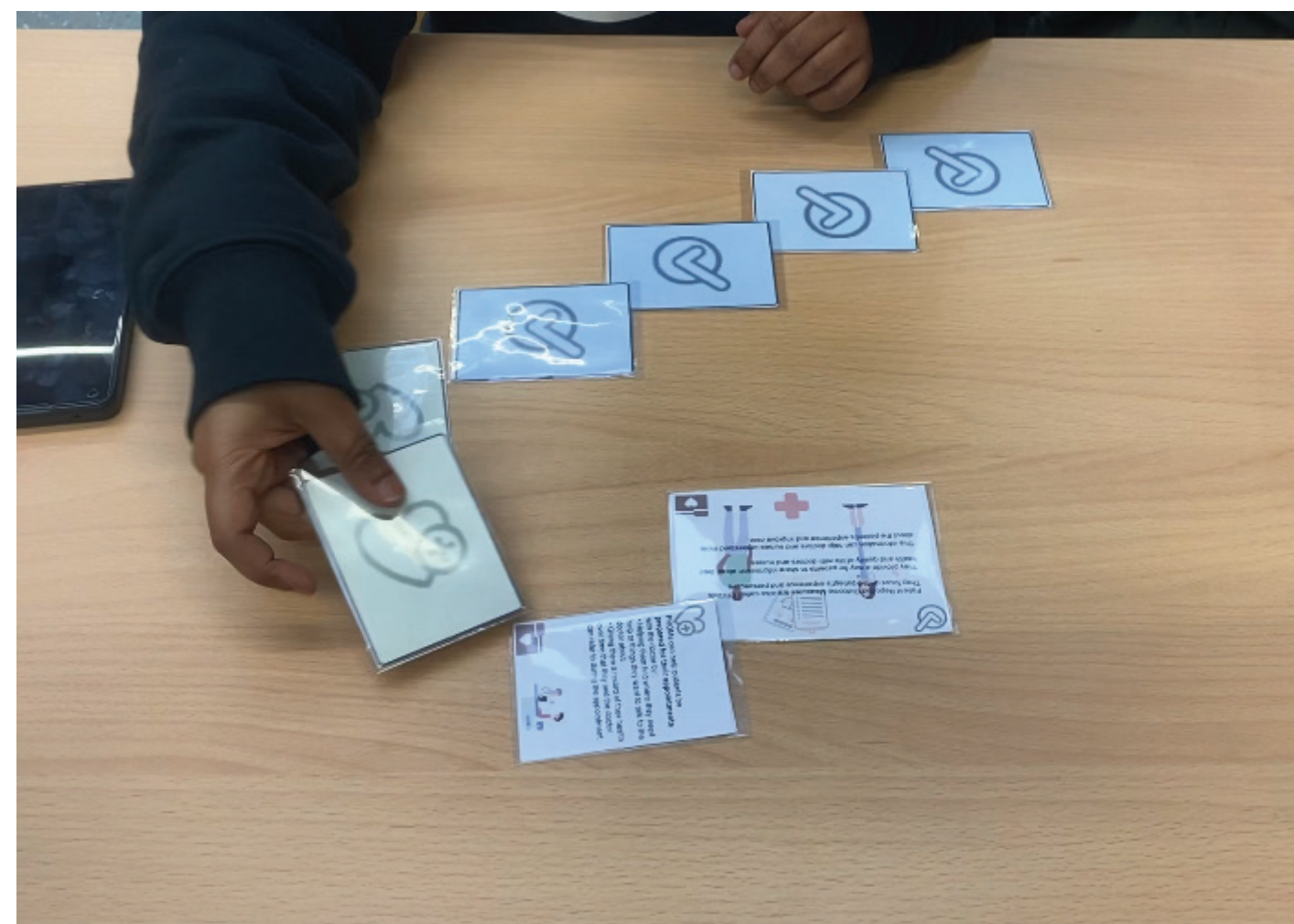
### 6.4.4 Takeaways

While many pain points found throughout the test were tackled in the previous section, the takeaways for future research were:

- **Potential in learning about PROMs**
  Most participants did not know what PROMs were before this test. After the test they have shown an understanding of the topic and how PROMs could benefit them

- **Potential for multi-player game**
  Some participants asked if they can play with a friend. During the game they have been debating the topics on the cards showing a deeper understanding

- **Potential for improved communication**
  Based on the previous takeaway there is a potential for learning by playing with multiple people. Due to the target group this will not be implemented, but will be asked in the next test with the target group

### 6.5 Final Concept

This section focuses on showcasing and explaining the final concept that will be tested with the target group.

**Final design**

PROMis for quality care is a single-player informative card game for PLHIV that teaches them about the benefits completing PROMs can have on their QoL. It has a focus on three key areas of PROMs, namely, what are the benefits, what are the topics, and how one uses MyChart to access it.
The game comes in three different versions and the one most fitting a patient's level of literacy, motivation, and language should be played.
The game also comes in two different packaging boxes. One meant for the waiting room at the hospital and another meant for the home.

The starter card can be seen in Figure 58. The different types of cards are seen in Figures 59, 60, and 61.

The new back and icons can be seen in Figures 62 and 63.
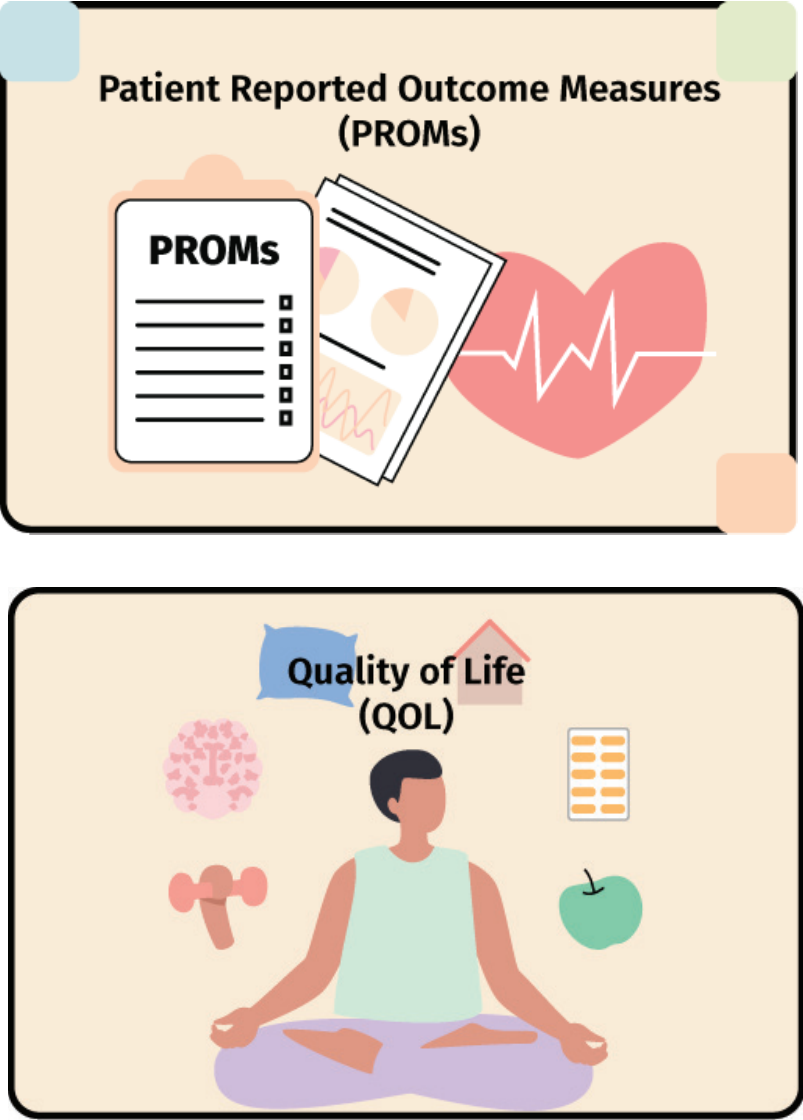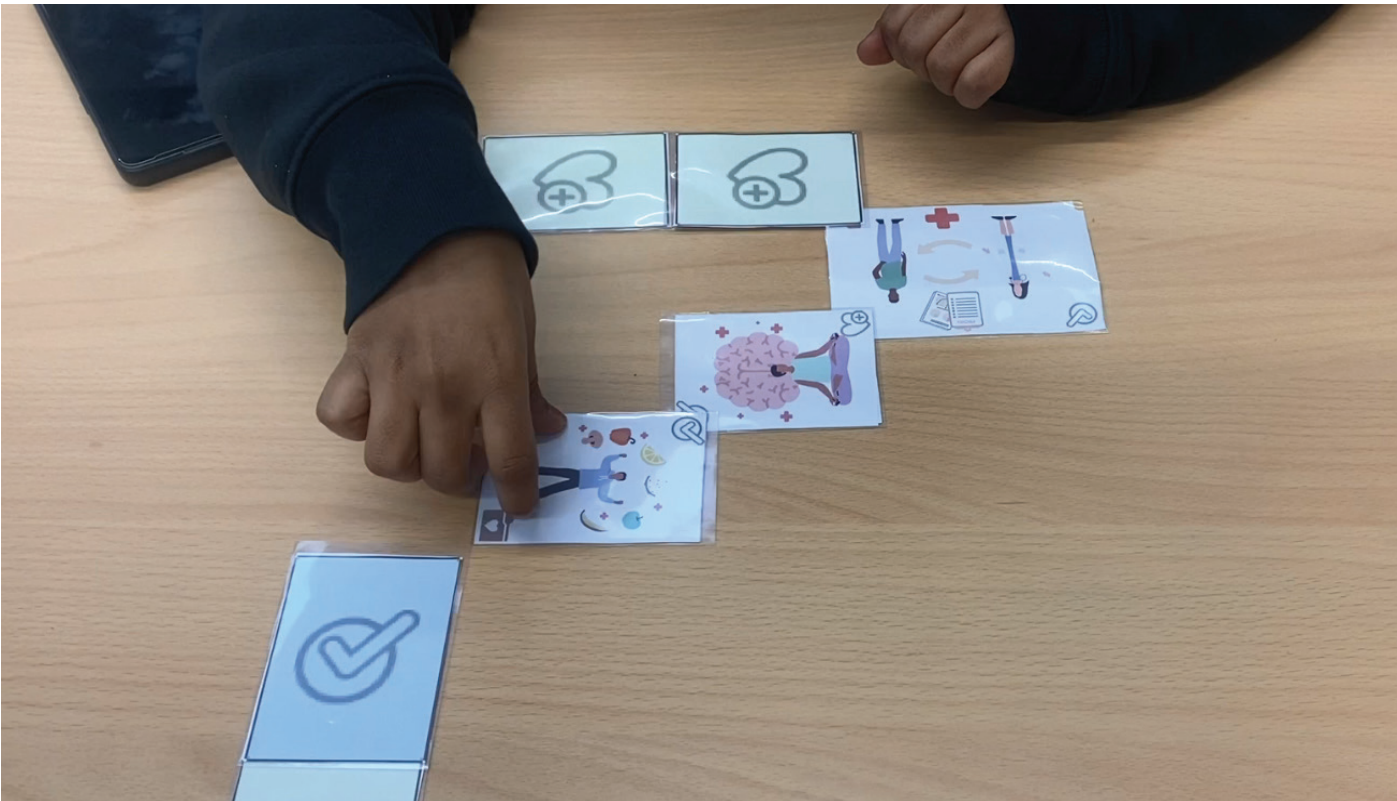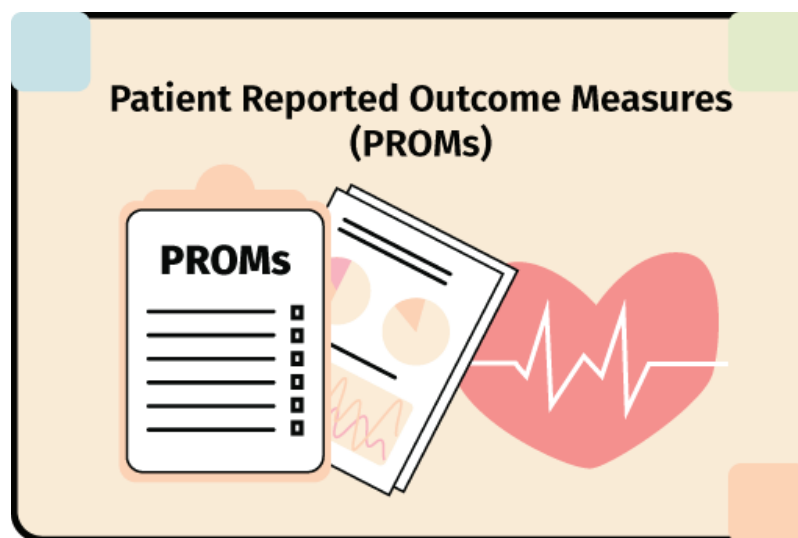
The packaging can be seen in Figure 64.



