

APPENDICES



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Appendix 1: Project Brief

IDE Master Graduation

Project team, Procedural checks and personal Project brief

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

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

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

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

STUDENT DATA & MASTER PROGRAMME

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

family name Bartas
 initials AM given name Alexandra
 student number 5165369
 street & no. Wille
 zipcode & city 30
 country The
 phone 061
 email a.

Your master programme (only select the options that apply to you):

IDE master(s): IPD Dfl SPD

2nd non-IDE master: _____

individual programme: - - (give date of approval)

honours programme: Honours Programme Master

specialisation / annotation: Medisign

Tech. in Sustainable Design

Entrepreneurship

SUPERVISORY TEAM **

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

** chair Marijke Melles dept. / section: HCD/AED
 ** mentor Jasper Faber dept. / section: HCD/DA
 2nd mentor Kevin Moody
 organisation: Amsterdam UMC
 city: Amsterdam country: The Netherlands

comments (optional) 3rd mentor: Maarten Bedert
 Organisation: Amsterdam UMC
 City: Amsterdam; Country: The Netherlands

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

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

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

Procedural Checks - IDE Master Graduation

APPROVAL PROJECT BRIEF

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

chair Marijke Melles date 11 - 04 - 2022 signature M. Melles

CHECK STUDY PROGRESS

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

Master electives no. of EC accumulated in total: 41 EC

Of which, taking the conditional requirements into account, can be part of the exam programme 30 EC

List of electives obtained before the third semester without approval of the BoE

YES all 1st year master courses passed

NO missing 1st year master courses are:

name C. van der Bunt date 27 - 06 - 2022 signature CB

FORMAL APPROVAL GRADUATION PROJECT

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

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

Content: APPROVED NOT APPROVED

Procedure: APPROVED NOT APPROVED

also approved for Medisign
 - as discussed with the chair:
 - The full title should be: Augmenting the value of Patient Reported Outcome Measures -PROMS- for people living with HIV
 The 3rd mentor in the comments can be left out. _____ comments

- very late submission projectbrief explained by chair and accepted

name Monique von Morgen date 4/7/2022 signature MvM

Augmenting the value of PROMS for people living with HIV project title

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

start date 01 - 04 - 2022 end date 03 - 11 - 2022

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

HIV (human immunodeficiency virus) is a virus that affects the body's immune system, weakening its ability to fight infections and diseases (About HIV/AIDS | HIV Basics | HIV/AIDS | CDC, n.d.). Since its discovery, HIV treatment has made strides forward and with current treatments the future for someone affected does not look as grim as it used to. However, living with HIV creates a demand for self-management, health literacy, and treatment participation of patients for the rest of their lives.

This project takes its beginnings at the HIV outpatient clinic at Amsterdam UMC, that treats people living with HIV (PLHIV). Their focus is on improving the quality of life, with the intent of providing small-scale and personal treatment for patients. The 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.

Patient Reported Outcome Measures (PROMs), is a tool that will be implemented by the HIV outpatient clinic at Amsterdam UMC in May 2022. The clinic's aim is for patients to engage with PROMs and, hopefully, better engage in their own healthcare. PROMS is a scientifically validated tool which will be handled by the digital system of Epic and therefore not changeable under the scope of this project. PROMs are used to measure the quality of life of patients, and act as an early signaling system for the individualized care. To gather the data on PROMs it is essential that patients fill in questionnaires prior to their clinical consultation. The questionnaire provides the HIV treatment team with important insights into a patient's mental situation, treatment compliance, substance use, burden of HIV stigma, and more.

Research has shown that patients often do not see PROMs' long term value in helping them in their care. One of the reasons seems that PROMs do not have an immediate impact on the patient. This lack of short term payoff as well as under-utilization by clinicians leads to a lack of motivation in completing PROMs (Van Muilekom et al., 2021). Based on previous studies in other medical settings the team at Amsterdam UMC expects that gathering this data might therefore be difficult. However, if patients are more engaged with PROMs it could lead to a better overview of their own health and possibility to provide help when needed in a timely manner.

There is evidence that patients who are more engaged in their care have better health outcomes ("Patient Engagement," 2013). The relationship between what is called patient engagement, -enablement, -empowerment and -activation is overlapping and often times wrongly used synonymous, as we know from Fumagalli et al., (2014). Going by these definitions figure 1 was created as a guide for the terms in this project. In it, we see that patient engagement can both be the cause and consequence of patient empowerment, and it includes a form of participation and involvement. Patient empowerment is defined in three ways, either as the process of acquiring power, motivation, and ability, or the state of having these, or as the behavior of taking advantage of these. PROMs fits into these definitions as it 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.

Therefore, the goal of this project is to improve the patient engagement of people living with HIV with and through the use of PROMs.

space available for images / figures on next page

introduction (continued): space for images

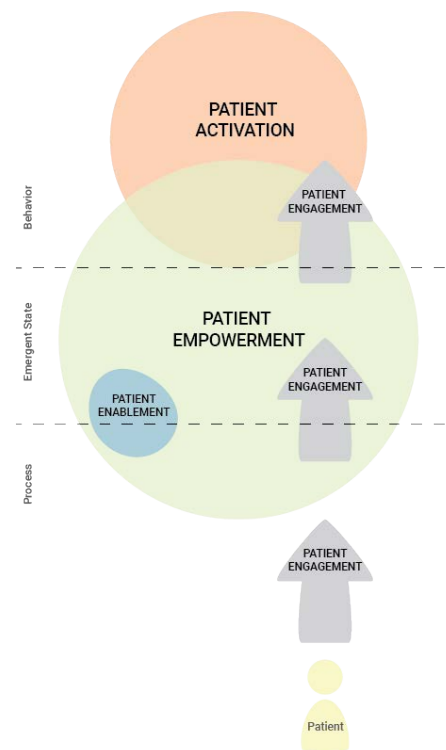


image / figure 1: Patient Engagement, Empowerment, Activation Model. Based on Fumagalli et al., 2014.

Types of patients at Amsterdam UMC outpatient HIV clinic:

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



image / figure 2: Types of patients based on staff observations at Amsterdam UMC outpatient HIV clinic.

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

Amsterdam UMC is planning to work with PROMs to collect patient data and insights on how to improve their patients' quality of life. Their intention is for the patients to fill out the PROMs at home before their appointments. During their appointments at the outpatient clinic, the patients will find out their scores and discuss them 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 longer wait times for the correct help. Additionally, if the patients do not fill in PROMs before appointments, they would at the clinic. Spending that time at the clinic to find out the answers to a PROM is also not a desirable solution. Patients might omit important information that can feel embarrassing to say aloud or they can otherwise forget the struggles they may have had since their last appointment.

Changing the current PROMs contents and the way it is designed to address patients feeling of disinterest 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 PROMs questionnaires for different types of patients (examples seen in figure 2) is also impossible.

The above concerns have been expressed by the team at Amsterdam UMC and are based on pilot studies and previous literature research with PROMs. The literature research from Amsterdam UMC and the literature research for this project brief focused on other groups of patients such as patients from pediatric care. Additionally, the PROMs for those studies were facilitated by the KLIK PROM Portal, a digital system that facilitates the use of PROMs for patients and HCPs. There is limited research regarding PROMs facilitated by EPIC for PLHIV, which is a potential limitation (and challenge) for this project.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

The project aim is to develop a design intervention that increases the engagement of people living with HIV in their own health and care process by means of PROMs.

The project will start with literature research: What has been done already in patient centered healthcare? How do health outcomes change based on how involved the patient is? What has been done in PROMs to stimulate patient engagement in their own health? How to use behavioral models to influence the patients' experience with PROMs?

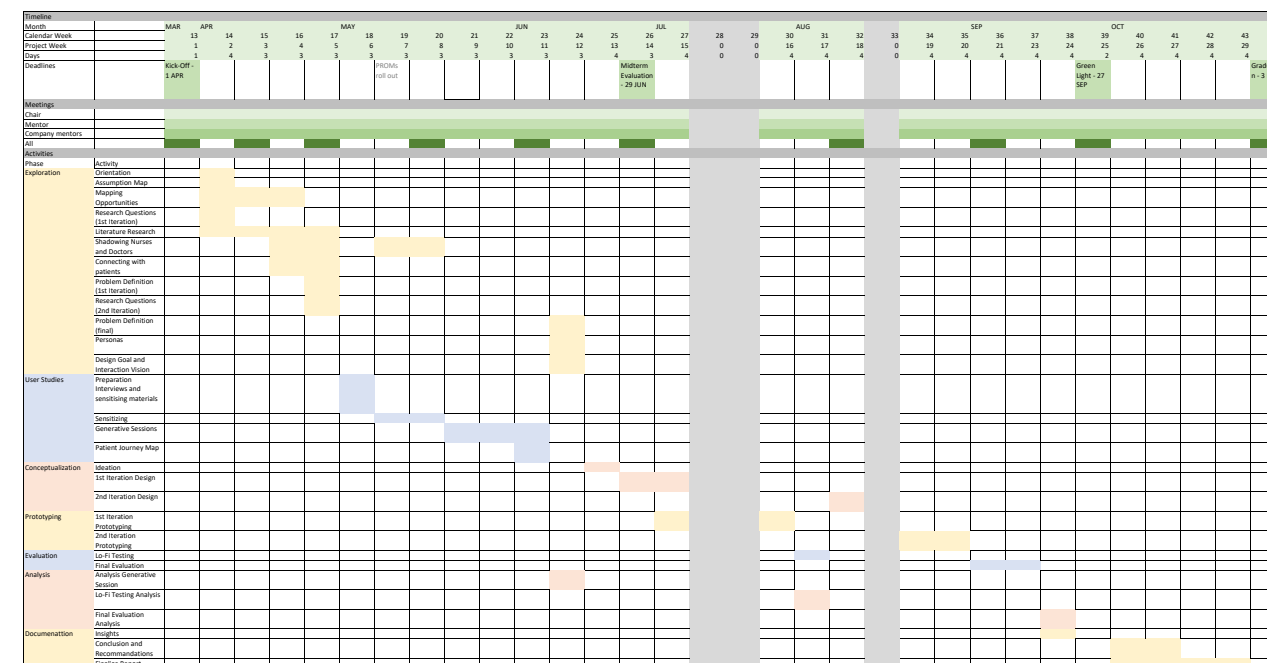
Simultaneously, I want to dive into the context, by shadowing healthcare professionals at the HIV outpatient clinic. During this time I plan to connect with the patients at the clinic. Amsterdam UMC is also working on putting together a panel of patients, that I will have the opportunity to work with. This will allow me to better define the scope of the project and start user studies, as they are the main focus.

After initial discussions I aim to include the users in the design process by conducting generative sessions, including sensitizing materials to better prepare them for the sessions, interviews and tools to engage in co-creation with the users. Since this is a sensitive topic, these sessions will be done with one patient at a time to preserve anonymity. I want to involve the patients throughout the project to ensure the resulting design fits them. Low fidelity prototypes will be used for the initial testing. The goal for the final deliverable will be a more high fidelity prototype of a design intervention that increases patient engagement through interaction with PROMs.

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 1 - 4 - 2022 3 - 11 - 2022 end date



The project plan takes into account 100 days of work, starting from 1st of April and ending on 3rd of November. The project week will generally consist of 4 working days, due to a part-time job.

There are 11 weeks that will contain 3 days of work, of which 9 are due to taking a course, that will take place on Tuesdays. The course is Drawing the Human Figure (ID5462), which will improve my visualization skills for this project and future projects. Due to my background being more technical and research oriented I strive to improve my visualization skills as a designer.

The other 2 weeks containing 3 days of work are due to the Easter holiday and taking a day off after the midterm presentation. Similarly, during week 39 I have scheduled only two days so I can recover after the green light meeting.

Additionally, 3 weeks off is included during the summer break. The last week of vacation is currently placed in August due to having to renew my passport, those dates are not final as it is not possible to know the exact date for this appointment.

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, Stick to no more than five ambitions.

I am passionate about designing for health, especially to help vulnerable groups. So this project aligns very well with some of my core values, because I think design should be all about the people it serves. With my background in Medisign this project will test my skills within the area and I hope to bring everything I have learned to bear.

The thing that speaks to me about this project is its focus on the wellbeing of patients, in all areas. Getting to experience and interact with this approach will only strengthen me as a designer.

I am looking forward to the opportunity to get some first hand experience in shadowing and observing in the health care context. The theory I have learned on observation and in-context studies will be refined into proper skills.

I hope to improve my skills in interviewing and use what I learned in courses like Context mapping and Context and Conceptualization. This is why I want to use what I learned in those courses through design and using generative tools.

As mentioned previously, my background is more technical and research oriented. This is due to my Bachelor's being in Medialogy (at Aalborg University), where projects focused on literature research and argumentation, implementation and statistics. In this project I aim to focus more on the design phase, especially ideation where I will experiment with different ideas. Due to the time constraints of this project, low fidelity prototypes will be used for the initial testing. The goal for the final deliverable will be a more high fidelity prototype.

References:

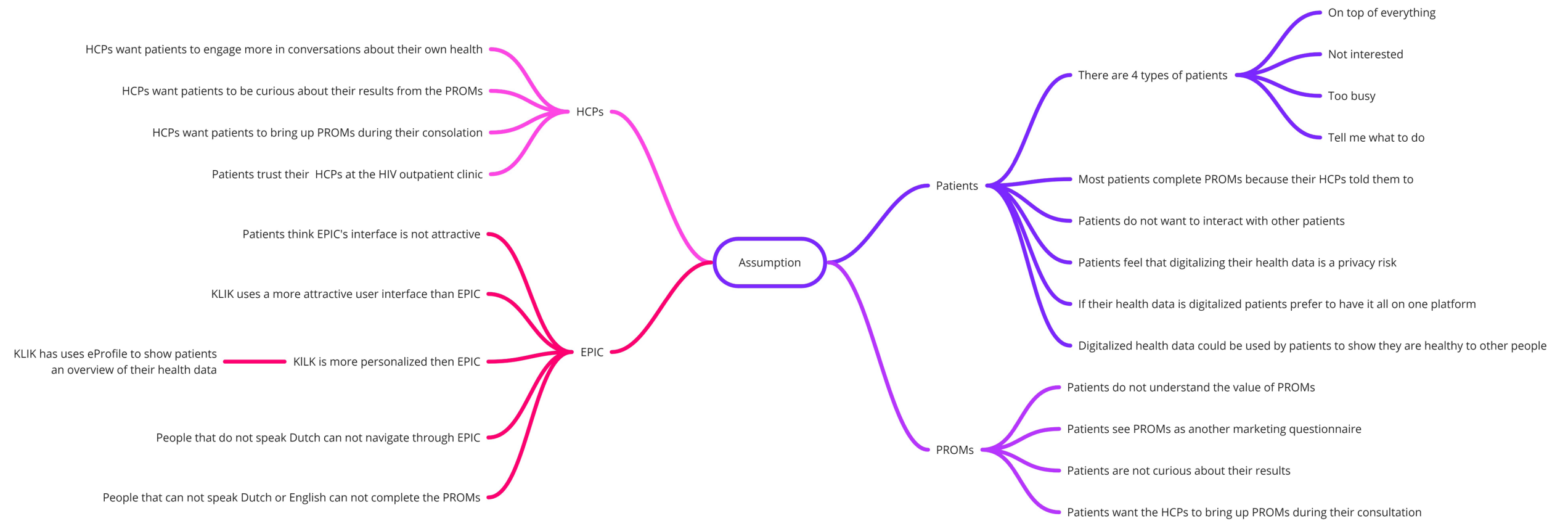
1. About HIV/AIDS | HIV Basics | HIV/AIDS | CDC. (z.d.). Centers for Disease Control and Prevention. Geraadpleegd op 1 april 2022, van [https://www.cdc.gov/hiv/basics/whatishiv.html#:~:text=HIV%20\(human%20immunodeficiency%20virus\)%20is,healthy%20and%20prevent%20HIV%20transmission.](https://www.cdc.gov/hiv/basics/whatishiv.html#:~:text=HIV%20(human%20immunodeficiency%20virus)%20is,healthy%20and%20prevent%20HIV%20transmission.)
2. Van Muilekom, M. M., Teela, L., Van Oers, H. A., Van Goudoever, J. B., Grootenhuis, M. A., & Haverman, L. (2021). Patients' and parents' perspective on the implementation of Patient Reported Outcome Measures in pediatric clinical practice using the KLIK PROM portal. *Quality of Life Research*, 31(1), 241–254. <https://doi.org/10.1007/s11136-021-02950-x>
3. Health Affairs, & James, J. (2013). Patient Engagement. *Health Policy Brief*. <https://doi.org/10.1377/hpb20130214.898775>
4. Fumagalli, L. P., Radaelli, G., Lettieri, E., Bertele', P., & Masella, C. (2015). Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. *Health Policy*, 119(3), 384–394. <https://doi.org/10.1016/j.healthpol.2014.10.017>
5. Moody, K. & EATG PROMise Task group. (2021, February). PROMs in HIV Research and Development: Analysis of Community Needs and Engagement. <https://www.eatg.org/wp-content/uploads/2021/10/eatg-proms-in-hiv-research-referencereport.pdf>

FINAL COMMENTS

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

Appendix 2: Assumption Map

An assumption map was used to have a visual representation of any assumptions made at the beginning of this project. It is a tool that helps identify and document the assumptions made about the target group, the problem, and the solution, and it is used to understand the potential risks and limitations of a design. The map was made based on initial meetings with the clients and initial research conducted. Not all assumptions are needed to be answered for the project e.g. In this instance the assumption that patients do not think the EPIC software provides an attractive interface will not be answered because changing the interface is out of the scope of the project.



Appendix 3: Interview Guide for Patients

Interview Guide

Participants:

People living with HIV,

People that follow treatment at Amsterdam UMC, location AMC.

Timing:

1. Part 1: Introduction: 5 min
2. Part 2 Provotype 1: 5-7 min
3. Part 3 Provotype 2: 6-7 min
4. Part 4 Provotype 3: 7-9 min
5. Part 5: Wrap up: 3-5 min

(Total time: 26-33 min)

Materials:

1. Consent form
2. Interview script
3. 1st Provotype
 - visual storyboard
 - visual guide (only contains first 2 steps, as it is meant to immerse the participant, not to be used)
4. 2nd Provotype
 - visual storyboard
 - board with pins
5. 3rd Provotype
 - visual storyboard
 - speaker
 - phone with audio files
6. Pen and paper
7. Audio recorder
8. Gift card

Text Format:

Talking

Notes

Heading

- Question
 - Follow up question

Interview Guide

Part 1: Introduction

Thank you for taking the time to do this interview with me. I am Alexandra and I am coordinating this research project.

