Focus on underserved patients

Improving the collection of PROMs within the HIV outpatient clinic of the Amsterdam UMC

Focus on underserved patients

Improving the collection of PROMs within the
HIV outpatient clinic of the Amsterdam UMC

Master Thesis

Sharda Wolterink

Design for Interaction & Medisign
Faculty of Industrial Design Engineering
Delft University of Technology

Supervisory team
Marijke Melles (Chair)
Jasper Faber

In collaboration with Amsterdam UMC
Marc van der Valk
Kevin Moody
Maarten Bedert

Defended on February 23rd 2020

Acknowledgement

Dear reader,

This graduation project concludes my studies at the TU Delft. The past years have been quite the journey and brought me so much more than I could have wished for. I learned new things till the last day of my graduation and hope to never stop learning. The outcome of this project lies close to my heart and I am excited to be able to share this with you. Before we get to it, I want to thank everyone who played a role in my life while I was working on this project.

Firstly, I want to thank my entire supervisory team. Marijke, thank you for believing in me that I was, and still am, the right person for this project. Your trust helped me to be the best version of myself. Jasper, thank you for your “down to earth”-ness and for making sure I stayed realistic. Marc, thank you for opening the doors to all places I wanted to go, I felt truly welcome. Maarten, you came as a nice surprise addition to the team, your advice was extremely helpful. Even when your feedback did not seem to end, you reassured me that it was all from the best intentions and you always knew how to spark my enthusiasm. Lastly, an extra big thanks to Kevin. Kevin, you were amazing, your guidance was deeply heartwarming and turned out to be one of my biggest motivations throughout my thesis journey. Next to that, you thought me more about English grammar than I did throughout high school.

Secondly, I want to thank the ShivA foundation, the HIV consultants, and doctors who opened their doors to me. And especially the ShivA team and HIV consultants who have talked to me for hours or have helped me to find extra participants and solve practial matters.

A special thanks to my family, who always supported me and allowed me to develop myself throughout my entire student career. Your unconditional love and support helped me every day. With an extra shout out to my little sibling, Kiran, who taught me so much by being the biggest inspiration I could have wished for.

I want to thank all my friends, de Lekkerbekjes and OarsomeFoursome in particular, for always putting up with me over the past years, you guys really made my years in Delft unforgettable. I especially want to thank Simona and Kwa for their endless coffee breaks and food delivery sessions.

Lastly, I want to thank everyone who played a role during my years studying, my friends from Huize Fortuin, Proteus-Eretes, IDE, and all random places. You made my time in Delft truly amazing.

I hope my thesis can make a contribution to the field of HIV. Enjoy reading.

Love,

Sharda
Wolterink

Abstract

Background

Amsterdam UMC is implementing digital people-reported outcomes measures (PROMs) in routine care in the HIV outpatient clinic to improve the quality of life (QoL) for people living with HIV. This assignment was to design tools to promote the inclusion of underserved patient groups (i.e., migration background, digital or health illiteracy).

Methods

Two sets of methodologies were used: qualitative research methods informed the development of a ‘patient journey’ and design-thinking methodologies informed the tool development. Participant observation and in-depth semi-structured interviews were conducted to gain insights in patient- and system-related characteristics. Design-thinking methodologies facilitated the transformation of qualitative data into insights that drove design concepts. Three ideation methodologies were used to create four concepts, leading to the final concept.

Results

Observations of 17 individual consultations (6 female, 11 male) at the HIV outpatient clinic resulted in six recurring themes. These themes were: Personal relationship; Disclosure; Impact of the diagnosis; Health literacy & Health involvement; Communication; No-shows. The observations and additional literature research informed the development of an interview guide. Seven interviews (5 female, 2 male) were conducted with participants with a migration background from Ghana, and Nigeria. The observations and interviews informed the patient journey (PJ). The PJ showed that patients experience stress and anxiety during their hospital visit but fully trust doctors and nurses. Based on the insights the design challenge was addressed, leading to the following concepts: “Peer support community”; “Wellbeing Diary”; “Waiting Room Inspiration”; “Hospital Roadmap”.

Conclusions

Amsterdam UMC will adopt the “Wellbeing Diary” which embodies the following characteristics: independence from relying on other organisations for implementation; a visual design that can be used independent of literacy level; and its affordability. The paper diary will provide a low-threshold tool for people to record PROMs-like experiences that will prepare them for their consultations at the outpatient clinic.

How to read this report

This section functions as a guide to explain how to read this report.

Each Chapter starts with an introduction and, if applicable, ends with an overview of the key takeaways. Sometimes a double-lined box appears with a text, this is a note that I have written while stepping out of the shoes of the researcher to add additional information on a personal note.

The report is structured in the following way:

This is a main heading

Sub heading

Sub sub heading, or, theme/topic

Main text

Observer notes

Written observer notes

“Quotes”

Important elements are highlited with a block like this

Personal note

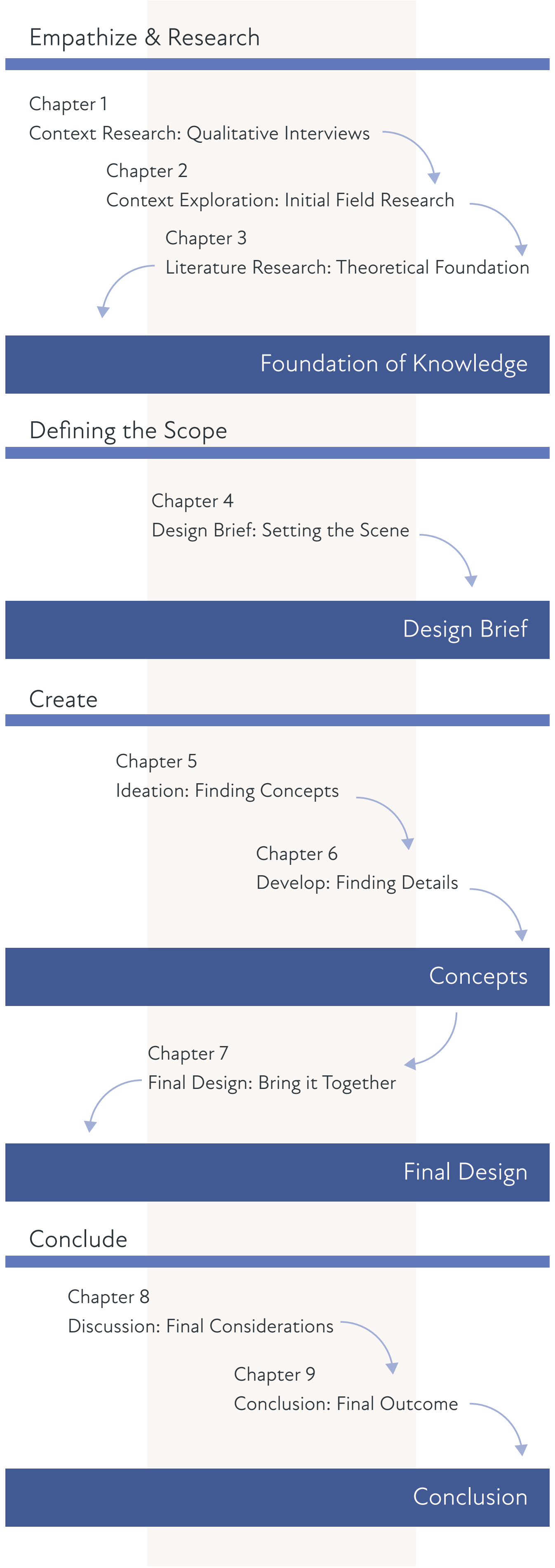
Key takeaways

Abbreviations

AIDS	Acquired immunodeficiency syndrome
AMC	Academisch Medisch Centrum,
Amsterdam UMC	Amsterdam Universitair Medische Centra
COM-B model	Capability, opportunity, motivation, behaviour model
F&Bs	Facilitators and barriers
HBM	Health belief model
HCPs	Healthcare professionals
HIV	Human immunodeficiency virus
IFR	Initial field research
LoR	List of requirements
PB/S	Positive brothers and sisters, part of the ShivA foundation peer support community
PJ	Patient journey
PROMs	Person-reported outcome measures also knows as
QoL	Patient-reported outcome measures Quality of life

Content

What to expect



Empathize & Research

Chapter 1
Context Research: Qualitative Interviews

Chapter 2
Context Exploration: Initial Field Research

Chapter 3
Literature Research: Theoretical Foundation

Foundation of Knowledge

Defining the Scope

Chapter 4
Design Brief: Setting the Scene

Design Brief

Create

Chapter 5
Ideation: Finding Concepts

Chapter 6
Develop: Finding Details

Concepts

Chapter 7
Final Design: Bring it Together

Final Design

Conclude

Chapter 8
Discussion: Final Considerations

Chapter 9
Conclusion: Final Outcome

Conclusion

0

Introduction

Background

Since the discovery of HIV, quite some progress has been made in terms of treatment for people living with HIV. The diagnosis of HIV is no longer the death sentence it once was, and the life expectancy is nearly equal to that of the general population (Nakagawa et al., 2013). Still, the life of a person living with HIV looks different from someone who has not been diagnosed with HIV. People living with HIV have a significantly higher risk of various comorbidities, among others cardiovascular disease, chronic kidney disease, cancer (Gallant et al., 2017). In addition, people living with HIV might develop these comorbidities at a younger age than someone who is not living with HIV (Lerner et al., 2020). Active self-management and health literacy are therefore essential for the remainder of the patient's life. Because of this, the Amsterdam UMC HIV outpatient clinic is focussing on improving quality of life (QoL), intending to provide individualised care to people living with HIV. The HIV outpatient clinic provides the tools for them to engage in their health care to live as healthy and free as possible. To support this focus on improving the QoL, the Amsterdam UMC HIV outpatient clinic recently started a trajectory in which person-reported outcome measures (PROMs) form an integral part of treatment. This trajectory aims to provide an early signalling system to serve individualised care to achieve early intervention where needed. To collect data on PROMs, people completing questionnaires before their outpatient visit is essential. These questionnaires give the HIV treatment team insight into the patient's physical functioning, mental situation, treatment adherence, substance use, the burden of HIV stigma, and other relevant topics. To streamline and digitise the collection of this data, a platform is in development. This transition to digital healthcare provides multiple opportunities for improvements, but at the same time widens the gap between people with high digital skills and those who are not digitally inclined (van Winkle et al., 2017). This creates the risk for people who are not digitally inclined to fall behind, which can be one of the characteristics of people within the underserved patient group.

Today, an estimated 24,000 people are living with HIV in the Netherlands (Soa Aids Nederland, 2020). In 2008 an estimation was made that 25% of people living with HIV in the Netherlands have a Sub-Saharan Africa or Caribbean background (RIVM & Van Veen, 2010). In research of Van den Berg et al. (2005), and Nellen et al. (2004), it was found that people living with HIV of non-Dutch population groups have a higher risk of failure to achieve early viral suppression. Within the Amsterdam UMC the observation is made by the healthcare professionals (HCPs) that a large part of the patient population has a migration background originating from Ghana and Nigeria, therefore the decision is made to narrow the scope and focus on this patient population.

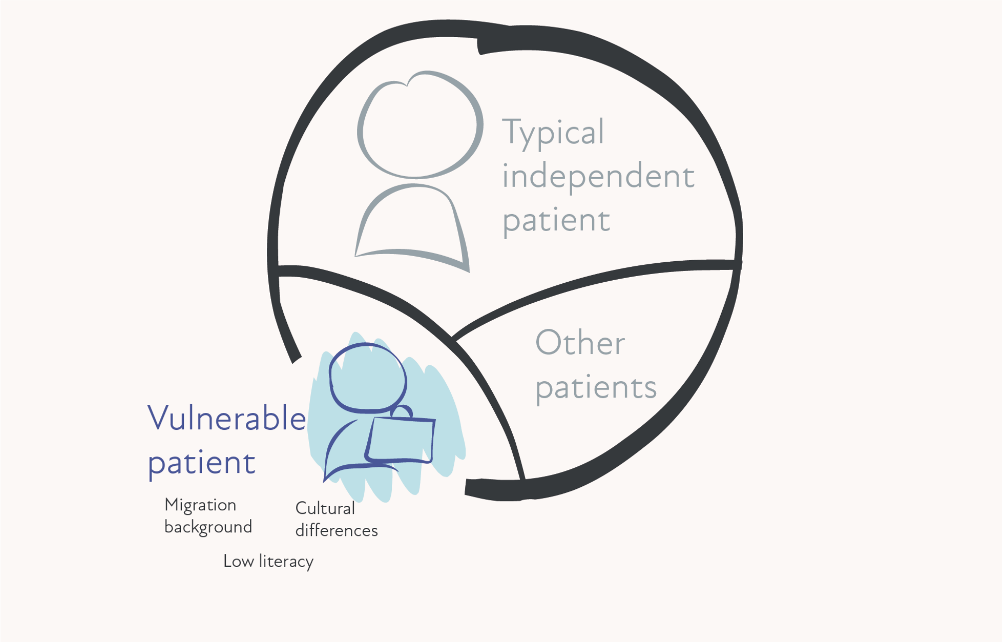


Figure 1 - Patient population

HIV/Aids

HIV, human immunodeficiency virus, as the name suggests attacks the immune system of their host human body. In particular, the CD4 helper cells or T cells which are needed to fight off other infections (Nall, 2020). When HIV is left untreated, the amount of CD4 cells will decrease and the immune system will worsen. Today, HIV is very well treatable, by taking the HIV medication known as antiretroviral therapy (ART), someone living with HIV can live a healthy life without being sick (HIV.gov, 2021). When the HIV medication is successful, HIV will not be detectable in the blood anymore and then will not be transmittable. We call this u=u (undetectable = untransmittable) (Soa Aids Nederland, 2021). Hence, if someone is in HIV care and the treatment is successful, they will not be sick and will not be transferring the virus to other people.

When HIV treatment does not succeed, it is not available, or someone has no access to a testing facility, it could be the case that HIV is able to continue destroying the CD4 cells in their host human. As this proceeds, the immune system of the person will eventually be severely damaged that the CD4 cells will be in such a low number that the stage of the HIV infection is considered as Aids (HIV.gov, 2021).

Aids, acquired immunodeficiency syndrome, the immune system of the person infected is in such a damaged stage that their body can no longer fight against viruses, making them extremely vulnerable for infections such as tuberculosis, toxoplasmosis, and pneumonia (Nall, 2020). If this person is not treated properly, it can be expected that they will survive for approximately 3 years (HIV.gov, 2021).

What are PROMs

> *Patient-reported outcome measures (PROMs) are defined as standardized, validated questionnaires (which are also called instruments) completed by patients to measure their perception of their functional well-being and health status*
> *- National Health Service (2009)*

PROMs are questionnaires that have been tested and validated to gain more insights into the perceived well-being and health status of the person filling in the questionnaire. PROMs in HIV care can be implemented for multiple different purposes. As described in a report by Moody and EATG PROMise Task group (2021) PROMs can, on an individual level, help to make clinical decisions to facilitate personalised care. Also to find the current needs of the patient to prioritize the discussion during the doctor consultation. For example, when the patient indicates to be under severe stress caused by financial problems, the HCP can decide to prioritize that before discussing other routine topics. On an institutional level, PROMs can also be used to evaluate the quality of care between different hospitals. Taking another step back, you can also use PROMs on a population level when addressing the diverse needs of different people within the population. Lastly, on a national level, PROMs can be used to create an overview of the systematic problems faced by people living with HIV within a country.

A crucial element of PROMs is that they are not used to assess the quality of care, they are purely designed for the assessment of the patients' own perceived health and health-related quality of life (Devlin et al., 2010).

An underserved patient.

> *"There is ample evidence that social factors, including education, employment status, income level, gender and ethnicity have a marked influence on how healthy a person is. In all countries – whether low-, middle- or high-income – there are wide disparities in the health status of different social groups. The lower an individual's socioeconomic position, the higher their risk of poor health."*
> *-World Health Organization (2018)*

Different factors influence someone's socioeconomic position. When someone has a low socioeconomic status and is in care for a specific condition, they would be considered a vulnerable patient. In this project, this patient population will be considered as "underserved", taking responsibility as a provider who is not serving the patient sufficiently.

Why focus on underserved patients?

In the Netherlands, we are living in a multicultural society. People from all over the world have moved to the Netherlands, some for love, some for better job opportunities and some because their native country was no longer a safe place to stay. A multicultural community requires extra attention: entrenched Dutch traditions could not be accepted by this community. A world-renowned example is the black Pete ("zwarte Piet") debate, which needs no further elaboration here. Over the past years, we have seen multiple words disappear from our vocabulary, rebranding of certain products, and old traditions are being modernized. Unfortunately, not every Dutch citizen is happy with this change and prefers his accustomed traditions. Many of these people are not afraid to share their opinion and are often the ones with the loudest voices. Even in our Dutch House of Representatives someone recently mentioned that HIV does not exist for the general white straight male (AD & Van Rootselaar, 2021). These kinds of statements do not make it easier for people with a migration background, and people living with HIV in particular, to feel accepted or welcome. People living with HIV face a lot of stigma and people with a migration background face racism. One could imagine living with both, living with HIV and a migration background, might result in double the amount of struggles in daily life.

So, when working on improving healthcare in general, it is our job to make sure to include everyone. Within the patient population of the Amsterdam UMC, there is a big group of patients who emigrated from Nigeria and Ghana. Due to this significant representation within the patient population, the decision was made to focus on this patient group as this will lead to relevant and interesting design opportunities for improvements within the offered care. In further stages of the overall improvement of the HIV outpatient clinic, the outcome of this project can be taken further and adapted to be relevant for a broader audience.

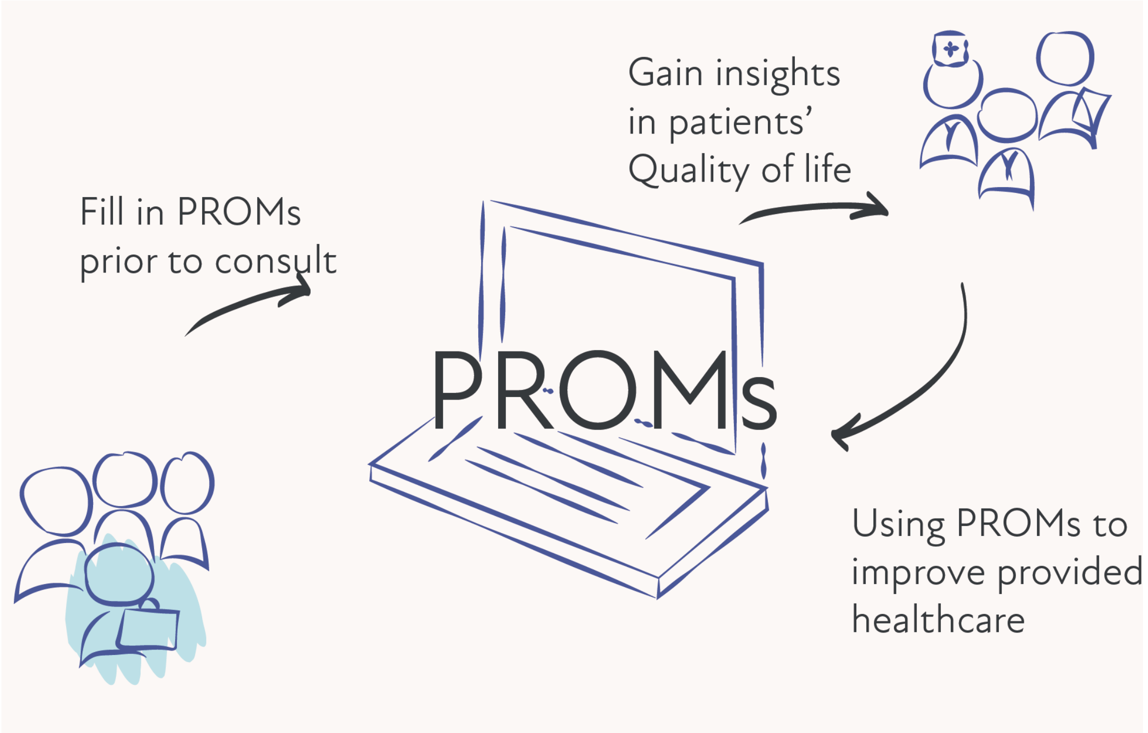


Figure 2 - PROMs placement

Assignment

Amsterdam UMC is working with PROMs to gather more insights into the quality of life (QoL) of people living with HIV. The problem is that the underserved patient group is at risk of falling behind when only standard methods are used. In a recent study by Amini et al. (2021), that identified facilitators and barriers for the implantation of PROMs, it was found that the most commonly reported barrier is the language barrier (76%). Therefore, a language barrier is primarily seen as the root cause of the PROMs not being responded to properly, but then – prima facie – a simple solution of translating these requires significant time. First, a PROM needs to meet "psychometric integrity" requirements and can therefore not be altered in any way. If we wish to translate the PROM, or change or remove even one question, the PROM needs to be validated once again (Moody & EATG PROMise Task group, 2021). Second, when translating the PROM, it is still the question if you can compare the Dutch and translated PROM with each other, and draw general conclusions about the entire patient population. Last, someone's cultural background plays a significant role regarding how open and honest a person wants to be when sharing personal details in the PROMs. Globally, living with HIV is still seen as a major taboo, and in some countries, it is seen as a punishment or just "what you deserve", and transmission of HIV is actively criminalised. In a report by Maman et al. (2009) from Tanzania and Zimbabwe, behaviours that led to HIV were often described as "irresponsible", "reckless" and "immoral."