Figure 58: Starter Card

## Visual

This version of the game is made for patients who lack health literacy or are facing a language barrier. The cards have nothing more than a title and a visual to help the player identify what category it belongs to.

The visuals are meant to speak for themselves and use recognizable items to help patients be able to identify what exactly it is.

Compared to the combined version this set of cards may be more inviting for patients who arrive stressed out at the clinic. The design is easy on the eyes and use a blend of soft and warm colors.
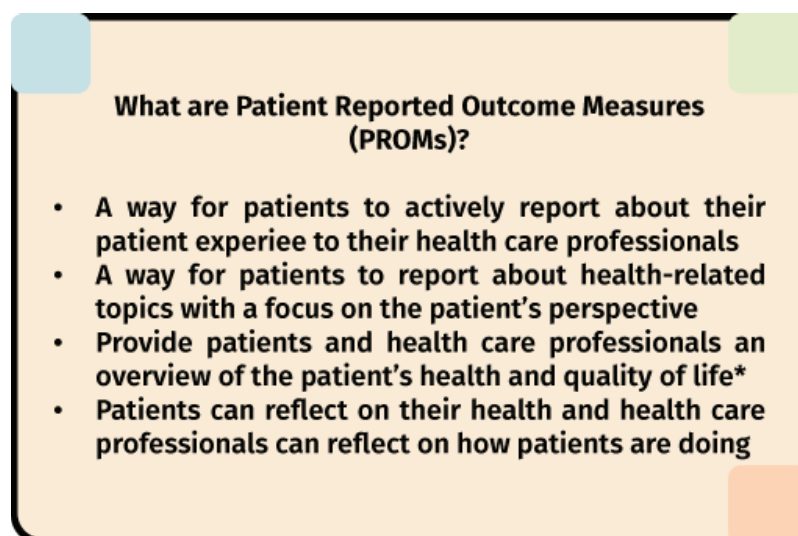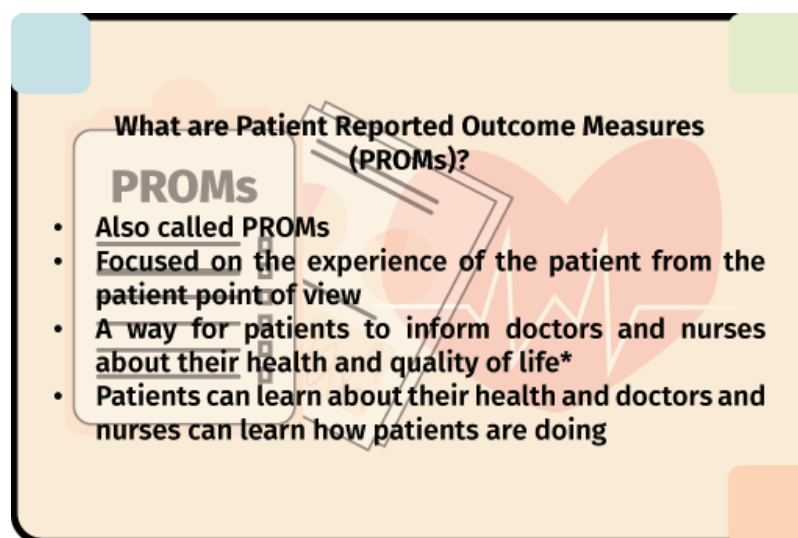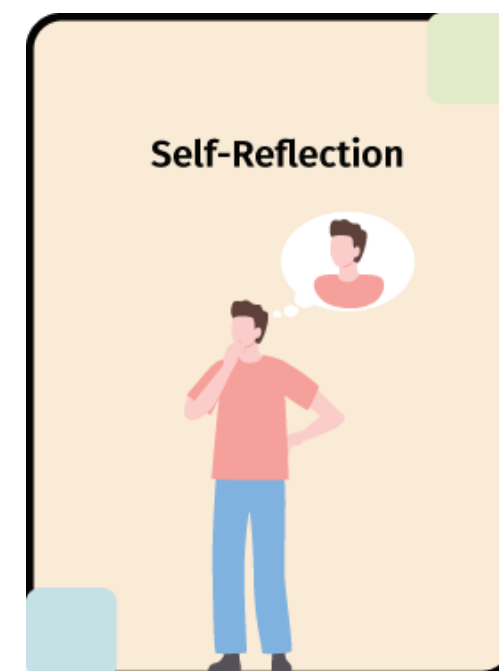
### Patient Reported Outcome Measures (PROMs)

PROMs

### What are Patient Reported Outcome Measures (PROMs)?

PROMs
- Also called PROMs
- Focused on the experience of the patient from the patient point of view
- A way for patients to inform doctors and nurses about their health and quality of life*
- Patients can learn about their health and doctors and nurses can learn how patients are doing

### What are Patient Reported Outcome Measures (PROMs)?

- A way for patients to actively report about their patient experiee to their health care professionals
- A way for patients to report about health-related topics with a focus on the patient's perspective
- Provide patients and health care professionals an overview of the patient's health and quality of life*
- Patients can reflect on their health and health care professionals can reflect on how patients are doing

Figure 59: Starter Card, PROMs side, all 3 versions.

## Combined

This version of the game is made for patients who are interested in learning more about PROMs and their impact on their care and QoL.