Amsterdam UMC is looking at ways to encourage patients to get more **involved** with about their well-being and health care experiences. Today, I would like to engage you to explore some possibilities to see what the most **acceptable and effective** way would be to **present reporting tools** to patients. Reporting tools consist of **questionnaires** that will be delivered through e-mails and on the web that will be filled out in preparation of the consultation at the hospital.

For this interview I prepared 3 possible **scenarios**. I would like to go through them with you as if you are experiencing the scenarios **firsthand**. For this I prepared some pictures and interactive materials to show what these scenarios would look like. The goal of these scenarios is to get your **expert opinion** as a patient.

I will be taking notes during this interview. I also have an audio recorder so I can look back to the interview in case I missed anything. Only I will read and have access to those notes and audio file.

Before we begin, I would like to give you a consent form.

Are there any questions you have before I start the interview?

Help them with any questions they might have.

If you are ready, I will start the audio recorder.

Start audio recorder.

General questions

I will start with some general questions.

- Where are you from?
- How old are you?

We are presenting people with a tool to report to us through MyChart/Mijn Dossier.

- Do you have an account with MyChart/Mijn Dossier?
 - *If yes:* How would you describe your experience with MyChart/Mijn Dossier?
 - *If no:* What is preventing you from getting an account with MyChart/Mijn Dossier?
 - *If they do not know what MyChart/Mijn Dossier is, give a brief introduction to MyChart.*

Brief explanation of MyChart/Mijn Dossier: MyChart/Mijn Dossier is a patient portal used by Amsterdam UMC where you can keep track of your appointments, manage your health information, be in contact with the healthcare professionals and have access to the reporting tools I mentioned previously.

From now I will refer to those reporting tools as PROMs.

- Have you heard about PROMs before?
 - *If yes:* What is your impression of PROMs?

Part 2: Provotype 1

1st Provotype

Now I will present you the 1st scenario. This scenario is set in the waiting room at the clinic. As we go through the scenario, I will show you some pictures to help visualize what is happening. Afterwards I will ask you some questions about the scenario.

Keep in mind that we are looking to see what the most acceptable and effective way would be to present reporting tools to patients. Feel free to ask any questions you have about the scenarios.

Show illustration of frame 1.

Frame 1: This is the first picture where you as the patient 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 and find the PROMs on MyChart.

Hands the patient the visual guide.

To show you what the visual guide would look like, I am showing you the first page.

Show illustration of frame 2.

Frame 2: The receptionist shows you to a computer in the waiting room.

Show illustration of frame 3.

Frame 3: 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.

Show illustration of frame 4.

Frame 4: The receptionist helps you with this step and shows you how to find the PROMs.

Show illustration of frame 5.

Frame 5: You complete the PROMs.

Show illustration of frame 6.

Frame 6: You log out of your MyChart account and find a seat in the waiting room for the remaining waiting time before your appointment.

Questions:

- Do you see yourself going through this scenario in the future?
 - Why?
 - Do you feel comfortable?
 - Do you think you would have any challenges in this scenario?
- How do you feel about filling in PROMs in the waiting room?

Part 3: Provotype 2

2nd Provotype

Let's start with the 2nd scenario which is also set in the waiting room. I will follow a similar structure to the previous scenario.

Show illustration of frame 1.

Frame 1: You enter the waiting room passing through the reception desk. The receptionist greets you and asks you if you have completed the PROMs before your appointment.

Show illustration of frame 2.

Frame 2: If you have completed the PROMs before your appointment, the receptionist gives you a box of pins that you can put on the waiting room wall.

Show illustration of frame 3.

Frame 3: 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. You are thinking about what to add to it yourself.

Similar to the picture, the wall would look like this...

Present the participant with a board with pins (Existing prompts before the interview: What is your dream travel location? How do you feel today? Show it with pins! or Do you have a headache?)

If you were in this scenario, what would you add to the wall? Can you use these pins to show me?

Participant adds to the board.

Questions

- Do you see yourself going through this scenario in the future?
 - Why?
 - Do you normally have enough time before your appointment to use pins?
- Would this be something that would motivate you to complete PROMs?
 - How?
- What did you think about the questions on the board?

- What were your thoughts when placing the pins?
- Do you see opportunities to fill out the PROMs should this become part of your care at the AMC before coming to an appointment?
 - How?
- *If they heard about PROMs before:* Did you have a chance to fill in PROMs yet for your appointments?
 - *If yes:* What helped you in completing PROMs?
 - *If no:* What has prevented you from completing PROMs?
- When was the last time you waited for a long time?
 - What did you do while you waited?
 - How would you have liked to spend that time?
 - *If they responded with a waiting instance outside Amsterdam UMC:* Is this something you would like to do while waiting for your appointment at Amsterdam UMC?
 - *If no:* How would you like to spend the time in the waiting room at Amsterdam UMC?

Part 4: Provotype 3

3rd Provotype

This will be the last scenario which is set at your home. In this scenario you own a chatbot/AI assistant such as Siri or Alexa.

- *Are you familiar with these?*
 - *If no: brief demonstration with Siri. e.g. Hi Siri! What is the weather today?*

The chatbot/AI assistant wants to aid you in completing your PROMs. I will use this prompt (*show speaker*) to play as your chatbot/AI assistant, so you will be able to interact with it during the scenario. Let's get started.

Show illustration of frame 1.

Frame 1: You are at home and your chatbot wants to ensure you have time to talk about your health.

Audio File 1: Good evening! Do you have time for a quick chat?

Feel free to respond!

Response from participant.

Optional: Show illustration of frame 2. (This frame is optional based on the remaining time of the interview.)

Frame 2: The chatbot wants to make you sure you feel comfortable, so it gives you a few options to create a calming atmosphere.

Audio File 2: What would make you feel more comfortable at the moment: a calming scent, calming music or some breathing exercises?

Response from participant.

If the participant chose calming scent: open lavender scent bottle.

If the participant chose calming music: Play Audio File 3 with 15 sec of calming music.

If the participant chose breathing exercises: Play Audio File 4 with 15 sec of a breathing exercise.

Show illustration of frame 3.

Frame 3: The chatbot wants to help you complete the PROMs before your appointment.

Audio File 5: Did you have a chance to complete the PROMs?

Response from participant.

If yes: Audio File 5: I am happy to hear that!

If no: Audio File 6: I want to help you complete the PROMs before your appointment. Do you have any questions for me?

In case they do not respond: What would you ask the chatbot?

Response from participant

Based on their answer: Interesting question!

- Why did you ask the chatbot...?
- Why is it important for you to know...?

This chatbot was trained to answer a few questions. What question would you ask from the following illustration?

Show illustration of frame 4.

Frame 4: You are asking the chatbot one of the following questions: 1. How much time does it take to complete the PROMs? 2. Who can see my answers?

Response from participant

Based on the response:

If they chose 1: Audio File 7: Completing PROMs takes about 20 min.

If they chose 2: Audio File 8: Only the medical team has access to your data.

Questions

- Do you see yourself going through this scenario in the future?
 - Why?
 - Do you feel comfortable?
 - Would you feel comfortable talking to a chatbot/Ai assistant about PROMs?
 - Why?
 - What topics would you be comfortable discussing with the chatbot?
 - Why?
 - *If they do not mention health related topics:* Would you feel comfortable talking to a chatbot/Ai assistant about your health?
 - Do you think you would have any challenges in this scenario?
- What digital tools/technology do you use in your daily life? (*In case they need examples: this could be a phone, computer, tablet...*)
 - How do you use them?
- With whom would you feel comfortable to talk about PROMs?
 - Why?
- (*If they completed the PROMs*) Have you had a chance to discuss PROMs with a HCP?
 - *If yes:* How did you feel about that experience?
 - *If yes:* What have you learned from that discussion?
 - *If no:* Would you like to discuss PROMs with a HCP?
 - Why?
- (*If they did not complete the PROMs*) Would you like to discuss PROMs with a HCP?
 - Why?
- What do you do when you have questions regarding your health between appointments?

Part 5: Wrap up

Additional questions

- What was your preferred scenario?
 - Why?
- Which scenario did you not like?
 - Why?

We are approaching the end of the interview, so I have a few last questions for you.

- Is there anything else you would like to discuss?
- Do you have any questions for me?

Thank you again for your time, if you have any other questions do not hesitate to contact me!

Give them a gift card.

Appendix 4: Interview Guide for Nurses

Interview Guide

Participants:

Nurses working at the HIV outpatient clinic at Amsterdam UMC, location AMC.

Timing:

1. Part 1: Introduction: 2 min
2. Part 2: Questions about the relationship between nurses and patients: 3 min
3. Part 3: Questions about patient involvement in their own healthcare: 4-6 min
4. Part 4: Questions about PROMs: 7-8 min
5. Part 5: Questions about MyChart: 5 min
6. Part 6: Wrap up 2 min

(Total time: 23-26 min)

Materials:

1. Consent form
2. Interview script
3. Pen and paper
4. Audio recorder
5. Gift card

Text Format:

Talking

Notes

Heading

- Question
 - Follow up question
 - Follow up to the follow up question

Interview Guide

Part 1: Introduction

There is an expectation that I have previously introduced myself to the nurses during an earlier stage of my project, where I shadowed them during consults.

Hello, first I would like to thank you for taking the time to do this interview!

As you might know, I am looking into ways that can help patients be more involved with their own health, with a focus on PROMs.

For this interview I have prepared three types of questions. First, I would like to better understand your perspectives on patient experiences and the relationship you have with patients. Second, I would like to better understand your perspectives on underserved populations. Third, I would like to find out how you assess on the patient involvement with their own healthcare.

I want to add that this research is not focused on the current implementation of PROMs but how they would ideally serve the patients in the future.

I will be taking notes during this interview. I also have an audio recorder so I can look back to the interview in case I

missed anything. Only I will read and have access to those notes and audio file.

Before we begin, I will give you a consent form.

Are there any questions you have before I start the interview?

Help them with any questions they might have.

If you are ready, I will start the audio recorder.

Start audio recorder.

Part 2: Questions about the unique relationship between nurses and patients.

I will start with some general questions.

- How long have you been working as a nurse at this clinic?
 - How would you compare your relationships with patients now as opposed to when you started here?
- How would you describe your experience as a nurse?
 - How many patients do you see in a day?
 - How does this affect your relationship with patients?

Based on the previous answers in Part 2, the following anecdote can be introduced to spark further reflection:

For A: Three of the patients whose consultation I observed gave you some heartfelt farewells for your retirement. I remember one of them gave you a thank-you card.

- What did that mean to you?
- How would you define your relationship with those patients?
 - And how would you define your relationship with patients in general?

For the other nurses: Three of the patients whose consultation I observed gave a nurse who is retiring some heartfelt farewell. I remember one of them gave the nurse a thank-you card.

- Do you think this reflects the general relationship between nurses and patients at this clinic?
 - Why?
- How would you define your relationship with patients?

Part 3: Questions about the current patient involvement in their own healthcare.

- How involved do you feel the patients are in their own healthcare?
 - *Optional question based on time:* How often do patients research and bring up new information regarding their health?
 - What type of information do they usually bring up?
 - What patients would this apply to?
 - What type of questions do patients have during appointments?
 - How do your expectations change for each appointment based on the patient?
 - Is there anything you would like patients to discuss more?
 - Why?
 - What patients would this apply to?
- What is the best way to explain a health-related issue to a patient?

Part 4: Questions about PROMs:

I will continue with some questions about PROMs.

- What would you like to get out of PROMs in your own practice?
- What should patients get out of PROMs?
 - Do you think patients are aware of this?
 - In what way?

- *Optional question:* Do you feel patients are aware of how PROMs can benefit them?
- What are patient attitudes towards PROMs?
 - Can you give me an example?
- What concerns have patients brought up regarding PROMs?
 - *For each concern of interest:* Why do you think they brought up this concern?
 - *For each concern of interest:* What patients would have this concern?
- What do **you** think are the main challenges patients might experience with PROMs?
- How do you think digital skills or access to technology can affect patients interacting with PROMs?
- What do you think might help patients to complete PROMs?
- Can you describe for me who the patients are that would benefit most from PROMs in your practice?

Part 5: Questions about MyChart:

In the future, for patients to have access to PROMs, they first need to get an account with MyChart. Therefore, I would like to ask you some questions about the patient experience with the platform.

For A: During my observations, I remember that you introduced a patient to MyChart and that this was not their first appointment at this clinic.

For the other nurses: From my observations, I remember a patient being introduced to MyChart during their consultation with a nurse. I also remember that this was not their first appointment at this clinic.

- Is MyChart introduced in this way to all patients?
 - Why?
 - How?
 - At what point after becoming a patient at this clinic are patients introduced to MyChart?
- How many patients do you think could use MyChart?
 - What patients are likely to use MyChart?
 - What patients are least likely to use MyChart?
 - What patients could become more likely to use MyChart
 - How?
- What concerns have patients brought up about MyChart?
 - *For each concern of interest:* Why do you think they brought up this concern?
 - *For each concern of interest:* What patients would have this concern?
- How do you think the concern for privacy can affect patients using MyChart?
 - *For each concern of interest:* What patients would have this concern?
- *Optional question based on time:* What do you think are the main challenges patients might experience with MyChart?
- Can you think of ways to introduce patients to my chart more effectively?

Part 6: Wrap up

We are approaching the end of the interview, so I have a few last questions for you.

- Can you describe the type of patient we can help with this project?
- Is there anything else you would like to discuss?
- Do you have any questions for me?

Thank you again for your time, if you have any other questions do not hesitate to contact me!

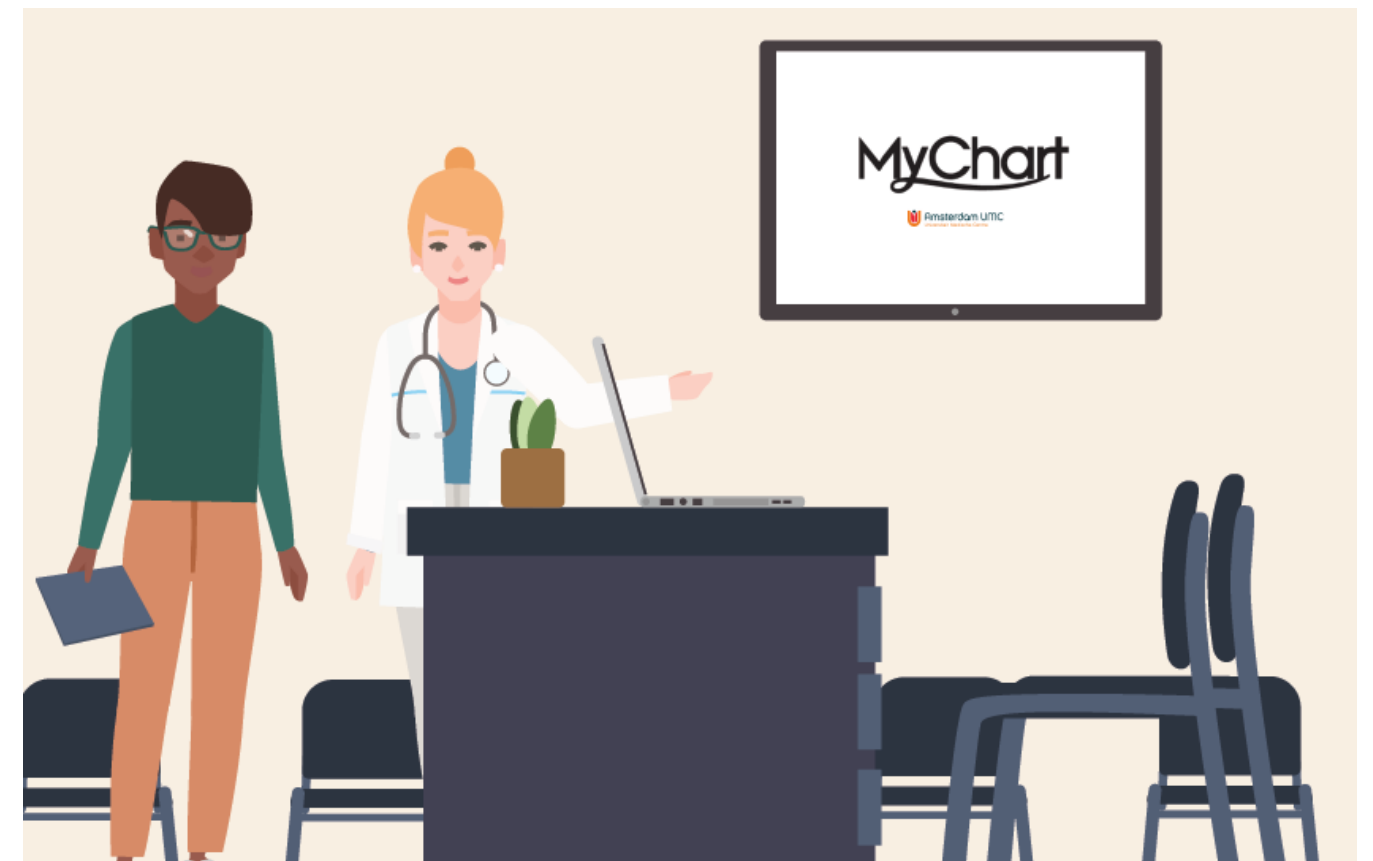
Give them a gift card.

Appendix 5: Provotypes in English and Dutch

Provotype 1 in English



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.



The receptionist shows you to a **computer** in the waiting room.



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.