> *"As a result, many individuals in these countries felt that PLWHA got what they deserved in terms of being punished for their reckless behaviour."*
> *– Maman et al. (2009)*

PROMs are being implemented via a digital platform, but the digital skills and access to digital tools are not sufficient for all people living with HIV with a migration background. Therefore, digital literacy is another issue to consider when looking at the practical side of implementing PROMs in this field of healthcare.

The main goal of this graduation project is to improve the collection of PROMS from people living with HIV with a migration background. Therefore, this research will have its focus on identifying the deeper issues regarding participation in PROMs for people living with HIV with a migration background, originating from Ghana and Nigeria. Furthermore, it will investigate how design can have a positive impact on the overall patient journey and engagement with PROMs.

1

Context Exploration: Initial Field Research

1.1 Introduction

As I was never a patient for a longer period, I have no experience with building a personal bond with a HCP. Next to the lack of experience in my private life, I do not have any medical knowledge as I am educated in the field of Industrial Design Engineering. Combining these two elements with writing my graduation brief, allowed an intrinsic curiosity to emerge. Before I was able to dive deeper into the topic of my thesis, I needed to know how this department works. Thus, during the first week of my graduation project, I immersed myself in the infectious diseases outpatient clinic of the Amsterdam UMC hospital. There, I shadowed different HCPs and saw what is happening behind closed doors during consultation hours.

1.2 Goal

Every department of every hospital follows the established guidelines from the board of the hospital, but still, there are many unique ways of working that will differ per department. Therefore, conducting qualitative research in the infectious diseases outpatient clinic of the Amsterdam UMC hospital is an essential step to create a feeling for this specific department. The goal of this initial field research (IFR) is to explore the context and find insights, by analysing the interaction between HCPs and patients. This will create a foundation on which further research questions are determined, and a global understanding of the culture of this specific department is created.

1.3 Method

To explore the context, ethnographical research is conducted. This include participant observations and informal interviews during consultations, conducted by different HCPs in the HIV outpatient clinic. The HCPs exist of a mix of different doctors and nurses specialized in HIV care. The doctors are specialized in infectious diseases and the nurses are trained HIV consultants. For 4 days, I observed the consultations in blocks of a maximum of 4 hours per day. Each consultation had a duration of 20 minutes. Due to the high number of no-shows, 17 different patients have been observed. See Figure 3 for an overview of general information of the observed patients.

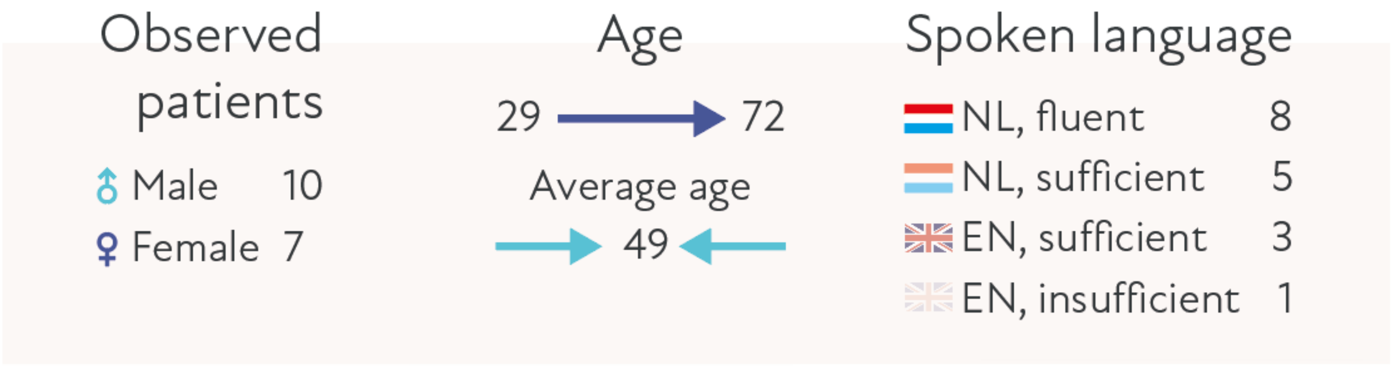


Figure 3 - Observed people

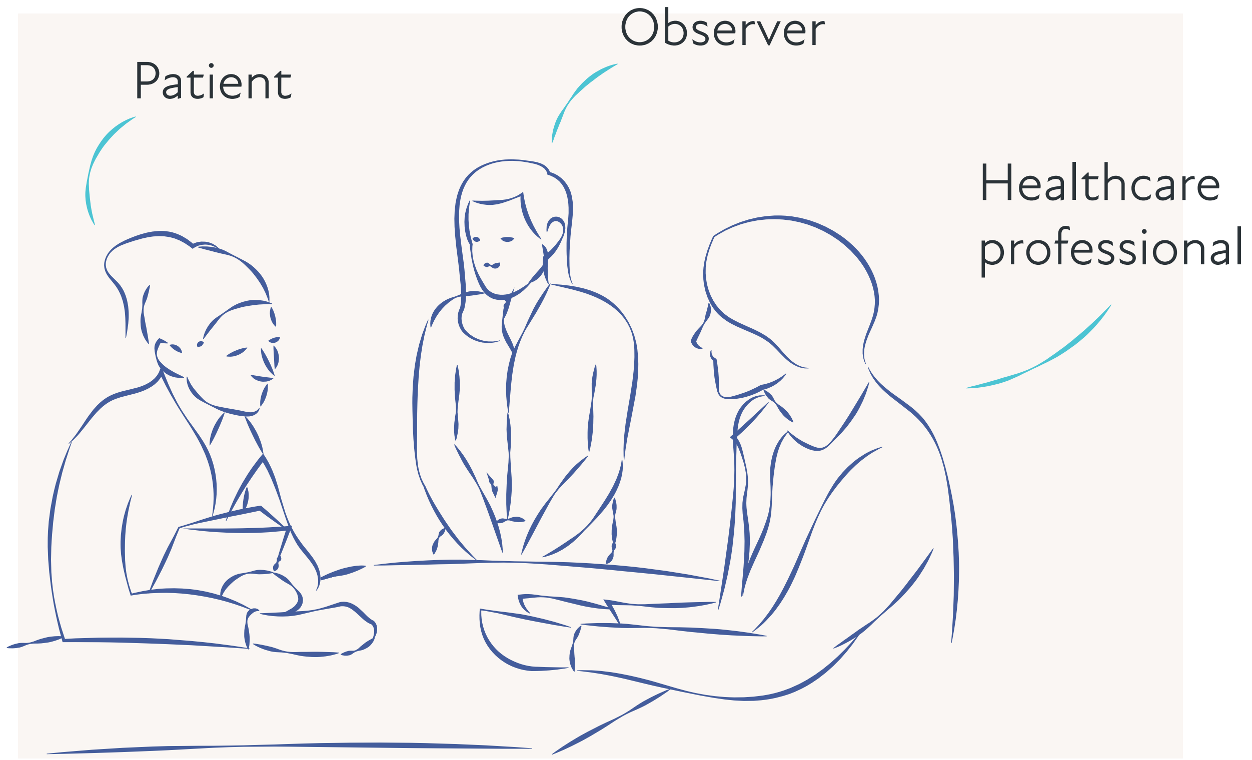


Figure 4 - Representation of observation setting

During the observations, I sat between the HCP and the patient with a little distance to not be intrusive but still be a part of the conversation, as visualised in Figure 4. I followed the conversation and made notes regarding the interaction and the acts that stood out. The notes include the gender, age, and heritage of the patient. During the consult, an estimation of the Dutch language skills of the patient is made. No audio recordings were made because the medical information is not essential for this initial explorative research. The interaction between HCPs and patients is the main focus throughout the consult, therefore I made notes regarding the concrete observations and what feelings arose. When the opportunity presented itself, I was able to ask some informal questions that arose during the observation. This was only the case when the patient visible felt comfortable and the HCP in charge invited me to ask a question, or when the patient was curious about my project and a conversation was started.

1.4 Analysis

After the participant observations and the informal interviews, I was fully immersed in the context. With the personal experience and written notes, I was able to search for the relevant and reoccurring themes within the consultations at the HIV outpatient clinic. Mindmaps and brainwriting helped me to create a systematic overview that is translated into the themes described in the results.

1.5 Results

Throughout the different consultations, a variety of reoccurring topics were found that were noticed during the observations and informal interviews. The most important themes induced an overview of the insights.

Theme 1 - Personal relationship

- People living with HIV are bound to the healthcare system for the rest of their life after being diagnosed; they see their HCPs regularly for many years.
- Patients and HCPs within the infectious diseases department of the Amsterdam UMC have a unique bond that is built over time throughout the different consultations.
- The HCPs know what to expect from their patients and the other way around.

A first impression

On my first day, I came in before the start of the consultation hours to get to know the first nurse who would take me along. She told me many things about her job and the department. She opened her calendar and we scrolled down the list of people who had an appointment that day. As we went over the names, she was able to give an impression of every patient.

> *"This patient will definitely think it's alright if you join the consult, he is always so much fun!"*
> *- Nurse 1*

The first patient I saw was a young male, born and raised in the Netherlands whose parents have a migration background. As Nurse 1 told me beforehand, this patient was a pleasure to meet. He was kind and cheerful and we laughed during the consultation. This was a dimension of interaction between a nurse and a patient that I had not experienced myself. Patient 1 told us all about his current life and how he has been feeling lately. He told us that no one in his environment knows about his positive status.

He mentioned that living with HIV doesn't change his life, except for the fact that he has to take his medication every day and visit the hospital regularly. With his current healthcare, he feels confident that he will grow old happily and healthy. He, therefore, feels like telling his family and friends will only worry them and he is afraid of the stigma that will arise. It was an interesting contradiction to see that someone who talked this openly inside of the Nurse's office, did not want to disclose his positive status to the people close to him in his private life.

Similar to the relationship between Nurse 1 and Patient 1, all the healthcare professionals knew all their patients like they had been friends for a long time. Depending on the personal style of the healthcare professional, there were some differences in how the relationships looked like. Before a patient would walk through the door, the healthcare professional had already told me what to expect from that consultation. Every time, the impression they had shared with me beforehand, matched the actual patient perfectly. However, in every conversation, there was more than just a medical monologue from a healthcare professional to a patient.

> *"My HIV infection plays a big part in my life, but it has no big effect on my life"*
> *-Patient 1*

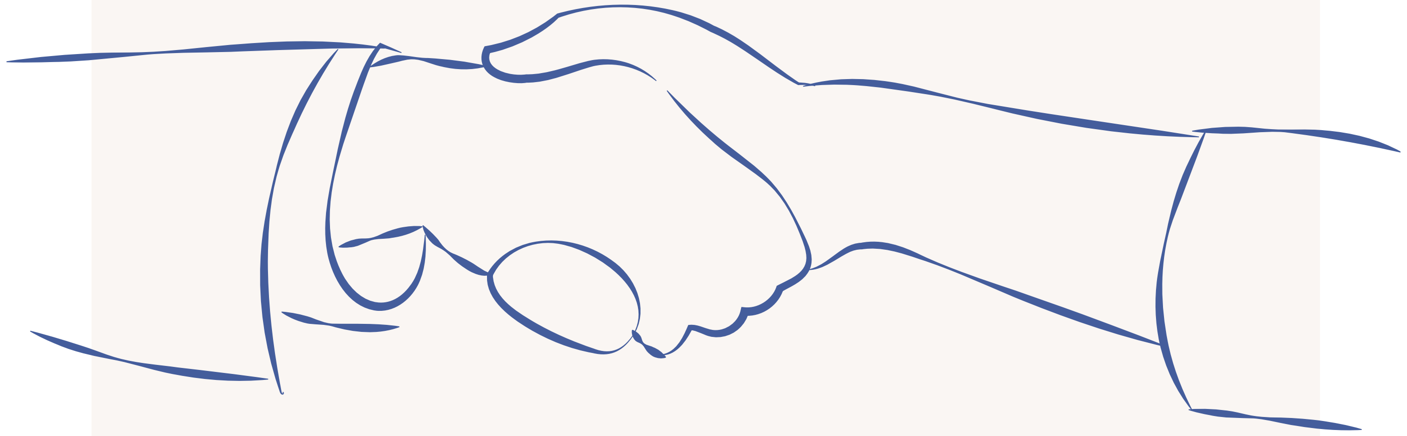


Figure 5 - Personal Relationship

Theme 2 - Disclosure

- No expectations can be made about people living with HIV being open about their positive status.
- Stigma and shame are the main cause of people living with HIV being hesitant when trusting people and disclosing their positive status.
- During deeper qualitative research, it is important to pay full respect to the boundaries of the people living with HIV and make sure that a safe environment is established, where discussions can take place without fear of exposure.
- For further development of design directions, discretion is an essential element. The design cannot create any unwanted exposure.

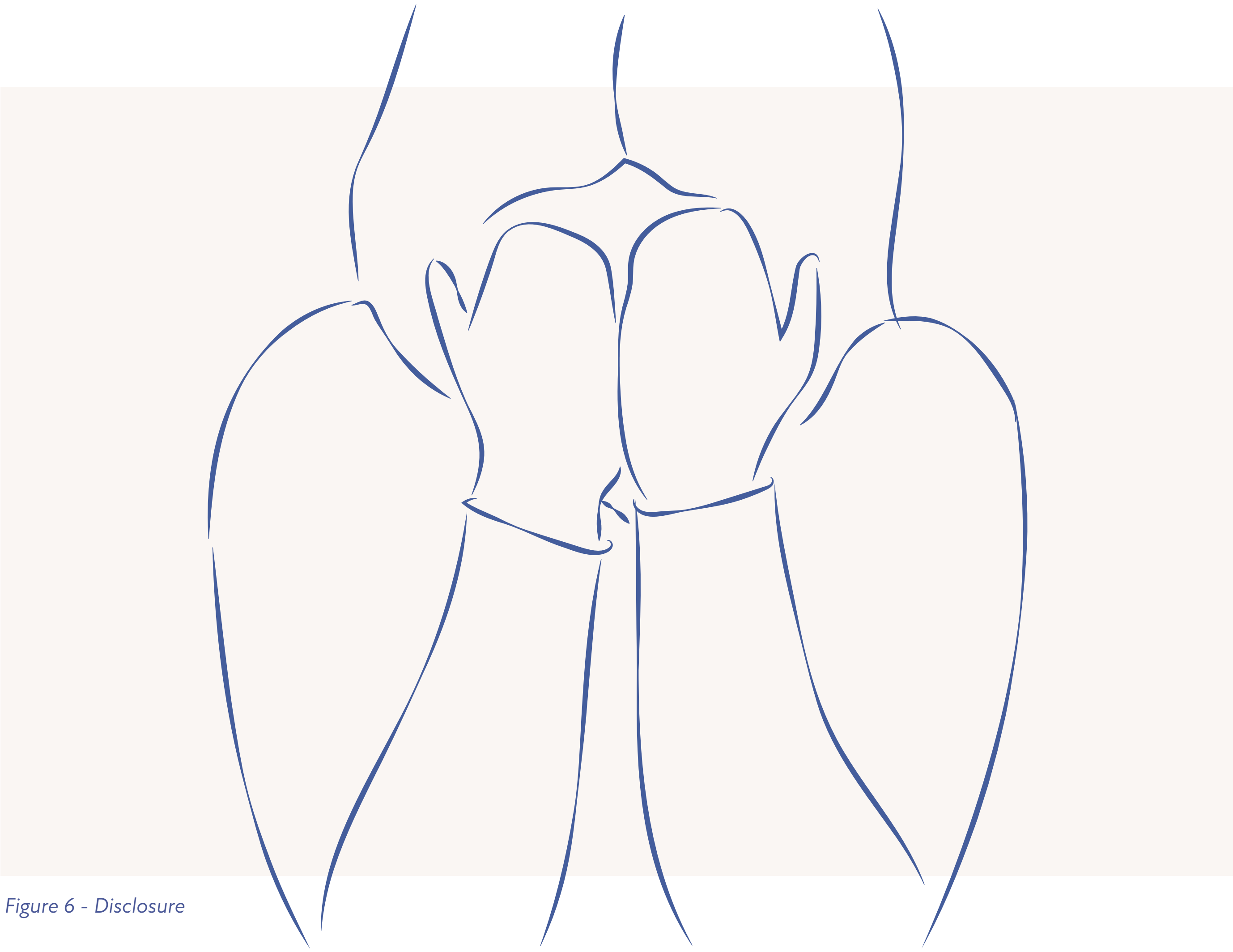


Figure 6 - Disclosure

Who can be trusted?

As mentioned in “Theme 1 – Personal bond” Patient 1 did not disclose his positive status to his friends and family members close to him. This turned out to be a recurring theme I found in the conversations between healthcare professionals and patients. Many patients keep their positive status a secret. They don’t want to be judged for what happened in the past and they don’t want to become a burden. Only a few patients have their status disclosed to some people close to them.

Some patients find companions via organisations made for people living with HIV to find support in each other. These patients show that it is easier to talk to someone who is going through the same thing. They assume/feel that their family would not be able to understand the emotions they experience

Patient 16, a woman with a migration background, told Doctor 4 during a consultation that her boyfriend wants to have a child with her, but she has not told him about her positive HIV status because she is afraid that he will leave her when he finds out. Her previous boyfriend left her when she disclosed her status. I could see the trauma and emotion regarding this issue. This is a perfect, but a tragic example of the effect of the fear of the response when someone discloses their positive status. The personal bond, as described in “Theme 1 – Personal bond”, turned out to be of great value for this case. As patient 16 used to be a patient of another doctor, she was familiar and comfortable with Nurse 2. Doctor 4 asked Nurse 2 if she was able to talk to Patient 16. Normally Doctor 4 is supported by Nurse 3, but in this case, Doctor 4 took the liberty to ask the help of the other nurse who already had a personal connection with Patient 16.

Despite the current knowledge we have in the world about HIV and AIDS, there is still a significant stigma attached to the disease. A patient who is living with HIV can still feel a lot of shame when it comes to this topic. They keep their status to themselves and carry the weight of their disease alone. They often only feel comfortable sharing their struggles with the healthcare professionals within the context of the hospital. This is extremely valuable as it creates a safe haven for the patients where they can talk about their life without any judgement.

Theme 3 - Impact of the diagnosis

- No assumptions can be made about why and how someone experiences living with HIV. In what gravity a person experiences living with HIV, differs per individual. And why someone experiences it in a certain way also differs per individual.
- Someone who feels a heavy burden when it comes to living with HIV might be feeling like that due to the (fear of) stigma and preconception from their peers, or it might be from the fact that they don't know all the facts and might therefore be scared for the effects on their health and the health of their family members.
- In contrast, when it comes to patients who are not taking the infection too heavy-heartedly, many differences can be found. Some patients might look at it soberly and see that a suppressed infection has little effect on their health and are therefore not worried, while others might take it this lightly as a coping mechanism.
- A good understanding of the disease, i.e. medical understanding and understanding of the effect on their lifestyle, may help people living with HIV to take away (part of) their worries and enlighten the weight of their diagnosis.

Lightweight

Some patients are living their life without any worries. Tthey take their medication daily and visit their doctor when they are asked. When a person is diagnosed with HIV and under care in the medical system, they need to regularly see a healthcare professional for a physical check-up to see if the HIV is still correctly suppressed. However, besides visiting these demanded appointments, they won't let HIV have any effect on the way they would like to live their life.

Patient 8, a 60-year-old Dutch male, is getting older and is starting to experience typical elderly ailments like high blood pressure, but he does not take it seriously. He is under the care of Doctor 2 and she stressed the importance of him taking good care of himself. His partner was also present during the consultation. He agreed with the doctor and assured that he would help with finding a more healthy lifestyle.

"I need to be strict with this patient as he can be quite nonchalant in taking care of himself"
- Doctor 2

Heavyweight

At the other end of the spectrum, we can find the group of people who are carrying a heavy burden. In our society, we still see a lot of stigma around HIV and AIDS. The knowledge regarding HIV and AIDS of the average person is still minimal. People have little idea of the actual effects on someone's life when they receive a positive HIV diagnosis.

This goes quite hand in hand with "Theme 2 - Disclosure" where is discussed that some patients feel very bad about their positive status. These negative feelings are caused by different reasons. Some patients have been severely traumatized before or when they came to the Netherlands as refugees from a war zone. In some cases, the HIV infection is a result of sexually transgressive behaviour, and the infection is an everlasting weight the patient will carry for the rest of their life. Being infected with HIV has different effects on all patients and their mental well-being. Some patients can even suffer from depression due to the mental load they feel. One patient came in and when the doctor asked how she was doing, the answer was short but said it all.

"Depression..."
- Patient 7

The doctor took her time to talk to the patient, trying to Figure out what was troubling her. During the conversation, she found out that the patient was unaware of the fact that when HIV is suppressed, it cannot be transmitted to another person. This allowing someone to have unprotective intercourse and even get pregnant without passing the virus on to the baby. When this patient heard that her daughter, who is living with HIV, can start a family without passing the virus on, the patient said that she felt like she was cured of her depression. Patient 7 said that a friend of hers tried to explain this earlier, but she did not believe it. Now that the doctor said it, it must be true and she was convinced.