Compared to the text version this version of cards may feel easier to pick up for patients who are usually too busy to seek out new information.
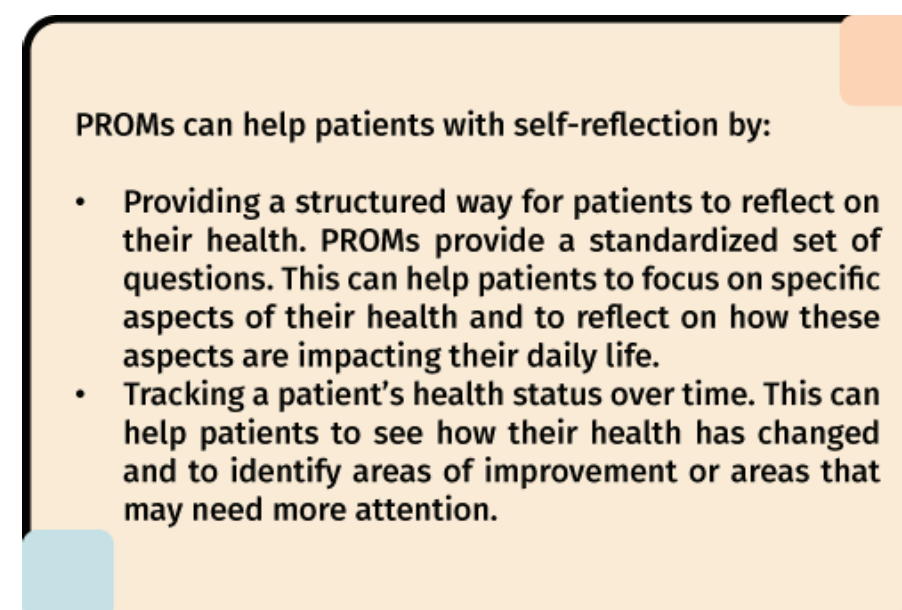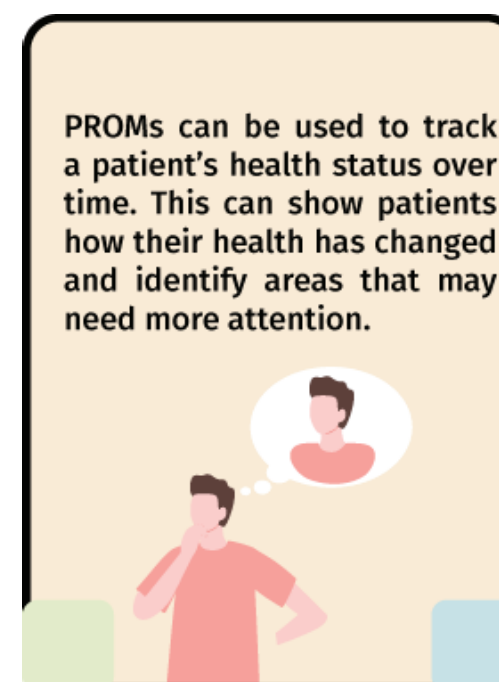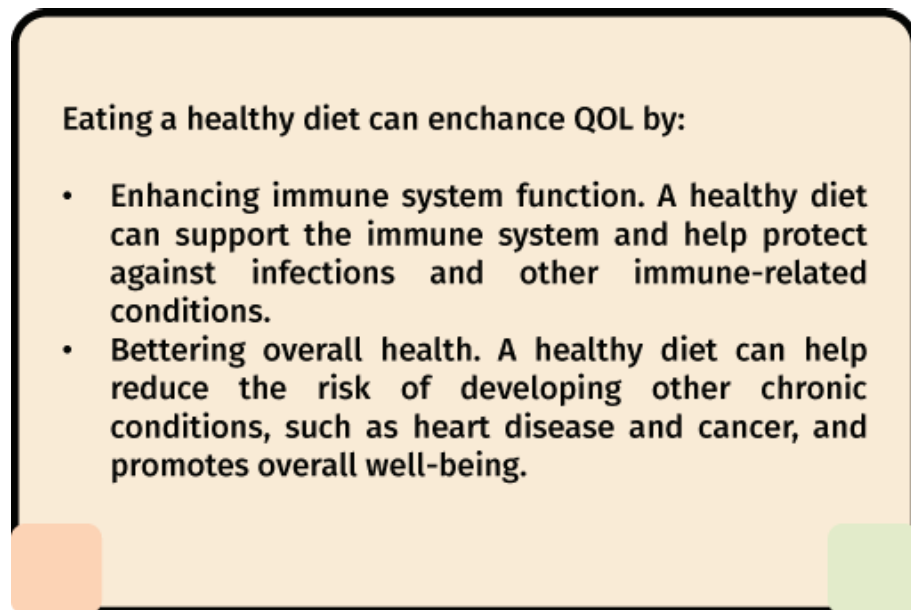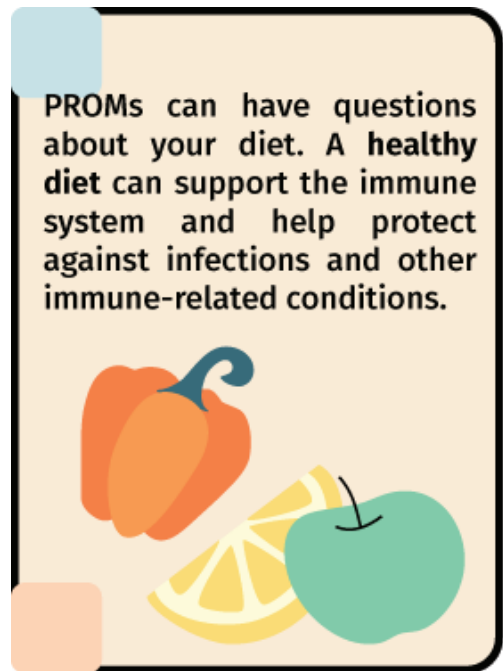
### Self-Reflection

PROMs can be used to track a patient's health status over time. This can show patients how their health has changed and identify areas that may need more attention.

PROMs can help patients with self-reflection by:

- Providing a structured way for patients to reflect on their health. PROMs provide a standardized set of questions. This can help patients to focus on specific aspects of their health and to reflect on how these aspects are impacting their daily life.
- Tracking a patient's health status over time. This can help patients to see how their health has changed and to identify areas of improvement or areas that may need more attention.

Figure 60: Benefit Card, all 3 versions.

**Eating Healthy**

PROMs can have questions about your diet. A **healthy diet** can support the immune system and help protect against infections and other immune-related conditions.

Eating a healthy diet can enchance QOL by:

- Enhancing immune system function. A healthy diet can support the immune system and help protect against infections and other immune-related conditions.
- Bettering overall health. A healthy diet can help reduce the risk of developing other chronic conditions, such as heart disease and cancer, and promotes overall well-being.

Figure 61: Topic Card, all 3 versions.

## Text

This version of the game is made for patients who really want to learn.
The only visual elements on the card are the colored squares used for building a path.

These cards use bullet points to help disseminate information and tend to contain more terminology that requires some level of health literacy to understand.

Compared to the combined version the text here is also going much closer to the borders of the card.



Figure 62: New Icons

## New icons

The other icons previously used on both the front and back got replaced by this new version for the new card backs. This was done in order to have a more unified design of the icons, ensuring that they share the same art style, height, and width.

This coherent design of the new icons also allowed the packaging for the game to look nice as the three icons could be used in a repeating pattern on the outside of the box meant for the waiting room at the hospital.
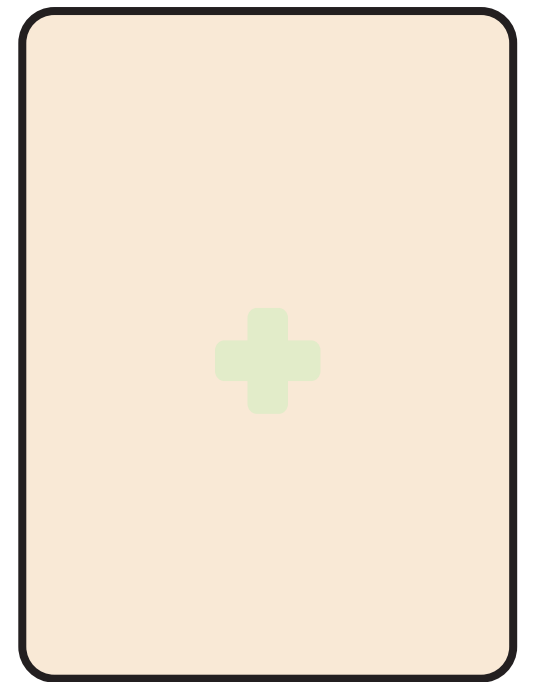


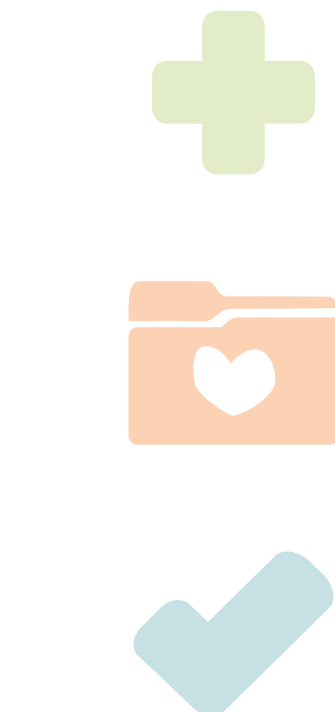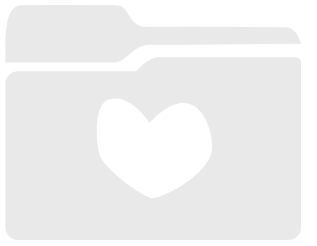Figure 63: New card back to prevent accidental cheating



Figure 64: Packaging

**Chapter 7**

# EVALUATION

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The purpose of this chapter is to cover the process of evaluation of the card game implemented in the previous chapter. The evaluation includes testing with the target group, healthcare professionals, and the peer navigator at the HIV outpatient clinic.

## 7.1 Introduction

The evaluation of the final concept with the target group is a crucial step in the design process, as it provides valuable insights into the user experience and helps to ensure that the end product meets the needs and expectations of the target group. This chapter, introduces the research questions and the methods used to gather feedback and assess how the final concept is received by the target group, nurses and peer navigator. This information will be analyzed and used to make informed decisions about the final product.