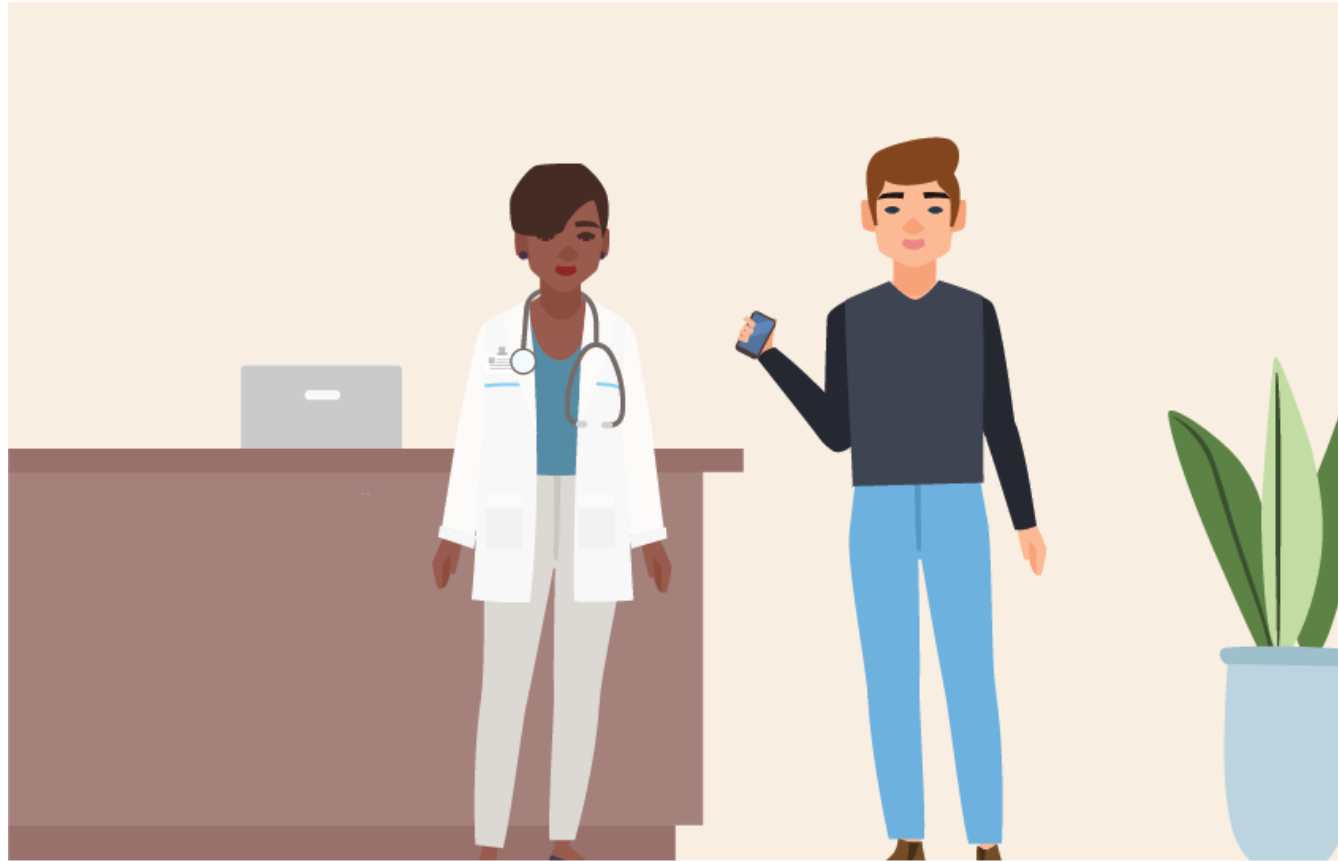
You complete the PROMs.



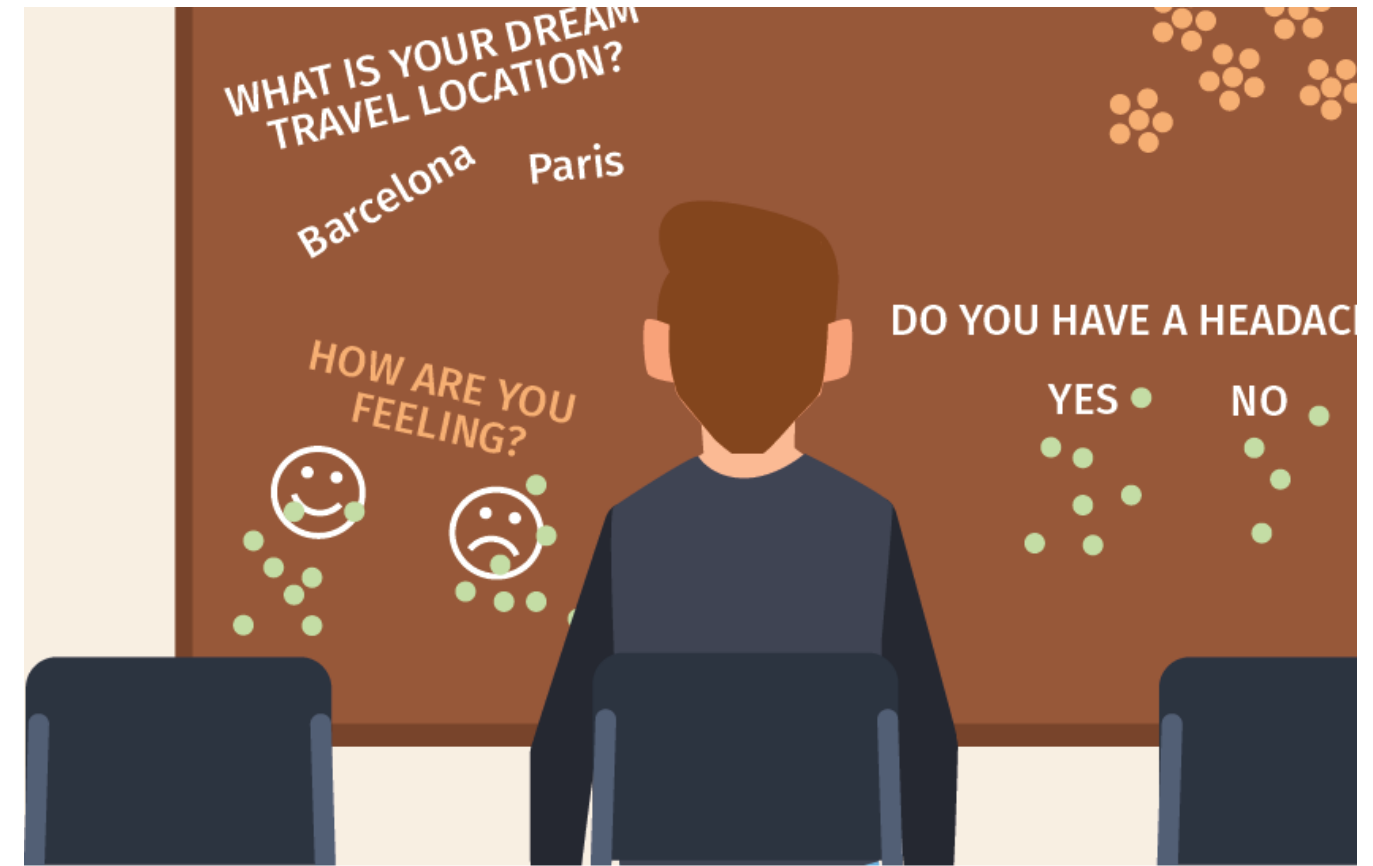
The receptionist helps you with this step and shows you how to **find the PROMs**.



You **log out** of your MyChart account and find a seat in the waiting room for the remaining **waiting time** before your appointment.



You enter the **waiting room** passing through the reception desk. The receptionist greets you and asks you if you have completed the PROMs.



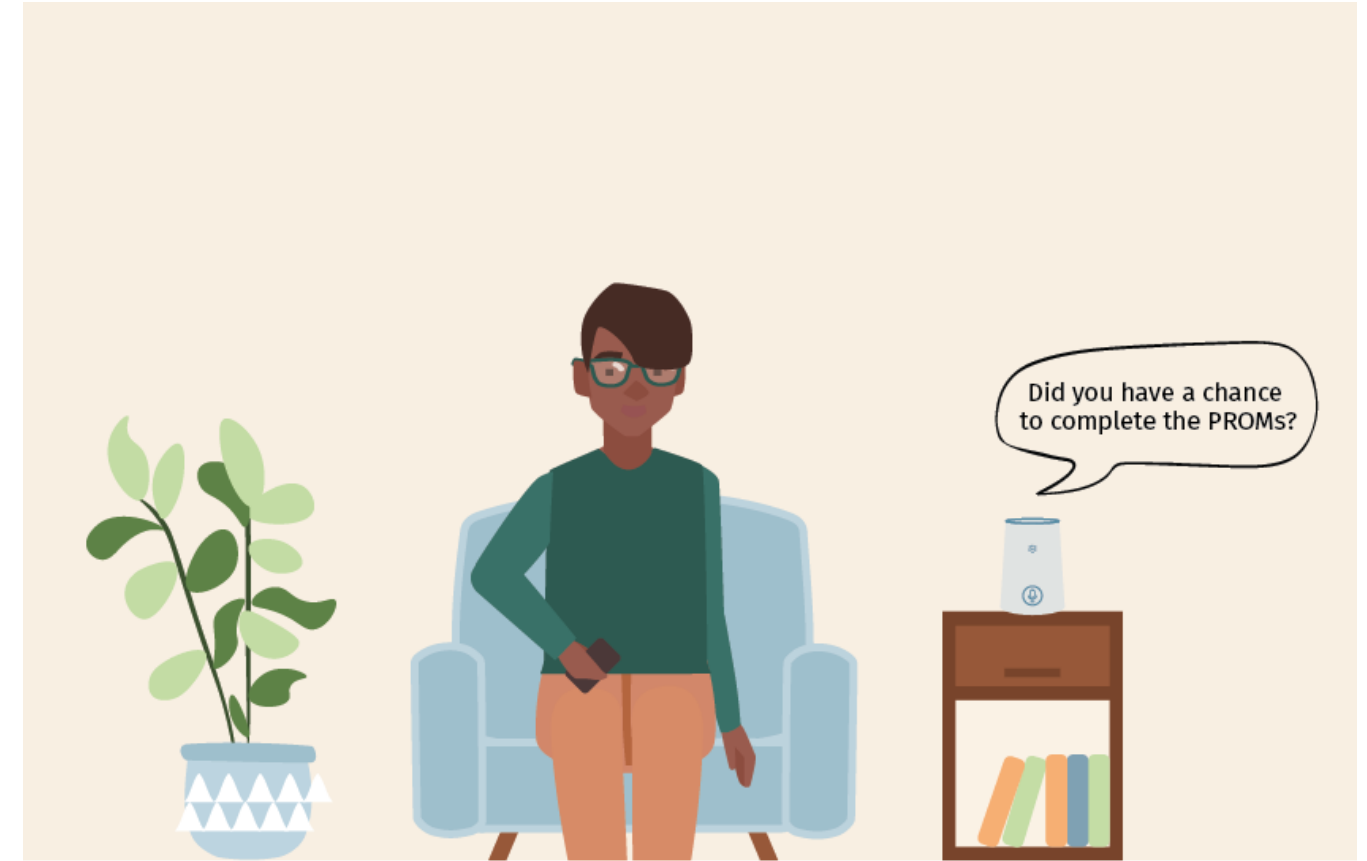
You sit down in the waiting room and see that the **wall** has some drawings and some prompts to conversation that **other patients** contributed with.



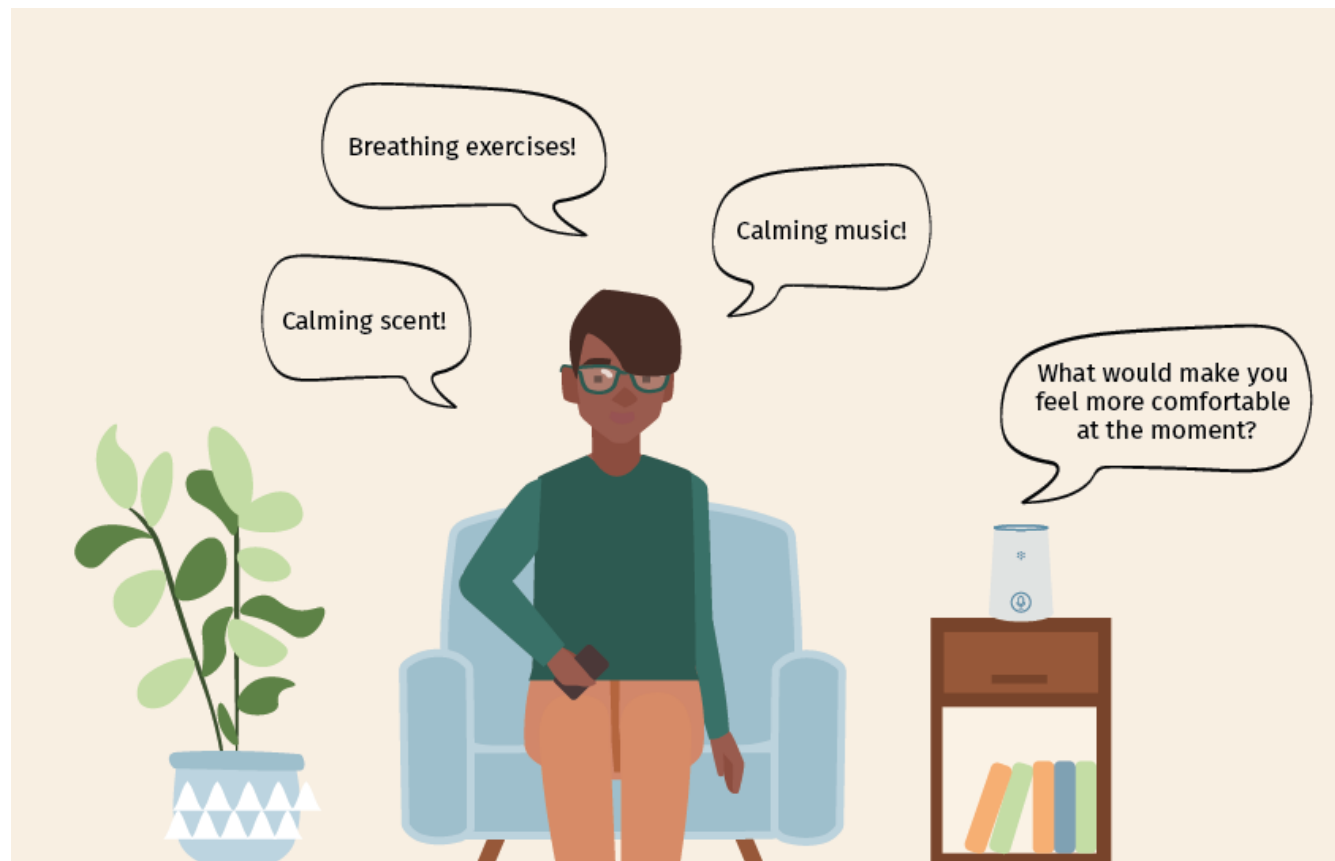
You completed the PROMs and the receptionist gives you a **box of pins**.



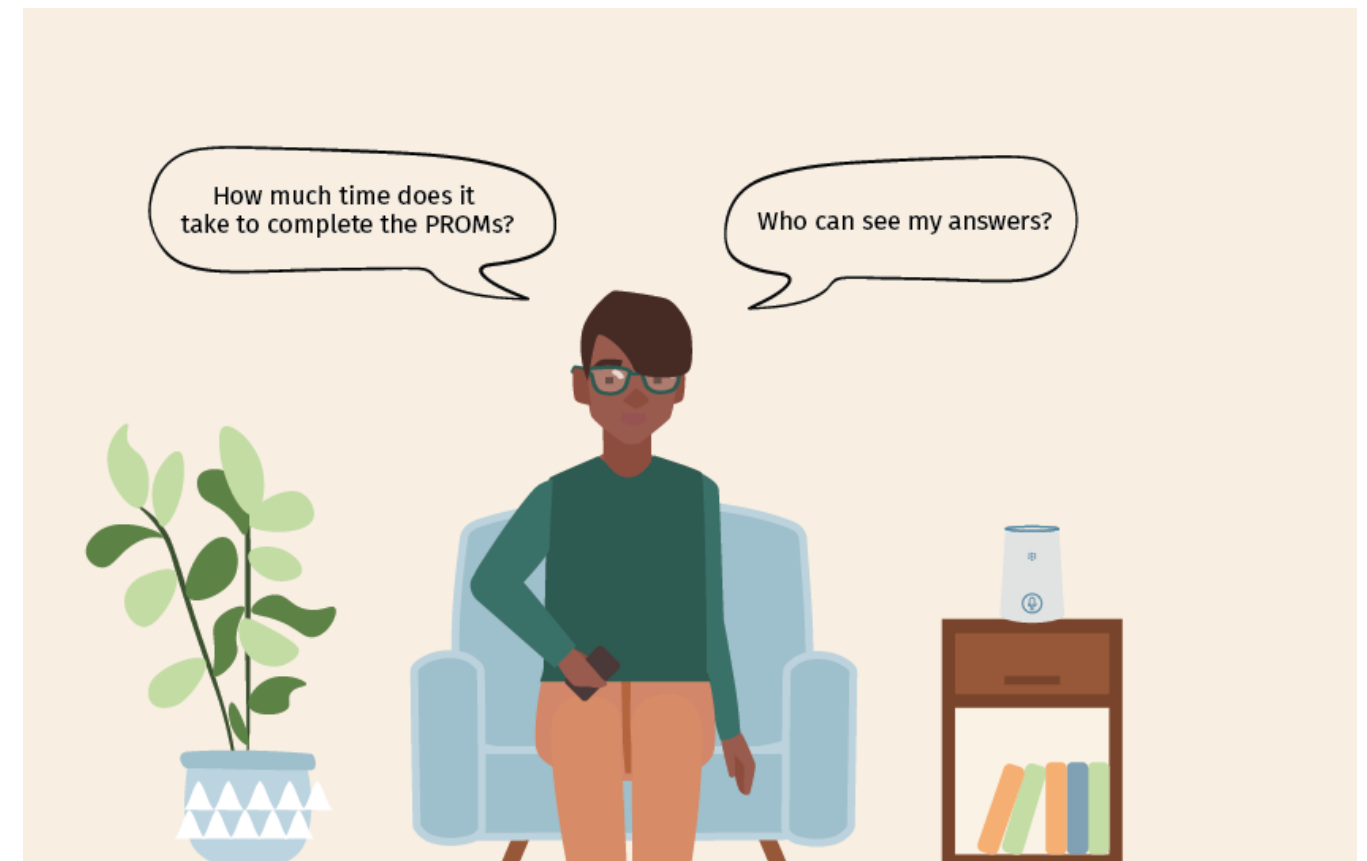
You are at home and your **chatbot** wants to ensure you have time to talk about your health.



The chatbot wants to help you complete the PROMs before your appointment.



The chatbot wants to make you sure you feel **comfortable**, so it gives you a few options to create a calming atmosphere.