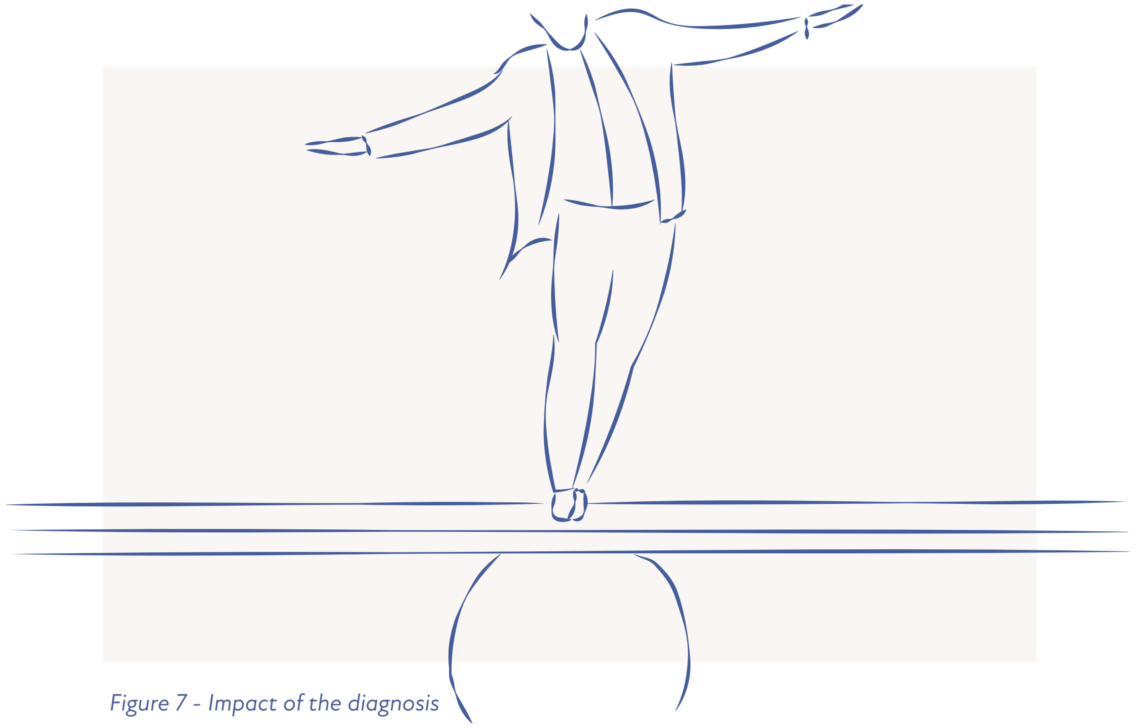


Figure 7 - Impact of the diagnosis

Theme 4 - Health literacy & Health involvement

- The level of health literacy has a big variation within the overall patient population of the Infectious Diseases Department. No assumptions can be made about people living with HIV being fully informed about the effects of their positive status on their well-being.

- The question arises, what lies behind a low level of health literacy. Does it come from the lack of resources or the incapability to consult resources, or is this caused by an entirely different reason?

- The involvement with personal health per patient varies too. Some patients feel little or no reason to be involved with their health, therefore it will be unrealistic to move towards a direction that is taking their involvement for granted.

- Many patients feel the urge to check everything with their doctor, as they feel like they cannot fully trust their found information or their interpretation of this information.

The effects of health literacy

As described in Theme 3, when someone understands their disease, the weight of their diagnosis might be a little bit lightened. This is shown in the example of Patient 7 who felt depressed due to a misunderstanding of the transmittance of the virus. When I shared my experience about the big reaction of patient 7, he told me that this happens quite often. He even told me that I could expect a similar conversation during the next consult. This indicates that low health literacy forces HCPs to share the same information multiple times with the same patient.

During multiple consultations, the healthcare professionals had to explain things that they assumed were already familiar topics for their patients. The lack of health literacy does not make it easy to understand the essence of what the healthcare professional tries to explain. There were many times when I wondered if the information was making sense to the patient as you could see the confusion on their faces. During different consults, the doctors and nurses share a lot of information with the patient. Without a medical background, it can be hard to understand what everything means. Not knowing basic effects of living with HIV, makes it almost impossible to follow and understand what is going on.

Figure 8 Health literacy & Health involvement

Being involved with personal health, or not.

To become health literate, you need to have an intrinsic interest in the disease and be motivated to educate yourself. There is a big division within the patient group of the Infectious Diseases Department. On one hand, you have the people who take matters into their own hands and Google everything and when the doctor discusses their current health, they know exactly what they are talking about. On the other hand, you have the group of people who accept everything the doctor tells them, which is not that weird knowing that the doctor has studied for many years to be where they are now. Thus, a division has been noticed between the more passive patients and the proactive ones.

Patient 9 came in with a list of questions he had to ask the doctor. He did his online research and there were some topics that he wanted to fact-check or wanted to know more about. He also mentioned the fact that there was a new medication on the market and he was wondering why he wasn't offered to switch to that one, as this new pill only contained 2 medicines.

> *"Less medication is always better when more is not necessarily" - Patient 9*

Even though some patients do their research and come to their consultation with specific questions, they still feel the need to talk to their doctor and fact-check their findings. This shows that even the assertive patients don't know what information found online can be accepted as fully trustworthy. Some patients come to their consultation with a list of things they would like to discuss, some patients come to absorb what the HCP has to say.

Theme 5 - Communication

- A significant part of the patient group struggles with the Dutch language as they migrated to the Netherlands at a later stage in their life. Therefore, speaking, reading and writing Dutch does not come naturally for this group.
- Communication between healthcare professionals and patient requires extra energy and effort, but eventually, both parties understand each other sufficiently.
- Without direct feedback, it will be harder to guarantee the correct interpretation when non-human communication devices are used. Any kind of communication cannot be restricted to the use of purely Dutch writing.

Figure 9 - Consultation representation

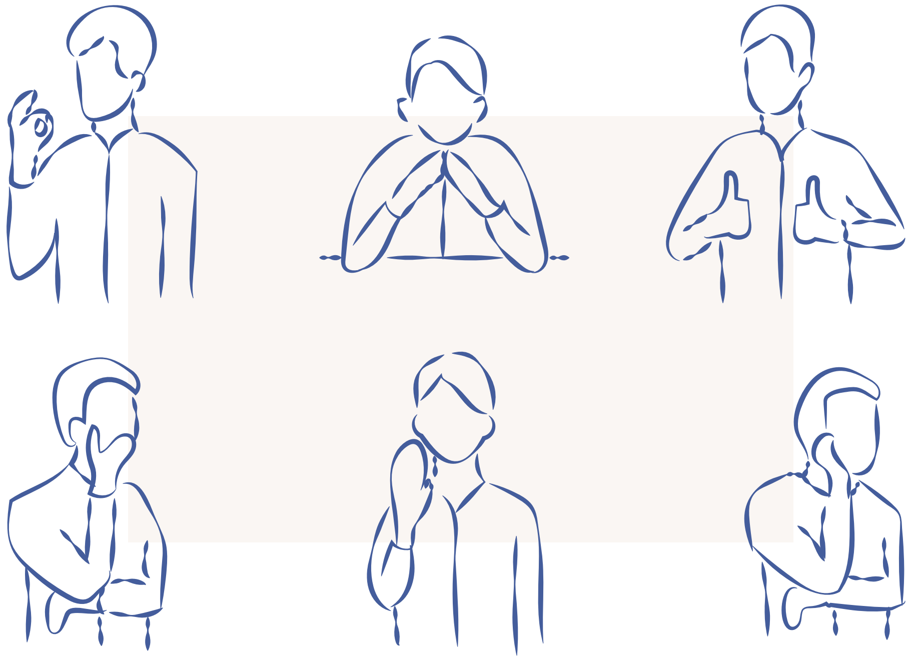


Figure 10 - Non-verbal communication

Bridging the language gap

When looking at the overall patient group within the HIV outpatient clinic, we see a variety in ethnicity and origin. A significant number of patients moved to the Netherlands later in their life, and therefore, Dutch is not their first language and often not even their second one. For 7 patients, from the 17 that have been observed, Dutch was their first language and 1 patient learned to speak Dutch on a native skill level. The other 9 patients did not speak Dutch or possessed some basic knowledge of the Dutch language. For the patient group who are not fluently speaking the Dutch language, an extra challenge arises: when patients and healthcare professionals speak the same language, there is always a lot of information that is quite specific and complicated, so even when both people in the conversation speak the same language there is still the issue of understanding each other. When adding the element of a different language, understanding another is even more complicated.

During the consultation with Patients 3 and 4, an elderly couple with a migration background, I noticed that Doctor 1 used many gestures and body language to emphasize the important elements from what he tried to explain. For example, Patient 4 explained that he had a stomach ache by rubbing over his stomach and saying a few words that indicated that he was in discomfort. When Doctor 1 tried to Figure out if Patient 4 suffered from heartburn, he tried to make hand gestures that resembled the acid refluxing in the oesophagus. This kind of conversation where gestures played a big part in mutual understanding, happened quite often. This showed that, despite the language barrier, the communication is good enough to understand the essence of the message. The HCP is constantly searching for feedback to confirm whether or not the patient understands what they are explaining. As an HCP you pledged to give your full effort to make sure that every patient is treated as good as possible (Artseneed & Commissie Herziening Artseneed, 2003). Therefore as an HCP, you are expected to give your full commitment to help each patient. However, that does not come without a price. When helping a patient requires more effort than the average patient does, the HCP has a more exhausting task to complete.

Theme 6 - No-shows

- A significant number of the patients fails to show up when they were supposed to have an appointment with their HCPs.
- Due to the nature of the disease, being physically present at the hospital is important to monitor the development of the virus load.
- What causes the high rate of no-shows is unknown. It could be caused by a complicated psychological reason, for example, feeling aversion due to being confronted with a part of your life that you would rather forget. Or it could be just as simple as forgetting about the scheduled appointment.

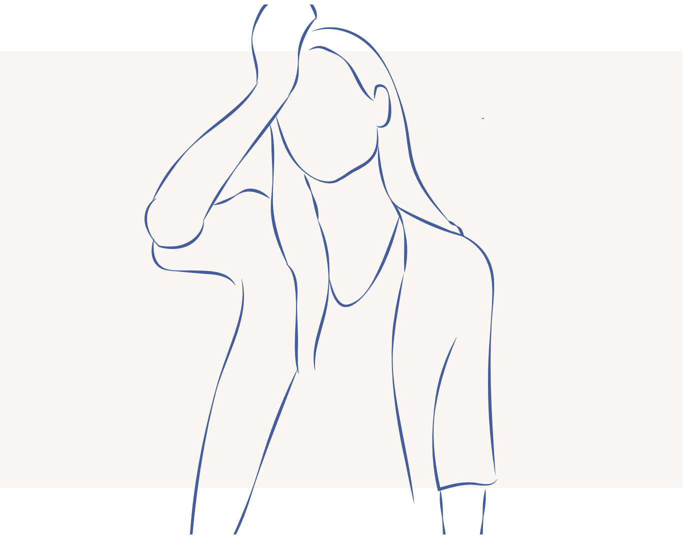


Figure 11 No-shows

Missing people

In theory, the calendars of the HCPs were filled with back-to-back appointments with patients, but a significant number of them did not show up. In some cases, the healthcare professional expected beforehand that the patients would not show up, but for others, they were a bit surprised and disappointed. Several patients would show up late. Patient 14 came in quite late and she said that she thought her appointment was half an hour later than scheduled. I noticed that Doctor 4 was kind towards this patient and was just happy that she came to her appointment. However, this did mess up the schedule making the other patients wait longer. Fortunately, in this case, another patient did not show up either which allowed the doctor to make up for the lost time. The attitude of Doctor 4 towards Patient 14 also reminded me of "Theme 1 - Personal bond", where the personal relationship between healthcare professionals and their patients have been described. Doctor 4 was more concerned about her patient showing up to the appointment rather than the specific time she would arrive, being genuinely concerned about her patient's health.

The HCPs reach out to the patients who do not show up to their appointment to reschedule the appointment. People living with HIV need to have regular blood tests to monitor how the virus is responding to the treatment. When a person does not show up to their appointment, the healthcare professional does not know how the body is responding to the medication. When a person does not show up for a longer period, they cannot proceed with giving this person their medication. As the medical staff is responsible for the health of the patient (Artseneed & Commissie Herziening Artseneed, 2003).

1.6 Key takeaways

A strong relationship

People living with HIV are part of the health care system for the rest of their lives, and in the care of their personal HCPs for many years. This allows HCP and patient to build a strong relationship. The patient can fully trust their HCP, and the HCP knows what to expect from the patient

Privacy of people involved

People living with HIV are often stigmatized and prefer to keep their positive status undisclosed. The privacy of the people involved in this project should always be a top priority.

Different weights of the burden

The weight of the burden of living with a positive status differs per individual. While some people might see it as an insignificant part of their lives, others might be lying awake worrying about it every night.

Different levels of health literacy

The level of health literacy differs greatly within the patient group of the HIV outpatient clinic in the AMC hospital.

Different degrees of personal health involvements

The degree to which a person living with HIV is involved with their health is also really variable. While some patients might have a passive role and listen to their HCP, other patients want to do their research and have a shared decision with their HCP.

The Dutch language

A significant part of the patient group struggles with the Dutch language as they migrated to the Netherlands at a later stage in their life.

No-shows

A significant number of patients fail to show up to their appointments at the AMC hospital.

1.7 Next steps

The IFR allowed me to understand how the Department of infectious diseases functions. I now know how HCPs work and interact with their patients. Next to that, I understand the context better, what topics are being discussed behind the closed doors of the doctor's office. PROMs will be implemented to help the HCP to give better care to the patients, but it seems to me like the current provided physical care is of excellent quality already. From the IFR, the foundation of knowledge is generated based on how things work in practice. Moving forwards in this project, more knowledge needs to be gathered. In the following Chapter, literature will be reviewed to broaden the knowledge. This literature should fill the knowledge gaps that could not be filled during the IFR.

2

Literature Research: Theoretical Foundation

2.1 Introduction

From the IFR the first part of the knowledge foundation was created, but this opened new questions. For example, what can be learned from other institutes that already implemented PROMs, or why is the current status quo of stigma alive? Luckily, not all information has to be retrieved during primary research. Many other researchers wrote articles or books about overlapping topics, such as the implementation of PROMs, stigma against HIV, and how people with a migration background experience healthcare. These topics, amongst others, can be used as building blocks for the knowledge foundation of this project.

2.2 A foundation of knowledge

In this project, I worked towards a final design that can improve the collection of PROMs for people with a migration background from Nigeria and Ghana. I do not fall into this target group and neither does she have experience in the field of PROMs implementation. The goal of this Chapter is to create a foundation of knowledge retrieved from existing literature on topics that play a role in this research. This will help to make well-supported choices and determine the next steps for the research.

At the beginning of this phase, several research questions were formulated to give shape to the search query. Each topic was defined with concrete research questions to which the answer should give a general understanding of the essence of this topic.

2.3 Results of the literature research

2.3.1 Implementation of PROMs

What can be expected when implementing PROMs?

PROMs can be implemented in many different ways. In the department of infectious diseases, patients are asked to complete the questionnaire of the PROMs before their appointment. In other departments, they might ask the patients to fill in the questionnaire multiple times per week to monitor the fluctuations in their perceived wellbeing more carefully. As each specific department within one hospital is specialised in another disease or condition, each department might need a specific way of implementing the PROMs. Depending on what needs to be monitored and in what frequency, the method of PROMs deployment for each department will be determined.

Kozak et al. (2011) conducted a study in which patients had to routinely complete questionnaires on an online platform every four months. Their research showed that the use of PROMs was only suitable for people who are adequate literate and have sufficient digital skills. Within the scope of participants who were included in the research of Kozak et al. (2011), they demonstrated that the lack of face-to-face interaction decreased the influence of social desirability bias which improved the reliability of the data capture of the more sensitive topics like substance use.

A potential strength of the implementation of PROMs in the early detection of depression was discovered by Schumacher et al. (2012), where they used routine depression screening in a real-world HIV treatment clinic. In this study, the significant benefit of access to depression treatment is demonstrated. A decrease in depression scores was found after the integration of the assessment for depression, as mental health services are only available with a referral and therefore allows patients to get the professional help they need in an early stage. Kozak et al. (2011) found that longstanding diagnoses, such as depression, are not always re-evaluated during every consultation due to time constraints or focus on other clinical events. Even though PROMs can help in the early detection of mental health issues, the cut off is arbitrary and may lack sensitivity (Schumacher et al., 2012). The most important element is access to the correct treatment, as this will be the essential cause of the decrease in depression scores (Schumacher et al. 2012). However, the results of the research conducted by Schumacher et al. (2012) do indicate that routine depression screening in the outpatient clinic can identify patients at risk with a variety of co-morbid psychiatric illnesses.

Hauth et al. (2009), investigated the acceptance of PROMs within a patient population of the department of Radiation Oncology. The participants of this study received radiotherapy or radiochemotherapy. During the trial they were asked to fill in the PROMs whenever they felt like it, but at least once a week. They would receive a weekly email to remind them to fill in the PROMs. Within this study population, there was a high acceptance rate. Over 80% of the participants completed the PROMs regularly. Hence, the conclusion was drawn that the use of PROMs is an effective complementing tool next to the face-to-face patient-physician interaction. An important side note here is that this patient population was already digitally inclined, which makes the usage of a digital platform easy. Within the scope of this project, the focus lays on a patient population that is known to be less digitally skilled. Therefore, the implementation of a digital platform can be expected to be a challenge. Another element that makes the comparison of this research with the HIV outpatient clinic more complicated, is that during a cancer treatment patients tend to suffer from severe side effects. During the HIV treatments, the changes in perceived physical wellbeing are more subtle or slow.

Takeaway in this research context

For the implementation of PROMs in the Amsterdam UMC, a problem arises because PROMs cannot be altered in any way after they have been validated. When the content of a validated PROM set is changed, it loses its “psychometric integrity” (Moody & EATG PROMise Task group, 2021). So, when a certain patient group is not skilled with the Dutch language, we cannot let the platform auto-translate it to their preferred language.

Implementing PROMs in the HIV outpatient clinic will add value to the currently offered care. During my IFR, I found that the patients have a strong relationship with their HCPs. The lack of face-to-face contact might decrease the social desirability bias as Kozak et al. (2011) formulated. Many patients feel safe when talking to their HCP, so the question arises if the patients struggle with sharing information that is not socially desired. The main positive effect reached by the implementation of PROMs is the routine checks for different potential risks. This saves the HCP quite some time which they can spend on more other tasks.

The main barriers, according to the literature above, are the patients’ lack of digital skills and low literacy. Both are required to effectively fill in PROMs. For further research, I want to find out more about the skills of the target group of my project to explore the significance of these barriers.

2.3.2 Stigma

Before I officially started with my thesis, I started telling my friends and family about the project. I noticed that even highly educated friends did not know what HIV was and what the difference is from AIDS. Someone asked me if I was supposed to wear protective clothing when interacting with the patients to not get infected myself. I noticed how some people were a bit hesitant to ask anything, scared to say something "stupid". A friend said that he felt bad for not knowing anything about this disease. Even some friends questioned if it was worth my time and effort as this disease was something that these patients could have prevented from getting if they only would have been more careful. Overall, I was quite shocked by some of the responses from friends but this really showed me how big the stigma is, even here in western culture.

What is keeping the stigma around HIV/Aids alive and what is the effect on people living with HIV?

According to the study by Maman et al. (2009), HIV-related stigma and discrimination are fed by factors like the fear of transmission, fear of suffering and death, and the burden of caring for people living with HIV. In this study, they examined the HIV stigma and discrimination in five high prevalence settings. When many people are living with HIV with less than optimal healthcare, the virus has a chance to attack the immune system and weaken the body of the person living with HIV. So, if you are living in a prevalent setting and the people living with HIV are visibly sick, it is not weird to be scared of the disease when you do not know how it can be transmitted. When Maman et al. (2009) asked the participants how they feel about people living with HIV, most participants expressed sympathetic or neutral attitudes. However, upon further probing, the participants were less compassionate. Attitudes like blame, othering, and disgust were described. This is a perfect example of how people try to be compassionate but when dig deeper, the stigma takes overhand in the way someone might feel towards people living with HIV.

The stigma around HIV does not make the lives of people living with HIV easier. Multiple studies have shown that stigma is associated with stress, depression, and a lower perceived quality of life among people living with HIV (Simbayi et al., 2007, Wingood et al., 2007). Besides the stigma that people who are not living with HIV project on people living with HIV, there is also a lot of self-stigma where people living with HIV are agreeing with the stigma and are internalising them. Self-stigma is also linked to depression, but also to lowered self-esteem and self-efficacy, anxiety, and hopelessness (Kalichman 1998; Lee et al. 2002; Treisman and Angelino 2004). This all will also create a lower perceived quality of life as these elements contribute to an unhealthy state of mind.

Takeaway in this research context

Battling stigma is something that our society needs to continue with if we want to keep on improving the wellbeing of people living with HIV. As found in the literature described in this Chapter, the current ongoing stigma regarding HIV and Aids is a burden on the lives of people living with HIV as they struggle with different negative attitudes from peers and/or their own negative thoughts.

Unfortunately, within the scope of this project, the battle against stigma is not included. Therefore, in this project, the existence of the persistent stigma against HIV needs to be taken into consideration. Meaning, in the next stages it is important to remember that people living with HIV are often stigmatised and therefore sensitive topics might be perceived as uncomfortable. When interacting with people living with HIV it is important to stay respectful and empathise with the person, adjusting the topic when needed to maintain a positive and comfortable atmosphere.

2.3.3 Disclosure

Why are people living with HIV not disclosing their positive status?