RQ related to the **purpose** of the card game:

1. *What is the **perceived value** of the card game according to the patients?*
   a. *What is the perceived potential of the card game for future applications for patients?*
2. *How do patients perceive their **knowledge about PROMs** being affected by the card game?*
   a. *How do patients perceive their **knowledge about the purpose of PROMs** being affected by the card game?*
   b. *How do patients perceive their **knowledge about the benefits of PROMs** being affected by the card game?*
   c. *How do patients perceive their **knowledge about how their data is being handled** being affected by the card game?*
   d. *How do patients perceive their **knowledge about the connection between PROMs and QOL** being affected by the card game?*
3. *How do patients think the card game will affect their **motivation** to complete PROMs?*

RQ related to the **usability** of the card game:

4. *How **easy** is the card game to use and understand for patients?*
   a. *How **clear** are the text and visual elements of the card game for the patients?*
   b. *How **accessible** does the card game feel for the patients?*
5. *How **guided** do patients feel they are when playing the card game?*
6. *What are the **pain points** of the card game?*

RQ related to the **context** of the card game:

7. *What is the perceived value of the card game according to the **peer navigator in their role** with the patients?*
8. *What is the perceived impact of the game **packaging** according to the patient?*

## 7.2 Aim

The aim of this study was to assess the final concept with the target group. The main focus was on:

- Purpose: Does it fit with the purpose of the project, design goal and interaction vision.
- Usability: Is the target group able to use it
- Context: Does it fit with the context and the role of the peer navigator.

For these the following research questions were made:

## 7.3 Method

The evaluation went through four phases:

- Phase 1:
  The researcher gave a brief introduction of the game, what is the goal of the game, how to play it and the difference between the three categories (visual, combo, and text). This included a short demonstration of the gameplay. In this phase, the researcher answered any questions the participants might have about the game.

- Phase 2:
  The participant played through the game while thinking out loud. They could choose which category they wanted to play with.

- Phase 3:
  The participant filled in a usability questionnaire while thinking out loud. The questionnaire also included questions about how the participant's perceived knowledge of PROMs was affected by the game.

- Phase 4:
  Semi-structured interview about their experience with Phase 1 and 2. The participant will have access to all categories of the game during the discussion.

**Semi-structured interviews**

Similarly, to the methods in chapter 3, semi-structured interviews were used. The evaluation guides for the patients, nurses, and peer navigator can be seen in Appendix 10, 11, and 12. The setup of the interview can be seen in Figure 65.

A pilot study, as seen in Figure 68, was conducted with each version of the interview to make sure it makes sense, has a natural flow and fits within the time set for the interview.

**Questionnaire**

A modified SUS (System Usability Scale) questionnaire was used. (Brooke, 1995) The SUS is a standardized questionnaire designed to measure perceived usability. When selecting items for a Likert scale, one wants to capture strong expressions of attitude. This means that statements should be unambiguous and not leave too much space for interpretation. Then when assembling the items into the questionnaire it is important to alternate positive and negative statements to avoid responders bias by them not having to think about the statement. The full questionnaire can be found in Appendix 13.
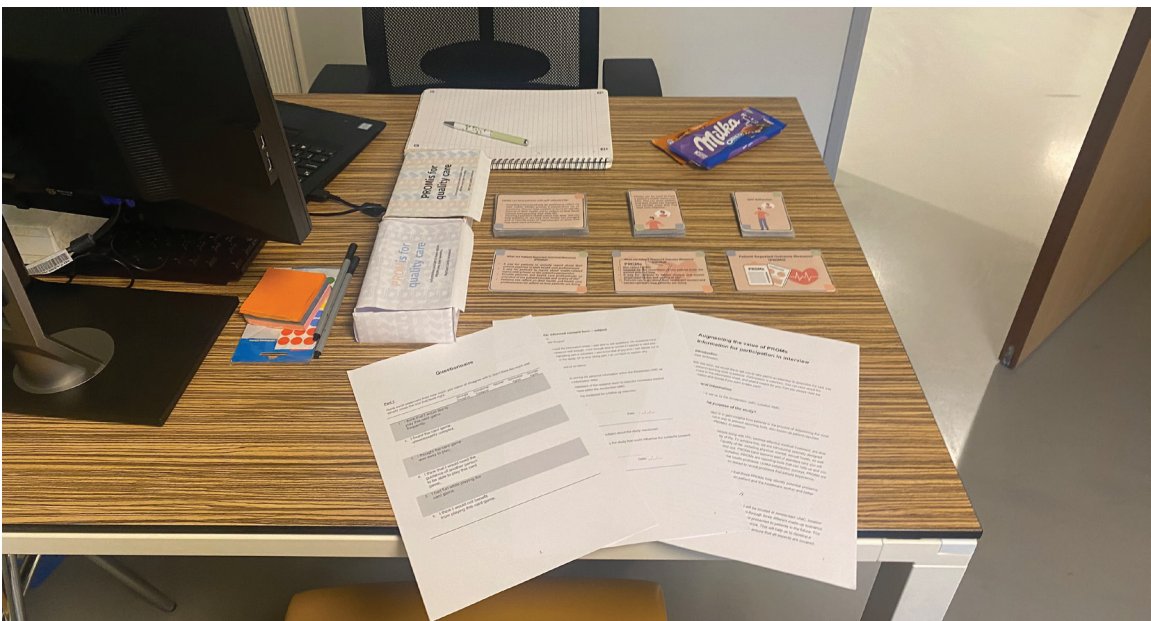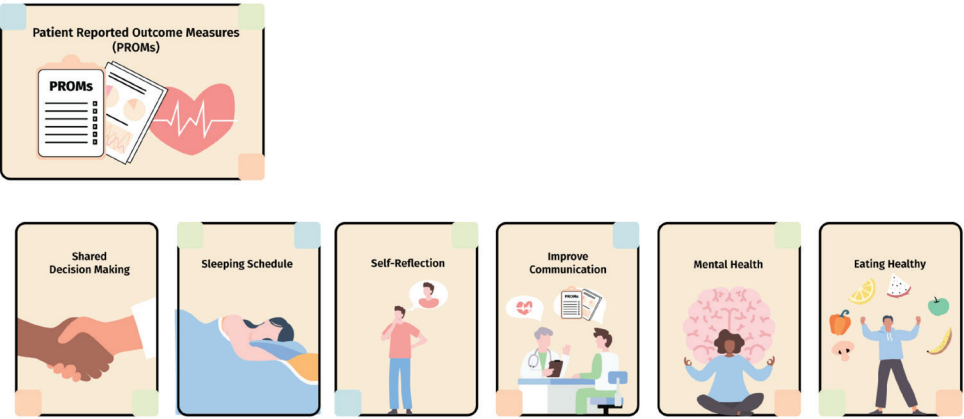


Figure 65: Setup for the evaluation study with the game and packaging of the game in the middle.

## Step 1: Cards in hand

Choose version of the game
Pick 1 starter card and 6 playing cards



## Step 2: Play

How: Match the colors
Goal: Get the highest score by matching as many cards as possible
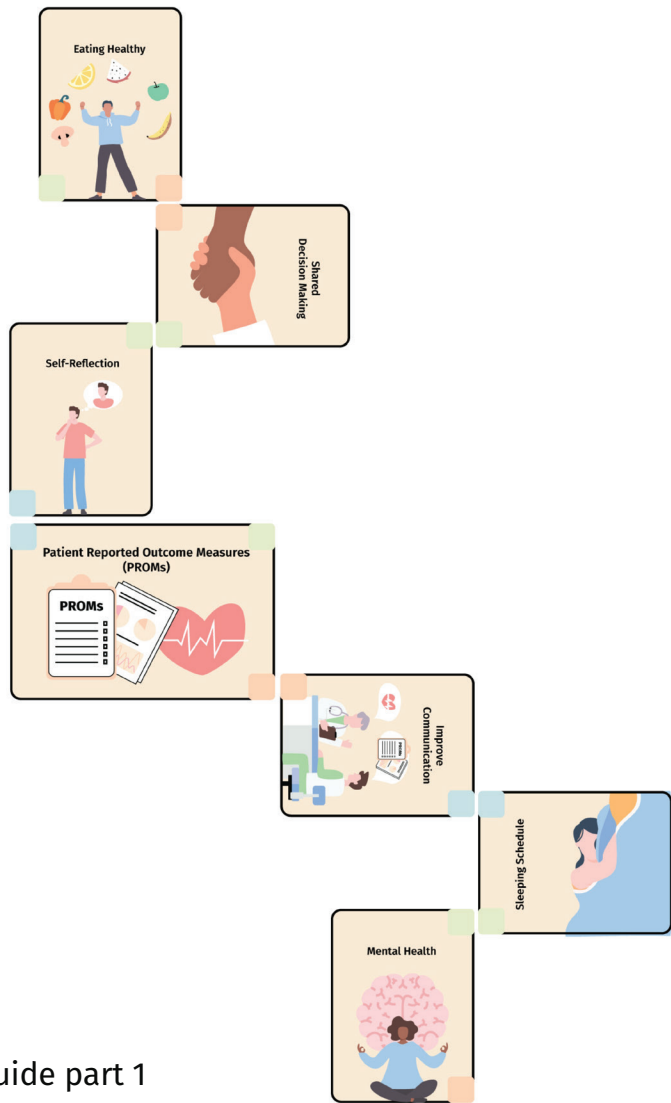Scoring system: 1 card = 1 point



Figure 66: Visual guide part 1

**Online Interview**

The online interview was possible by putting the digital versions of the cards of the game on Miro, an online collaboration tool (The Visual Collaboration Platform for Every Team | Miro, n.d.). The patients received a link to join the platform, where they could see a board with the game. No personal data was retained through that platform, it was solely used to play the game. The participant could see all three versions of the cards laid down on the digital board.

Figures 66 and 67 are a simplified visual guide that goes through the steps of playing the game tested in the evaluation study. This guide was created for the online interview with the patient. The interviews that take place offline follow the same steps, however, the researcher is able to demonstrate the steps in person.