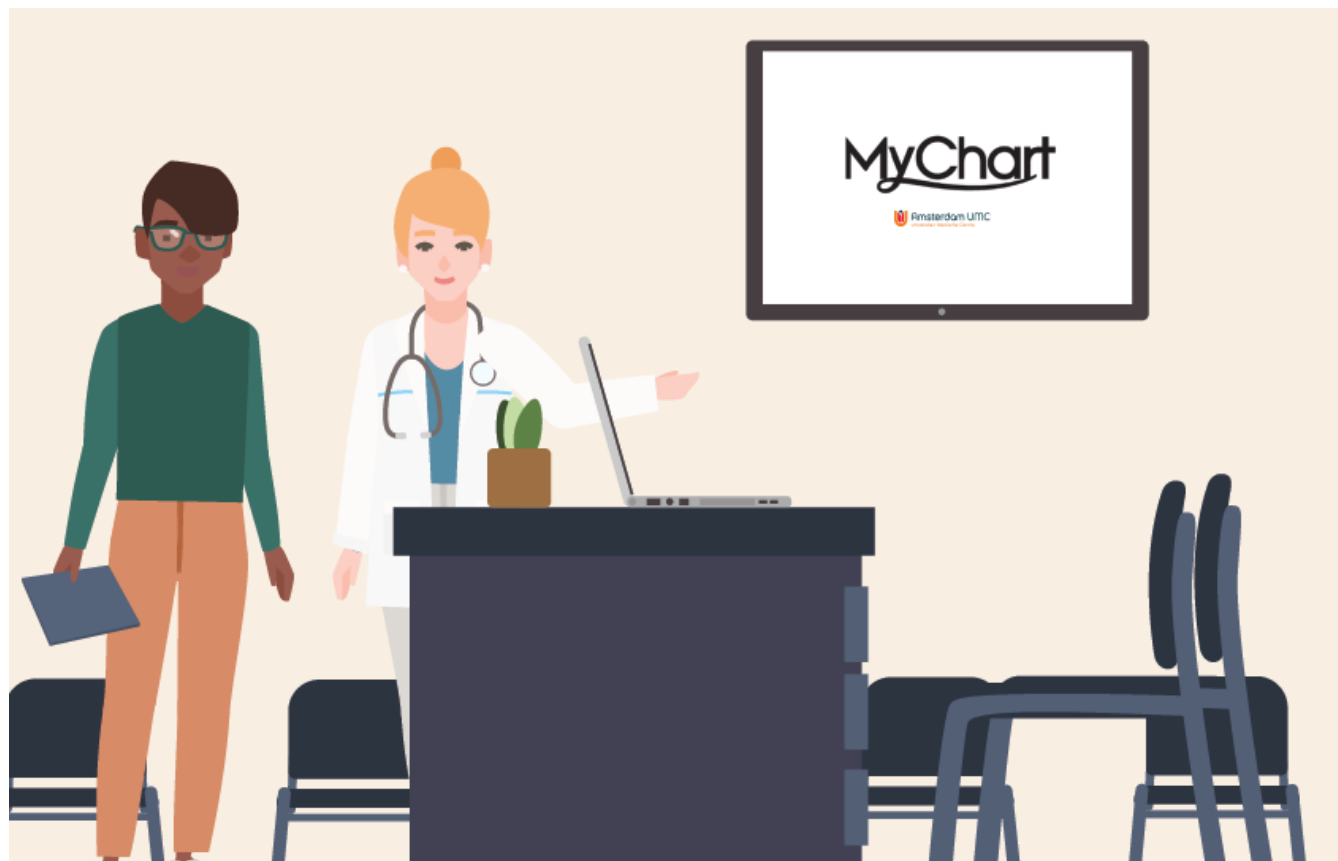
You are asking the chatbot one of the following questions.



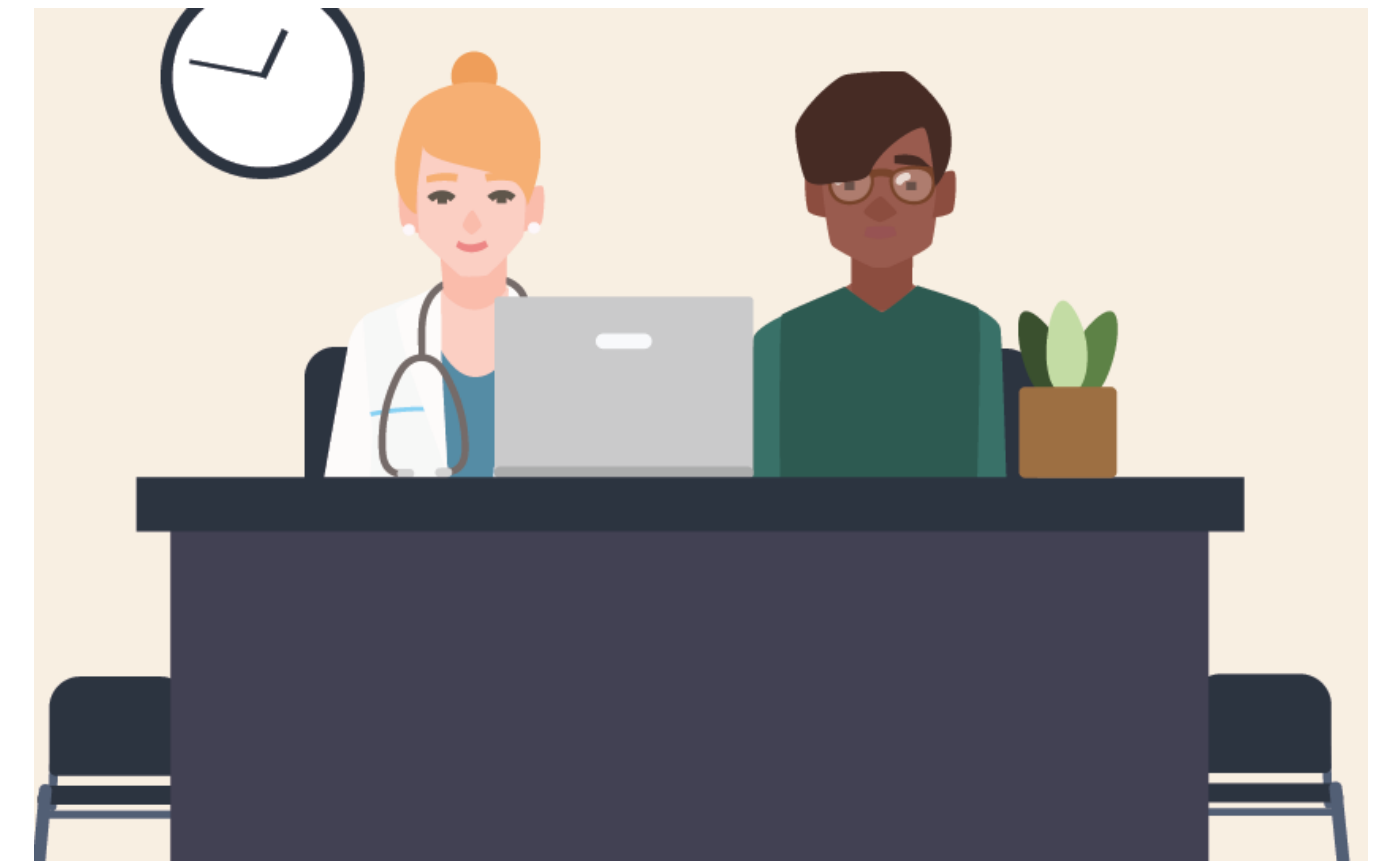
U komt de **wachtkamer** binnen via de receptie.
De receptioniste begroet u en overhandigt u een **visuele gids** over hoe MyChart in te stellen.



U volgt de visuele gids en maakt een account aan met MyChart.
Echter, u loopt vast bij de stap waar u de PROMs moet vinden.

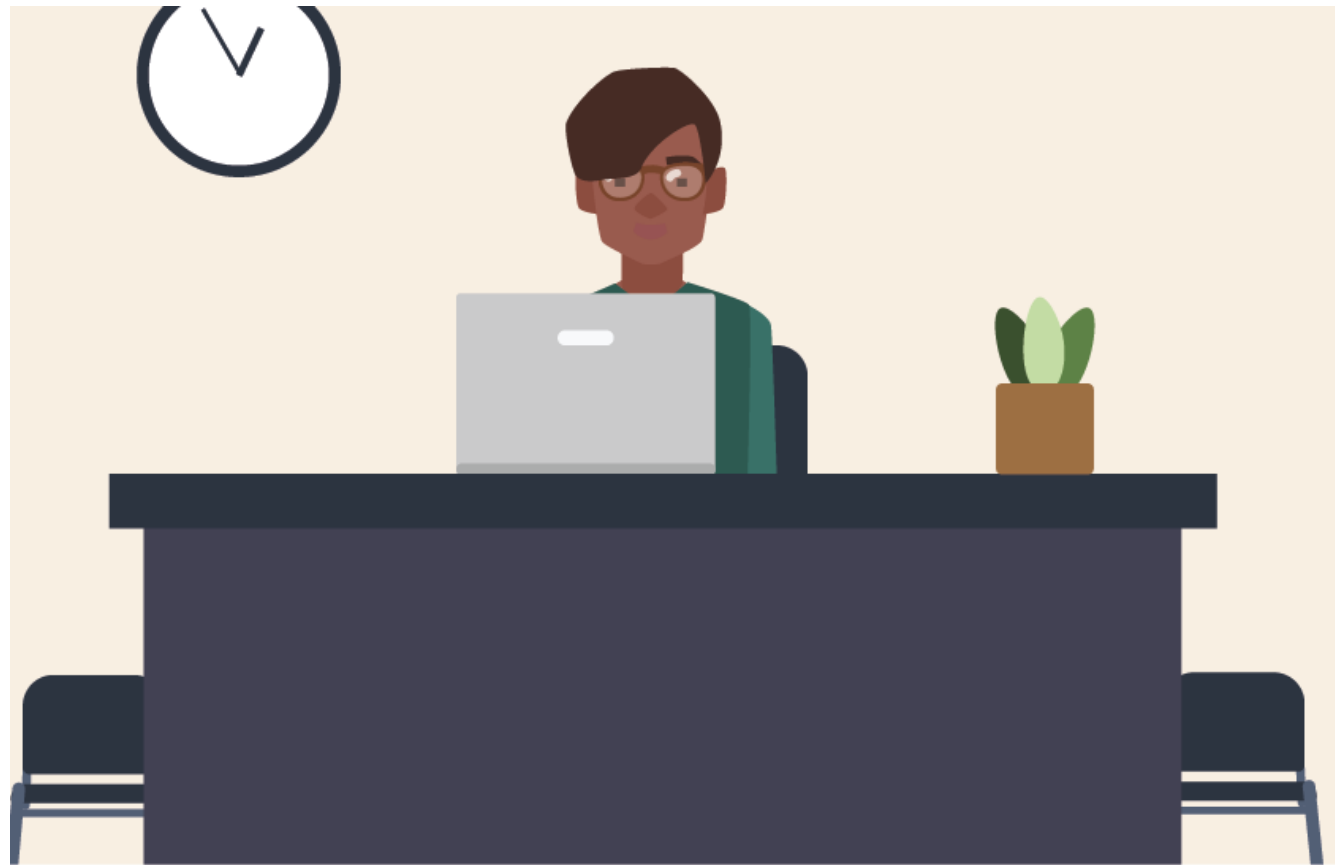


De receptionist wijst u de weg naar een **computer** in de wachtkamer.



De receptioniste helpt u bij deze stap en toont u hoe u de **PROMs kunt vinden**.

Prototype 2 in Dutch



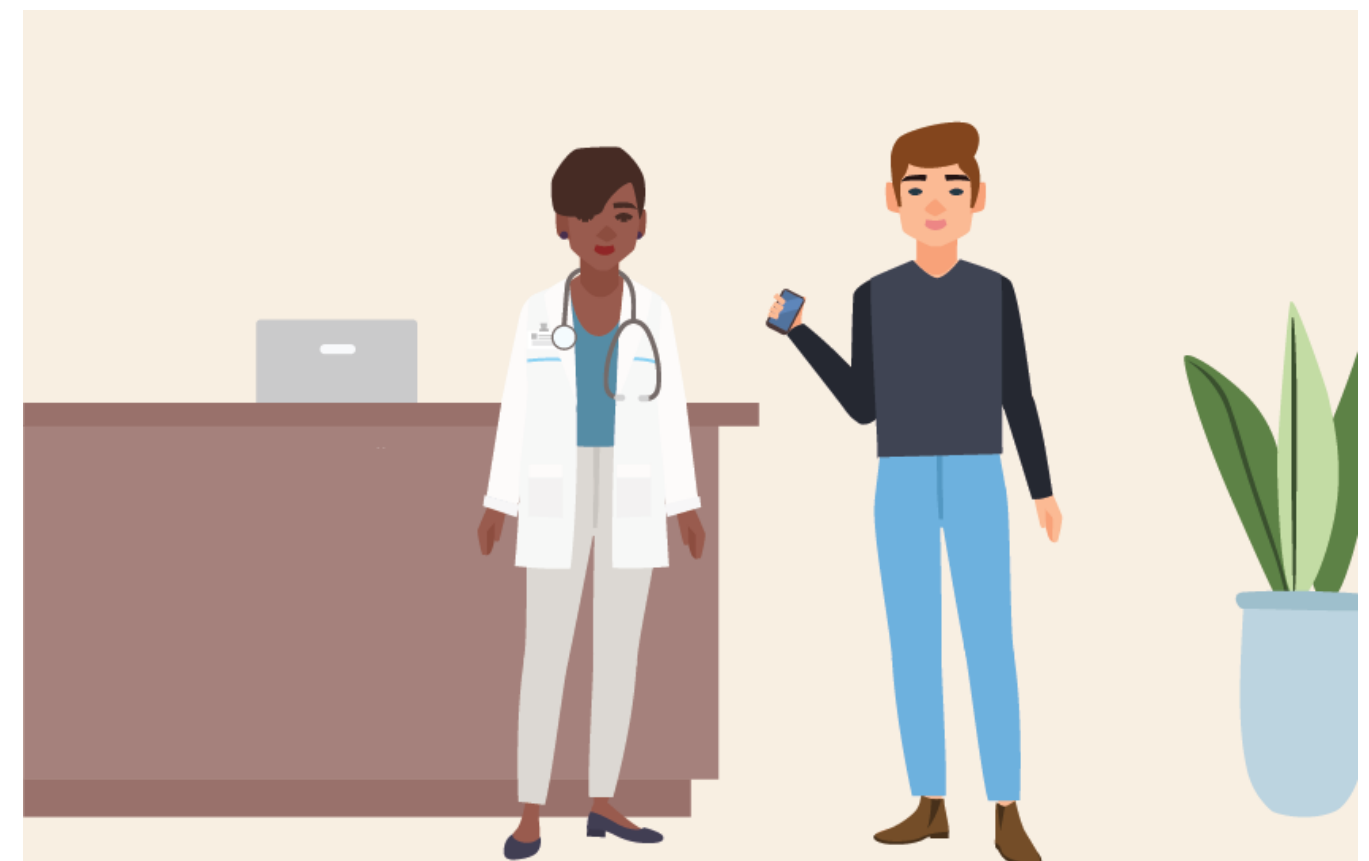
Je hebt de PROMs voltooid.



Als je de PROMs hebt ingevuld, geeft de receptioniste je een **doos met spelden** die u op de muur in de wachtkamer kunt hangen.



U **logt uit** van uw MyChart account en zoekt een plaats in de wachtkamer voor de **resterende wachttijd** voor uw afspraak.



Je komt de **wachtkamer** binnen langs de receptie. De receptioniste begroet u en vraagt u of u de PROMs heeft ingevuld voor uw afspraak.

Provotype 3 in Dutch



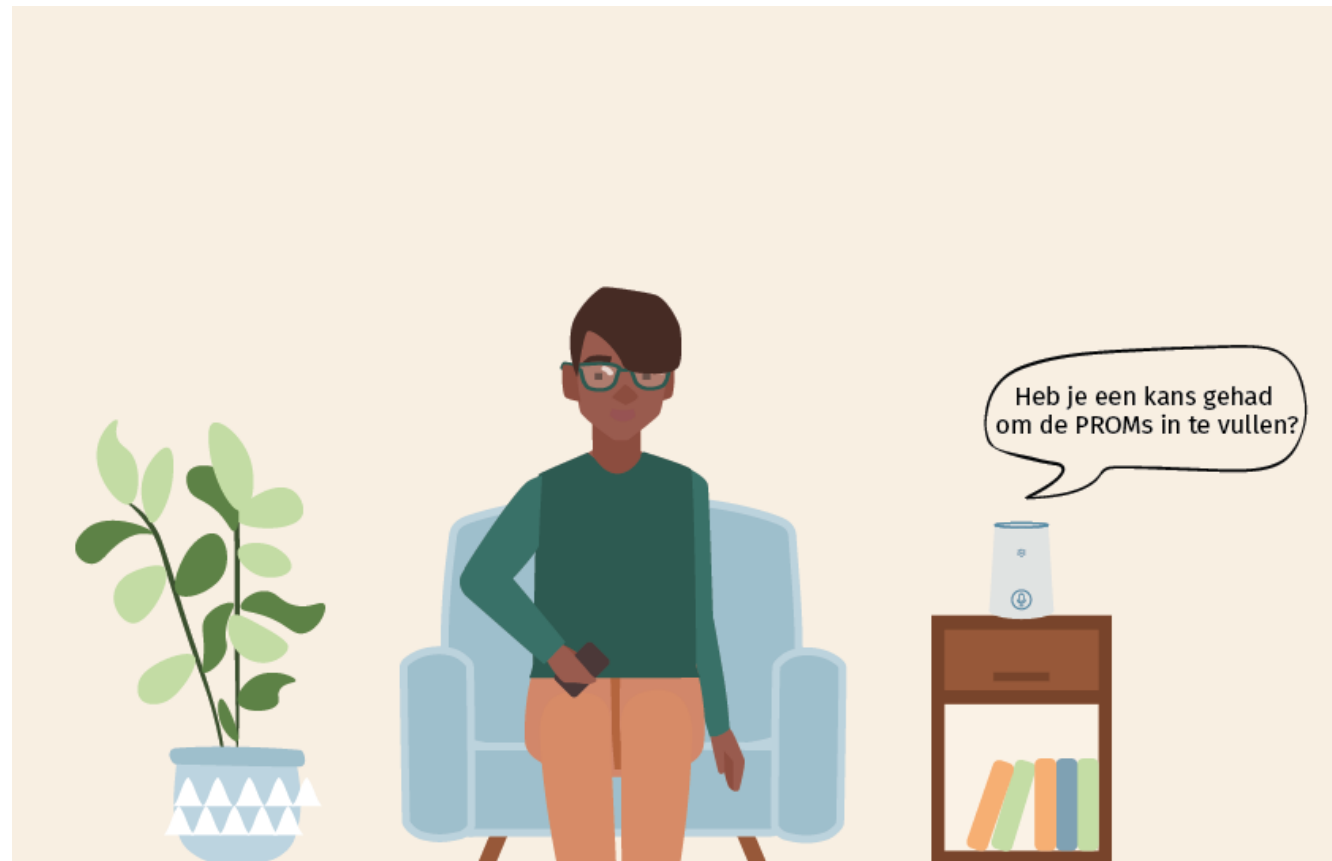
Je gaat in de wachtkamer zitten en ziet dat er aan de **muur** wat tekeningen hangen en wat gespreksaanknopingspunten waar **andere patiënten** aan hebben meegewerkt.