With the stigma as described in the previous section of our society, it is quite understandable that people living with HIV are not always open and honest about their positive status. In other words, disclose themselves about their positive status. In 2008, Mayfield Arnold et al. already found that disclosure affects health, mental health, disease transmission and the quality of relationships. They stated: "Disclosure is intimately related to how communities stigmatise or accept HIV and how individuals perceive themselves, their identities and their roles in their communities" - Mayfield Arnold et al. (2008). Furthermore, the importance of disclosure behaviour will only increase when life expectancy and treatments have improved. Currently, we are still facing the persistent stigma while the life expectancy and treatments have been improved. There is a lot of literature available that goes deeper into the importance of disclosure of a positive HIV status, showing that people living with HIV are not disclosing their positive status due to the fear of stigma.

Takeaway in this research context

Following the statement of the effect of stigma on this project, it is essential to keep in mind that a majority of people living with HIV are not (yet) willing to disclose their positive status to the entire world. When working with people living with HIV, we need to make sure to stay discrete and not create any unwanted exposure. This is something that has also been found during the IFR, see Chapter 1. The significance of privacy needs to be taken seriously throughout to entire project.

2.3.4 Access to Healthcare

How are people with a migration background experiencing healthcare in their new homeland?

People with a migration background have in general more hurdles to overcome when it comes to their daily life than someone who does not have a migration background. Data suggest that migrants across Europe, including the Netherlands, are doing less well within the issue of healthcare, as they are more likely to enter clinical care with a late-stage or even a further advanced HIV infection (Bil et al., 2019). This late diagnosis can be caused by the fact that, according to Hernando et al. (2015), migrants face barriers when it comes to accessing and utilising HIV health services. In the recent study conducted in the Netherlands by Bill et al (2019), their participants with a migration background most frequently reported that they were uncertain about their right to access healthcare and face language barriers. The fact that people living with HIV with a migration background are doing less well is a problem because 43% of people living with HIV in care have a migration background (Bil et al., 2019).

Takeaway in this research context

Overall, people with a migration background have more difficulties when it comes to accessing healthcare. Improving the access to healthcare does not fall within the scope of this project. But for those who managed to enter the care system of the Amsterdam UMC, it is important to optimise the patients' utilisation of the services that are offered.

2.3.5 Health literacy

How does low health literacy affect a patient?

In Chapter 1, the observations about the difference in the level of health literacy are described. When moving towards a healthcare culture where shared decision making gets a more prominent role, being sufficiently health literate will help you to feel confident when making decisions together with the doctor.

Limited health literacy is seen as a potential contributor to health disparities (Curtis et al., 2012). In line with these results, low health literacy is linked to lower self-reported physical and mental health (Bennett et al., 2009, Wolf et al., 2005), limited usage of preventive healthcare services and less frequent health promotion practices (Wolf et al., 2005, Wagner et al., 2007). When you are unaware of what it means to have a certain disease, it will be hard to understand what kind of behaviour will help you. And when you do know what is going on with your health, symptoms can be understood making you feel less confused. This corresponds to the study of Bekker and Lhajoui (2004), which stated that first-generation Moroccan Berber speaking women who were sufficiently health literate reported better health than those that were not sufficiently literate.

According to a study by Ghaddar et al. (2011), the availability of a reliable source of health information has the potential to improve adult health literacy. Additionally, they recognised school systems as a potential intervention point when it comes to health literacy promotion. Expecting that this will result in adolescents who have a healthier lifestyle on a long-term basis.

As discussed in Chapter 2.3.4, people with a migration background are generally less aware of the regulations and customs of the health system of their new home. Therefore, immigrants tend to be an important subject for research on health literacy (Kreps & Sparks, 2008). Health illiteracy can be caused by illiteracy, when patients are unable to read they will automatically be incapable of reading written information about their disease or health in general. In the case of people with a migration background, their illiteracy can be caused by the fact they have not been able to learn how to read and write in Dutch and/or English.

According to Erlen (2004), when patients are functionally health illiterate, nurses stand in a unique position where they can serve as advocates, mediators, and translators. In this situation, nurses need to help the patients to make their own decisions but also need to protect them so others do not coerce them or bias their decision making. Erlen (2004) also describes that nurses build a relationship of trust with their patients, which stands in line with the observations in Chapter 1 where the personal relationship between the healthcare professional and patient has been observed.

Takeaway in this research context

When working with patients who are functionally health illiterate, healthcare professionals have an important role. But accepting the fact that a patient is health illiterate is not optimal as being health literate would help the patient to understand their disease and might even increase their perceived quality of life.

2.3.6 Health psychology and intrinsic motivation

How is behaviour regarding health influenced?

In the 1950's, social psychologists of the U.S. Public Health Service developed the health belief model (HBM) to explain why people failed to participate in programs that would prevent and detect diseases (Hochbaum, 1958; Rosenstock, 1974). Kirscht (1974) extended the HBM to study people's responses to symptoms and Becker (1974) added the behaviour in response to the diagnosis of an illness, focusing on the adherence to medical regimens. The HBM, as formulated today, contains several concepts of individual beliefs that predict why people take certain actions to either prevent, screen, or control illness conditions. Image 13 shows an overview of the HBM and how the elements are linked to each other (Glanz et al., 2008), and Figure 12 shows an overview of the definitions of the HBM.

Takeaway in this research context

According to the HBM, behaviour regarding health is influenced by beliefs. Only when someone believes that a certain action or behaviour will help their health and beliefs that the (perceived) barriers are worth overcoming, then the person will take the action or change their behaviour.

As found in the IFR in Chapter 1, the patients fully trust the HCPs, which works to the advantage of the HBM. HCPs can educate the patients and adjust their beliefs.

Concept	Definition	Application
Perceived susceptibility	Belief about the chances of experiencing a risk or getting a condition or disease	Define population(s) at risk, risk levels Personalize risk based on a person's characteristics or behavior Make perceived susceptibility more consistent with individual's actual risk
Perceived severity	Belief about how serious a condition and its sequelae are	Specify consequences of risks and conditions
Perceived benefits	Belief in efficacy of the advised action to reduce risk or seriousness of impact	Define action to take: how, where, when; clarify the positive effects to be expected
Perceived barriers	Belief about the tangible and psychological costs of the advised action	Identify and reduce perceived barriers through reassurance, correction of misinformation, incentives, assistance
Cues to action	Strategies to activate "readiness"	Provide how-to information, promote awareness, use appropriate reminder systems
Self-efficacy	Confidence in one's ability to take action	Provide training and guidance in performing recommended action Use progressive goal setting Give verbal reinforcement Demonstrate desired behaviors Reduce anxiety

Figure 12 - HBM definitions

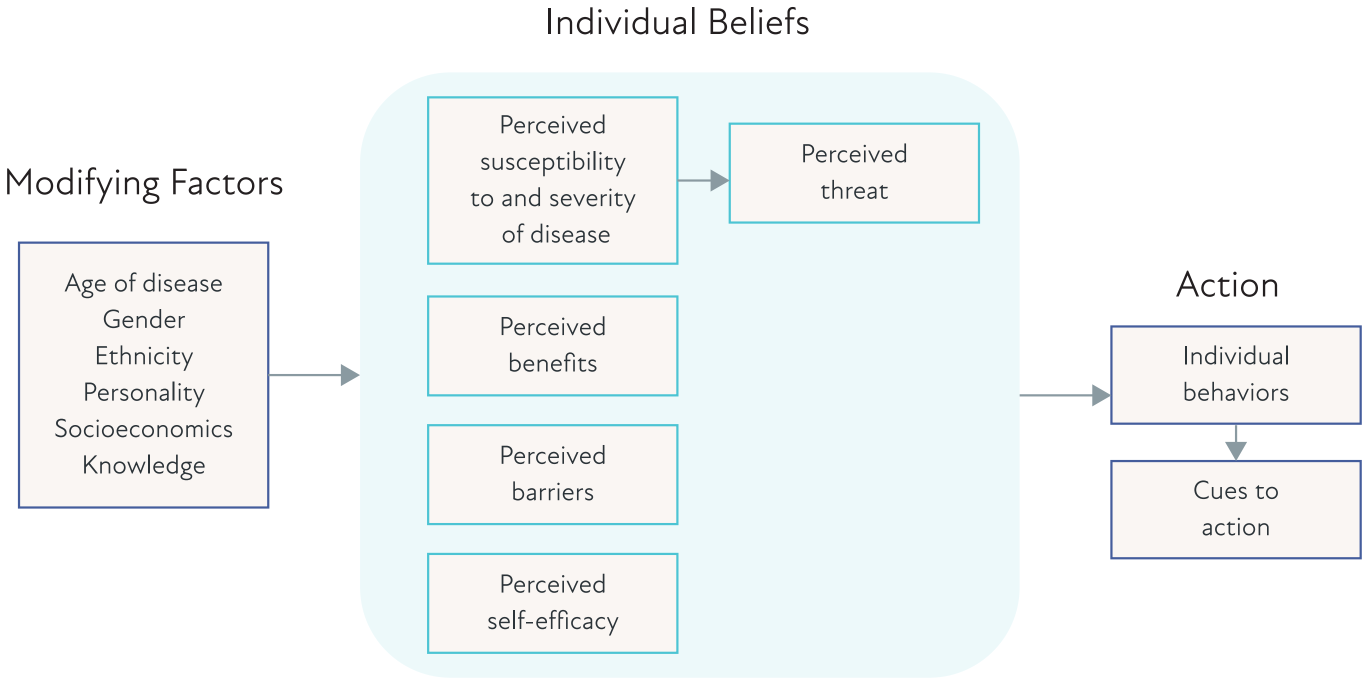


Figure 13 - Health Belief Model

2.4 Key takeaways

Benefits of PROMs

The benefits of the implementation of PROMs will be optimised when the boundaries are overcome.

Respect and empathy are key

People living with HIV are facing a lot of stigma and self-stigmatization. Respect and empathy will play an important role when interacting with a person living with HIV.

Disclosure

People living with HIV do not always disclose their positive status to the outside world.

Bridging the literacy gap

HCPs have an important role for patients who are not functionally health literate.

Individual beliefs

A person will only take certain actions or change their behaviour when they believe that the benefits outweigh the barriers.

2.5 Next steps

The found literature helped to create a foundation of knowledge as intended. New information was found about the implementation of PROMs, and how individual beliefs influence someone's behaviour. Furthermore, the literature gave new insights into how HCPs. Nurses, in particular, play quite a crucial role when interacting with patients who are illiterate or not health literate. Simultaneously, the literature underpinned insights that were already found in the IFR in Chapter 1. No literature has been found that contradicted the found insights. From here it is now possible to start the qualitative research by conducting interviews with the target group.

3

Context Research: Qualitative Interviews

3.1 Introduction

From the IFR in Chapter 1 and the literature research in Chapter 2, I was able to create a basic understanding of the context and what elements are crucial for the project and further research.

In quantitative research, specifically in research where the researcher is aiming to understand how people live their lives, conducting interviews is an effective way to retrieve information (Schwandt 2001, Lambert and Loiselle 2008, Schultze and Avital 2011). When you want to capture the voices and the ways people make sense of their experiences, qualitative interviewing is a flexible and powerful tool (Rabionet, 2014).

> *"We interview to find out what is in and on someone else's mind, to gather their stories".*
> *- Patton (2002)*

Interviews are this popular because interviews are being held while talking and talking is natural (Griffée, 2005). Rabionet (2014) mentioned a rise in the number of studies within the health field in which interviews are used. This is standing in line with the shift to person-centred health care systems where the perception and experience of the patients are becoming more and more important. For my project, the focus lies on the perceived experience of people, therefore conducting qualitative research will lead to the most relevant and important insights.

3.2 Goal

The goal of the qualitative interviews is to find rich information regarding the experience of people with a migration background regarding their health care experience before, during, and after their hospital visits. The rich information leads to the formulation of the different facilitators and barriers (F&Bs) that the target group experiences during their interactions with the hospital. Next, this will help compose the patient journey (PJ) that maps out the hospital journey of patients within the HIV outpatient clinic of the Amsterdam UMC.

3.3 Method

For this research, semi-structured interviews were conducted. Chapter 1 and 2, led to the first insights and takeaways. The insights and takeaways form the initial starting point for the interview guide. This is only a starting point, in the interviews I am looking for new insights and unexpected information, therefore making sure that the interviews are flexible will allow me to find new and additional insights (Doody & Noonan, 2013).

The location of the interview must be consciously chosen. Holloway and Wheeler (2010) describe that the participant's home provides a relaxed atmosphere and places the participant in a position of control, but at the same time, the household obligations and family commitments may result in distractions and interruptions. The most important aspect is that the participant is in a comfortable setting and free of distractions (Doody & Noonan, 2013). Because the patients are familiar with the AMC hospital, it is preferred to conduct the interviews in one of the doctor's offices as this will create a safe environment where the patient knows that they can talk in private.

During the interview, many elements need to be established to have a successful session. All of these elements can be included in the interview protocol. According to Rabionet (2014), an interview protocol consists of two components; (1) how do you as an interviewer introduce yourself to the participant, and (2) which questions will be asked.

Before this research could start, a request for non-WMO approval was done at the 'Medical Ethical Research Committee' of the Amsterdam UMC. This application was approved and therefore the research could officially start. See Appendix 2 for the approved research protocol and see Appendix 3 for the official approval statement.

3.3.1 Interview Guide

The decision has been made to conduct semi-structured interviews to allow unexpected information to be gathered. An elaborate interview guide has been made to ensure the quality of the results.

The themes and questions from the interview have been formulated based on the inspiration derived from the insights described in Chapter 1 - Initial Field Research. The general outline of the interviews was the following;

- Introduction of the research and the researcher.
- Informed consent form
- General questions about the patient; age, heritage etc.
- Experiences during the hospital visit.
- Disclosure in a private setting.
- Personal relationship with the healthcare professionals.
- Communication → PROMs
- Health literacy and ways to gain information regarding HIV.
- Appointments and no-shows
- Anything the participant would like to share

See Appendix 1 for the full interview guide.

3.3.2 Participant Recruitment

The target group for this project is quite specific: people living with HIV, with a migration background originating from Nigeria or Ghana, who are under care in the Amsterdam UMC, location AMC.
Therefore the inclusion criteria are:

- A person living with HIV;
- Under care at the Amsterdam UMC, location AMC;
- Migration background origination from Nigeria or Ghana.

This is a group you cannot simply recruit by hanging flyers in the hall of the facility or sharing a catchy message via any kind of social media platform, seducing them to participate The recruitment requires extra attention and care, as we are working with a vulnerable target group. It is important to think about every word to avoid coming across as insensitive or stigmatizing.

Two methods are used to recruit participants.

The Shiva Foundation

The ShivA foundation is a community in the Netherlands where people can find (peer) support when they, or someone they know, is living with HIV or Aids. I made an appointment to talk about my graduation project and my research, to discuss if there would be a possibility to cooperate. The contact person was open to helping and she managed to find 4 participants, who met all the inclusion criteria, who were willing to participate in this research.

Recruitment via the nurses

The nurses were asked to ask the patients who come in for their appointment, who comply with the inclusion criteria if they are open to an interview. This allows the patient to participate when they are already at the hospital. Therefore, the Interview can take place shortly after their consult, avoiding extra travelling time.

3.3.3 Analysis of interviews

See Appendix 4 for the full written analysis of the first interview and my personal reflection after the first interview.

The interviews resulted in a lot of scattered information that needed to be analysed. The information was analysed with the use of “statement cards” (Sanders & Stappers, 2013). This method relies on the use of interesting quotes from the interview transcription with the interpretation of the researcher, as shown in Figure 14. When the statement cards of all interviews have been created, they can be clustered into overlapping themes to find interesting F&Bs that the different participants encounter. Next to the F&B’s, a PJ is created based on the outcomes of the interviews. See Appendix 5 for the written statement cards, and Appendix 6 for the entire overview of the process of the analysis. From the different themes that came to the surface during the analysis, requirements for the final design have been formulated. They will be further discussed in Chapter 4

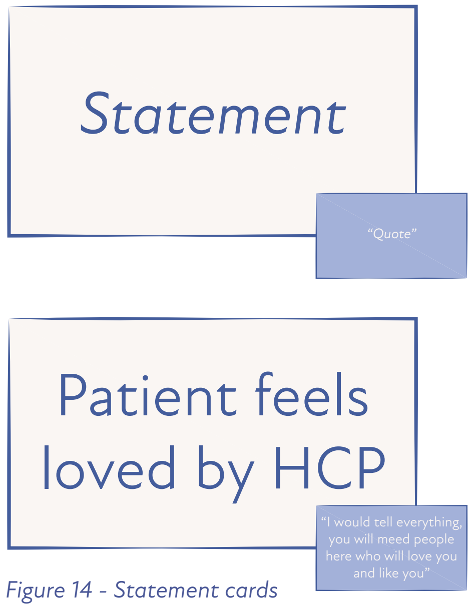


Figure 14 - Statement cards

3.4 Results of the analysis

Seven different people participated in the qualitative research via semi-structured interviews. See Figure 15 for an overview of the characteristics of the interview participants.

Code	Pi1	Pi2	Pi3	Pi4	Pi5	Pi6	Pi7
Age	69	49	38	52	46	63	31
Gender	Female	Female	Male	Female	Male	Female	Female
Communication langauage	English - Speach - Litterate	English - Speach - Litterate	Dutch + English - Speach - Litterate	English - Speach - Litterate	English - Speach	English - Speach	English - Speach - Litterate
Background	Ghana	Nigeria	Ghana	Nigeria	Nigeria	Ghana	Ghana
			Born in the Netherlands, second generation migration background		Undocumented in the Netherlands since 2018		

Figure 15 - Participant characteristics

3.4.1 Facilitators and Barriers

From the interviews an overview of the facilitators and barriers is found, these are the positive (= the facilitators)and the negative (=the barriers) factors which the patients experience during their outpatient clinic visits. These F&Bs are clustered into bigger themes to find the areas that are most important.

Some of the F&Bs are clear to be negative or positive, but there are some that might be considered as a negative factor but have created a positive effect. Therefore a distinction between the facilitators and barriers has not been made. Based on the insights from each theme, different requirements are formulated.

Theme 1 - Burden

- *Stress and anxiety arise when being near the outpatient clinic, in wing Q1*
- *Negative responses from peers and family*
- *Past (negative) experiences*
- *Mutual respect and understanding within the HIV communities*

Elaborate insights

All participants [7/7] claimed to keep their positive status undisclosed from the outside world. Only Pi7 said that her husband is aware of her positive status. The reason for the secrecy is caused by the persistent stigma regarding living with HIV. Two participants [Pi1 & Pi4] mentioned not sharing their status due to being afraid of rumours and gossip within their community. Pi4 added that with her medication, she is not sick and therefore has nothing to share with her community. Pi6 doesn’t share her status with her children because she does not want to burden them with her problem. Within the HIV communities, the participants do feel free to share their status. They can find support with their companions.

Pi3 explained that he feels stress and anxiety when approaching the outpatient clinic, in wing Q1. He says that when he is still in the general area of the hospital, and he would walk into a familiar face, he would be able to make up a random excuse of why he is there. Once he gets closer to Q1, it gets harder to defend himself about why he is there. Inside the waiting area of Q1, he tries to keep his head low and make sure to not be there too early. Hoping that no one he knows will see him there. Pi6 mentioned a similar feeling, she also mentioned that her blood pressure rises significantly when she is at the outpatient clinic. Pi6 is also conscious of the fact that someone she knows might see her there.

Pi1, Pi2, and Pi4 claimed to not be worried. They say to be there for their disease and to be helped, if someone sees you there and makes a statement about this within their community, people will be suspicious about why this person was there themselves. So, there is a silent agreement about keeping quiet. What happens inside Q1, stays inside Q1.

Key insights

The existing and persistent stigma regarding living with HIV lies at the root of the burden of living with HIV. People feel the need to keep their status undisclosed because of their fear of negative reactions. Unfortunately, fighting stigma falls outside of the scope of this project. A design that will let stigma disappear will not be created in this project, but the design direction needs to pay respect to the privacy and be discreet. In the PJ the change of negative emotions during a hospital visit is highlighted. How does this change during the different phases of the visit?

In the ideation phase of this project, extra attention will be paid to finding different ways to maintain the privacy of the patient.

Found requirements

- The design must be discrete regarding sensitive topics.
- The design must ensure that the HIV status stays unknown to outsiders.

Theme 2 - Personal connection with HCP

- *HCPs do their best to create a personal connection and build a bond of trust over time with their patients.*
- *Sensitive topics can only be discussed with the personal HCPs, after building a trust bond.*
- *Different faces of different HCPs within and outside Q1.*

Elaborate insights

As described in Chapter 1, patients and HCPs have a personal connection. This was again emphasised during the interviews. From the interview participants, 5 have been in care for many years and all of them expressed to be fond of their HCPs.

> *“I would tell everyone, you will meet people here who will love you and like you.” - Pi1*
>
> *“They are so perfect and wonderful. They are very good because we have known each other for a long time.” - Pi4*
>
> *“He is very sweet, very nice. Anything I can ask from him and he does it for me.” - Pi6*

Topics that can be discussed during the HIV consultations can have a sensitive character. Pi3 explained that, especially at the beginning phase after his diagnosis, he was struggling with opening up to his HCPs.

> *“In the beginning, I had to get used to it, you get to discover something about yourself which is not that nice.” - Pi3*

But today, he feels totally fine when talking to his HCPs. He feels free to share his story and this helps him. As he speaks to the doctor and the nurse, he gets a chance to tell two different stories he wants to get off his chest. He’s able to share things he cannot share with people from his private life. But this is possible due to the bond of trust that has been established over time.