## Step 3: Add up your score

Turn cards around
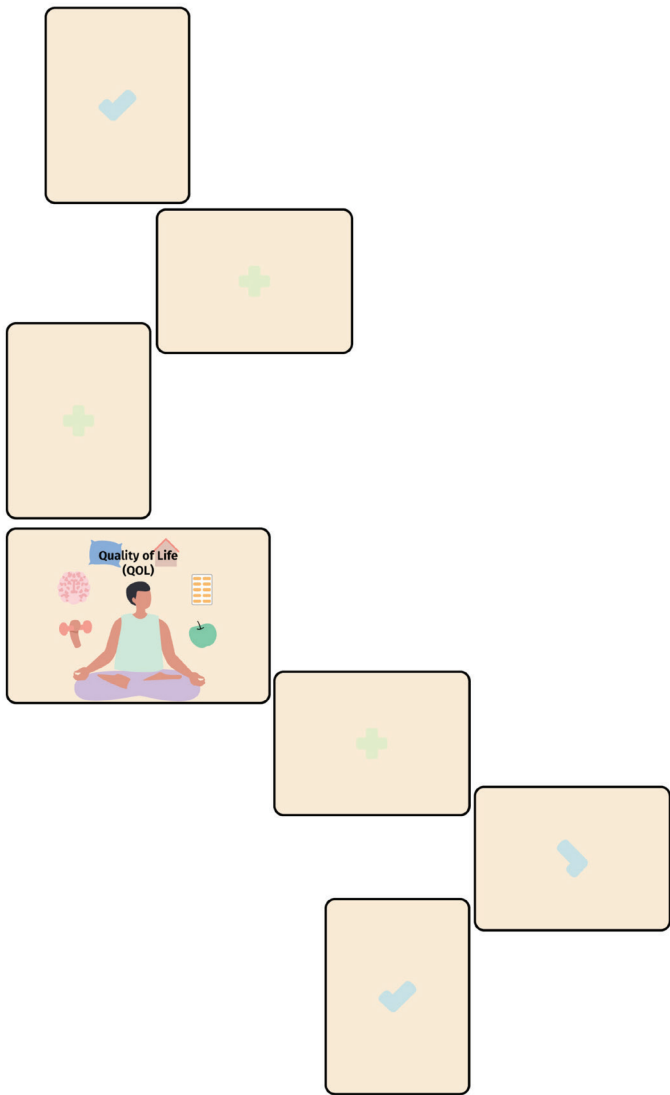Only cards next to the same type of cards are worth a point



Figure 67: Visual guide part 2

**Participants**

The description of the participants for this study is the same as the one for the qualitative interviews in the user research chapter. This means that both patients and nurses were interviewed for this study. The recruitment of the participants was the same as well. Two patients that participated in the qualitative interviews have been recruited for this study. This was done as they expressed an interest in further development of the study. The nurses in this study also participated in the qualitative interviews. In addition to them a new nurse at the clinic observed one of the interviews and provided feedback on the game. Similarly, a doctor at the clinic provided feedback to the game. That feedback was taken into consideration when creating the themes from the insights of the study. The overview of participants can be seen in table 4 and table 5.

To add to that, this study included an interview with the peer navigator at the clinic. As seen in the journey map the peer navigator can be the first point of contact between the patients and PROMs and MyChart. The interview with the peer navigator aims to see how the solution of the project can interact with their role. Since the peer navigator is also a patient, they will also be asked similar questions to the students about their experience with the game.

**Analysis**

Similarly, to the qualitative interviews used earlier in the project, statement cards were made and used to the notes and audio files from this study. These cards were used to capture key findings. Afterward, they were clustered based on recurrent themes to find overall takeaways.



Figure 68: Pilot study for the evaluation study

| Code | Gender | Background | PROMs | Notes |
|---|---|---|---|---|
| PE1 | Male | Dutch and Surinamese | Participated in pilot study about PROMs | Participated in the qualitative interviews and participated in the evaluation study online |
| PE2 | Male | Caribbean Islands | Not introduced to PROMs | |
| PE3 | Male | Dutch | Participated in pilot study about PROMs | Participated in the qualitative interviews |
| PE4 | Male | Dutch | Introduced to PROMs | Healthcare Professional (currently working in Indonesia) |

Table 4: Overview of patients that participated in the evaluation study.

| Code | Gender | Background | PROMs | Notes |
|---|---|---|---|---|
| NE1 | Female | Dutch | Received training in PROMs and trained other nurses | Participated in the qualitative interviews |
| NE2 | Male | Dutch | Received training in PROMs | Participated in the qualitative interviews |
| DE1 | Male | Dutch | Received training in PROMs and trained other nurses | Provided feedback |
| NE 3 | Female | Dutch | Received training in PROMs | Observed another interview and provided feedback |

Table 5: Overview of the HCPs that participated in the evaluation study.

## 7.4 Insights

The insights of the interviews were derived into themes. Figure 69 shows one of the interview games played by a participant.
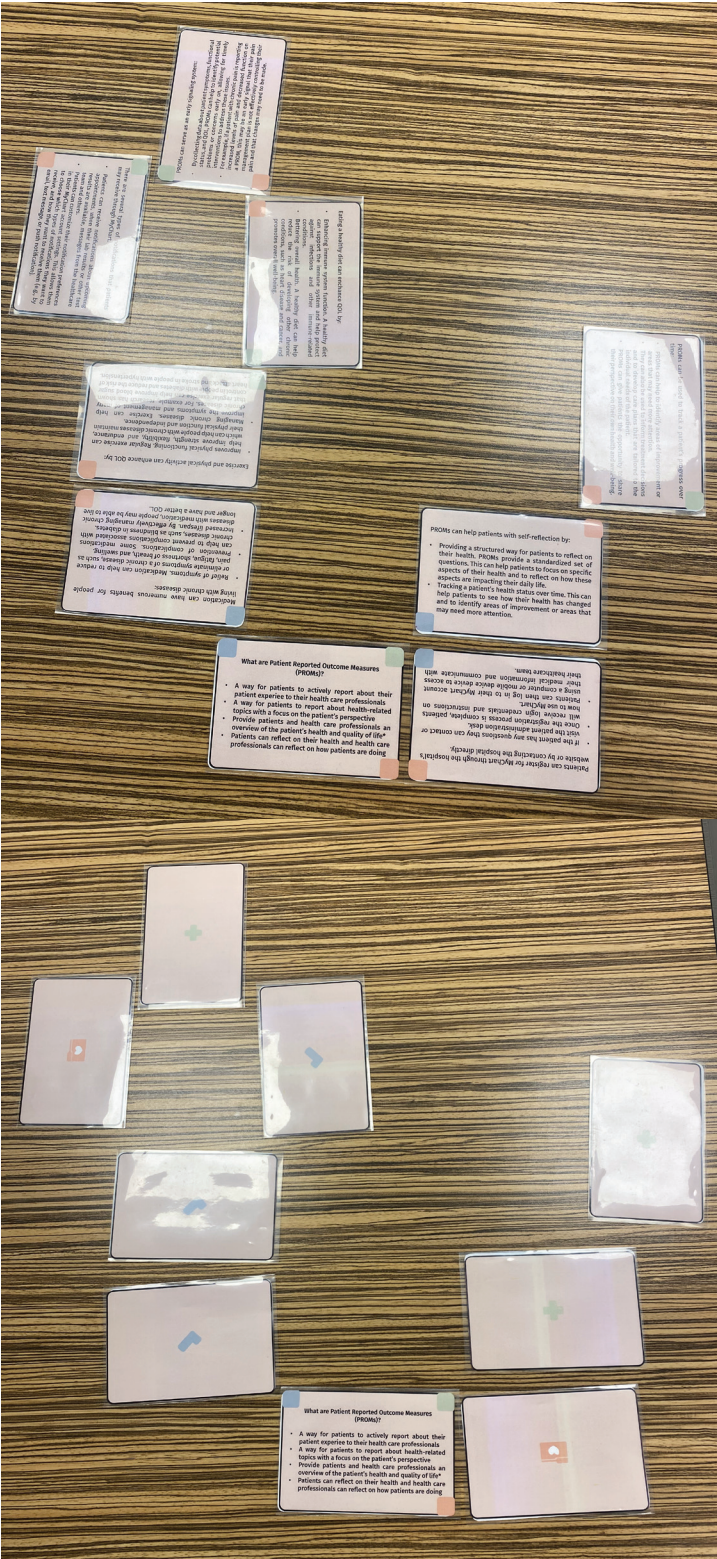


Figure 69: One of the games played by a participant.

### Theme 1: Learning potential of the card game

After the participants tried playing the game, they were asked what they had learned from it. All participants were able to answer that question with something they learned. For example, PE2 said *"I have a better idea of what PROMs can do to improve the QoL"* and PE4 stated *"I learned that it can improve communication with the HCPs, that they can help with preparation before a consultation"*.

Earlier in the interview PE3 mentioned how they think PROMs are not helpful for them because they are involved in their care. When asked why they are completing PROMs, they said to help the HCP. After playing the game they expressed that they see the added value of understanding how the system works, that it can help both the HCP and the patient.

PE2 mentioned how they think PROMs can *"help you by giving you the idea of what you can do to better your QoL"*. They expressed that they never thought about some of the topics on the cards e.g., mental health. When asked if anything is missing in the game, they said a place to follow up the information and find out more.

### Theme 2: Voice of patients in treatment throug patient emowerment

One of the participants, who works as a medical professional, thought that the game could create awareness for patients, by showing them that they have a vote in their care. They were mostly referring to the cards about the benefits of PROMs e.g., shared decision making and autonomy. They stated, *"This could help with the voice of patients in treatment"*.

Another patient, expressed a similar idea, where they see the cards help patients gain more control in care. They said that the card game could be a *"Nice tool to explain yourself"* to the HCP. They also added to that saying that they feel PROMs cannot represent them, since they feel like they have to often explain answers on PROMs that do not have a neural option or do not apply.

Some of the nurses thought that the card game could play a role in patients showing them what is important to them. They expressed that they thought this could increase motivation in patients to learn more about their health.

### Theme 3: Different stnadpoints on QoL and different engagementin care

QoL can mean different things to different people. At the beginning of the interview the patients were asked about their opinion on the text from the main card. All patients said that it fit their belief, while adding more definitions. For example, PE2 defined QoL as things that make them happy in life.