U bent thuis en uw **chatbot** wil ervoor zorgen dat u tijd heeft om over uw gezondheid te praten.



De chatbot wil ervoor zorgen dat je **comfortabel** voelt, dus het geeft je een paar opties om een kalmerende sfeer te creëren.



De chatbot wil u helpen de PROMs in te vullen voor uw afspraak.



U stelt de chatbot een van de volgende vragen.

Appendix 6: Filled in Wrosheets for Nurses

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!

I am the one that asks questions	Not up to me				Problems from the PROMs	Will be brought up even without the PROMs
Would like them to think they can ask everything	How they are doing	Feelings	How it feels when they come to the clinic		Not a lot of time to ask about everything	Where PROMs can help
Being ashamed of HIV	Coping with HIV for a longer period of time	If there is anything the nurse misses	Trauma from the past	No-show WHY?		
Sexual health	Children /Partners	Do they want children	Using protection during sex	Sexuality (only some patients)		



It is a nurse's responsibility to drive the discussion in the consultation

Nurses would like patients to talk about their feelings in general

Nurses think topics from PROMs would be brought up in consultations even without PROMs

Nurses would like patients to talk about their feelings about HIV

Nurses would like patients to talk more about their sexual health

What is the added value of PROMs for you?

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!


Not a lot of time during the consultation to ask about everything

Where PROMs can help

Not possible for PROMs to be the focus - need time during consults to e.g. discuss the blood result

Have a conversation about what is going on with the patient NOW

Get to the problem quickly



Opportunity to ask about a new topic during the consultation

See what they answer and if it is out of range

Sets a clear picture of the patient

Measurable psycho-social status

What is the added value of PROMs for patients?

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!

Think about different subjects at home - quite place

Reflect for themselves

Because the patient thought about it before coming to the clinic

Time to reflect

Talked about what is important to you


Patient has more autonomy in consultation

Satisfying that somebody looked at PROMs

Extra appointments

Early referral

Better knowing what we can do



Nurses think there is not enough time in the consultation to talk about PROMs.

Nurses think PROMs can be used to bring up new topics in a consultation.

PROMs are a way for patients to self-reflect on their healthcare.

Patients would find it satisfying if they knew someone looked at their answers from PROMs.

Nurses think there is not enough time in the consultation to talk about everything, which is why they see PROMs as a useful filtering tool.

Nurses do not think there is enough time in the consultation to talk about PROMs.

PROMs can give patients more autonomy during consultations.

PROMs can help nurses have a general picture about the patient with a measurable psycho-social status.

Nurses can learn how to support patients better by using PROMs.

What challenges 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!

Got a message from MyChart - Thought it was PROMs but it was a COVID questionnaire

Lost in notifications

Too many questionnaires

Not another questionnaire

people do not have an active account

More time to read - 20 min with patients

Time

Small screen on mobile phone

Privacy

through email - privacy (2)

Not talking to a person

Worried they can be used against them

Worries about MyChart being hacked

I do not like online questionnaires

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!

Technical - not having the app, not used to it, not looking at the results

Access to technology

Confronted with their own behavior

Same questions about housing and sexuality (after each other)

The amount of questions

Privacy

It would be good if people at the front desk ask about MyChart

Patients have communicated to nurses that there is an overflow of notifications from the hospital in general.

Patients have communicated technical issues with MyChart.

Nurses think technical issues or access to technology can play a big role on the likelihood of patients to fill in PROMs.

Nurses think patients have privacy concerns when it comes to PROMs and MyChart.

Patients have communicated concerns about privacy in regard to PROMs and MyChart.

Patients complained about the amount of time it takes to complete the PROMs.

Nurses think the questions from PROMs can be confronting to the patients.

Nurses think it would be helpful for patients to have an info point for MyChart where they can ask questions and voice any concerns.

Nurses think the amount of questions in PROMs can be discouraging to patients.

What do you think might help patients to complete 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!

Inform them why it is important

Let them know how it will benefit them

Explain what PROMs are

Have less questions (ask only relevant ones to the patient)

Good if they want to see new questions

Good if they want to see subjects they do not think about

Help them fill in the questionnaires

Make it available in more languages

Help activating the MyChart account

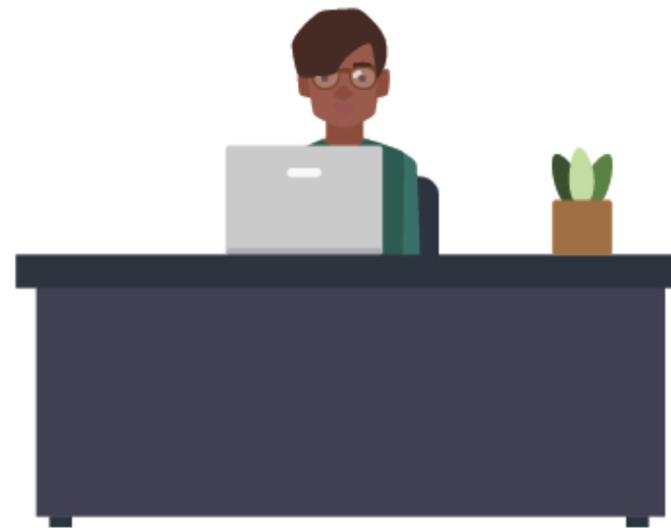
Help with access to MyChart

digital literacy - generation thing

anonymous sender - did not know what it was

once you have a my chart account, it is easy

I do not want myChart



Nurses think explaining what PROMs are and their benefits can help patients fill in PROMs.

Nurses think PROMs need to be more accessible for patients struggling with technology or language barriers.

Nurses observed that there are patients that do not want MyChart.

Nurses think patients would be more likely to fill in PROMs if they had less questions.

Nurses think some patients would fill in PROMs if they would receive help, especially at the beginning, with both PROMs and MyChart.

What patients are likely to use MyChart?

Men who have sex with men

highly educated people

Patients that are involved with their care

Young people

What patients are least likely to use MyChart?

Women, especially from Africa and Suriname

Non Dutch English - speaking

People from Africa and Suriname

non English or Dutch

can not read or wright

No access

older people

Concerned with privacy (especially women)

What patients could become more likely to use MyChart?

All, but it might just be harder

Educated

After an explanation - men

With the help of a nurse they trust

People that can overcome technical issues

Nurses think patients that are most likely to use MyChart are men who have sex with other men, highly educated, involved in their own healthcare.

Nurses think patients who are least likely to use MyChart are women, people from Africa and Suriname, non-Dutch and non-English speaking, illiterate, older, concerned with privacy and who has no access to technology. These categories can overlap.

Nurses think patients that can become more likely to use MyChart are educated, men (especially after receiving an explanation).

Nurses think all patients could become more likely to use MyChart, but it might just be harder for some.

Nurses think patients that can overcome technical issues can become more likely to use MyChart.

Appendix 7: Information Letter and Consent

Augmenting the value of PROMs

Information for participation in interview

Introduction

Dear Sir/Madam,

With this letter, we would like to ask you to take part in an interview to determine the best way to present reporting tools to patients. Participation is voluntary. You can read about the interview in this information sheet, and what it means for you. Can you please read the information and decide if you want to take part?

1. General information

This project is set up by the Amsterdam UMC, Location AMC.

2. What is the purpose of the study?

The aim of this project is to gain insights from patients in the process of determining the most acceptable and effective way to present reporting tools, also known as patient-reported outcome measures (PROMs), to patients.

We want to ensure that people living with HIV, besides effective medical treatment, are able to experience a good quality of life. To achieve this, we are introducing specially designed tools to measure aspects of quality of life, including physical, mental, sexual health, as well as stigma and drugs and alcohol use. PROMs have become part of standard care you will receive during your annual consultation. PROMs are reporting tools that can help us and you identify possible physical or mental health problems. Unlike satisfaction surveys, PROMs are medical instruments that have been tested to reveal problems that people experience.

We know from experience elsewhere that these PROMs help identify potential problems earlier, improve communication between patient and the healthcare worker and better prepare patients for their consultations.

3. What happens during the study?

The interview will last around 30 to 40 minutes and it will be located at Amsterdam UMC, location AMC. During the interview, the researcher will go through three different made-up scenarios which include ideas of how reporting tools could be presented to patients in the future. The researcher will ask questions related to these scenarios. This will help us to

develop a suitable way to present reporting tools to patients to ensure that all aspects are covered.

4. If you don't want to participate or you want to stop the study

You decide whether you want to participate in the study. Participation is voluntary. If you don't want to participate you will continue receiving care as before. In case you participate, you can always change your mind and stop, also during the course of the study.

5. Use and storage of personal data

You decide whether you want to participate in the study. Participation is voluntary. If you don't want to participate you will continue receiving care as before. In case you participate, you can always change your mind and stop, also during the course of the study.

As part of this study, we collect and store personal data. It concerns your name and contact details, telephone number and/or email.

How do we protect your privacy?

To protect your privacy, the data will be stored locally with no access to the cloud. Your name will be kept private. Your name will be anonymised, and contact details will be stored under an alias. Even in reports and publications about the study, nobody will be able to see that it was about you.

Who can see your data?

Some people within the Amsterdam UMC-AMC can see your name and other personal information without an alias. These are people checking whether the investigators are carrying out the study properly and reliably. These people will keep your information confidential. We ask you to give permission for this access.

For how long do we store your data?

We store your coded data for 1 year, from the conclusion of this project, within the Amsterdam UMC.

Do you want to know more about your privacy?

- Do you want to know more about your rights when processing personal data? Visit www.autoriteitpersoonsgegevens.nl.
- If you have any complaints about the processing of your personal data, we recommend that you first discuss them with the research team. You can also contact the Data Protection Officer of Amsterdam UMC-AMC: Marleen Inge Email: fg@amc.nl Tel.: 020-5662 015.

6. In case there are any questions

When questions arise, you can contact:

Researcher / designer: Alexandra Bartas. Email: a.m.bartas@amsterdamumc.nl

[Amsterdam UMC researchers:](#)

[Kevin Moody, k.moody@amsterdamumc.nl](mailto:Kevin.Moody@amsterdamumc.nl)

[Maarten Bedert, m.r.d.bedert@amsterdamumc.nl](mailto:Maarten.Bedert@amsterdamumc.nl)

7. How do you give consent for the study?

You can first think carefully about this study. Then you tell the investigator if you understand the information and if you want to take part or not. If you want to take part, fill in the consent form that you can find with this information sheet. You and the investigator will both get a signed version of this consent form.

Thank you for your attention.

Appendix: Informed consent form – subject

Belonging to
Research Peer Support

- I have read the information sheet. I was able to ask questions. My questions have been answered well enough. I had enough time to decide if I wanted to take part.
- I know that taking part is voluntary. I also know that at any time I can decide not to take part in the study. Or to stop taking part. I do not have to explain why.

- Please tick yes or no below.

- I give consent to storing my personal information within the Amsterdam UMC as described in this information letter
- I give consent to members of the research team to copy the necessary medical details and store these within the Amsterdam UMC.
- I give consent to being contacted for a follow up interview.

I want to take part in this study.

My name is (subject):

Signature:

Date : __/__/__

I declare that I have fully informed this subject about the study mentioned.

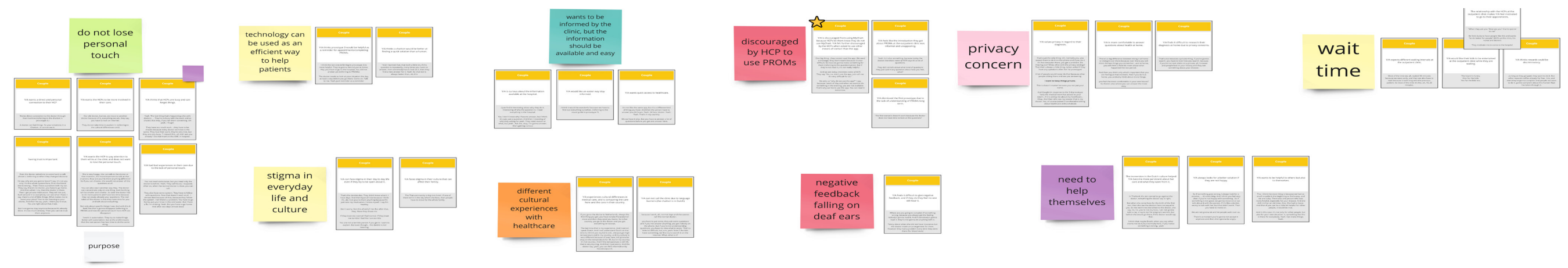
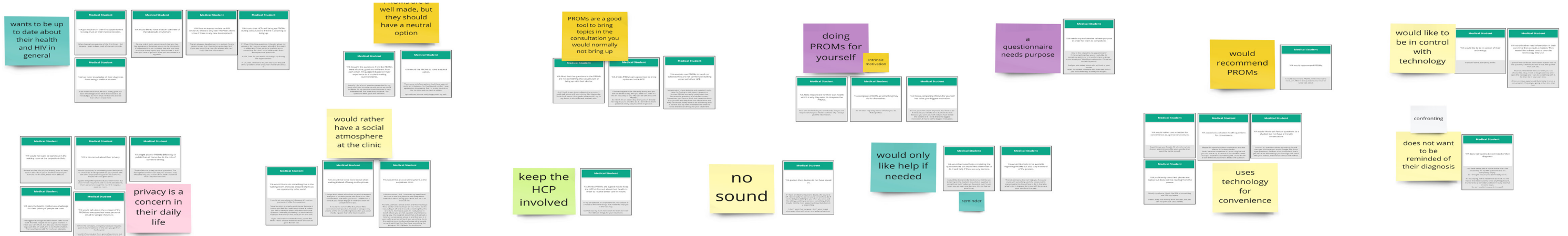
If any information becomes known during the study that could influence the subject's consent, I will let this subject know in good time.

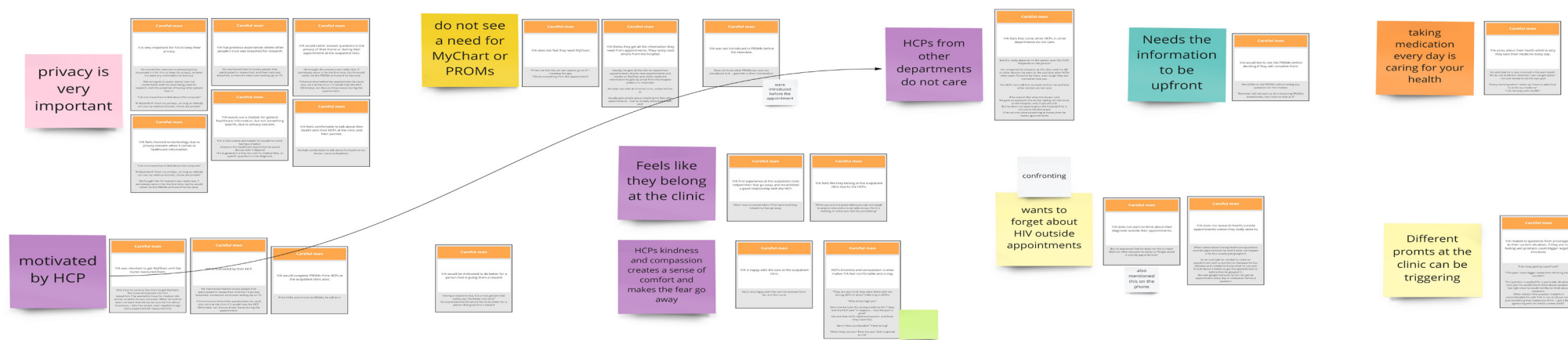
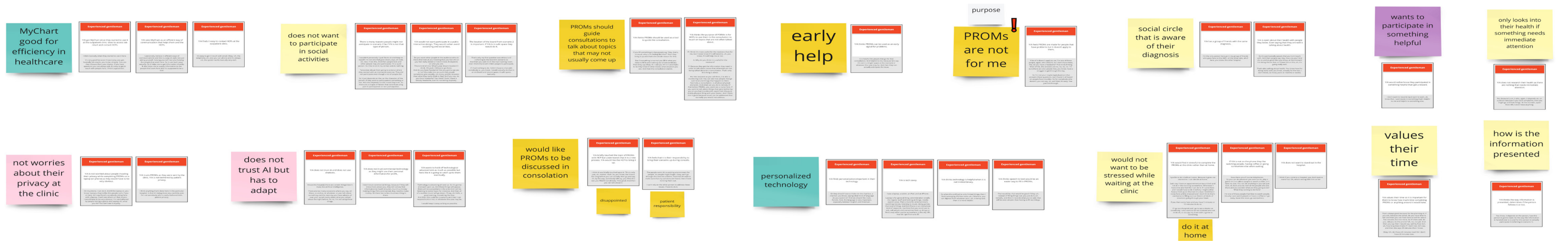
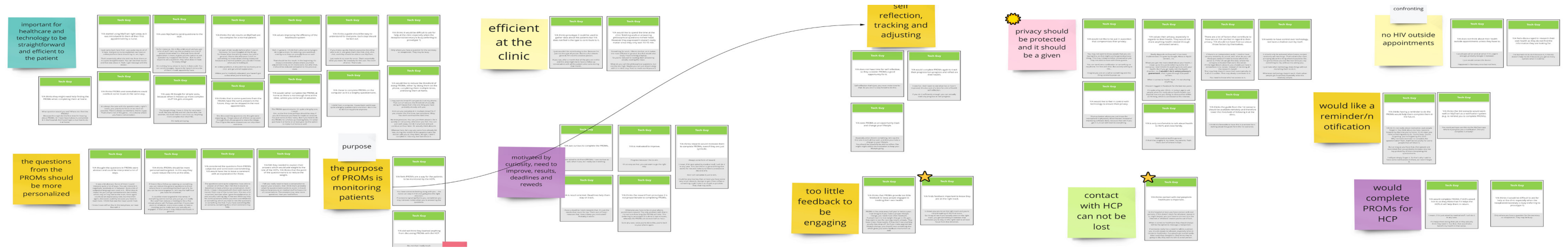
Investigator name (or their representative):

Signature:.....