From 7 participants, 2 [Pi5 & Pi7] have only been in care for approximately six or eight months and have therefore not yet built a relationship with their HCP. Pi5 is simultaneously in care at multiple outpatient clinics and under the guidance of the social worker, he mentions to be unaware of which person is his HIV practitioner. Pi7 is unaware of the names of her HCPs, but she does mention being satisfied with the provided care.

Key insights

The HCPs within the Amsterdam UMC established a precious relationship with the patients. The people have an incredible amount of trust in the HCPs. This is a great facilitator to make use of in the further stages of the project.

Found requirements

- The design must be connected to the Amsterdam UMC to create trust.
- The design should guide the user to get in touch with HCPs
- The design should guide the user to find trustable information regarding HIV and treatments.
- The design should have a minimal extra workload for the HCPs

Theme 3 - Making use of the knowledge provided

- *Only the HIV-HCPs are fully trusted*
- *Personal beliefs can get in the way of the prescribed treatment*
- *The doctor gives the best advice and makes sure the physical things are in order*
- *Patients find their ways to deal with different elements*

Elaborate insights

The HCPs have a bond of trust between them and their patients, this trust is also reflected in the trust the patients have in their healthcare questions which are not directly connected to HIV. Pi4 and Pi6 said that they were worried about Covid-19 but did not understand what it meant. During the consultation with their HCPs, they both raised the topic and asked for advice. Their HCPs explained what the pandemic meant to their health and what they should do. Pi6 mentioned that many different people told her to get a vaccination, but she was scared because of all the horror stories she heard in her community. But only after her HCP reassured her that it is for the best to get the vaccination, she was convinced to take it. At the following appointment with her HCP, six months later, she was proud to show the HCP her vaccination proof.

> *“So today I came to show it to him, doctor, see I took them both. He said “I am happy this is very good”. So anytime when he says that something is good for me and I do it, he is very happy that I did it.” - Pi6*

Despite the trust that Pi6 has in the medical care she receives from the HCP, she also has her own beliefs. She explained that she has a homemade medicine based on ginger that will help her body to fight Covid-19. Pi6 said that her HCP does not believe in her African medicine, but she is convinced this helped her recover from a Covid infection she had months ago.

The effectiveness of ginger-based remedies have not been scientifically proven, but many people believe in the positive effects of ginger on your health. Either way, the most important thing is that ginger has no harmful effects on someone’s health. So, this behaviour of Pi6 should not be anything concerning.

Pi7 however, did take matters into her own hands in such a way that this could negatively affect her health.

> *“So, it was too much for me and they had to encourage me to take less.” - Pi7*

During her pregnancy, Pi7 decided to take triple the amount of prescribed medication.
Pi3 was the only participant who has ever searched for references regarding HIV. He wanted to know if a specific medicine could be combined with his HIV treatment. He was unable to find a satisfying answer and decided to use “MyChart” to send a message to his HCP. Within 2 days he received an answer and knew what to do.

This stands in line with the fact that all 7 participants see their HCP as the all-knowing source for their questions. All participants feel satisfied with the information they can retrieve from the HCP during their consultations at the outpatient clinic. They do not feel the need to search for more information about living with HIV and its effects. The doctor does occasionally ask a patient what he or she thinks about it themselves, but the participants think that the doctor knows best.
The participants see their appointments as important

"If something is not going well, the doctor asks me "why is this not good", but I tell him that I don't know, he is the doctor!" - Pi1

and are always willing to show up. Pi4 highlights that you should always be honest to the doctor without hiding anything, this way the doctor can know what he needs to do for you. Pi5 and Pi7 both mentioned that it's important to regularly visit the doctor to establish early detection of new diseases.

Key insights

The reason behind "not feeling a need to search for more information" can easily be found in an excuse like the lack of interest or curiosity. But for this specific target group, we need to keep in mind that there is a difference in cultural values. As reflected in the interviews, this patient group sees the doctor as a highly educated person who does not need to be questioned. Next to that, we see that the patients are interested in early detection and want to help the doctor by sharing anything he or she needs to help the participant best. It almost seems like the participants take a serving role to help the doctor to do their job.

The decision Pi7 made to take triple the amount of prescribed medication was made with the best intentions. She just wanted to protect her unborn child from getting infected with HIV. This shows that Pi7 is invested and interested in her health and how to improve this, but due to a lack of health literacy, her actions did not have the desired effect.

Found requirements

- The design needs to give the user a feeling of control.
- The design needs to allow the user to take a proactive role in their disease management.
- The design needs to increase the health literacy of the user

Theme 4 - The lack of skills and the effect

- *Getting in touch with the right person*
- *Feeling uncomfortable when using digital platforms or systems*
- *The inability to read and write*

Elaborate insights

During the interview with Pi1, the first observation was made before the interview officially started. Pi1 was listening to a video on her smartphone while waiting in the waiting area. When Pi1 was invited to the interview room, she was struggling to turn the video off correctly. This showed how she struggled with the use of her smartphone. Pi2 mentioned that she does feel comfortable when using a digital platform, but she needs to be in a good mood otherwise it might be frustrating when things are not working as they should. Pi5 and Pi6 both mentioned to be low literate, written information does not make any sense. Pi6 says that when she receives printed information, she needs to ask someone to read it out for her. However, this makes her feel uncomfortable.

Even though Pi5 says that he is illiterate, he does know how to use his smartphone effectively. He explains that he uses YouTube to watch inspiring videos of people living with HIV, he thinks that people living with HIV who are open about their positive status have a lot of courage. Pi5 is a refugee, he has fled his home country and has been through a lot over de past years. Even though he is undocumented, he is managing to keep his head above water and stay positive. Being new in the Netherlands does bring its challenges. Pi7 has also recently relocated to the Netherlands. She moved to the Netherlands to be with her husband who has been in this country for more than 30 years already. When she was pregnant she had no idea how to get in touch with a midwife, her husband had to arrange this for her. While being pregnant, she was not in treatment for her HIV infection in the Netherlands. The midwife helped her to book an appointment at the HIV outpatient clinic of the AMC hospital. Right now, Pi7 want to schedule an appointment with a gynaecologist but has no idea how to do so. Pi7 also explains that she struggles with getting the right person on the phone when she calls the AMC hospital. Expect Pi5 Pi7 all participants [5/7] say that it is easy to get in touch with the HCPs of the HIV outpatient clinic.

Pi1 and Pi2 have both been familiar with the Dutch healthcare system for multiple years. Both said that their HCP will help them find the correct specialist when they have any non-HIV related issues. Pi1 and Pi2 see this as something really good.

"And he will ask me if I have any complaint. And then he will recommend any other appointments for me which another doctor will have to. He will book the appointment in the other department. So they will check my other problem." -Pi1

Key insights

For people who are still getting used to the Dutch healthcare system, it can be a challenge to get in touch with the right person for each specific matter. From the interviews, it can be concluded that this target group faces more barriers when accessing healthcare.

Using a smartphone for its basic functionalities, and using it for the more advanced functionalities, cannot be compared or seen as equal. Being able to effectively use a smartphone, or digital device is not a skill that everyone masters.

For someone who is low literate, being confronted with written text can be quite stressful. This person can be afraid that the text includes references to HIV which is a risk of exposure when someone who is literate will see the text.

Found requirements

- The design must be understandable for someone who is functionally illiterate.
- The design must be usable for someone with low digital skills
- The design should guide the user to understand PROMs.
- The design should guide the user to fill in PROMs.

3.4.2 Patient Journey

In Chapter 3.3, the results of the analysis of the interviews have been explained. Another result from the interviews is displayed in the PJ. The PJ is one of the main results of this project, it gives a clear representation of the hospital journey of the patients within the HIV outpatient clinic of the Amsterdam UMC. The experiences of the different interview participants have been taken into consideration to find the most important representative reflection of the experience of an average patient. As a designer, I was fully immersed in the experiences of the participants, which allowed me to step in their shoes and visualise their journey. Throughout the different interviews, two average patient types arose.

In the first version of the PJ, shown in Figure 16, I visualised each step in such a way that the overall journey was easy to interpret what steps the patient goes through. The focus lies here on the overall journey but does not indicate the time for each step scaled. Therefore, I made another version in which each step is relatively scaled to the duration, this is shown in Figure 17. I would like to emphasise how long the overall hospital journey can be for a patient when compared to the consultation with the doctor and nurse.

The PJ is divided into multiple rows that indicate important elements that can play a part.

Phases

The overall journey of a patient can be divided over different phases; each phase has its function. Before the appointment, the preparatory steps need to be taken, like receiving the invitation for the consultation and travelling to the hospital. The next phase is a longer phase which indicates that the patient is inside the hospital building. Within the “Enter hospital” phase, there are other phases that connect without overlap. Ending with the “Wrap-up after” phase, where the patient travels back home and waits for the lab results.

Interactions

Within each phase, the patient comes across different touchpoints with which whom they interact. These can be as significant as the consultation with the doctor or as little as exiting the hospital building. Each interaction has its importance in the journey of the patient. The timespan of each interaction step is estimated to indicate the duration of the overall journey.

Stakeholders

As the patients go on their journey, they come across different interaction steps as mentioned above, but with each interaction, another stakeholder is involved. The stakeholders are categorized into the unfamiliar and the familiar stakeholders. This means that the unfamiliar stakeholders are the people that have interactions with the patient because they are coincidental working that day, while the familiar stakeholders include the personal HCPs that have had the chance to create a personal connection with the patients.

Emotions

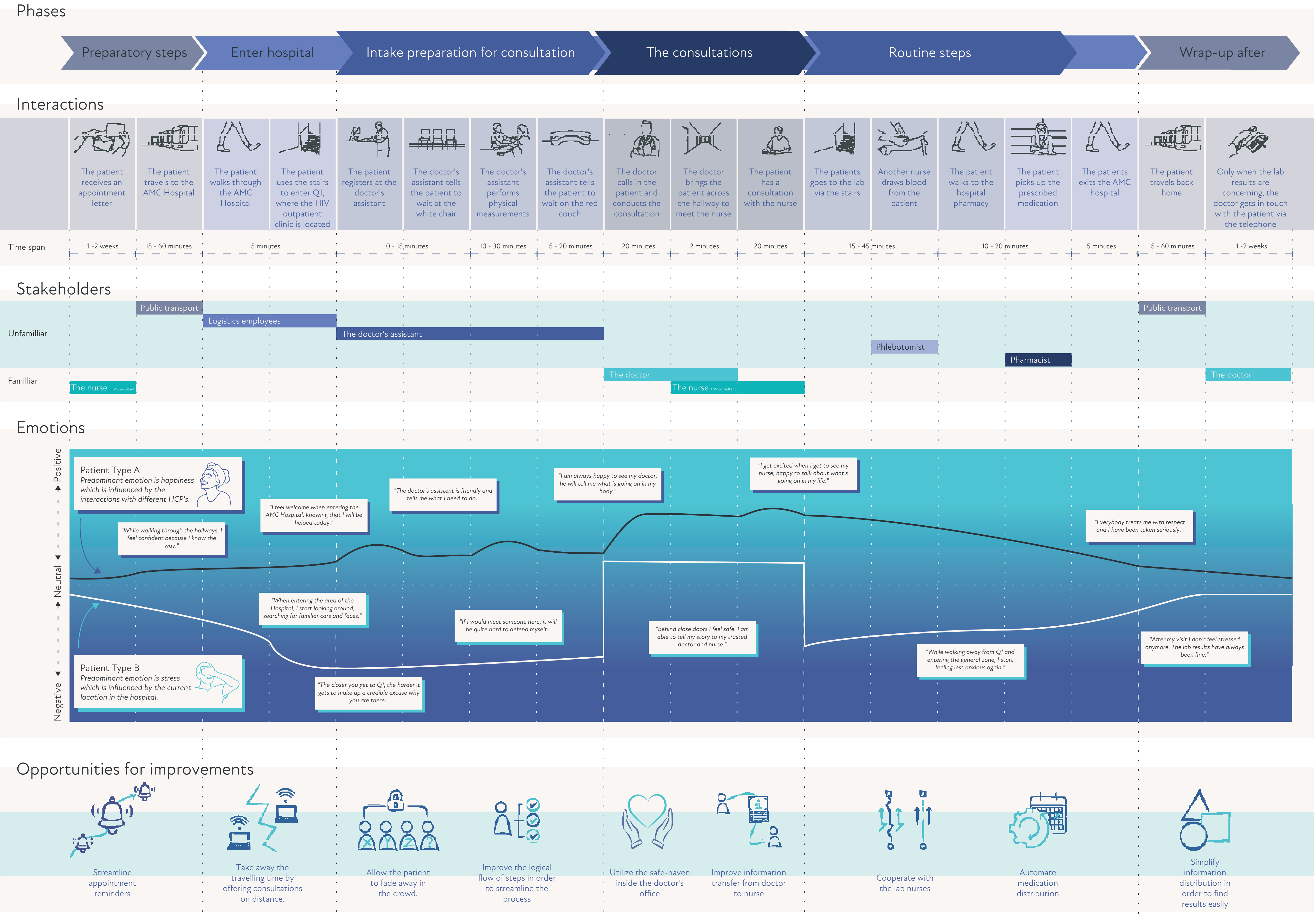
In the qualitative research, described in Chapter 3.4.1, it has been found that different patients undergo different changes in emotion during their journey. The predominant emotions were either the negative emotion of stress or the positive emotion of happiness. How they change during the journey is visualized in the row of emotions.

Opportunities for improvements

The last row consists of a brain dump of potential opportunities for improvements. These mini ideas will be used for the design directs to spark the initial ideation.

A patient-centered hospital journey of people living with HIV

The results of an exploratory interview study with people living with HIV with a migration background originating from Nigeria or Ghana (N=7)



Phases

Preparatory steps
Enter hospital
Intake preparation for consultation
The consultations
Routine steps
Wrap-up after

Interactions

- The patient receives an appointment letter
- The patient travels to the AMC Hospital
- The patient walks through the AMC Hospital
- The patient uses the stairs to enter Q1, where the HIV outpatient clinic is located
- The patient registers at the doctor's assistant
- The doctor's assistant tells the patient to wait at the white chair
- The doctor's assistant performs physical measurements
- The doctor's assistant tells the patient to wait on the red couch
- The doctor calls in the patient and conducts the consultation
- The doctor brings the patient across the hallway to meet the nurse
- The patient has a consultation with the nurse
- The patients goes to the lab via the stairs
- Another nurse draws blood from the patient
- The patient walks to the hospital pharmacy
- The patient picks up the prescribed medication
- The patients exits the AMC hospital
- The patient travels back home
- Only when the lab results are concerning, the doctor gets in touch with the patient via the telephone

Time span
1 -2 weeks
15 - 60 minutes
5 minutes
10 - 15 minutes
10 - 30 minutes
5 - 20 minutes
20 minutes
2 minutes
20 minutes
15 - 45 minutes
10 - 20 minutes
5 minutes
15 - 60 minutes
1 -2 weeks

Stakeholders

Unfamilliar
Public transport
Logistics employees
The doctor's assistant
Phlebotomist
Pharmacist
Public transport

Familliar
The nurse HIV consultant
The doctor
The nurse HIV consultant
The doctor

Emotions

Positive
Neutral
Negative

Patient Type A
Predominant emotion is happiness which is influenced by the interactions with different HCP's.

"While walking through the hallways, I feel confident because I know the way."

"I feel welcome when entering the AMC Hospital, knowing that I will be helped today."

"The doctor's assistent is friendly and tells me what I need to do."

"I am always happy to see my doctor, he will tell me what is going on in my body."

"I get excited when I get to see my nurse, happy to talk about what's going on in my life."

"Everybody treats me with respect and I have been taken seriously."

Patient Type B
Predominant emotion is stress which is influenced by the current location in the hospital.

"When entering the area of the Hospital, I start looking around, searching for familiar cars and faces."

"The closer you get to Q1, the harder it gets to make up a credible excuse why you are there."

"If I would meet someone here, it will be quite hard to defend myself."

"Behind close doors I feel safe. I am able to tell my story to my trusted doctor and nurse."

"While walking away from Q1 and entering the general zone, I start feeling less anxious again."

"After my visit I don't feel stressed anymore. The lab results have always been fine."

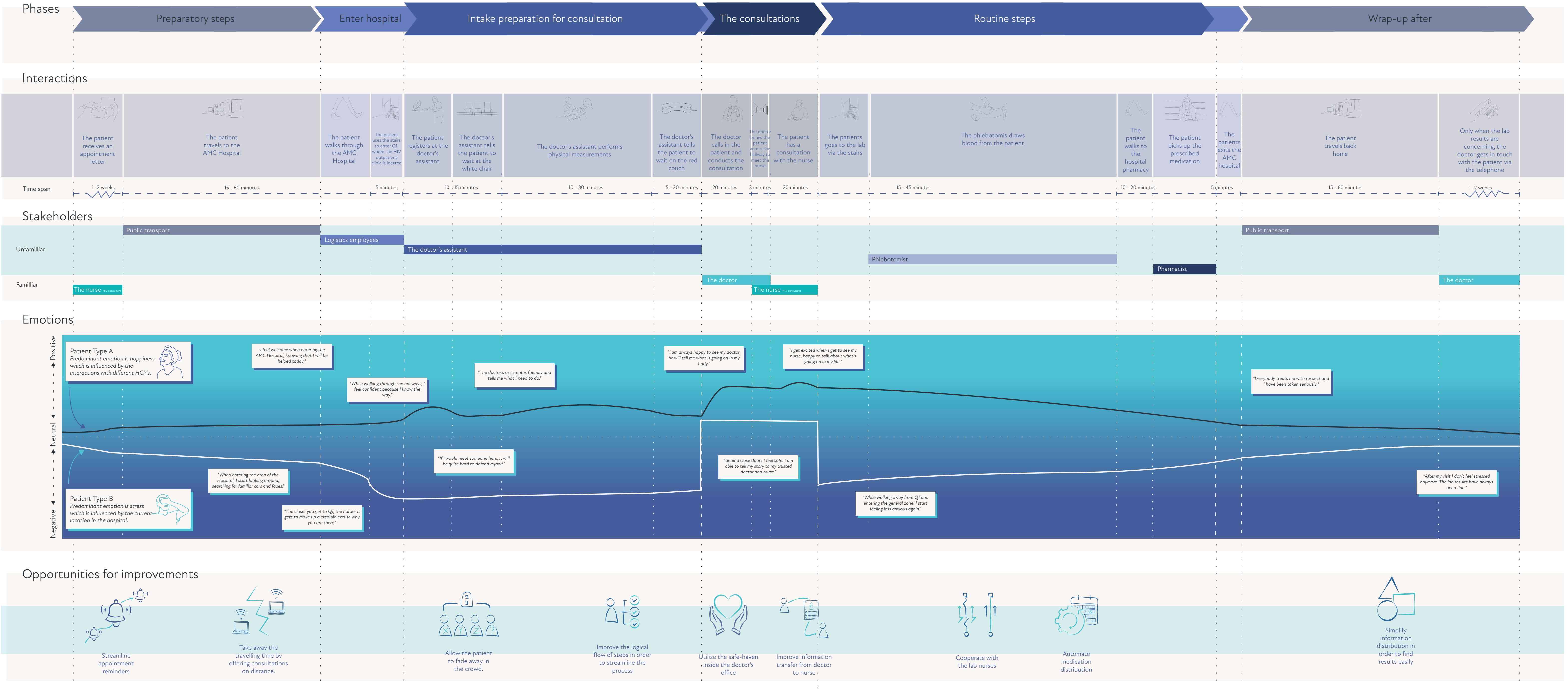
Opportunities for improvements

- Streamline appointment reminders
- Take away the travelling time by offering consultations on distance.
- Allow the patient to fade away in the crowd.
- Improve the logical flow of steps in order to streamline the process
- Utilize the safe-haven inside the doctor's office
- Improve information transfer from doctor to nurse
- Cooperate with the lab nurses
- Automate medication distribution
- Simplify information distribution in order to find results easily

Figure 16 - Patient journey

A patient-centered hosptial journey for people living with HIV

The results of an exploratory interview study with people living with HIV with a migration background originating from Nigeria or Ghana (N=7)



Phases

- Preparatory steps
- Enter hospital
- Intake preparation for consultation
- The consultations
- Routine steps
- Wrap-up after

Interactions

Interaction	Time span
The patient receives an appointment letter	1 -2 weeks
The patient travels to the AMC Hospital	15 - 60 minutes
The patient walks through the AMC Hospital The patient uses the stairs to enter Q1, where the HIV outpatient clinic is located	5 minutes
The patient registers at the doctor's assistant The doctor's assistant tells the patient to wait at the white chair	10 - 15 minutes
The doctor's assistant performs physical measurements	10 - 30 minutes
The doctor's assistant tells the patient to wait on the red couch	5 - 20 minutes
The doctor calls in the patient and conducts the consultation	20 minutes
The doctor brings the patient across the hallway to meet the nurse	2 minutes
The patient has a consultation with the nurse	20 minutes
The patients goes to the lab via the stairs The phlebotomis draws blood from the patient	15 - 45 minutes
The patient walks to the hospital pharmacy The patient picks up the prescribed medication	10 - 20 minutes
The patients exits the AMC hospital	5 minutes
The patient travels back home	15 - 60 minutes
Only when the lab results are concerning, the doctor gets in touch with the patient via the telephone	1 -2 weeks

Stakeholders

Unfamilliar

- Public transport
- Logistics employees
- The doctor's assistant
- Phlebotomist
- Pharmacist
- Public transport

Familliar

- The nurse HIV consultant
- The doctor
- The nurse HIV consultant
- The doctor

Emotions

Positive · Neutral · Negative

Patient Type A
Predominant emotion is happiness which is influenced by the interactions with different HCP's.