PE4 stressed that *"There is a difference between feeling healthy and being medically healthy "*.
This is why it is important for patient to be part of the decision in their care, as only they can decide what is important to them. They gave an example of a person getting a mastectomy. For a medical point of view, it is better to remove the entire tissue to increase survival rate. However, this might not be better from the patient's point of view that might have a decreased QoL.
PE4 mentioned that the cards could be used to start a discussion where the doctor gives more advice based on the cards chosen by the patient.

### Theme 4: Impoving communication with the HCP

Following their idea from the previous theme, PE4 thought that *"This toolset could help educate both perspectives"*. Meaning the patient and HCP perspective. This could be done by improving communication between them. The patient can express their needs and the doctor could learn how to communicate advice based on what the patient needs or values. This has been expressed by PE1 who thought the game could improve communication between both patients and HCP.
PE2 mentioned seeing themselves play the game with the HCP as *"It could guide the conversation"*.

## Theme 5: Clinical Potential of the card game

As their perceived benefit of the game was a main topic in the interviews, participants expressed different ways the cards can be used as well. This was seen in the previous theme about improving communication with the HCP.

The nurses and the doctor interviews also expressed interest in playing the game one on one with the patient. They mentioned using the game to encourage patients to talk about topics during consultation. Or they could be used as preparation for the next appointment, by saying something along the lines of *"How do you think about yourself in relation to…healthy eating "*, example used by NE2. They expressed this could serve as a replacement for PORMs, especially for people that cannot have access to PROMs.
However, they also expressed concern as they would not have time to play the game in the 20-minute consultation.
One of the nurses thought it would be a good idea to include the game in workshops for PLHIV as the setting is more playful.

## Theme 6: Social aspect of the card game

Originally the game was designed to be played alone, however, one of the patients who is also a medical professional, expressed wanting to play the game with their family and friends. When asked to elaborate, they said that they would like to see what their perception is on some of the topics, how empowered they think they are and how PROMs can add to it.

They said that the cards *"Can help realize there is a lot of awareness to be created"*.

The peer navigator also thought of the game as a way to communicate with friends and family. They expressed that, from their personal experience, after a long time of being diagnosed with HIV, they stop asking about it. This could be a playful way to start communicating with them again about this topic.

## Theme 7: Physical comtext of the card game

P2 said that they would like to play it at home where they have more time. When asked where they would keep it, they said with other boxes and games since they like playing games. They also expressed being open about their diagnosis which could influence their decision of keeping it home.

P3 expressed that they would play the game in the waiting room but would not want to keep it home as they only see themselves playing it a few times. If they had a choice, they would bring it home because they would have unlimited time to play it, but they would like to be able to bring it back after. They also expressed concern about enough table space in the waiting room.

The HCP brought up a concern about patients feeling anxious in the waiting room which could deter them from playing the game.

## Theme 8: Packaging in alternating contexts

When asked about the packaging, most patients expressed that it should be louder. One patient said that if it is too subtle they might not see it, but if it was in bright colors, it would spark their curiosity.

One patient mentioned that the package made for the waiting room looks like a present which is appealing, but it was still too subtle for them to notice.

Another patient mentioned that usually they like to read things in the waiting room so if anything would grab their attention e.g., a magazine they would pick it up.

When asked about taking home the cards in the different packaging, the patients expressed that they did not have a preference. It is important to keep in mind that 3 of the 4 participants expressed being open about their diagnosis.

HCP agreed with the sentiment that the package for the waiting room is too subtle, however, they thought the package for taking home might be not subtle enough. The peer navigator brought up patients they met that were anxious about being put in a situation where they have to answer any question that might allude to their diagnosis. "Most socially isolated people would not bring it home. They do not tell their spouse or children about their diagnosis. Even PROM or MyChart can reveal something."

The game should be friendly and not be disclosed in any way. Many patients are not open about their diagnosis.

Theme 9: Compassioante design in a hospital setting

One of the HCP expressed that they did not see highly educated patients playing this game. They added that they could see them playing a digital version where more sources can have an impact. When asked to elaborate, they expressed the game could feel childish to some people, especially in a hospital setting.

The patients that participated in this study were all highly educated. And the majority expressed interest in the game and though it looked *"pleasant and inclusive"*.

The peer navigation expressed how a lot of patients feel the hospital is very cold and gray which adds to their anxiety. However, the cards could help alleviate these feelings: *"usually the hospital is without beauty and these cards give care and compassion"*.

The peer navigator added that "Both visual (cards) and text and visual (cards) appeals to me, only text (cards) is not my preference. Imagine coming to the hospital, stressed about who will see me, it is a lot to read, especially if you are not highly educated." Compassionate looking design could alleviate those feelings.

**Insights from the peer navigator**

When asked about their impression of the card game they responded:

*"I like the awareness and serves as a reminder of self-care"* and *"It was fun, I like games."*

The peer navigator has had visual dialogue training or also called visual communication training and uses non-violent communication in their role. They found the visuals on the card game similar to what they use in their role.

*"This is what I talk to people in my room, more focused on the emotional side."*

They said that the toolset could be used in their role as a way to start a conversation:

*"I would use this toolset to engage patients in conversation: "What is more challenging at the movement". Or I could ask them questions especially about social support and mental health."*

Based on their background on visual communication, they gave a few recommendations for future design iterations:

Recommendations for the visuals
• Heard and empowered card: have the HCP look the other way to create empathy, or share a heart between HCP and patient, to show all emotions are welcome
• Change name of the card 'track progress' to 'track my progress'
• Autonomy card: add question mark for the doctor
• exclamation point on the patient to emphasis the conversation dynamic
• Main card: put a body around the heart to illustrate physical health
• Managing medication card: add a sandwich as you need to take your medication with a full meal medication with a full meal

**Additions for the role**
• Add a card about self-compassion and self-acceptance: very important since patients can feel a lot of guilt
• Add a card about sexuality: when brought up that it could be disclosing, the peer navigator said to name it 'dating' or 'relationships'
• Add card about reproductive health: it is important to teach woman about their reproductive health and how it impacts their life. This includes having children, "that was my first questions to my HCP".
• Add card about addiction e.g., alcoholism
• Add card about emotions and needs
• Add card about grief

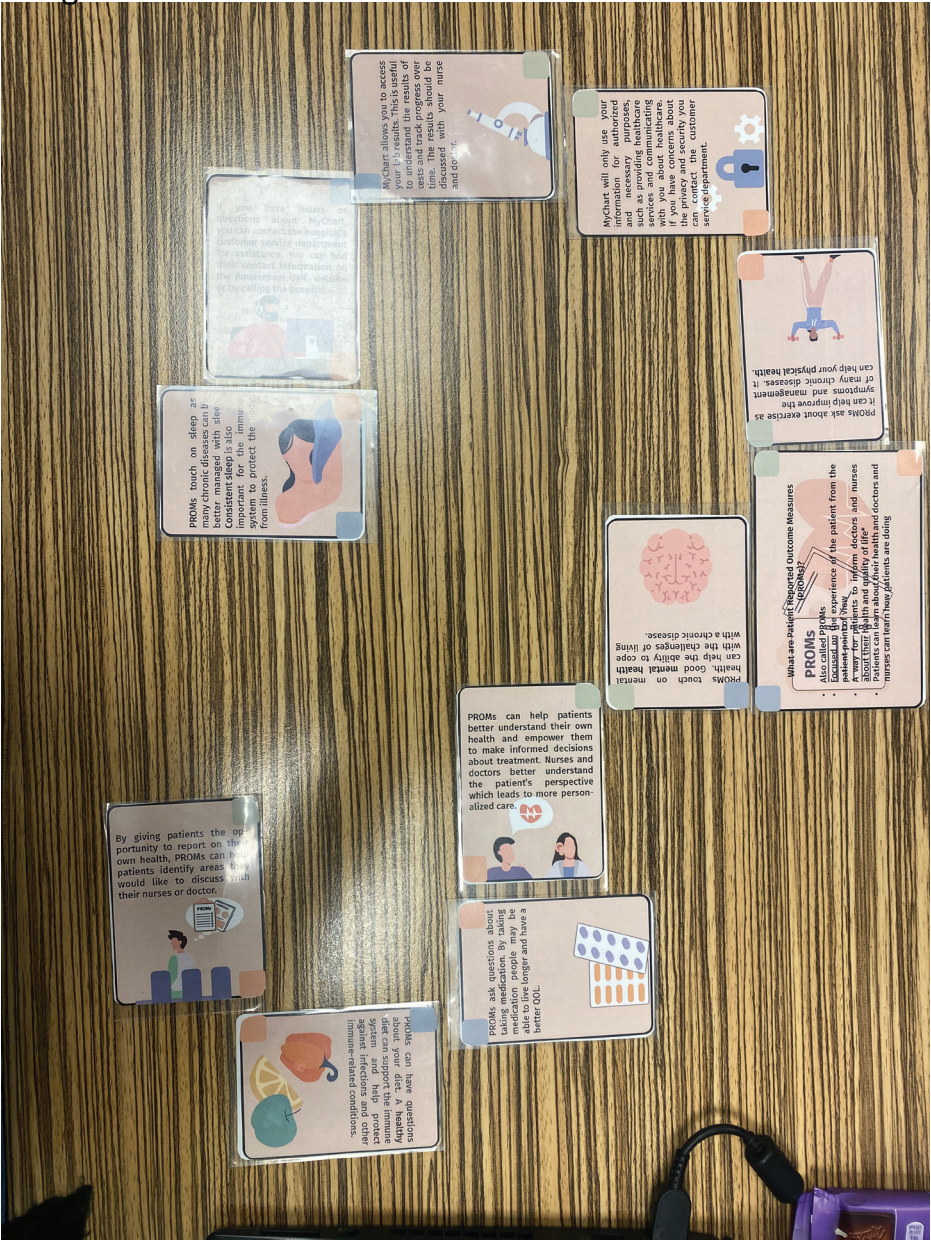Figure 70 shows the game played by the peer navigator.