Date: __/__/__

Appendix 8: Analysis: Statement Cards and Clustering





bonds with patients over time

N4
YIA started working on the patient clinic since 2016, but worked in HIV care since 2006.

N4
Because it is a chronic illness people see the HCP regularly which helps form a connection.

N4
It is important for YIA to create a non-judgmental space where people can share their experiences. YIA describes it as good when people that they have the intense relationship with feel this way.

non-judgmental space

encourages patients to fill in PROMs, but let's them know they are not obligated to

N4
YIA stimulates people to complete PROMs as they believe in them.

N4
YIA lets the patients know that the PROMs are for their own benefit and they should not be obligated to fill them in.

does not think patients should fill in PROMs for the HCP

N4
YIA does not think PROMs are supposed to help the HCP but patients who assume that might think the job is not easy.

N4
Well, that's not the meaning of the PROMs that's for sure. If you think about it, if they say I wanna make the best of the resources, then you could think that they have the feeling it's not easy for us, but maybe that means that we don't have to use everything.

healthcare involvement depends on the patient, from wanting to know their results to activism

N4
YIA thinks patient involvement in their own care is a very dependent of the patient.

N4
YIA thinks if the patient is showing interest in their blood results or showing up to appointments that means they are involved. In that case more patients are involved.

N4
Some patients are living with patient organizations. Some are into activism for example, it's that involvement in that activism? Because it doesn't really have to do with health involvement.

bonds with patients that have more problems

N4
YIA tends to bond more with people that need more help and that YIA sees more often.

N4
The more problems the patient has, the closer the relationship with the nurse.

N4
Some patients within a strong bond with the nurse even if everything is going well, due to the impact the nurse had on them during their first appointments (when things were not as well).

even when they overcome the problems the bond stays

do not need PROMs

N4
YIA believes the quality of consultations will not change if people do not complete PROMs.

N4
YIA would not complete PROMs if they were a patient.

N4
If patients have any problems, they usually come up in the consultation.

N4
YIA personally thinks the order of questions in PROMs is a bit strange.

would not fill in PROMs themselves

order is strange

some bring up different topics to the consultation

N4
Patients bring up questions about a cure, relationships, travelling, medication etc.

N4
Patients prefer to ask the HCPs about different health topics because they trust they have the right information.

some trust the HCP to know best

the consultation can not cover every question from the PROMs nor should it focus on them.

N4
PROMs can be used to skip topics that are not urgent in a consultation. But you should not spend time on every topic.

N4
The added value is that you have a conversation about something that is really going on now with the patient.

N4
So you don't have to discuss a lot of things that are not a problem at this moment or people don't really care about at the moment. So yeah, think that it's valuable. So the best part is it's not everything that has to be discussed during consultation.

N4
As you are saying that it should not become the focus of the consultation?

N4
I think it would be great if it was, but it's not possible because there are more things. The patient doesn't see the doctor at the same time, but it's only with the nurse. There are a lot of other things to do well. Like discuss the blood results. Maybe your consultation should be a little bit longer, but I think that can help to focus more on things that really matter to the patient.

stigma intensifying the bond

N4
Due to stigma of the chronic disease compared to other chronic diseases the bond between the patient and nurse is more intense.

N4
I believe it's more than in other chronic diseases, but I don't really know. I think the impact of HIV on your social life that something that has with other chronic diseases. Because you have to deal with the stigma and the judgment of other people.

N4
For some people, it's the only place that they can talk about it, think that makes the relationship that intense.

recommending resources

N4
YIA usually recommends the HIV patient organization websites and the resources they provide for patients that want to know more.

N4
I do not look for the website of HIV patient organization. For example, and there are a lot of links there are the other you can trust.

N4
As you recommend those sites to patients is that something that you want?

N4
So it's not that only with the website, but we report and say that you can find information about us, when you see here and you want a lot of information, you can look here or you want to meet peers and you want to have different support groups.

N4
And then I don't know how to do that, I don't know if they look again, that people want to write it down or they put it in the phone.

N4
I think it helps if you actually speak with the website. Then they can have a link to it on their phone.

PROMs can help with topics that do not come up in consultation

N4
PROMs can identify issues earlier, that may not have come up in the consultation at all.

N4
As you have time to ask about every single issue for all patients?

N4
No, no. And that's for us a really good thing about PROMs.

N4
Because you don't have to ask everything during a consultation, because sometimes you start talking to somebody and they immediately say, I wanna talk about this thing, or it's good that I have because things are going really well with my relationship, for example.

N4
And then you talk about death and you also talk about all the other subjects. It's not that you don't have to, but it's good if you today it would really help to talk about this and then you don't have to, to talk about all the other things at the same time, it's not of your PROMs work.

N4
And then you have the feeling that you help somebody, I think better than if they come and say everything is okay, and then during the conversation sometimes you notice that not everything is okay, but that takes a longer time.

patients want PROMs to be discussed in consultations

N4
Patients would be more satisfied if PROMs were discussed in the consultation. This way they know someone looked at it and they did not do so for nothing.

N4
And I think for a patient it would be more satisfying probably, after you know that you had not just the PROMs, but somebody looked at it, you talked about the things that is important to you at the time, but I think that more satisfying to the patients.

technical difficulties can deter patient

N4
Some patients confused PROMs with other questionnaires sent by the hospitals.

N4
There were definitely some problems they experienced. That they got messages from MyChart and that they went to their MyChart app and they got a questionnaire about COVID.

N4
And because I think it's not the hospital they thought, oh, it must have been that questionnaire the HCPs when I asked. So they didn't see the PROMs questionnaire because they thought it was about COVID. Because there are a lot of questionnaires not only sent by us, but also sent by the HCPs in general. That's what I heard a couple of times.

N4
Not all patients use MyChart or use it regularly hiding them from doing PROMs.

N4
I think the technical thing that everybody has the app, not everybody is using it, or not everybody looks at their results regularly.

N4
YIA did not hear a lot of complaints about PROMs outside technical issues. Patients that have MyChart said they would do it for now time.

N4
Because they got it from a sort of appointment, they said, oh, I have something to do and I use a message, but I thought I'll ask you when you go to your appointment.

N4
And I did not get any real negative reactions if you explain it. Most people said, okay, next time I'll do it. The people with MyChart.

not a nurses job to introduce MyChart

N4
People that use MyChart regularly are more likely to fill in PROMs.

N4
YIA thinks people that are highly educated get MyChart. In contrast low educated, or people that do not speak the language do not.

N4
It's a general thing, I think a little bit, but I think that I don't think it's about that people who are highly educated people can speak the language. The highly educated people can speak the language.

N4
YIA believes it would be beneficial if patients when coming to their appointments would go to the front desk to get a link about/resolve issues with MyChart.

N4
But I think it would be good if people come to their appointments and they would go to the front desk and ask about MyChart if they are confused. And then they go to the front desk. Cause I really don't know how it works and it should be for us to work because it's an administration thing.

N4
I don't think that we have to make it more easy for them, because they are not going to get it on their own. It's easy once you have a MyChart account. I think, so I think the people have to be helped attaching their account. I think that it's a main problem, why people don't get access to the questionnaire.

some people especially the older generation prefers to talk to a real person

N4
There are patients that do not want MyChart and would prefer to call the nurse if there is any problem.

N4
But the people without MyChart, they a lot of times say I don't want it, I don't want MyChart, I don't want to see my results, I'm gonna call you if I have a problem and that's it.

N4
Because they're not really into doing everything digital. And everybody is used to that. I think my digital would not be either. It's generation thing, I think a little bit, but it's not that I don't think it's always that people.

N4
I think some people from other generations, they don't want to do all these things on their phone. They just wanna talk to somebody.

some patients do not get MyChart due to privacy

N4
Privacy is a reason patients do not get MyChart.

N4
Some patients come from countries where their private information can be seen by the government which makes them reluctant to share information.

N4
People with both high and low education mistrust technology.

illiterate patients can not fill in PROMs

N4
YIA thinks it will not be possible for patients that can not read or write to get MyChart and in turn fill in PROMs.

N4
But you also have people that cannot read or write. For those people it will not be possible because somebody can help them with that, but if they are alone, then they cannot continue.

witnessed the advancements in HIV and how patients experienced it

N3
Vik started working as a nurse when medical advancements changed the view from being a death sentence.

N3
Vik experiences how people were from allowing the more going to live to something positive rather than just being a death sentence.

HCP can sometimes be the only person patients share their experiences

N3
Vik has a close relationship with their patients, as he is one of the few people who can talk to them about their experiences with the disease.

HCP needs to learn how to ask the right questions and coach the patient

N3
Vik and their patients know each other well. Vik has to ask the right questions in order to better the patients in the right direction and give them proper support.

N3
Vik tries to coach patients to solve their own problems.

PROMs can help patients who do not talk a lot

N3
Patients who do not talk a lot can benefit from PROMs, however they do the strong relationship between patient and nurse, Vik knows how to get around that.

Giving patients information helps them get MyChart

N3
If patients were interested in PROMs, Vik would try to get additional information to read from them.

N3
Some patients are hesitant to use MyChart or PROMs, however once Vik explains what they are they start showing interest.

Younger people and/or queer people see treat HIV more lightly than the older generation (that experienced earlier treatment)

N3
Younger people take the diagnosis more lightly than the older generation, which makes the latter angry.

N3
Moms that have sex with other men usually have a tendency to get angry when they have to start their treatment. Nurse and others to support them with that.

N3
Some patients take the diagnosis lightly at the beginning, however they change when they have to start their treatment. Nurse and others to support them with that.

might change once they realize it is a chronic disease

The first time at the clinic can create an impact and a strong bond with the HCP

N3
Nurses can make a lasting impression, especially the first time when patients feel their world is turning upside down.

PROMs is a good tool for self-reflection at home

N3
Vik thinks PROMs are a great tool for self-reflection, especially from the comfort of your home.

PROMs indicate if anything is out of range ahead of time

N3
Vik thinks PROMs can be helpful when you're feeling if there is anything out of range with your body. There is a good reason to bring it up during consultations.

N3
If there is an issue with a patient's VIK card, it's a good question to ask them for a patient.

PROMs can cover what is not covered in a consultation

N3
Vik thinks PROMs can cover subjects that are not normally covered in a consultation.

questions from PROMs can be discussed in consultation instead

N3
Vik also thinks that the questions from PROMs can be discussed in their consultation instead.

N3
Some patients do not use the value of PROMs as they believe they can talk about their feelings during their consultation.

women need most help

N3
Vik thinks women at the clinic are not that involved in their own health care.

N3
Vik thinks women, especially from Africa and Suriname, are less likely to have MyChart due to the lack of resources.

N3
Vik experienced women empowerment, including having access to technology and being ahead of other people learning about their health situation.

no time to talk about PROMs

N3
Vik thinks there is no time to talk about PROMs during an appointment, typically after the appointment has been.

PROMs are too long for patients

N3
Vik thinks PROMs can have too many questions and might take too much time for patients.

not for patients with language barriers

N3
Vik thinks the language barrier can affect patients getting MyChart.

privacy is important but the hospital does not make it transparent to the patients

N3
Privacy is important to patients, especially people that are from other countries, but the hospital does not make it transparent to the patients.

N3
Vik explains patients being afraid of facilities in Africa, that is people they have to be from other countries, but the hospital does not make it transparent to the patients.

N3
Vik thinks people that are very protective of their privacy, especially those that are from other countries, but the hospital does not make it transparent to the patients.

can still be exposed to others

can not be convinced

Filling in PROMs for the first time with a trusted HCP

N3
Vik thinks that starting the PROMs together with a trusted HCP can encourage people to do them.

education helps most when determining who has MyChart

N3
Vik thinks people who are educated and receive help to use MyChart and PROMs, after those are explained to them.

gay men are the most involved demographic in their own healthcare

N3
Vik thinks the demographic that is the most involved in their own healthcare is gay men who have access to care.

N3
Vik thinks that there are some other people who are more likely to use MyChart.

PROMs can get lost in other notifications

Y18: Patients get a lot of notifications from MyChart ranging from lab results to appointment reminders. Y19: Patients get a lot of notifications from MyChart ranging from lab results to appointment reminders. Y20: Patients get a lot of notifications from MyChart ranging from lab results to appointment reminders.

patients will fill in PROMs if they know the benefit

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

(no) difference in how patients open up in PROMs and normal consultations

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

not forcing patients to talk about PROMs

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

nurses do not know how MyChart works

Y18: Nurses do not know how MyChart works. Y19: Nurses do not know how MyChart works. Y20: Nurses do not know how MyChart works.

nurse-patient bond can help discuss the topics in PROMs

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

mindful of patients' trauma

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

being a patient at the clinic for a long time can strengthen the bond with HCP

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

open-minded and non-judgmental

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

proactive patients, know more than the nurse

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

trauma from early HIV treatment

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

apprehensive to talk about PROMs with patients they do not have a bond with

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

PROMs are limited with no middle option

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

patients get involved when it is serious

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

PROMs signal problems early on

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

likes PROMs because they are from patients perspective

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

no-shows

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

privacy and PROMs

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

confronting

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

adapting based on the patient

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

wish patients would communicate

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

help access MyChart and PROMs

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

talk more about feelings and sexual health

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

culture plays a role

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

other systems not as safe

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

to what does the role of a nurse extend to

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

diverse pool of patients

Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

presentation of PROMs

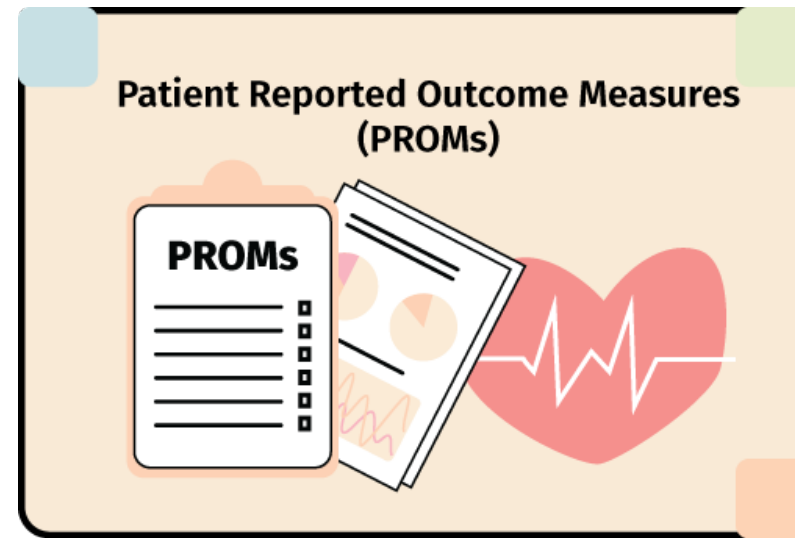
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Y18: Patients who fill in PROMs are more likely to be satisfied with their care. Y19: Patients who fill in PROMs are more likely to be satisfied with their care. Y20: Patients who fill in PROMs are more likely to be satisfied with their care.

Appendix 9: Final Design

Front

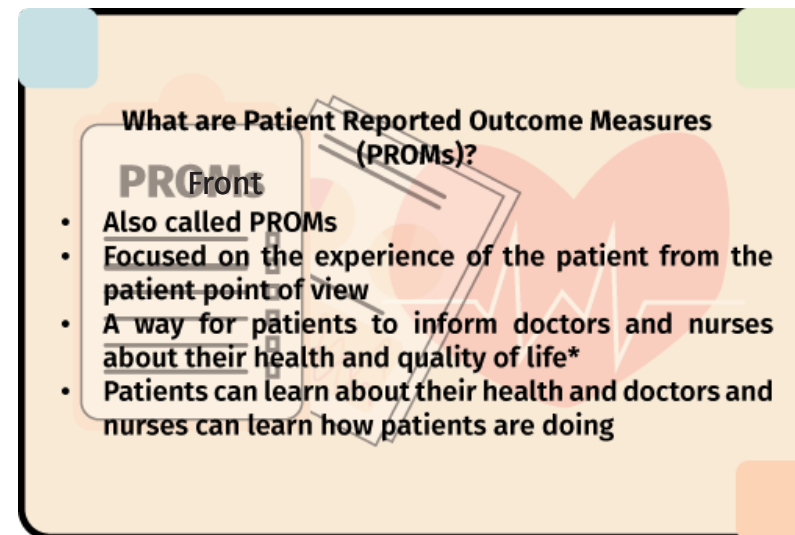


Visual version

Back

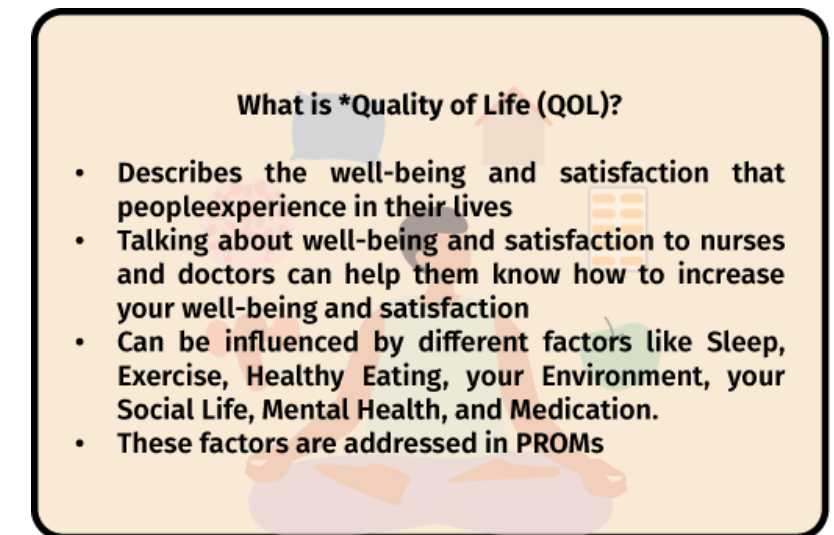


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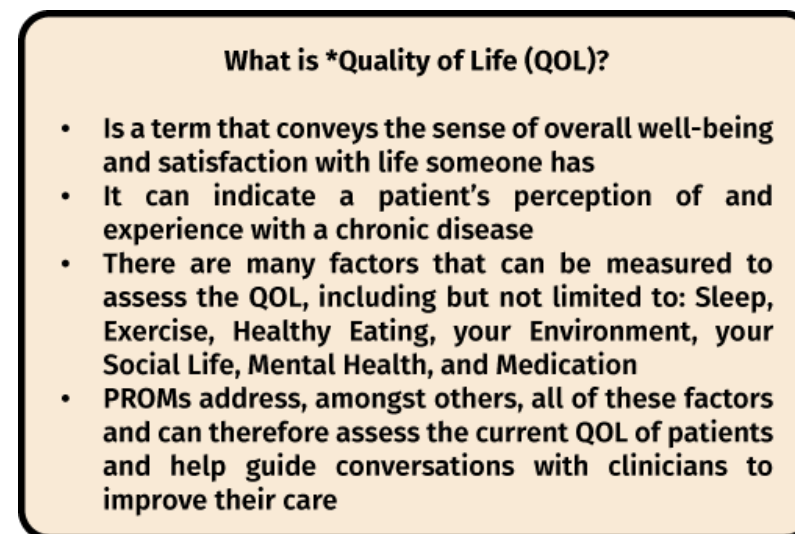