Patient Type B
Predominant emotion is stress which is influenced by the current location in the hospital.

"I feel welcome when entering the AMC Hospital, knowing that I will be helped today."

"When entering the area of the Hospital, I start looking around, searching for familiar cars and faces."

"The closer you get to Q1, the harder it gets to make up a credible excuse why you are there."

"While walking through the hallways, I feel confident because I know the way."

"If I would meet someone here, it will be quite hard to defend myself."

"The doctor's assistent is friendly and tells me what I need to do."

"I am always happy to see my doctor, he will tell me what is going on in my body."

"Behind close doors I feel safe. I am able to tell my story to my trusted doctor and nurse."

"I get excited when I get to see my nurse, happy to talk about what's going on in my life."

"While walking away from Q1 and entering the general zone, I start feeling less anxious again."

"Everybody treats me with respect and I have been taken seriously."

"After my visit I don't feel stressed anymore. The lab results have always been fine."

Opportunities for improvements

- Streamline appointment reminders
- Take away the travelling time by offering consultations on distance.
- Allow the patient to fade away in the crowd.
- Improve the logical flow of steps in order to streamline the process
- Utilize the safe-haven inside the doctor's office
- Improve information transfer from doctor to nurse
- Cooperate with the lab nurses
- Automate medication distribution
- Simplify information distribution in order to find results easily

Figure 17 - Scaled patient journey

3.4.3 Limitations

Within the HIV community, and especially the Ghanian and Nigerian communities, we are experiencing a lot of stigmas. Finding participants for this research was therefore quite a hard task. The people who did agree to take part in the interviews can be seen as “the best of the best”. Because 4 participants have been recruited via the ShivA foundation, we can say that they are proactive and involved within the peer support communities. From the participants who have been recruited during the consultations at the outpatient clinic, 2 of them were in care for quite a long period and felt safe with their HCPs. One of them, Pi6, said that she did not want to participate but did it for her nurse who said that he would appreciate it.
Due to this way of recruitment, we are working with a participant group that is not representing the entire population of the target group.

This project has been formulated because the department feels that there is a specific patient group that is falling behind in the care they are receiving. In the PJ, we see a positive experience for Patient Type A, in my opinion, this is an experience we want to establish for the entire patient population.

The patient journey has been formulated on basis of interviews with 7 different participants (N=7) and conversations held with the doctor’s assistant (DA) and different nurses (HIV-consultants). From the 7 different interviews, saturation on certain topics has been reached, while on other topics, individual answers were found. The question of whether or not full saturation was found cannot be answered completely positively. Due to the timeline of this project the decision has been made to stop after 7 interviews to successfully meet the deadline.

A more elborative discusission regardingt the limitations of the overall project is presented in Chapter 8.2.

After conducting my interviews, I felt like this department is doing an outstanding job. Everyone I talked to was extremely happy with the received care and, for those who have been in care at the AMC for a longer period, felt strong personal connections with their HCP’s. Also, the workflow of the waiting area seems to be working quite well. Despite the fact that it can be confusing for the patients who are not always understanding why they need to sit at a specific spot, it does help the DA’s to have an easy flow in their tasks.

3.5 Key takeaways

List of Requirements
The F&B’s are concluded in the list of requirements, this can be found in Chapter 4.

Many different faces
The patient sees a lot of different faces when they are visiting their HCPs in the AMC hospital. The entire journey takes the patient 2 to 5 hours, depending on their travelling time and the waiting time of each step. The actual consultations with the doctor and nurse are, in time, a small part of the journey, but in its meaning, they are the most important parts.

Feelings of stress or happiness
During the consultation, there is for Patient Type A (PTA) a peak in the positive feeling of happiness. The negative feeling of stress disappears for Patient Type B (PTB) when being behind closed doors during the consultation. Therefore, we can conclude that the doctor’s office is an important touchpoint for patients during their healthcare journey. This is a place where the patient is in complete privacy and free to discuss anything. When leaving the safe space again, PTB emotion drops down right back to being stressed. PTA gradually loses the peak feeling of happiness as they leave the outpatient clinic again.

Different steps
As visually shown in the stakeholder row, the patient meets a lot of different people during the journey. Some of them can be unfamiliar and just happen to be working on that day, and the others are the familiar HCPs. For some patients, it can be confusing to understand all the different steps that they need to take during their journey. Luckily, the doctor’s assistants guide the patient during the intake preparation to assure that everything happens smoothly. The doctor’s assistant (DA) said that some doctors prefer to perform the physical measurements themselves, while other doctors appreciate that this task has been taken off their hands. In the waiting room, there is a distinction between the white chairs and the red couch. The white chairs are explicitly for the patients who need to be called in by the DAs for the physical measurements. Therefore the DAs need to pay close attention to where each patient takes place to make sure that the right patients undergo the physical measurements.

3.6 Next steps

This Chapter concludes the overarching research phase. The gathered information functions as the foundation of knowledge from which the next phase, the development phase, will take off. Gathered insights function as inspirational and supporting documentation to formulate the design brief.

4

Design Brief: Setting the Scene

4.1 Introduction

From the gathered insights in the previous Chapters, the design brief will be created. This Chapter will determine the direction in which will be designed and the boundaries within the ideation will take place in the next Chapter. At the end of this Chapter, there will be a clear image of the problem that needs to be solved and which direction will be taken.

4.2 Design directions

In Chapter 3.4.2 in the PJ, a series of opportunities for improvements have been formulated. From these opportunities, potential design directions are synthesized. The different design directions are described with a short explanation.

1 Patient autonomy to improve shared decision-making

The patients are satisfied with the care they are receiving, but generally, they take quite a passive or submissive role in their healthcare management. As found in the F&B's in Chapter 3.4.1, the participants trust that their HCPs give them the best care possible, without ever questioning their skills. Now that the department is moving towards a more "shared decision making" way of working and implementing PROMS, this passive or submissive role will not be the best match. When looking at the entire PJ we see that, in a worst-case scenario, this can take up to 5 hours of which only two times 20 minutes are used for the consultations. Which is less than 1/7th part of the entire journey. As the consultations are the most important part of the PJ, the value of the consultations must be as high as possible. Therefore, one of the design directions is a time investment of the consultation.

2 The feeling of privacy

In the PJ, we see how the stress levels rise when approaching the outpatient clinic in Q1. During the interviews, Pi6 mentioned that her blood pressure significantly rises due to the stress. Also visible in the PJ is that when the doctor's office is entered, this stress disappears right away. Inside the doctor's office, you are in total privacy with only the HCP. A lot of stress could be avoided when the patient feels like they are in a setting where they are private. When a patient feels a lot of stress every time they visit the hospital, they might develop negative associations with their outpatient clinic visits. Eventually, this might lead to an increase in the threshold to adhere to their appointments and might lead to not showing up. Therefore, one of the design directions is to improve the feeling of privacy.

3 Lowering the threshold to use the online patient portal

The Amsterdam UMC is digitizing and is making use of "MyChart". MyChart is an online patient portal that allows the patient to have a digital overview of their patient files, it includes their appointments and medication but also allows you to get in touch with your HCPs. From the interviews, only one participant is using MyChart currently, this participant was also the only participant who was born in the Netherlands and is therefore fluent in Dutch. MyChart is currently only available in Dutch. If the online platform is easier to effectively use, the threshold for online consultations and getting in touch with the HCP will be lowered. Therefore, one of the design directions is to lower the threshold to the online patient portal.

4 Streamlining the steps during the PJ to decrease waiting times at different touchpoints

As mentioned before, the PJ can take up to 5 hours when the circumstances are less than ideal. The patient needs to follow many steps during their visit. If these steps are more streamlined, time can be saved. There are multiple ways to tackle this issue, but most importantly is that this will be affecting the entire logistics of the Amsterdam UMC. Chances are that this will be an issue that cannot be resolved within the HIV outpatient clinic, therefore this issue cannot be resolved within the current requirements of this project and falls outside the scope.

From my designer gut feeling, I decided to go for the first design direction "**Patient autonomy to improve shared decision-making**". When looking back at Chapter 0, the original scope of this project is to improve the collection of PROMs, PROMs are being implemented to increase the value of consultation. Therefore, this design direction matches the essence of the original assignment. The chosen design direction opens an interesting domain to explore and find new ways to contribute to an improvement of the experience for the patients at the HIV outpatient clinic.

4.1 Design Goal

I want to design a tool/product/system that will help people living with HIV to take control over their disease management in the comfort of their own homes in between appointments at the hospital to increase the value of the consultation without relying on literacy.

Problem analogy

To immerse me in the problem and emphasize with the final user, I have found an analogy that allows me, as a designer, to look at the problem from a different angle to feel inspired. Next to my benefit, this analogy allows an outsider to be able to easily understand the perspective of the user.

How I currently see the design problem can be compared to going for a hike to a beautiful viewpoint. Looking at the scaled version of the PJ, see Figure 17, it stands out how small the part of the consultation is in comparison with the entire journey. When the waiting times are long, it might take the patient an entire morning or afternoon, to only talk to their HCP during two consultations of both 20 minutes.

When I compare this to a hike, I can think of a time when I went to Lake Bled in Ljubljana with three friends. We travelled there by bus and walked to the lake. The lake was in some sort of valley, surrounded by hills. If you hiked uphill, you would have a beautiful view of the lake with the small island. We decided to go for the hike, unprepared, wearing sneakers and jeans shorts. The path uphill was not decent. We had to manoeuvre through the mud and trees to get to the viewpoint. Once uphill, we sat down and enjoyed the view. Afterwards, we had to go through the same hurdles to get back.

The hike, up and downhill, was not so much fun but it was worth it for the beautiful view. And we were with the four of us, we had fun while going through it together. How can the hike be worth it? Or how can the hike itself be less miserable? Or how can the hike be used to get the most out of the viewpoint?

Figure 18 - Analogy

4.2 Interaction Vision

The interaction vision is a means of communicating what the interaction between the user and final design should be experienced like. This is how the interaction is envisioned.

I want to design something that makes the user in control. The interaction with the final design could be compared to learning to ride a horse.

A horse is a big and strong animal. When you are not in control of the horse, she will be in control of you. Maybe she will kick you off her back, trample you while you down or kick you in the face. When you are still learning how to ride a horse, the idea of the horse controlling you might be scary, but when you have an instructor, you are not on your own. You as the horseback rider are in complete charge of the large animal, but if something goes wrong there is a safety net waiting for you. This feeling of being in control, without the need to be scared that something might go wrong when you lose control, is what I want to achieve.

4.3 Design criteria

From Chapter 3.4.1, the facilitators and barriers have been formulated which have been translated into design criteria. During the ideation phase, in the following Chapter, the aim is to fulfil or meet as many requirements as possible. The overall list of requirements (LoR) will be used to evaluate different concepts to choose the best option. The first five requirements are crucial, they have to be met for the concept to be acceptable. The other requirements can be seen as additional wishes. How well the concept scores on these requirements will affect how good the concept will be evaluated.

List of Requirements
1. The design must be understandable for someone who is functionally illiterate.
2. The design must be usable for someone with low digital skills
3. The design must be discrete regarding sensitive topics
4. The design must ensure that the HIV status stays unknown to outsiders.
5. The design must be connected to the Amsterdam UMC to create trust.

Wishes
6. The design needs to give the user a feeling of control.
7. The design needs to allow the user to take a proactive role in their disease management.
8. The design needs to increase the health literacy of the user.

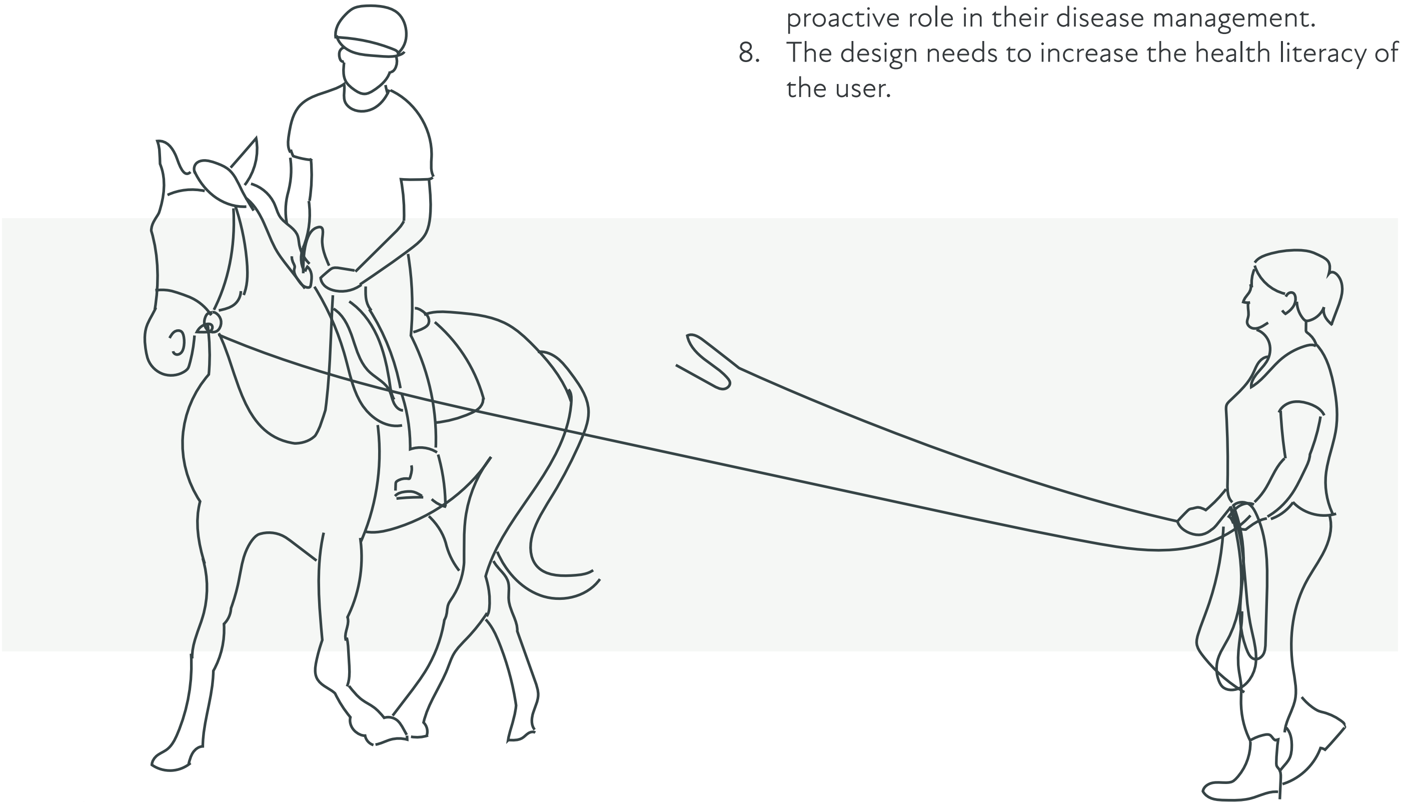


Figure 19 - Interaction Vision

5

Ideation: Finding Concepts

5.1 Introduction

The previous Chapter concluded the research phase in the translation of the design goal, interaction vision, and requirements. These form the starting point for the ideation phase to take off from. This Chapter discusses the ideation and conceptualization. Afterwards, a decision will be made between the potential concepts. That concept will be taken into further development in the next Chapter.

5.2 Method and Process

The steps shown in Figure 20 have been taken to come up with the concepts. See Appendix 7 and 8 for the results of each step during the ideation phase.

As visualized in Figure 20, the ideation phase started with a creative session with five participants. The participants were given five different "How To" and were asked to answer them with as many answers as they could come up with, without any restrictions. The participants have not been given any information regarding the purpose of the outcomes to keep their minds open without any prejudices. See Appendix 7 for the overview of the "How To" questions and the many different ideas that helped as inspiration for the next steps.

Afterwards, a creative session was conducted with 2 participants. This session started with the method of "Synectics" (Van Boeijen & Daalhuizen, 2013). In this method, the problem analogy is used as the real problem for which solutions need to be found. After this step, many ideas were created that would increase the enjoyment of a hiking trip. Since this is not the real problem, the method of "Force fitting" was used. This means that the ideas that were created to solve the analogy problem, were forced in such a way that they would solve the original problem and design goal. These force-fitted ideas were clustered to find interesting and fruitful combinations. These led to the forming of the concepts.

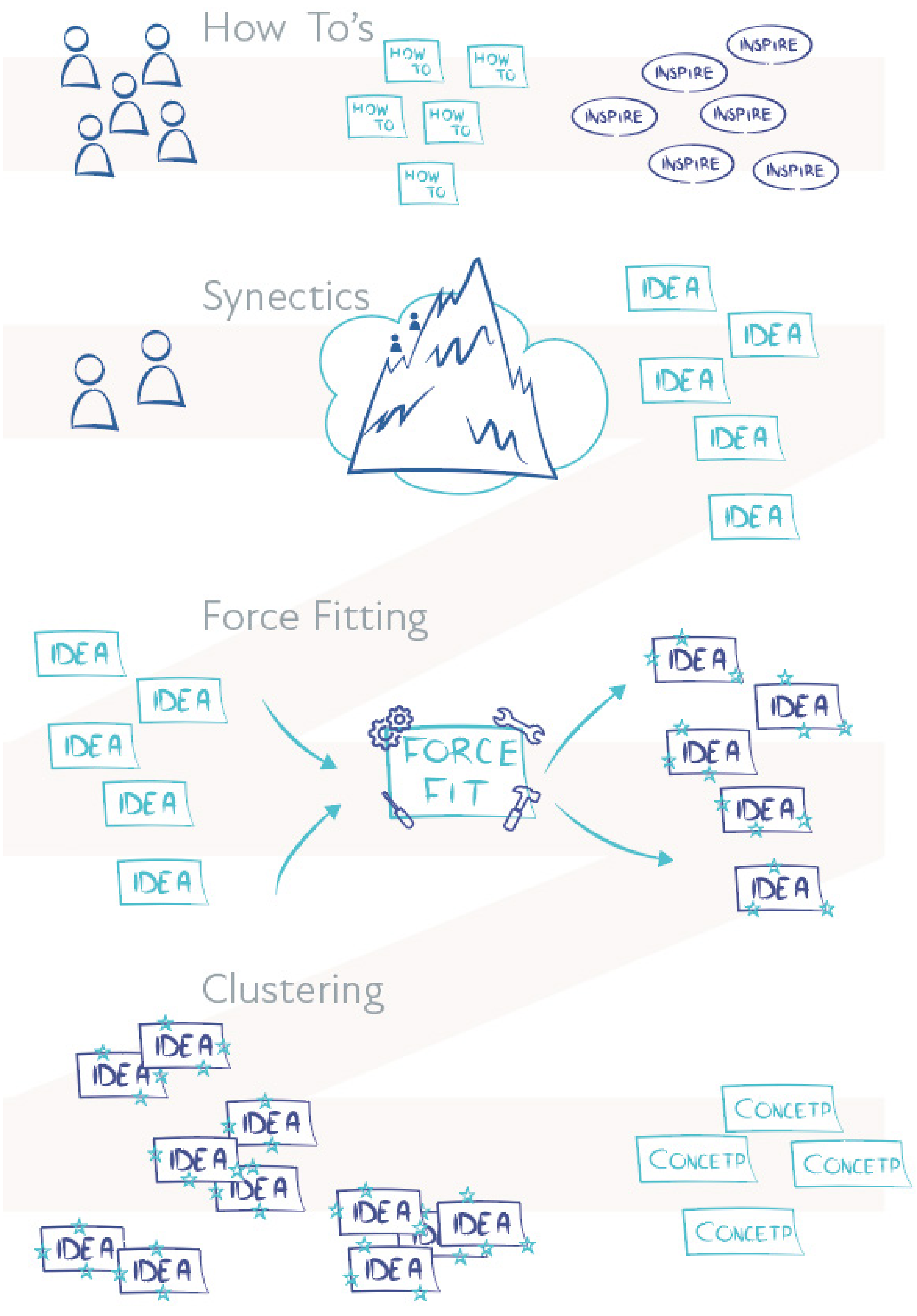


Figure 20 - Process of ideation

5.2 Concept presentation

Concept 1 – Positive Family

> When I am on a holiday with my friends, we always walk up a mountain or hill to find a beautiful castle or enjoy the view. We are not trained hikers, wearing our sneakers and jeans short while carrying a tote bag with a bottle of water and a few snacks. This has led to multiple "hikes" in which we had to overcome quite some struggles to get from A to B. But every time we did it and ended up where we needed to be, we forgot about the terrible walk.
>
> When being with friends during a tedious task, you are either able to complain about it together or talk about other nice things as a fun distraction. This helps to make the time go by faster, or enjoy the moment in another manner

The first concept, Concept 1 – Peer Support Community, uses the strengths of the existing Positive Brothers and Sisters program and expands it. The Shiva foundation created a peer-support system where people living with HIV are coupled based on different interests and their culture. Someone who is further in their process of accepting their positive status will be trained to become a Positive Brother or Sister (PB/S). When an HCP notices that they cannot offer the support that their patient might need, the HCP can get in touch with the Shiva foundation and they will start a procedure to connect the patient to a matching PB/S. The PB/S functions as a role model and helps their buddy to go through the process of acceptance and learn more about living with HIV. Within this program, multiple elements are already implemented to establish good quality and success rates.

A PB/S can be the role model for one or more buddies, in the Positive Family, the buddies are also connected. Not only will the new person be connected to someone that can help and guide them, but they will also get in touch with someone who is in the same phase as they are.