Figure 70: This set up was made by the peer navigator while playing the game.

| | | |
|---|---|---|
| 1. The game helped me to increase my knowledge and understanding of PROMs. | | 4.2 |
| 2. The game helped me to increase my knowledge and understanding of the purpose of PROMs | | 4.4 |
| 3. The game helped me increase my knowledge and understanding of how PROMs can benefit me. | | 4.2 |
| 4. The game helped me to increase my knowledge and understanding of how PROMs handle my data. | | 3.6 |

Table 6: Questions form questionnaire and their score

| | | |
|---|---|---|
| 1. I think that I would **like to play** this card game frequently. | | 2.8 |
| 2. I did not find the card game unnecessarily **complex**. | | 3.6 |
| 3. I thought the card game was **easy** to play. | | 3.8 |
| 4. I do not think that I would need the **guidance** of another person to be able to play this card game. | | 1.4 |
| 5. I had **fun** while playing the card game. | | 4.4 |
| 6. I think I would **benefit** from playing this card game. | | 3 |

Table 7: Questions form questionnaire and their score

**Insights from Questionnaires**

Table 6 shows the questions about the participants' perceived knowledge on PROMs, purpose of PROMs, benefits of PROMs and how PROMs handle data. The participants scored those questions high as they were able to recall the cards they were playing with. The lowest score is for how PROMs handle data. As the focus during the game and interview often shifted on the cards about PROMs topics and benefits, cards about data handling were only briefly discussed. Due to this most participants rated this neutral.

Table 7 shows the questions from the modified SUS questionnaire, where the questions have been adjusted so the scoring has the same meaning for all of them.

The guidance questions scored very low, when asked to elaborate the participants explained that because I guided them at the beginning, they thought they needed guidance at least once before playing the game. However, after briefly explaining teh game one, no participant had any issues or questions on how to play the game after. A visual guide should be explored in the future.

The question about playing the game frequently also had a low score due to some participants expressing they would only play the game once or a few times since they have a good grasp on the themes on the cards.

This questionnaire was filled by five people, meaning that the results are inconclusive, but the questions were used to ask further inquiries during the interview regarding the usability and learning potential of the game.

## 7.5 Takeaways

The following takeaways were made based on the findings:

- Packaging in the waiting room should be laude to spark curiosity. While packaging for home should be more subtle and not allude to the HIV diagnoses.

- The game should be friendly and not be disclosing in any way. Many patients are not open about their diagnosis.

- Potential in informing patients about benefits of PROMs, topics in PROMs, MyChart, and the connection with QoL. Also has potential in sparking curiosity.

- Can aid the peer navigator role in multiple ways (compassionate design, visual language), especially when introducing PROMs.

- Potential in empowering patients by improving communication with the HCP.

*1.   What is the **perceived value** of the card game according to the patients?*

All of participants reasoned that the card game was supposed to inform them about PROMs. Most patients thought they could use it to learn about PROMs and QoL. One patient even expressed being giving an understanding of the overall picture of PROMs where they can benefit from them.

*a.   What is the perceived potential of the card game for future applications for patients?*

Most participants thought of PROMs being used in consultations in the future to help guide the consultation or bring up certain topics.

When about their impression of the game and perceived value of the game. Some patients and HCP talked about how it could empower patients. Theme 2, talked about giving a voice to patients to better understand and talk about their health. Theme 3 and 4 touched on how patient engagement can improve communication with HCP and therefore improve their care.

In theme 6, a patient and the peer navigator talked about the potential of the game to help communicate about HIV diagnosis and patient empowerment with family and friends. I have a better idea of what PROMs can do to improve the QoL.

*2.   How do patients perceive their **knowledge about PROMs** being affected by the card game?*

The questionnaire used in the evaluation study showed that in the question regarding the knowledge about PROMs patients scored high.
This is in accordance with Theme 2 that goes into how patients feel they have learned from about PROMs from playing the card games and even expressed wanting to play again to see more of the cards.

*a.   How do patients perceive their **knowledge about the purpose of PROMs** being affected by the card game?*

From the questionnaire it can be deducted that the patients that participated in evaluation study thought the game had the potential to increase their knowledge about the purpose of PROMs. When asked to elaborate they mentioned benefits from PROMs. Theme 1 showed a participant shifting the focus of PROMs onto themselves rather than HCP.

-

*b.   How do patients perceive their **knowledge about the benefits of PROMs** being affected by the card game?*

This question also received a high score on the questionnaire and when asked to elaborate all patients were able to give examples from the cards they just played. It should be kept in mind that two patients that were part of the pilot study have been aware of some of these benefits.

*c.   How do patients perceive their **knowledge about how their data is being handled** being affected by the card game?*

As the focus during the game and interview often shifted on the cards about PROMs topics and benefits, this topic was not explored. Most patients put neutral as their response to this question in the questionnaire. Some that played with the MyChart card gave it a higher rating, but said that regardless of how MyChart handles data it is still out there and can be hacked. Even with these beliefs all patients had an account with MyChart. When asked why they referred to being pen about their diagnosis and it not being a big risk for them.

*d.   How do patients perceive their **knowledge about the connection between PROMs and QOL** being affected by the card game?*

While most patients were knowledgeable of topics related to QoL, P2 has expressed not being familiar with how they can affect their care. This patient scored a 5 on this question in the questionnaire and expressed having better understanding how PROMs can improve QoL. This should be explored with more patients.

*3.   How do patients think the card game will affect their motivation to complete PROMs?*

Most patients expressed being curious to learn more and a desire to bring it home where they have more time to go through it. P2 did not know what PROMs were before the evaluation study. However, at the end of the interview session when asked what they think of PROMs, they said they would want to fill them in if they will receive them in the future. They also expressed that the game made them curious to learn more about them.

**4.** *How **easy** is the card game to use and understand for patients?*

After a brief explanation which followed the guide in Figure 66, all participants were able to play the game without additional help. The peer navigator and P4, struggled with categorizing the cards as they felt some topics were not mutually exclusive. This is also in part to them playing with the visual version of the cards. Both of them expressed that after reading an explanation it was easier to split the categories. This should be kept I mind for future interactions of the design.

**a.** *How **clear** are the text and visual elements of the card game for the patients?*

During the evaluation study there has been no misunderstanding or confusion about text P2 and P3 chose to play with the text version of the game and expressed that it was clear. P4 chose the visual version which caused some confusion. For example, MyChart sent them a notification about preparation for their following consultation, which is why they thought the card about the benefit of PROMs, preparing for consultation, was a MyChart card. The peer navigator, who uses visual communication in their practice provided recommendations for future designs and referred to health magazines that use health related visualization.

**b.** *How **accessible** does the card game feel for the patients?*

The card game was made analogue to make it more accessible for patients that do not have access to technology or would be refined from using it due to privacy reasons. This is not the case for the participants in the observation study. When asked about moments of interaction with the game, some expressed that there might be not enough time before a consultation in the waiting room or a sit at a table available. This is why they expressed a preference to play the game at home.

**5.** *How **guided** do patients feel they are when playing the card game?*

After the initial explanation of the game, patients did not require further guidance. The is different than the score in the questionnaire about the requiring guidance. When asked to elaborate the participants explained that they would need someone to explain it once before being able to play. Further research should investigate if the patient would be able to pick up the game and play by themselves, or if they need a contact person before being able to play the game.

**6.** *What are the **pain points** of the card game?*

The most common pain points observed while participants were playing the game and thinking out loud were:
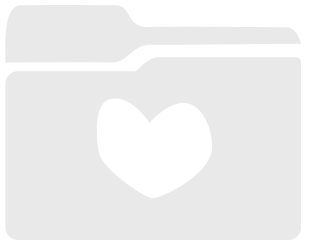- The starter card was hard to read due to the visual on the back of the text
- The asterisk on the starter card sparked confusion as participants though the card was incomplete
- Participants did not notice the bolded text (but expressed a desire for titles for all cards)
- Visual for tracking your health card looks like a megaphone.
- Autonomy card and improved communication car look and can be confused between each other.

**7.** *What is the perceived value of the card game according to the **peer navigator in their role** with the patients?*

As mentioned in the insights from the peer navigator, the cards are similar to what they are currently using in their role in regards to visual communication. They expressed that the card game imagery seems more compassionate and welcoming than what they use. Then they asked about future implementation of the cards. They said that it gives *"a complete image of their work"*.

**8.** *What is the perceived impact of the game **packaging** according to the patient?*

As explained in theme 8, the participants in the observation study were open about their diagnosis and did not think there was anything about the packaging that would prevent them from taking the game home. They mentioned it being too subtle in the waiting room to grab their attention. However, HCP and PN thought the package to bring home could be revealed by using words like PROM and MyChart.
Future research should study the interaction of patients in the waiting room with the design of the package.

**Chapter 8**

# DISCUSSION

The purpose of this chapter is to discuss our findings from the last chapters evaluation. It will address the design goal, discuss recommendations and limitations that have been found and finally there is a reflection.

## 8.1 Introduction

This chapter wraps up the project with addressing how the design answers the design goal and research questions set for this project. This chapter also explores the limitations encountered in this project, recommendations for future research and development and concludes with a personal reflection.