Visual and text version

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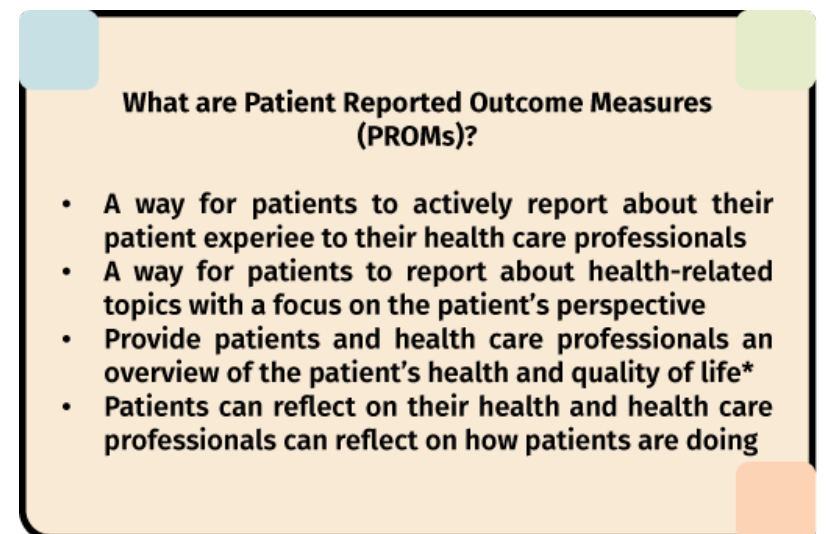


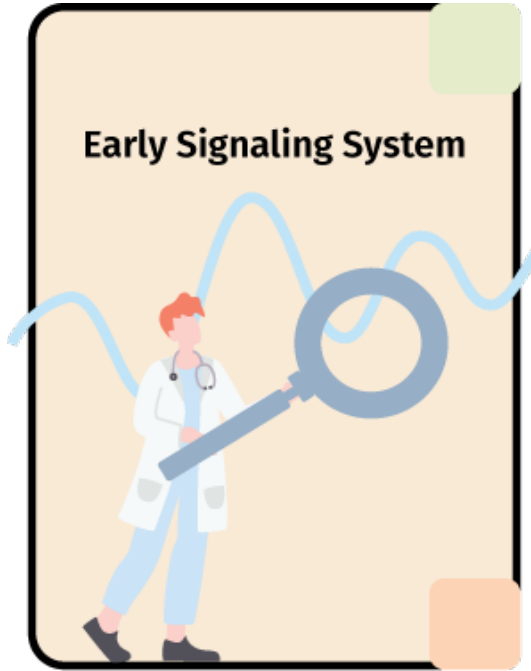
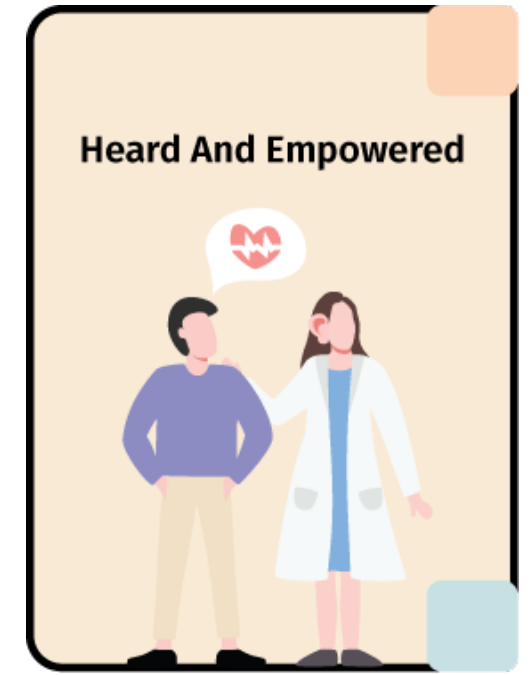
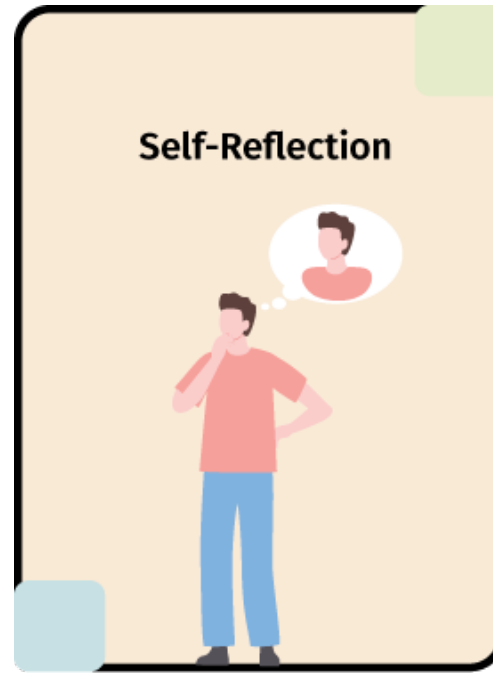
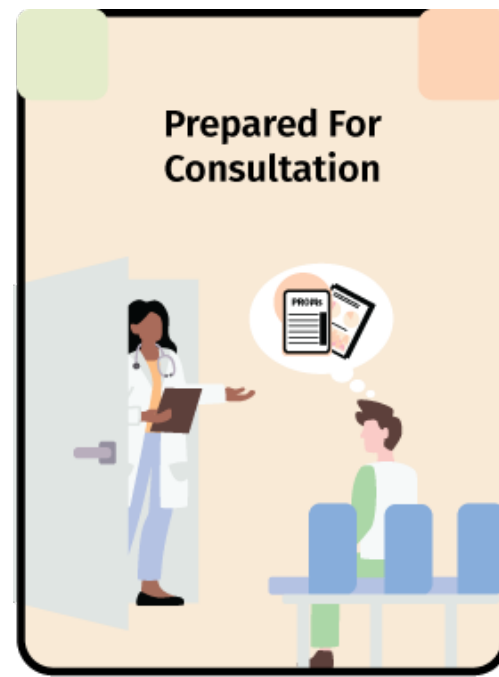
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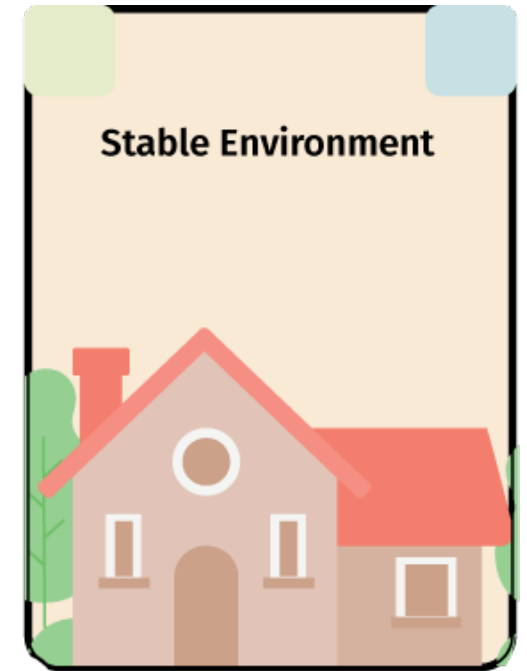
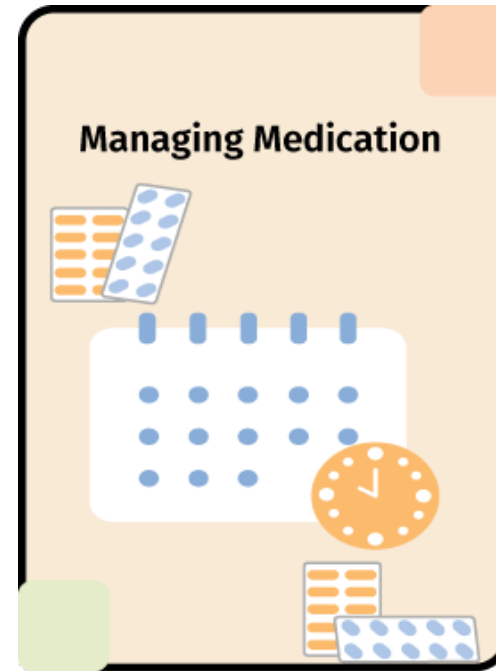
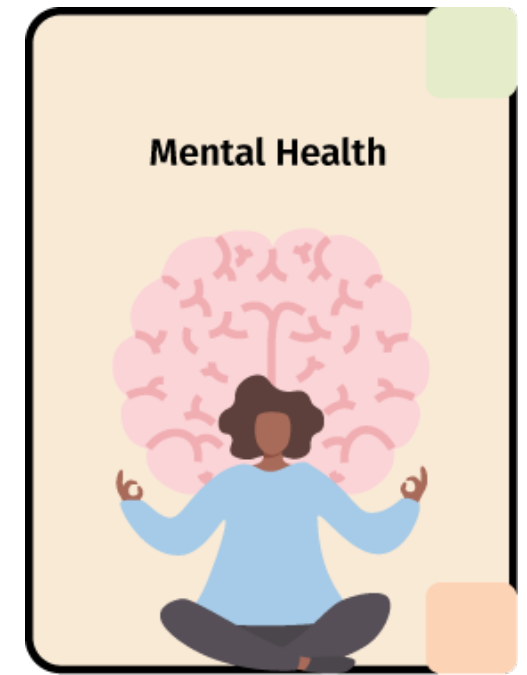
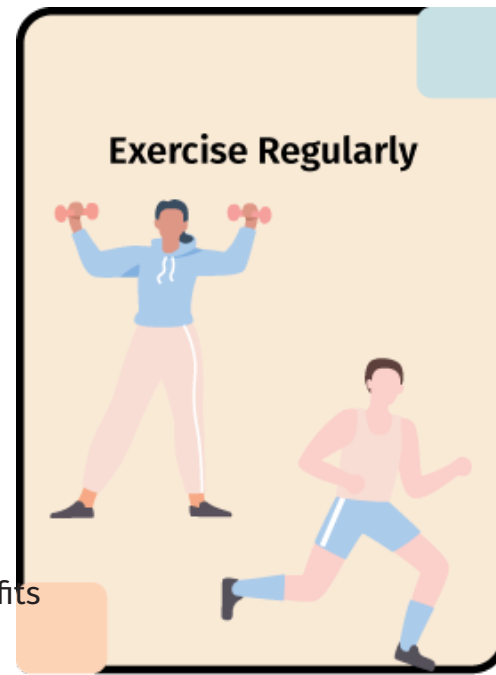


Text version

Back







By giving patients the opportunity to report on their own health, PROMs can help patients identify areas they would like to discuss with their nurses or doctor.



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.



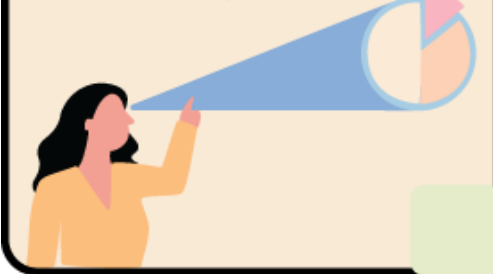
Giving a structured way for patients to communicate their health status. This can help ensure that patients and nurses and doctors discuss the same aspects of the patient's health.



PROMs can help patients better understand their own health and empower them to make informed decisions about treatment. Nurses and doctors better understand the patient's perspective which leads to more personalized care.



PROMs can be used to track a patient's progress over time and can help to identify areas of their life that may need more attention. They can also be used to adjust care plans to better fit the individual needs of the patient.



By giving patients the opportunity to report on their own health, PROMs can help make sure that care is made to fit the individual needs and priorities of the patient.



Shared decision making is a process where patients, nurses, and doctors work together to make decisions about treatment. PROMs can help this by giving patients a way to describe their priorities and by helping nurses and doctors understand the patient's perspective.



PROMs can work as an early signaling system by providing information about the health and well-being of patients. This can help identify problems early on, allowing for changes to prevent these issues.



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.



PROMs ask about exercise as it can help improve the symptoms and management of many chronic diseases. It can help your **physical health**



PROMs touch on sleep as many chronic diseases can be better managed with sleep. **Consistent sleep** is also important for the immune system to protect the body from illness.



PROMs touch on mental health. Good **mental health** can help the ability to cope with the challenges of living with a chronic disease.



Focused **communities and organizations**, for a chronic disease, can help by giving education, encouragement, and help with healthy lifestyle behaviors.



PROMs ask questions about taking **medication**. By taking medication people may be able to live longer and have a better QOL.



A **calm environment** can help reduce stress and promote relaxation, which can be beneficial for people with chronic diseases who may be at higher risk for mental health issues.



MyChart is an online portal that allows you to access your medical information, communicate with your nurse and doctor, and manage your healthcare.



Once registered, you can log in to MyChart on a computer or mobile device to access your medical information and communicate with your nurse and doctor.



MyChart will only use your information for authorized and necessary purposes, such as providing healthcare services and communicating with you about healthcare. If you have concerns about the privacy and security you can contact the customer service department.



MyChart allows you to access your lab results. This is useful to understand the results of tests and track progress over time. The results should be discussed with your nurse and doctor.



If you have issues or questions about MyChart, you can contact the hospital's customer service department for assistance. You can find their contact information on the Amsterdam UMC website or by calling the hospital.



You may receive notifications through MyChart about appointments, test results, messages from your nurse and doctor, and prescription refills. You can customize notification preferences in MyChart account settings.



PROMs can be used to track a patient's progress over time:

- PROMs can help to identify areas of improvement or areas that may need more attention.
- They can also be used to inform treatment decisions and to develop care plans that are tailored to the individual needs of the patient.
- PROMs can give patients the opportunity to share their perspective on their own health and well-being.

Help patient - healthcare professional communication:

- PROMs provide a standardized set of questions that patients can use.
- PROMs ask about symptoms and functional abilities, such as the ability to perform daily activities or level of pain. This can help healthcare professionals understand the impact of the condition on daily life.
- PROMs can help to shift the focus of care from the healthcare professional's perspective to the patient's perspective, allowing the healthcare professional to better understand the patient's priorities and needs.

PROMs can serve as an early signaling system:

- By collecting data about patient symptoms, functional status, and QOL, PROMs can help to identify potential problems or concerns early on, allowing for timely interventions to address these issues.
- For example, if a patient with chronic pain is reporting increased levels of pain and decreased function on a PROM, this may be an early signal that their pain management plan is not effectively controlling their pain and that changes may need to be made.

PROMs can help patients to gain autonomy:

- By giving patients the opportunity to report on their own health, PROMs can help to empower patients and encourage them to take an active role in managing their own health.
- PROMs can be used to inform treatment decisions and care planning. By giving patients the opportunity to report on their own health, PROMs can help to ensure that care is tailored to the individual needs and priorities of the patient.

PROMs allow patients to think about their health before their consultations:

- PROMs can help patients to identify areas of concern or areas that they would like to discuss with their healthcare provider.
- PROMs can provide a record of a patient's health status over time, which can be useful for both the patient and the healthcare provider to refer to during the consultation.
- So if there are any issues that they would forget bringing up PROMs can serve as a reminder.

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.

Shared decision making is a process in which patients and their healthcare providers work together to make decisions about treatment and care.

- PROMs help patients express concerns and preferences about their care which helps healthcare providers understand their perspective and needs.
- The results of the PROM can be discussed with the healthcare provider, who can use the information to help the patient understand the potential benefits and risks of each treatment option and make an informed decision about their care.

PROMs can help patients feel heard and empowered in their healthcare:

This is because they allow patients to express their own perspectives on their symptoms, treatment outcomes, overall well-being and experiences. PROMs can also help healthcare providers to better understand and address patients' needs and concerns, which can lead to more personalized and effective care.

Exercise and physical activity can enhance QOL by:

- Improves physical functioning. Regular exercise can help improve strength, flexibility, and endurance, which can help people with chronic diseases maintain their physical function and independence.
- Managing chronic diseases. Exercise can help improve the symptoms and management of many chronic diseases. For example, research has shown that regular exercise can help improve blood sugar control in people with diabetes and reduce the risk of heart attack and stroke in people with hypertension.

Eating a healthy diet can enhance 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.

Social support can improve the QOL of patients:

- Communities and organizations, can improve the management of the disease by providing education, encouragement, and accountability for self-management behaviors such as medication adherence and healthy lifestyle behaviors.
- Social support can provide emotional and practical support for people living with a chronic condition. A sense of purpose, belonging, and connection, can help reduce stress and promote well-being.

Medication can have numerous benefits for people living with chronic diseases:

- Relief of symptoms. Medication can help to reduce or eliminate symptoms of a chronic disease, such as pain, fatigue, shortness of breath, and swelling.
- Prevention of complications. Some medications can help to prevent complications associated with chronic diseases, such as blindness in diabetes.
- Increased lifespan. By effectively managing chronic diseases with medication, people may be able to live longer and have a better QOL.

Sleep plays a critical role in maintaining overall health and well-being by:

- Maintaining immune system functionality. Sleep deprivation has been linked to an increased risk of infections and other immune-related conditions.
- Managing chronic diseases. For example, research has shown that getting enough sleep can help improve blood sugar control in people with diabetes and reduce the risk of heart attack and stroke in people with hypertension.

A healthy environment can provide numerous health benefits for people with chronic diseases:

- Reducing stress. A calm and peaceful environment can help reduce stress and promote relaxation, which can be especially beneficial for people with chronic diseases who may be at higher risk for mental health issues.
- Improved air quality. A healthy environment with clean air can help improve respiratory function and reduce the risk of respiratory conditions.

Taking care of one's mental health can improve the QOL of someone with a chronic disease by:

- Good mental health can promote self-management behaviors such as medication adherence and healthy lifestyle behaviors.
- Good mental health can help build resilience and the ability to cope with the challenges of living with a chronic disease. It can also provide a sense of purpose, meaning, and connection.

Patients can register for MyChart through the hospital's website or by contacting the hospital directly.