After the new person has established a connection with their PB/S, the new person will be introduced to the other new person by their PB/S. The appointments in the outpatient clinic will be streamlined, so both people from one positive family can join each other during the consultation. One option is to join each other during the consultation, the second option is to have the consultations simultaneously and only join each other during the other steps throughout the entire patient journey. The most important element is that the waiting time around the consultation and all the extra steps that someone has to go through are being experienced together. As a ShivA family, you can discover everything related to living with HIV together, and the Positive Brother or Sister can help you where you need more guidance.

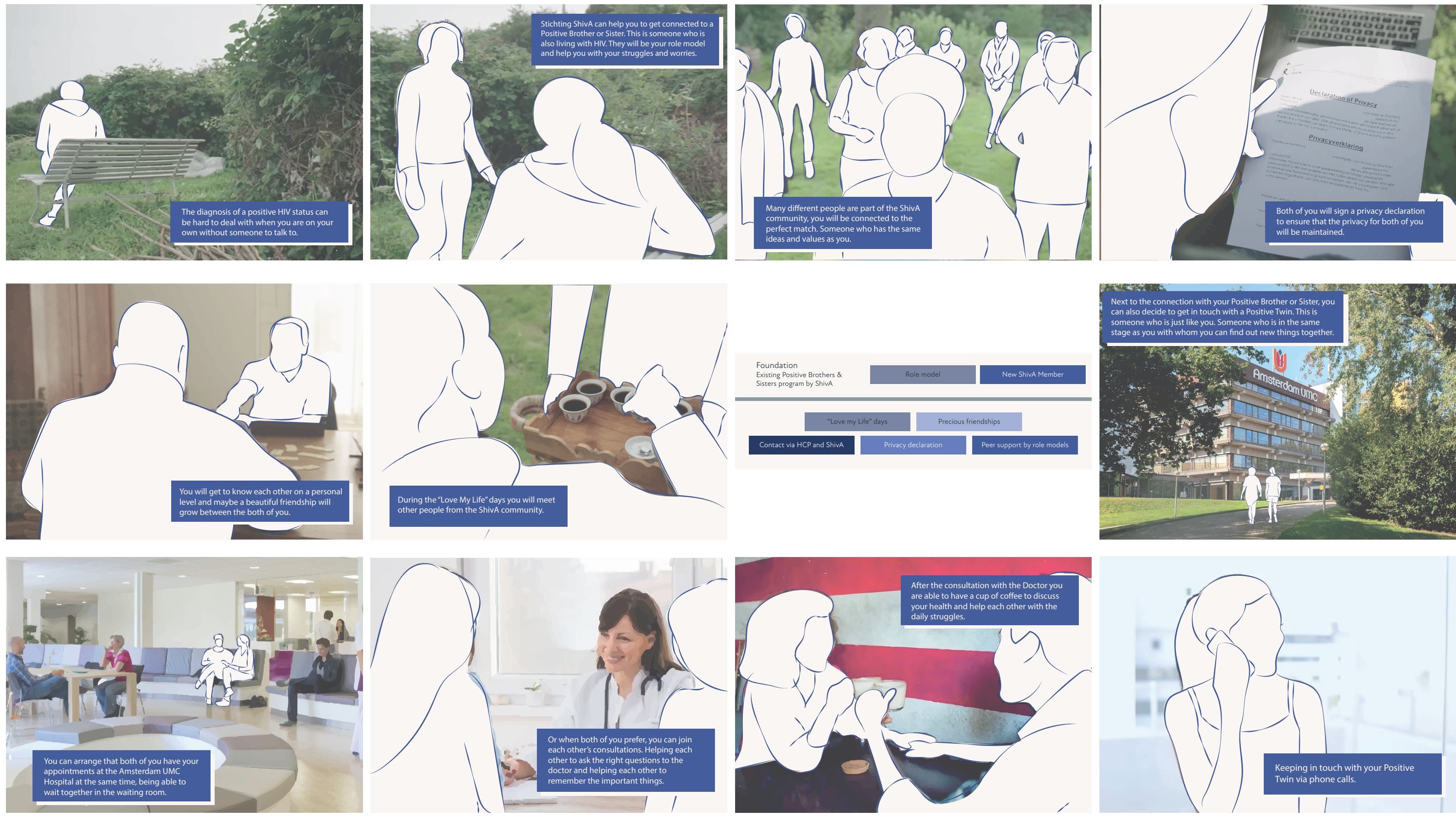


Figure 21 - Concept 1 (see Appendix 9 for a bigger version)

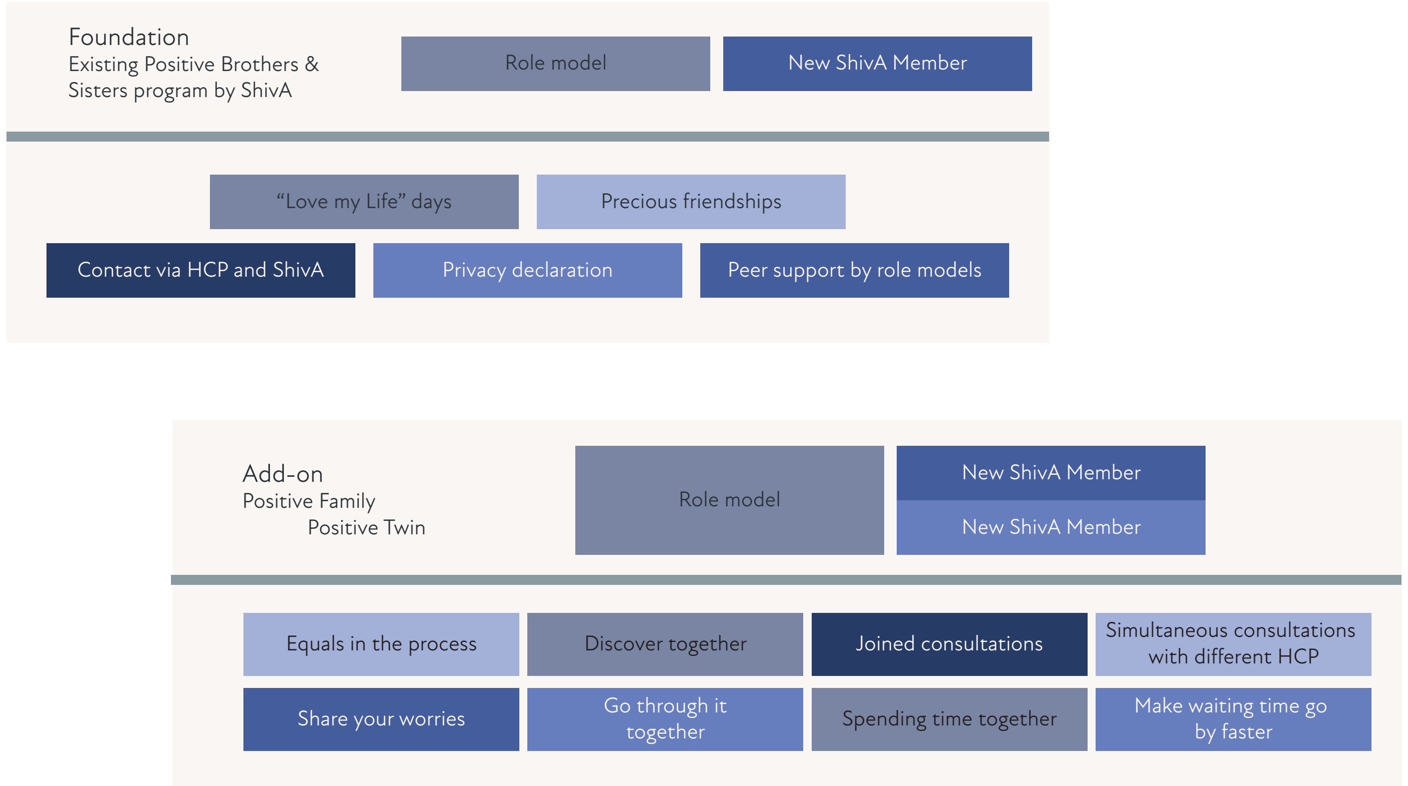


Figure 22 - Concept 1

Concept 2 – Wellbeing Diary

Once you have reached the top of the mountain or hill and you are ready to enjoy the view, you will be much more able to enjoy the view when you know where you need to look. During my holiday in South Africa, we reached a viewpoint where you were able to watch the watering hole. I did not know what I needed to see until someone pointed at the elephants playing around in the water. A view is just a random thing until you know where you need to look.

In Concept 2, the value of the consultation is increased by helping the user to collect insights into their wellbeing in between appointments. Once every six months a person has a consultation at the AMC hospital to monitor their health. People living with HIV, are more likely than the average person to experience comorbidities as described in Chapter 2. In HIV care extra attention is paid to other symptoms to make the right interventions in an early stage to avoid further development of extra diseases. During the consultation of 20 minutes, it's hard to summarize all the abnormalities that have occurred in the previous 6 months. A patient could have been sick for an entire month, but if this happened 4 months ago this might be forgotten in the meantime.

Concept 2 helps someone who has a chronic disease to keep track of the unnormal fluctuations in their health to have a clear image of the important events during the past period in between two appointments.

Figure 23 - Concept 2

Concept 3 – Waiting room entertainment by inspiration

Just like good company during your hike, good entertainment makes your excursion more enjoyable. Another thing that makes a hike better, is when you know what to expect from reviews from other people or maybe when you've read the brochure. Hearing the experience from someone else might improve your experience, you now know what amazing adventure lays ahead of you

Concept 3 focusses on the element of entertainment by inspiration. In the interviews Pi5 mentioned to feel inspired by other people living with HIV who are brave enough to stand up and tell their story. Allowing waiting patients fill their time with looking at the posters on the walls and magazines laying around at the tables.

The posters and magazines will include different stories that should be inspiring and informing. The exact content of the written text has not been determined. The content can include, but not be limited to, topics regarding coping with your diagnosis, sexual health, and how to keep your positive status disclosed.

Figure 24 - Concept 3

Concept 4 – Hospital Roadmap

“Are we there yet?” This is a sentence quite commonly said by people, often children, when they are on a trip without a clue how long the travel will take. When going for a hike, it can be quite helpful to see milestones and know how much longer you need to climb that mountain till you have finally reached your destination.

Concept 4 makes use of transparency in the process. Letting the patient know what steps are coming and which steps can be checked-off from the to do list. This should give the user a feeling of being in control as they know what is waiting for them instead of reaching in the dark without knowing what is there.

I experienced this myself one day when I had to come back for a check-up after breaking my elbow. The co-assistant talked to be, send me to to another department to let them make an xray. When I got back at the outpatient clinic, I had no idea what I was waiting for and what was going to happen. It frustrated me to be there waiting for something, but not knowing for what.

This concept should take away the feeling of not knowing what you need to do, and making sure the patients doesn’t be surprised when they need to take an extra step which they did not expect. Especially due to the long time span the entire patient journey can take in.

Figure 25- Concept 4

5.3 Concept choice

To end up with one final design, it is important to determine which concept has the most potential to succeed. Based on the list of requirements from Chapter 4, the concepts are evaluated with a Harris profile. Requirement 5; "The design must be connected to the Amsterdam UMC to create trust", has been excluded from the evaluation because this requirement can be met in different ways for all concepts but has not been worked out yet in this phase. Therefore, this requirement can be neglected for evaluation.

Figure 26 shows the filled in Harris profile for all four concepts. The concepts have been created with the requirements in mind. Therefore, it can be expected that all concepts have an overall positive outcome. The extent to which they meet each requirement differs per concept. The Harris profile functions as a scale on which the concepts scores to a certain degree. So for example, when a concept is considered to score well in meeting the requirement that concept will receive a double plus, but when it is considered to score poorly, it will receive a double minus.

Concepts 1 and 2 are both the most promising concepts according to the Harris profile. I will continue with Concept 2. This concept has the most potential to contribute to the collection of PROMs, as stated in the original assignment (see Chapter 0). Next to that, the implementation of Concept 2 lays fully in the hands of the Amsterdam UMC without any co-dependencies with other facilities. Concept 2 has a negative score for Requirement 3: The design must be discrete regarding sensitive topics, in the next stage of development, it is important that the connection with HIV is minimalised.

Strong elements to take along

Even though Concepts 1, 3, and 4 have not been chosen, they do have their strengths. For the next iteration of Concept 2, these elements can be used to increase the strengths of the final design.
The strengths of the existing Positive Brothers and Sisters program of the ShivA Foundation has been proven over the past couple of years. Concept 2 will be pitched to members of the community to test the desirability and find potential points that need improving.

Concept 3 shares inspiration with the users. It could be an interesting opportunity to include written information. This might not match with the requirement of allowing someone who is low literate to make use of it. A field to further explore is to make Concept 2 modular to better match the needs of each user.

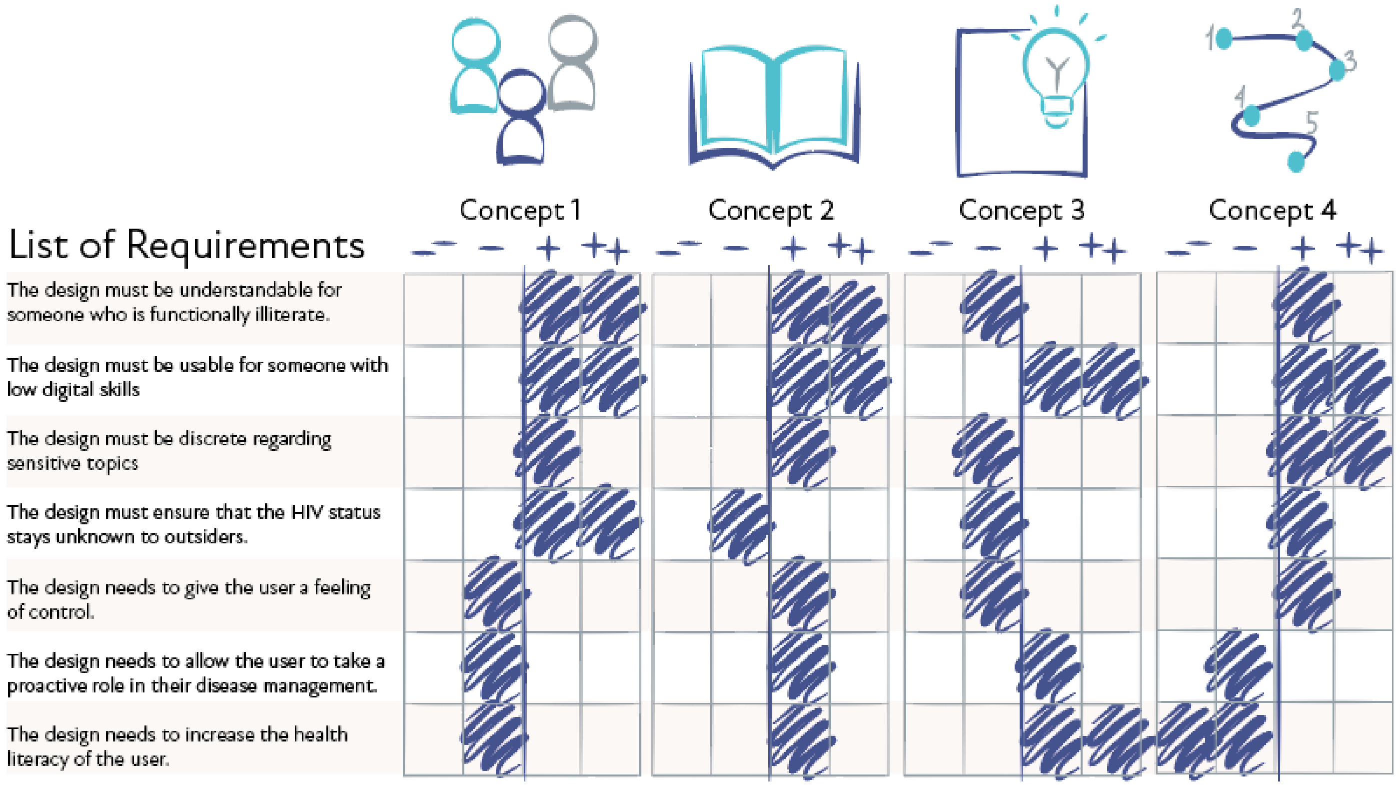


Figure 26 - Harris Profile

5.4 Key takeaways

Chosen concept
Concept 2 – the Wellbeing diary has the most potential and will be taken into further development.

Knowledge availabe
The strengths of Stichting ShivA will be utilized by conducting an evaluation of the design proposal.

Combining opportunities
Opportunities of concepts 2 and 3 can be explored in further stages of product development.

5.5 Next steps

In this Chapter, different potential concepts are presented. The decision is made to continue with Concept 2 – Wellbeing diary. In the next Chapter, details of the concept will be determined to create a concrete product proposal. With different evaluations, iterations will be made in order to end up with the final design.

6

Develop: Finding the Details

6.1 Introduction

In the previous Chapter, the decision was made that Concept 2 – Wellbeing Diary has the most potential to be a successful product when implemented in clinical use. First, in this Chapter, the concept is finalised into a concrete design. Second, this design is evaluated on how people perceive the different elements to test if the design is logical. Next, the insights from the logic test are used to iterate on the design and create an improved version of the design. Last, in this Chapter, the improved design will be evaluated with experts from Stichting ShivA. In the next Chapter, insights from the evaluation will be used to make the final iteration on the design and create the final design.

6.2 Detailing

The diary needs to include several elements that should help someone keep track of their perceived wellbeing. According to Rath and Harter (2010), five essential elements represent the categories that are important in the life of most people. These five essential elements are; Career Wellbeing, Social Wellbeing, Financial Wellbeing, Physical Wellbeing, and Community Wellbeing. Career wellbeing and financial wellbeing are the first and third elements, during the observations (described in Chapter 1), I noticed that this is a reoccurring topic that the nurses discuss lightly with their patients. Therefore, in the first design version, these elements will not be included. Your social wellbeing and community wellbeing are the second and fifth elements described by Rath and Harter (2010). For people living with HIV, these elements play a significant role due to stigma within society against people living with HIV. As described in Chapter 1, people living with HIV may experience more difficulties in their communities or love life. The fourth element is physical wellbeing, as PROMs are intended for (among others) early signalling of comorbidities, the element of physical wellbeing is important to keep track of. With the determination of the required elements, a quick brainstorm session is conducted to create the best visual representations of the needed elements (see Appendix 10). Figure 27 shows the first version of the design.

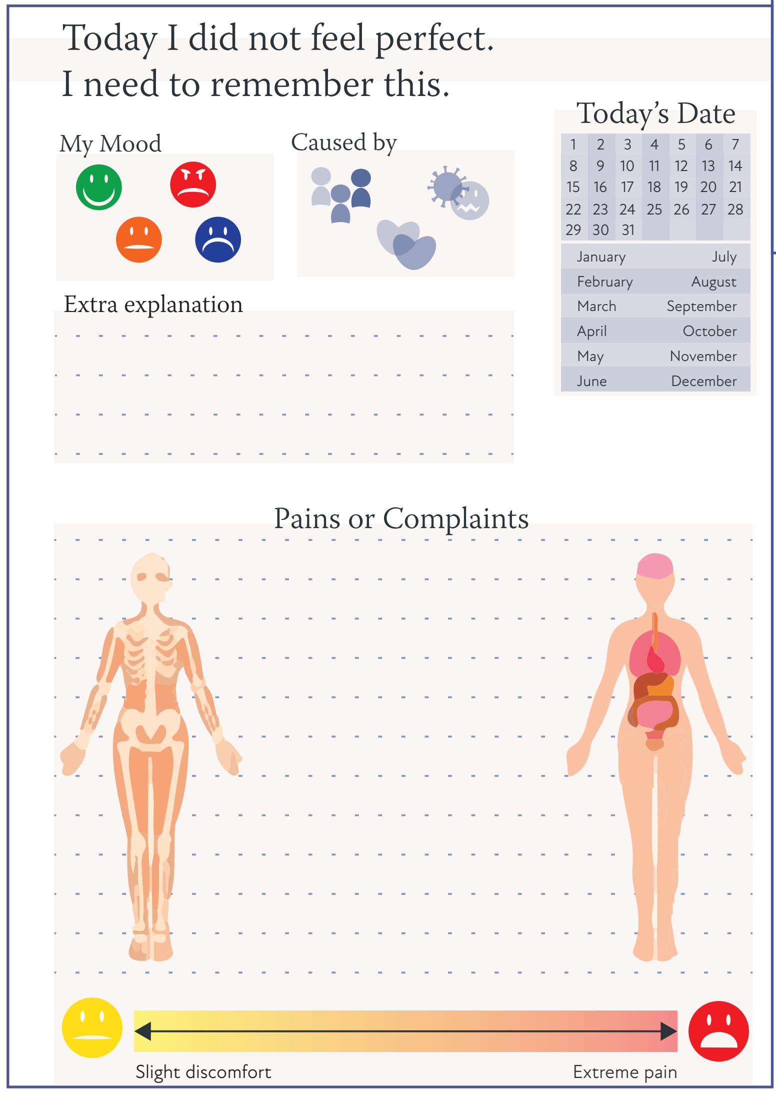


Figure 27a First version

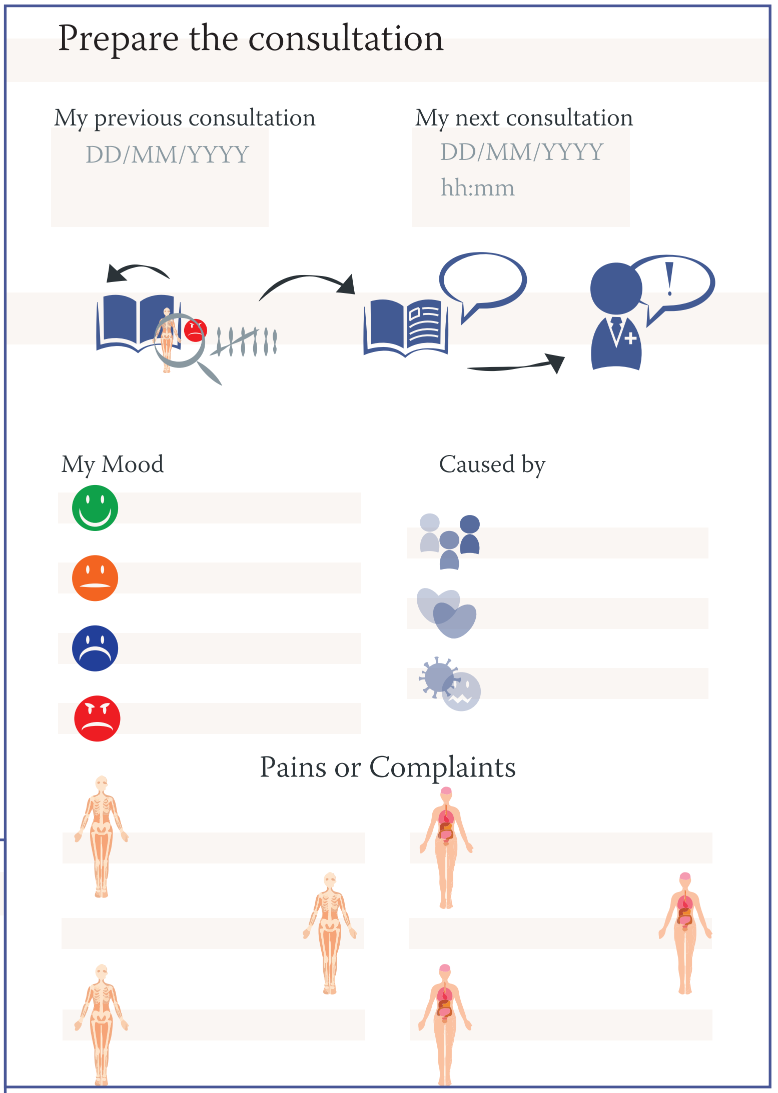


Figure 27b FIrst version

6.3 Logic test

6.3.1 Introduction

As a designer, it can be hard to look at your concept objectively. Especially when you need to determine if the concept "makes sense". Since you have created it to your best ability, you will feel like it is extremely logical. It is crucial to test your ideas with people who have not been involved in the design process to verify if it is as clear as you envisioned.