## 8.2 Addressing Design Goal

In chapter 4, the design goal was defined as follows:

*"The design goal is to increase patient engagement with PROMs by creating a clear and accessible way for them to be informed about the purpose of PROMs, how PROMs can benefit them and how their data from PROMs is being handled."*

To address the specific parts of the design goal the following division was made::

**Patient engagement with PROMs**

Whether this design solution will increase the patient engagement with PROMs remains to be seen. Presented in the project is a finalized prototype that underwent a small scale evaluation to determine its perceived value to the target group. The evaluation study showed potential in informing patients about PROMs and QoL, which could lead to increased engagement with PROMs. However, this would have to be tested over a longer period of time. Such a test should be made with a larger and more diverse group of patients than the observation study, as all participants were highly educated man that are on top of everything type of patients. These patients, except for one are already engaged in completing PROMs. with a control group to make sure the game is the intervention

**Clear and accessible way for the patient to be informed**

The design of the game was done while keeping accessibility guidelines in mind, a non-digital solution was chosen, and three versions of the game were created. All of this was to keep the information accessible and as clear as possible. The test conducted with students and the observation study with the target group were able to find and address pain points in the design. However, to design for accessibility means continuing testing with different people, especially people that need it the most. From literature research and and observation study it was found that part of the population at the HIV outpatient clinic are not involved in their care due to lack of access to technology, low health literacy, low digital or literacy skills. Unfortunately, testing with this population can be difficult in the context of this project. All of this is to say that we cannot clearly state that the game is clear and accessible. While the design process kept this in mind, more testing is required that involves a better representation of the patient population.

**Informed about purpose and benefits of PROMs and how their personal data is handled**

The design concept was an informative card game that can be played solo. As seen through Chapters 5 and 6 the game was designed to clearly convey information about PROMs (category of topics in PROMs), their purpose and benefit (category of benefits of PROMs), how patient privacy is handled (category of MyChart).
From the initial test done with the target group it seems the card game has the potential to inform patients about those topics. However, areas for improvement were also found. It is a fully playable game that contains information about PROMs, there is room for expansion as currently only 21 playing cards were designed. However, this was only tested with patients that are involved in their care and learn about it regularly. To add to that, the evaluation study looked into the immediate effect of the game rather than long term learnability.

## 8.3 Recommendations and Limitations

**Vulnerable group**

Due to the target group being vulnerable, finding participants for the user research and later testing stages of the project took a long time. To add to that, the participants were mostly people that are lily to participate in this type of research, which are highly educated Dutch men.
Additionally, obtaining the ethical approval needed for doing the study likewise took a long time, it was expected due to the project operating in a medical setting. There were several iterations made of the information letter and consent form that was sent out to find participants, but also of the interview guide, as it was important to carefully consider what is said to them during the interview. There was a strong need to make sure the information is clear to the participants and that they felt safe in the hospital setting and about their privacy.

**MyChart and PROMs**

Another limitation was not being able to see the Epic software other than on slides that were shown to staff at Amsterdam UMC. The same applied to the PROMs used at the HIV clinic, only examples from slides could be seen. In the context of user centered design, it provides a limitation on the designer, as getting the full context of the user is hard without the insights into how the tools they have to use work. In the future, having the designer completing a PROMs might give an idea of the experience the patients have, additionally so would having an account on MyChart. This could provide insights into how the software is navigated and could enrich the information passed on through the design solution. It would also be easier to understand how the patient feels when directly being able to replicate their struggles.

A general limitation both for the designer and some patients is that MyChart is only in Dutch and PROMs is only available in English and Dutch. Under this project it was not possible to make any changes to MyChart, any other EPIC software, or PROMs. It is strongly recommended to have MyChart and PROMs be available languages understood by the patient population.

**Literature**

It is important to keep in mind that the findings were taken from other implementations of PROMs for chronic conditions involving diabetes, depression, oncology, and palliative care. It must be kept in mind as to avoid working based on assumptions that may later be proven wrong given the different context of implementation. The literature on the implementation of KLIK showed how patients and HCPs in pediatric care interacted with PROMs, and what their attitudes were towards them. It also illuminated what limitations or barriers they met. The study is from a very different context than the one this project has been conducted in and the PROMs might very well be a different type. However, as there is limited research on the experience of PLHIV and PROMs, it is important to still explore any contexts with HCPs and patients having documented their experiences, attitudes, and wishes for continued usage of PROMs.

**Evaluation**

The evaluation phase should be conducted over a long period of time to test the impact of the design on the target group. The evaluation plan should also be expanded to include testing of participants' knowledge after playing the game and a few months later. Information on how much participants played the game should be recorded. This would shed some light on the game's ability to convey information and the retention of this knowledge. It should also be monitored whether there is an increase or not in the number of people at the outpatient clinic that start completing PROMs. This should be happening simultaneously with a control group that does not have access to the design solution, to see if there are other factors influencing the outcome.

**Card Game**

The visuals and text of the card were done based on literature research and knowledge obtained through the designers own research. Something that could have enhanced the design was working on these elements of the game in co-designing sessions with experts. One such expert could be the peer navigator that works a lot with visuals and visual languages in their role. During the interview with the peer navigator, most visuals on the cards were discussed. This resulted in them giving a few recommendations mentioned in the insight section. Those recommendations should be taken into account during the next iteration. Some HCPs would also be a great boon for some sessions of co-creation.

**Testing**

The lo-fi and hi-fi testing of the prototype was conducted with a majority of design students as participants. As getting participants alone was a time consuming challenge there were made no attempts at filtering the target group for participants. It would be a great benefit to test the cards with illiterate people and with people from a diverse set of backgrounds.

**Participants**

The participants from the target group that helped to test the card game expressed that they were open about their diagnosis. In the future it would be good to test the game with patients who are not open about their diagnosis. In this way the game can be more critically tested in regards to whether it is open and non-judgmental and does not confront players. It would also be possible to have a more in-depth examine and test whether the game would be played or not by the patient population.
Additionally, the number of participants is very low. This was affected by the vulnerability of the target group and available time. However, this is not a representative number of the patient population at the outpatient clinic and the results cannot be conclusive.

**Future exploration**

One of the insights from the user research was that patients thought PROMs can help bring up topics they would not normally bring up during consultation with their HCP. During the evaluation study when exploring different benefits the card game can bring to the patients, both patients and healthcare professionals said that they could be used to bring up topics the patient finds important in consultation and improving communication between patient and HCP. This could be an interesting topic for future exploration, especially when involving people with low health literacy as this could help them express their needs and values.

## 8.4 Reflection

Some of the interviews took a more empathic turn as I spent time listening to the participants. In one instance a participant opened up about a traumatic experience they had with an HCP. As they were crying, due to reliving such a moment of great emotional distress, I did not think it was appropriate to interrupt them in order to get back to the interview. This is considered bad practice in terms of interview conducting, but after the interview they thanked me for listening. While it did not answer any of the questions I had prepared, it still gave deep insights into some challenges multiple patients could have experienced and perhaps more importantly it reminded me about the people that are on the other side of this. Another participant did not want an audio recording and asked me several times during the interview about what will happen to my notes. Every time they would ask I would answer and in the end they wished me well on the study.

I also learned the difference between the attitude of the HCP and patient towards the design. The nurses that participated in the evaluation study thought it needed to be more serious and much less like a game. However, the patients seemed to enjoy the idea of the game and wanted to make it more competitive. The patients and the peer navigator expressed liking the feeling of inclusiveness and style of the game. The peer navigator mentioned how it took away from the depressive feeling of the hospital and they would even take the game home. It should be noted that these patients were open about their diagnosis, so they probably fear the stigmatization less.

I learned how challenging it is to create something that fits everyone. Both in terms of accessibility, difficulty, and the different circumstances surrounding patients. During the design phase I was questioning every decision I was taking. However, when testing with the target group I was getting a feeling of reassurance and sense of direction. The design can always be improved, but it is important to involve the end user in the process.
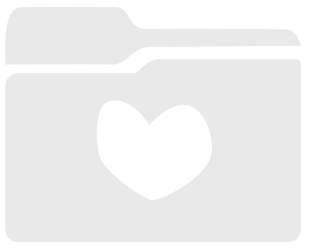
**Chapter 9**

# CONCLUSION

This chapter brings the project to a wrap.

This project aimed to design an intervention that can help PLHIV at the Amsterdam UMC HIV outpatient clinic complete PROMs. For this the project set out to research the context of PLHIV, how PROMs are implemented at Amsterdam UMC and what are current barriers patients face regarding PROMs. This was done through literature research that found Privacy is important due to the stigmatization of the disease, low health literacy prevents patients from engaging more with their own care, and all of this can negatively impact the QoL of patients. It was also found that PROMs can act directly as a tool for patient engagement.

Based on those finding the context was studied by shadowing HCPs. Additionally semi-structured interviews were conducted with both patients and nurses. The interviews with patients contained provotypes that were used to spark discussion regarding PROMs.

The main insights found from the user research were four personas of patients, on top of everything, too busy, tell me what to do, and not involved. These archetypes characterize how patients engage with their own care. Additionally it was found that a lack of understanding of the purpose of PROMs led to patients being less motivated to complete PROMs.

This helped create the following design goal: *"The design goal is to increase patient engagement with PROMs by creating a clear and accessible way for them to be informed about the purpose of PROMs, how PROMs can benefit them, and how their data from PROMs is being handled."*

The final concept was an informative single-player stacking card game. The card game aimed to inform patients about PROMs, their purpose and benefits, and how PROMs handle their data. This was done by creating three different knowledge categories of cards each related to one of those aspects. The game was then tested with the target group and the peer navigator working at the HIV outpatient clinic, location AMC.

In conclusion, the game evoked interest from multiple participants. Some expressed they learned something new after playing the game just once. Both patients and HCPs expressed that the game could help communication between them, and bringing up topics patients see as important to them during consultations. While there seems to be potential it is not possible to draw any conclusions at this time, given that a study at this level should be conducted over the span of a few years.
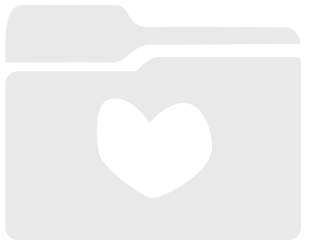
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