- If the patient has any questions they can contact or visit the patient administration desk.
- Once the registration process is complete, patients will receive login credentials and instructions on how to use MyChart.
- Patients can then log in to their MyChart account using a computer or mobile device to access their medical information and communicate with their healthcare team.

If patients have any issues or questions about MyChart, they can contact the hospital's customer service department for assistance.

- The contact information for the customer service department can be found on the Amsterdam UMC website or by calling the hospital directly.
- When contacting customer service, it is helpful to have the MyChart login information and any specific details about the issue the patient are experiencing.

There are several types of notifications that patients may receive through MyChart.

- Patients can receive notifications about upcoming appointments, when their lab results or other test results are available, messages from the healthcare team and others.
- Patients can customize their notification preferences in their MyChart account settings. This allows them to choose which types of notifications they want to receive, and how they want to receive them (e.g., by email, text message, or push notification).

MyChart is an online portal that allows patients of Amsterdam UMC to access their medical information and communicate with their healthcare team.

- MyChart is a secure and convenient way to manage their healthcare .
- Patients can view their medical records, test results, appointment information, and medication lists.
- They can also communicate with their healthcare team by sending and receiving messages, requesting prescription refills, and scheduling appointments.

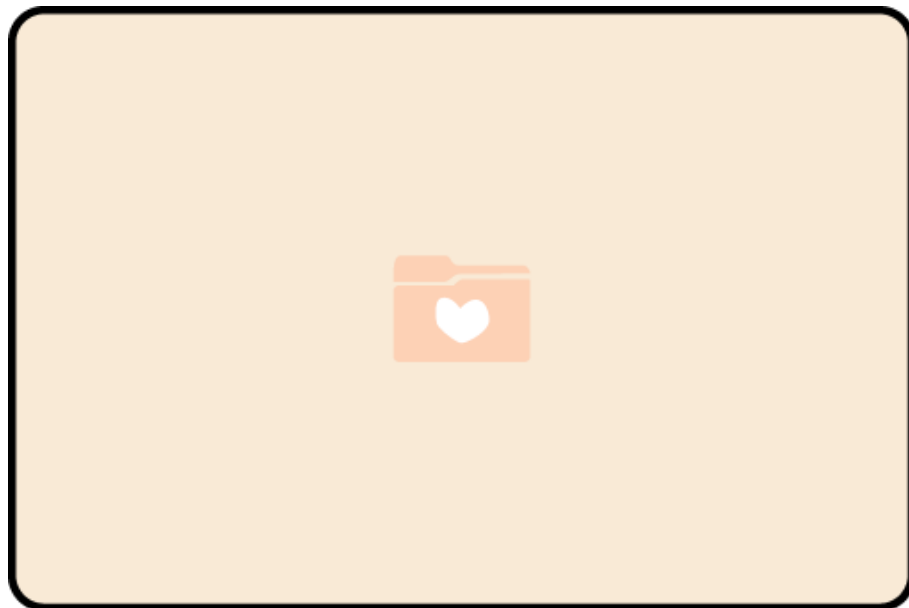
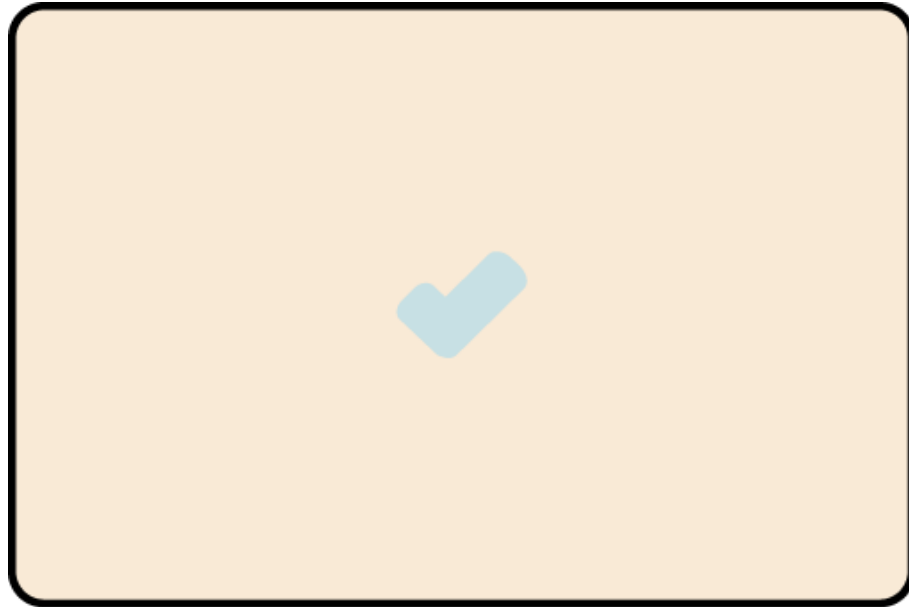
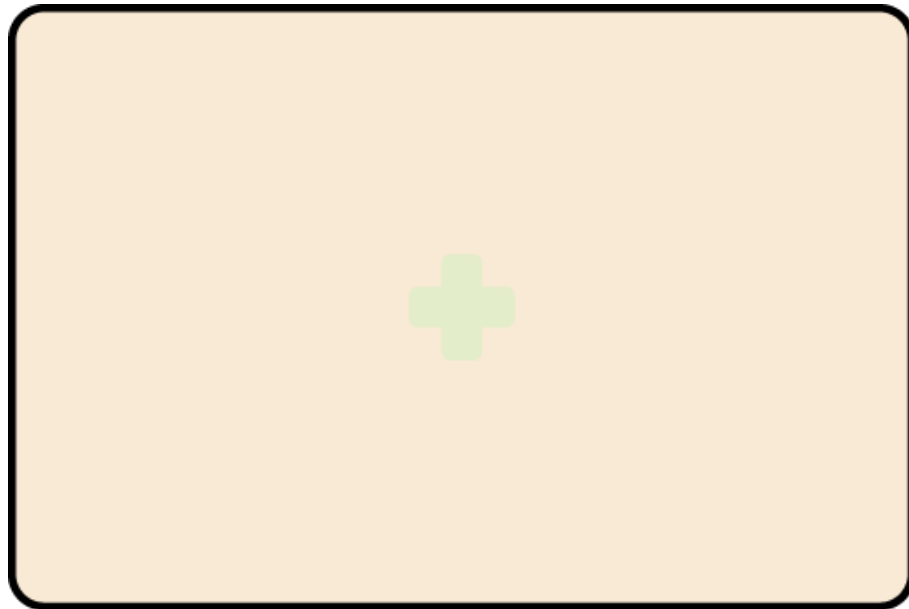
The privacy and security of patient information is a top priority for Amsterdam UMC.

- MyChart only uses patient information for authorized and necessary purposes, such as providing healthcare services, communicating with patients, and administering the MyChart portal.
- For privacy MyChart uses a unique login and password for patients and secure servers and encryption to protect patient information.
- For any concerns about the privacy and security contact Amsterdam UMC's customer service.

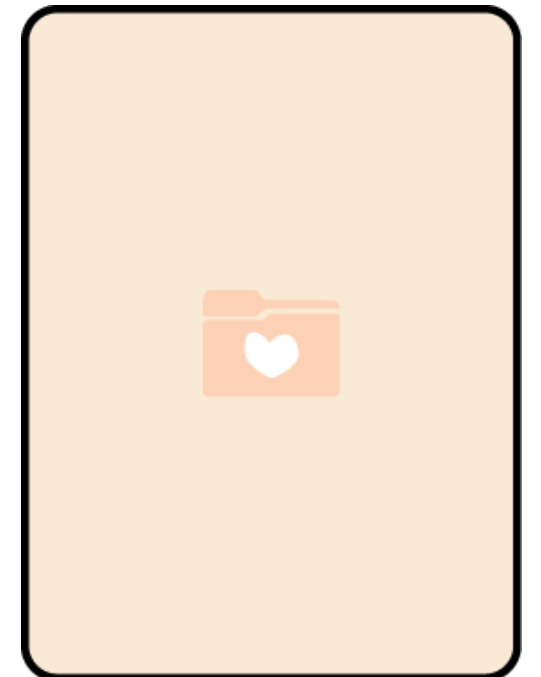
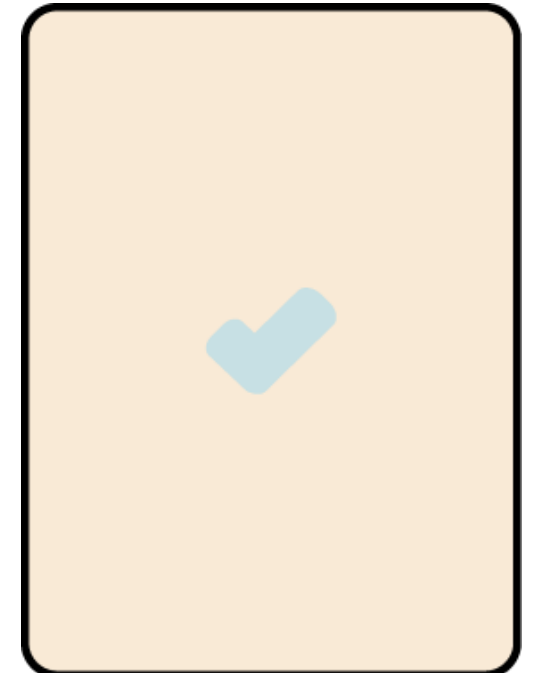
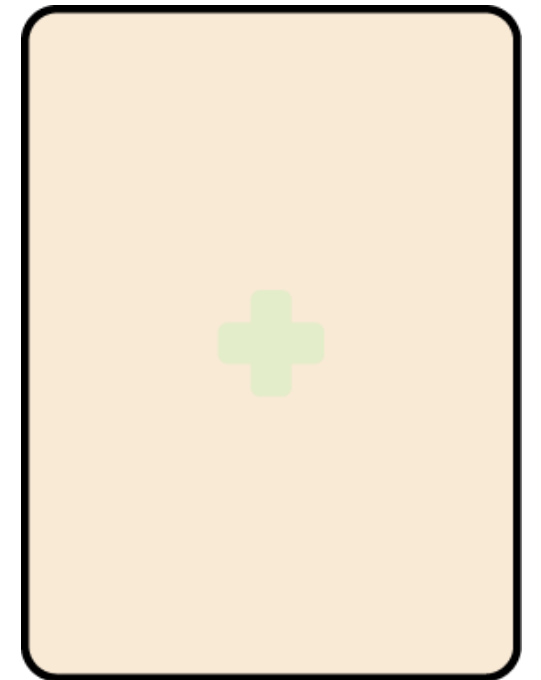
MyChart allows patients to access their medical information, including lab results.

- This allows patients to be more informed about their health and to be more involved in their healthcare decisions.
- By viewing their lab results on MyChart, patients can see the results of any diagnostic tests that they have had, such as blood tests or imaging tests. This information can be useful to track their progress over time.

Text version - backs



Visual and combo version - backs



Appendix 10: Evaluation Guide for Patients

Evaluation Plan

Research questions (RQ):

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

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

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

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

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

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

Procedure

The evaluation will go through three phases:

Phase 1: The researcher explains the game: what is the purpose and goal of the game, how to play it and the difference between the 3 categories. This will include a short demonstration of the gameplay. In this phase the researcher will answer any questions the participants might have about the game, project and/or consent form.

6-7 min

Phase 2: The participant plays through the game while thinking out loud. They can choose which category they want to play with.

10-15 min

Phase 3: Likert Scale (only for the patients and peer navigator)

5 min

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

20-25 min

Total time: 41-52 min

Participants

4-5 patients

- Target group
- From previous user research

2 nurses

- Provide holistic view on the patient population.
- Expert opinion on how patients receive information.

1 peer navigator

- Their opinion on the value of the game.
- Find out if it is something they can use.

Materials and Set-Up

- 3 categories of the card game
- Audio recorder (a backup to the audio recorder)
- Interview script
- Pen and paper

Interview script for the patients:

General questions:

- **What is your impression of the card game?**
- **Do you see yourself playing the card game?**
 - **Why?**
 - **Which category would you play with?**
 - **Why?**
 - **Where would you play the game?**
 - **Why?**
 - **Where would you put it in your home?**
- Do you play any similar games in your free time? (ex. card games/board games/puzzles)
- What value could this card game bring to you?
- What would you change to increase the value of the game?
- What are ways the game could motivate you to complete PROMs? (maybe ask in the end)
 - What can be changed to increase how the card game can motivate you to complete PROMs? Did it make you **curious** about PROMs
- What is the game **missing**?

Questions about the content:

- What is your impression about the content on the cards?
- What did you **learn** from playing this game?
 - What did you learn about PROMs? (Why did you score this question with a ... in the questionnaire?)
 - What did you learn about the purpose PROMs? (Why did you score this question with a ... in the questionnaire?)
 - What did you learn about the benefits of PROMs? (Why did you score this question with a ... in the questionnaire?)
 - What did you learn about how data is being handled by PROMs? (Why did you score this question with a ... in the questionnaire?)
- What do you think about the amount of information on the cards?
- What do you think about the images on the cards?
 - What do you think they mean? (focus on the more abstract)
 - What would you change about the visuals to make them more clear for you?
- How was your experience reading the text?
 - Did you have any difficulties when reading the text? Can you show me an example?
 - What would you change about the text for it to be more clear for you?
- **What content would you like to see on the cards?**
- What are the ways the content could influence your motivation to complete PROMs?

One of the items from the questionnaire was *I would need the guidance of another person to be able to play this card game* you where you gave a rating of...

- Can you explain your rating?
- **What kind of guidance would you need?**
- Who would you ask for guidance?

One of the items from the Liker questionnaire was *I found the card game unnecessarily complex* you gave a rating of...

- Can you explain your rating?

Other questions:

Show the patients drawings of the potential packaging

- What is your impression about the packaging of the box?
- **What would happen if you saw it in the waiting room?**
- **Does this seem suitable to have in your home?**
 - **Why?**
 - **What would need to change to be suitable to have home?**

Appendix 11: Evaluation Guide for Nurses

Interview script for the nurses:

General questions:

- What is your impression of the card game?
- What value could this card game bring to the patients?
 - How does this apply to the different types of patients?
- What would you change to increase the value of the game for the patients?
- Do you think patients would play the card game?
 - Why?
 - How does this apply to the different types of patients?
 - Why?
 - Which category would patients play with?
 - Why?
 - How does this apply to the different types of patients?
 - Where would the patients play the game?
 - Why?
 - How does this apply to the different types of patients?
- What would you change to make the game more appropriate for the different types of patients?
- What are the ways the card game could motivate patients to complete PROMs?
 - What can be changed to increase how the card game can motivate patients to complete PROMs?

Questions about the content:

- What is your impression about the content on the cards?
- What do you think the patients could learn from the card game?
 - What do you think patients could learn about PROMs?
 - What do you think patients could learn about purpose PROMs?
 - What do you think patients could learn about the benefits of PROMs?
 - What do you think patients could learn about how data is being handled by PROMs?
- How do you think the patients will receive the content on the cards?
 - What do you think about the amount of information on the cards in relation to the types of patients?
- What do you think about the images on the cards?
 - What do you think they mean? (focus on the more abstract)
 - What would you change about the visuals to make them more clear for the patients?
- How was your experience reading the text?
 - Did you have any difficulties? Can you show me an example?
 - What would you change about the text for it to be more clear for the patients?
- How would you present the content on the cards to the patients?
- What are the ways the content could motivate patients to complete PROMs?

Other questions:

- What do you think will be the impression different types of patients will have of the packaging?
 - What would need to change to be more appropriate for the waiting room?
 - What would need to change to be more appropriate for patients homes?

Appendix 12: Evaluation Guide for Peer Navigator

Interview script for the peer navigator:

General questions:

- What is your impression of the card game?
- Do you play any similar games in your free time? (ex. card games/board games/puzzles)
- What value could this card game bring to you?
- What value could this card game bring to the patients?
- What would you change to increase the value of the game?
- **How could this card game be applied in your role as a peer navigator?**
 - Which category would you use?
 - Why?
- **What would you change to help your role as a peer navigator?**
- What are the ways the card game could motivate you to complete PROMs?
 - What can be changed to increase how the card game can motivate you to complete PROMs?
- What are the ways the card game could motivate patients to complete PROMs?
 - What can be changed to increase how the card game can motivate patients to complete PROMs?

Questions about the content:

- What is your impression about the content on the cards?
- What did you learn from playing this game?
 - What did you learn about PROMs? (Why did you score this question with a ... in the questionnaire?)
 - What did you learn about the purpose PROMs? (Why did you score this question with a ... in the questionnaire?)
 - What did you learn about the benefits of PROMs? (Why did you score this question with a ... in the questionnaire?)
 - What did you learn about how data is being handled by PROMs? (Why did you score this question with a ... in the questionnaire?)
- What do you think about the amount of information on the cards?
- What do you think about the images on the cards?
 - What do you think they mean? (focus on the more abstract)
 - What would you change about the visuals to make them more clear for you?
- How was your experience reading the text?
 - Did you have any difficulties? Can you show me an example?
 - What would you change about the text for it to be more clear for you?
- What content would you like to see on the cards?
- **What content would help you in your role as a peer navigator?**
- **What would you change about the content to be more appropriate for your role?**
- How does the content influence your motivation to complete PROMs?

One of the items from the Liker scale was *I would need the guidance of another person to be able to play this card game* you where you gave a rating of...

- Can you explain your rating?
- What kind of guidance would you need?
- Who would you ask for guidance?

One of the items from the Liker scale was *I found the card game unnecessarily complex* you gave a rating of...

- Can you explain your rating?

Other questions:

- What is your impression about the packaging of the box?
- What would happen if you saw it in the waiting room?
- Does this seem suitable to have in your home?
 - Why?
 - What would need to change to be suitable to have home?

Appendix 13: Evaluation Qustionnaire

Questionnaire

Part 1

Rank each statement from how much you agree or disagree with it. Don't think too much and simply cross the box that feels right.

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
1. I think that I would like to play this card game frequently.					
2. I found the card game unnecessarily complex.					
3. I thought the card game was easy to play.					
4. I think that I would need the guidance of another person to be able to play this card game,					
5. I had fun while playing the card game.					
6. I think I would not benefit from playing this card game.					

Part 2

Rank each statement from how much you agree or disagree with it. Don't think too much and simply cross the box that feels right.

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
1. The game helped me to increase my knowledge and understanding of PROMs.					
2. The game helped me to increase my knowledge and understanding of the purpose of PROMs.					
3. The game helped me increase my knowledge and understanding of how PROMs can benefit me.					
4. The game helped me to increase my knowledge and understanding of how PROMs handle my data.					

Appendix 14: Extended Journey Map