Requirement 1: The design must be understandable for someone who is functionally illiterate.

6.3.2 Goal

The goal of this survey is to verify if requirement 1 is fulfilled. The target group for this project contains people with many different background stories, including people who are functionally illiterate or low literate. As requirement 1 states that these people must be able to understand the final design, it is important to verify if this requirement is met. The goal of this test is not to have a 100% score where all participants were able to luckily guess the correct answers. The test aims to find unexpected answers that will make the interpretation of someone who sees it for the first time clear to the designer. This will create opportunities for improvement. Additionally, the test should highlight the strong elements of the concept, i.e., the elements that are logical enough to understand without further explanation. These elements can be further exploited to increase the strength of the design

6.3.3 Method

Due to the current Covid-19 situation, testing with the actual target group in the waiting room of the outpatient clinic was not responsible. Therefore, I tested the intuition of the concept with people outside the target group. The aim was to test the compatibility with people who are functionally illiterate. Illiterate persons cannot read and thus cannot read and understand the questions. The participants of the logic test were literate. Therefore, I simulated their illiteracy by changing the written English text into a font that is indecipherable for anyone. This led to a version of the concept without understandable text. All questions in the survey were open questions about the meaning of different parts of the design and how it should be used according to the participant. During the analysis, the responses were labelled to retrieve quantitative results of how often similar responses were shared.

This resulted in 46 participants fully answering all questions of the survey. Figure 28 shows an overview of the general information of the participants.

6.3.4 Results

From the Logic Test, a few interesting insights could be concluded. The most important insight is that without any extra explanation of the product, people feel confused. The individual elements do make sense to the majority of the participants, but how they relate to each other is not clear enough.
Appendix 11 provides a detailed overview of the results from the Logic Test.

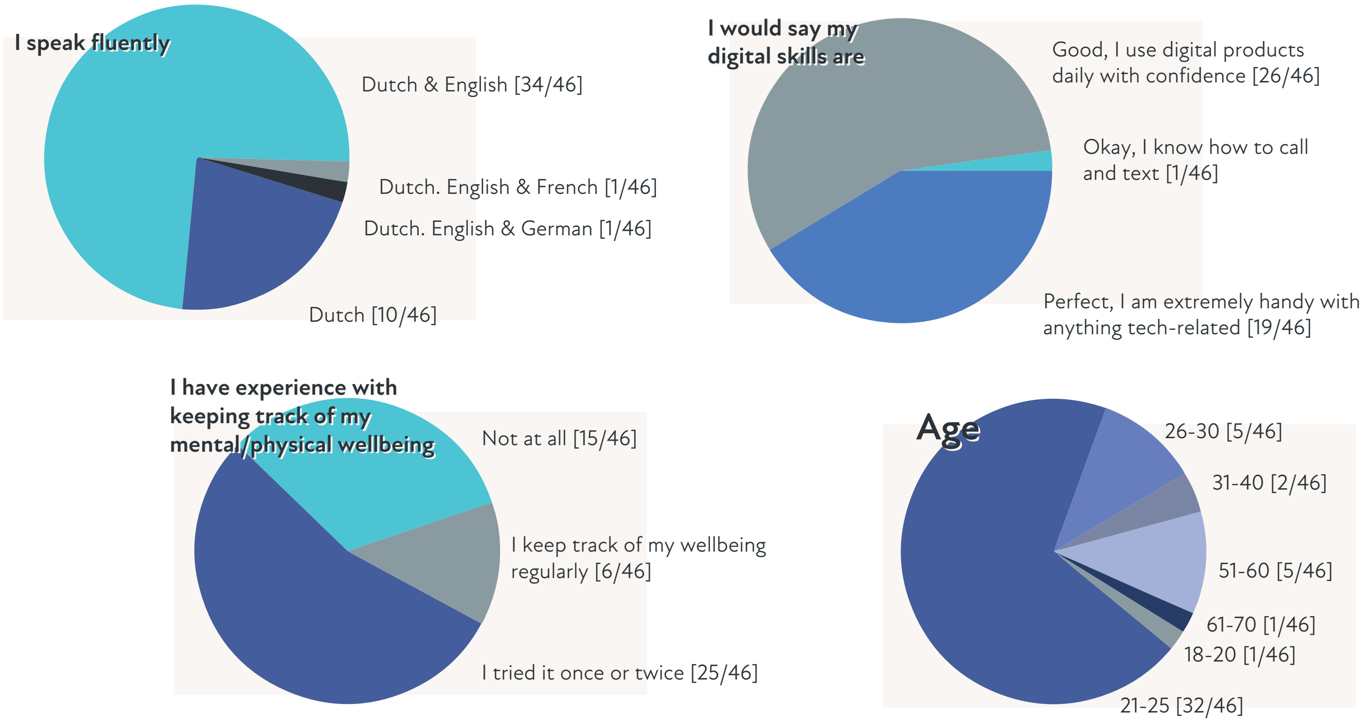


Figure 28 - Participant information

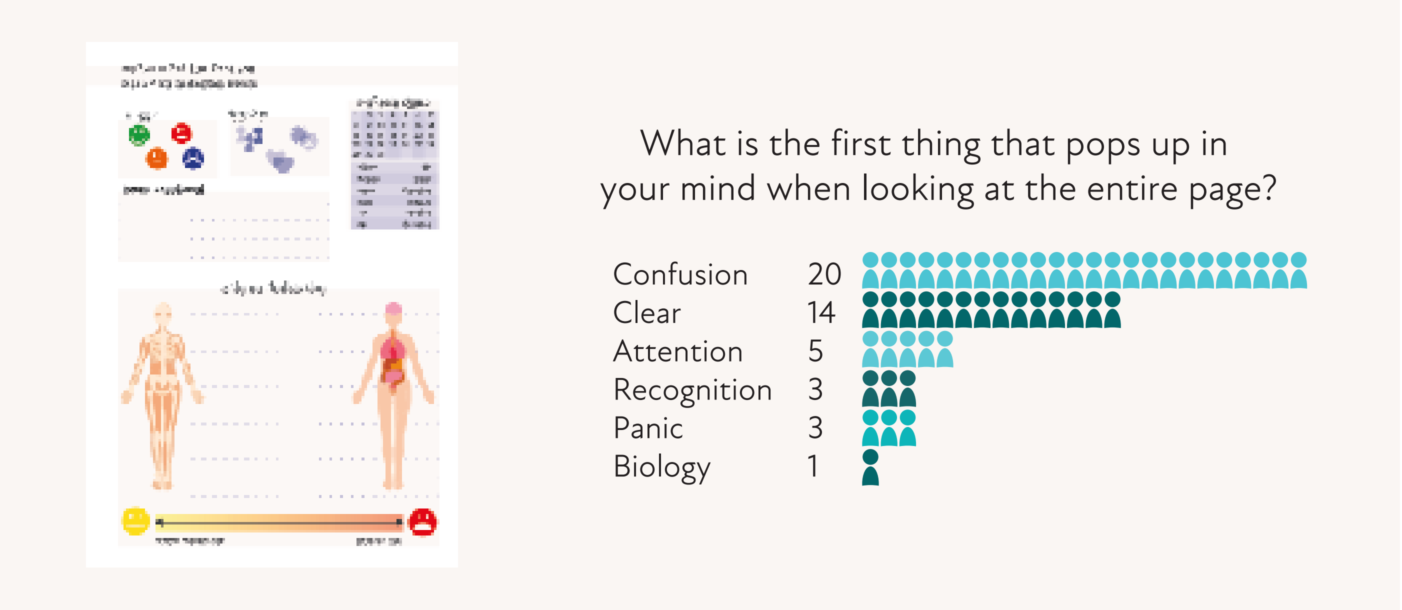
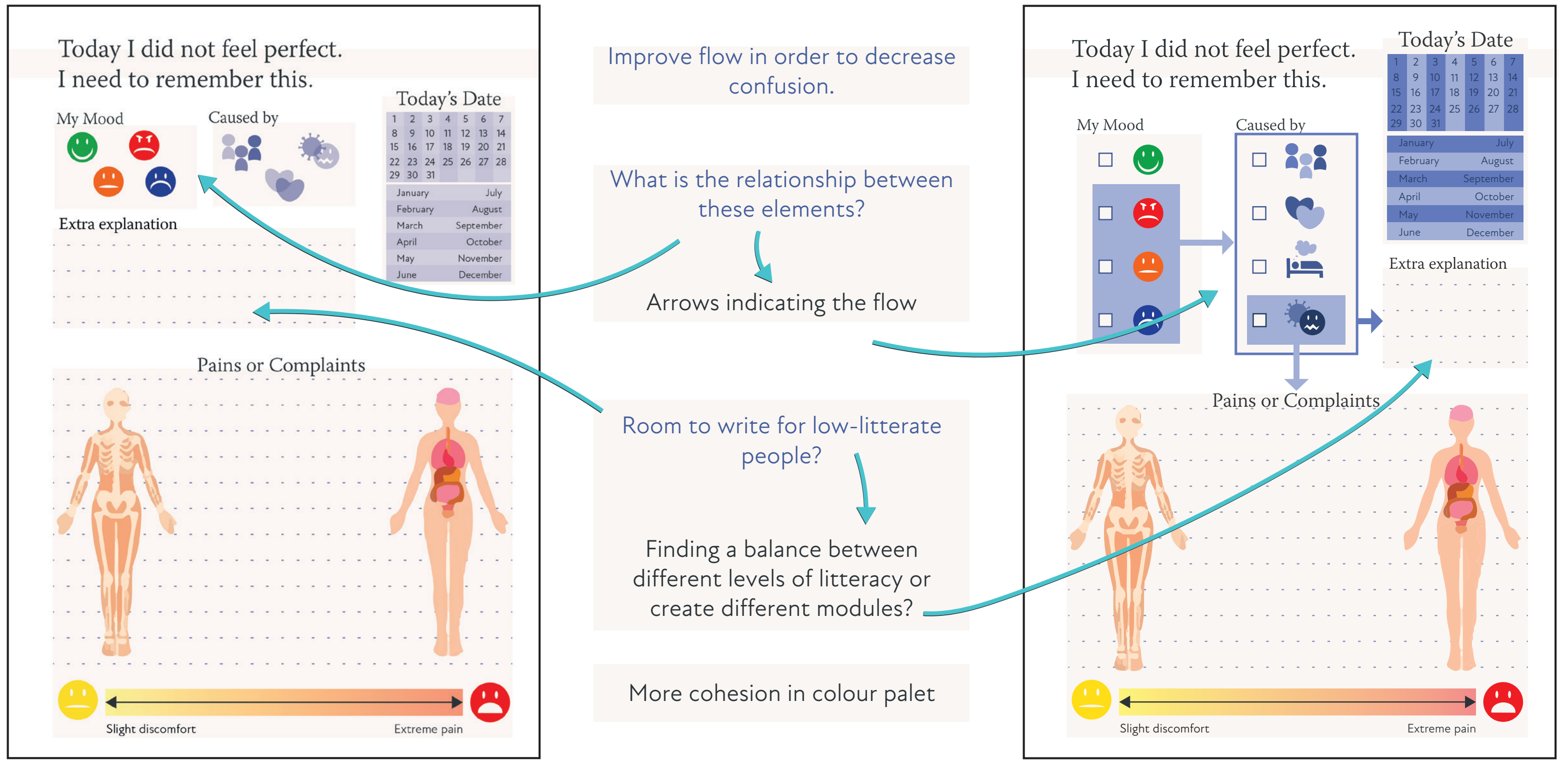


Figure 29 - Result of test



Improve flow in order to decrease confusion.

What is the relationship between these elements?

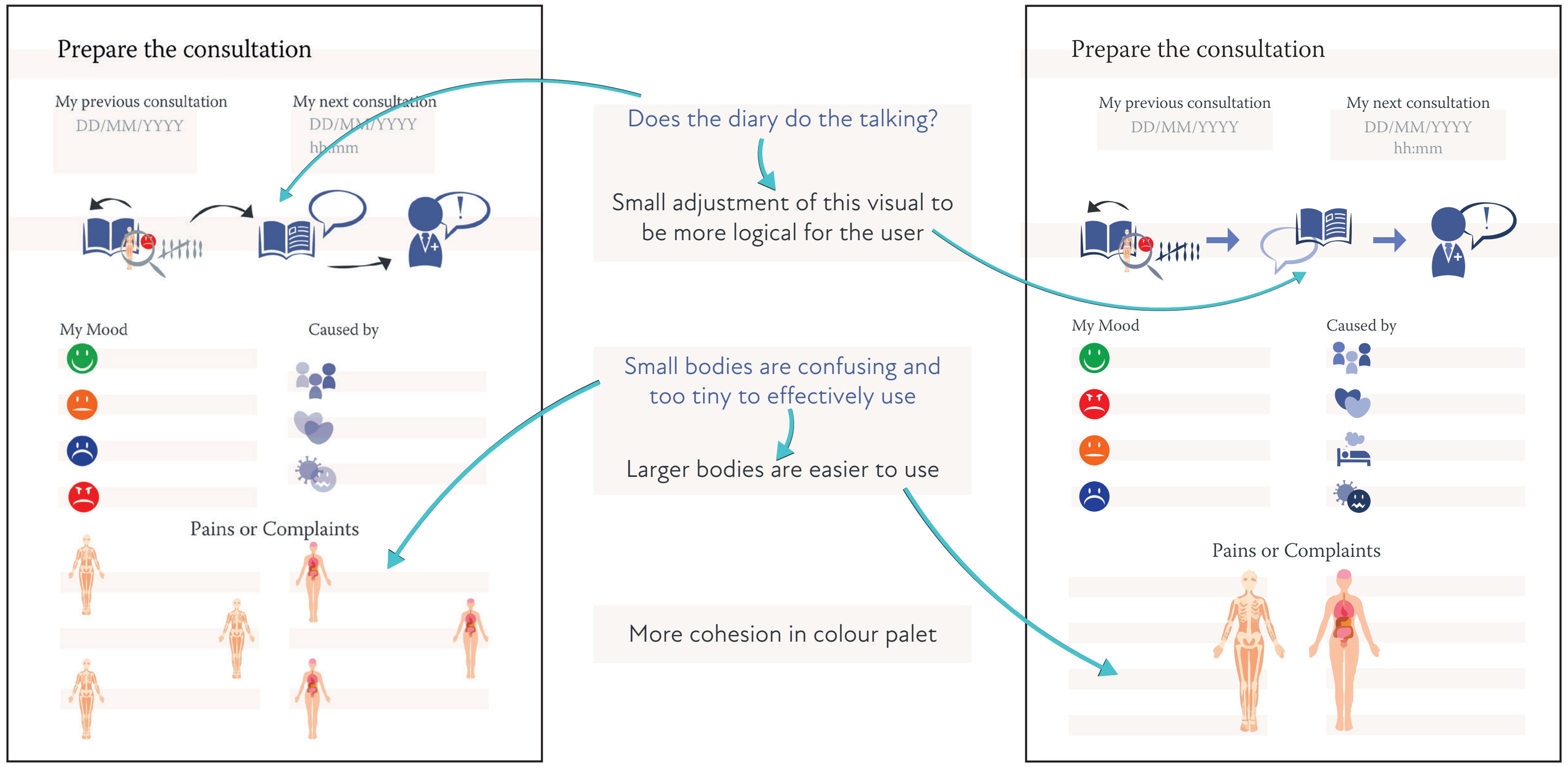
Arrows indicating the flow

Room to write for low-litterate people?

Finding a balance between different levels of litteracy or create different modules?

More cohesion in colour palet

Figure 30a - Iteration on the daily page



Does the diary do the talking?

Small adjustment of this visual to be more logical for the user

Small bodies are confusing and too tiny to effectively use

Larger bodies are easier to use

More cohesion in colour palet

Figure 30b - Iteration on the summary page

6.3.5 Iteration

Next to the results from the Logic Test, I used the diary myself to evaluate its use when you know how to use it. I Figured that when you would count the "causes" of your mood, the functionality will be lost when the positive and negative are summed. Therefore, the user should only fill in the cause of their mood when this is one of the negative feelings.

For the first version, the decision is made to exclude the elements of career and financial wellbeing. The PROMs which will be used for the screening of patients include topics such as PTSD, substance and alcohol use, and depression. Next, the HCP's want to know what the financial situation of the patient looks like to be able to help them where needed. This led to the decision to add more options that can cause a bad mood. I created two versions of keeping track of your mental wellbeing.

The first version as shown in Figure 31 focuses on the mood of the day and the specific reason that caused it. The second version, shown in Figure 32, displays all possible topics that can be discussed. The user can indicate for each topic what their mood is.

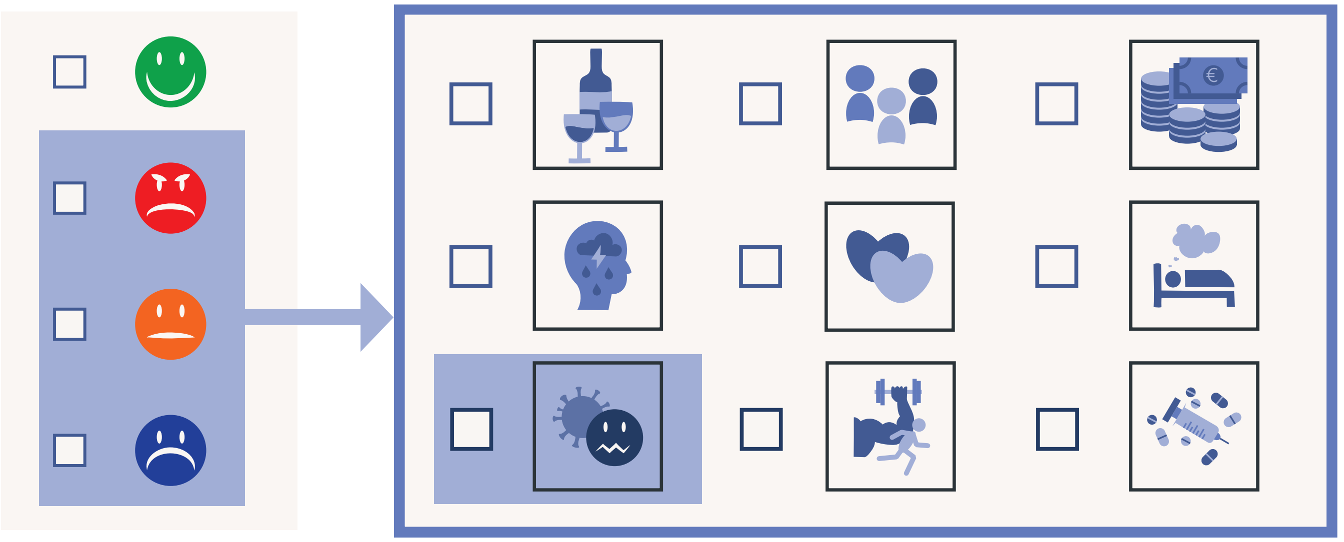


Figure 31 - Mood version 1

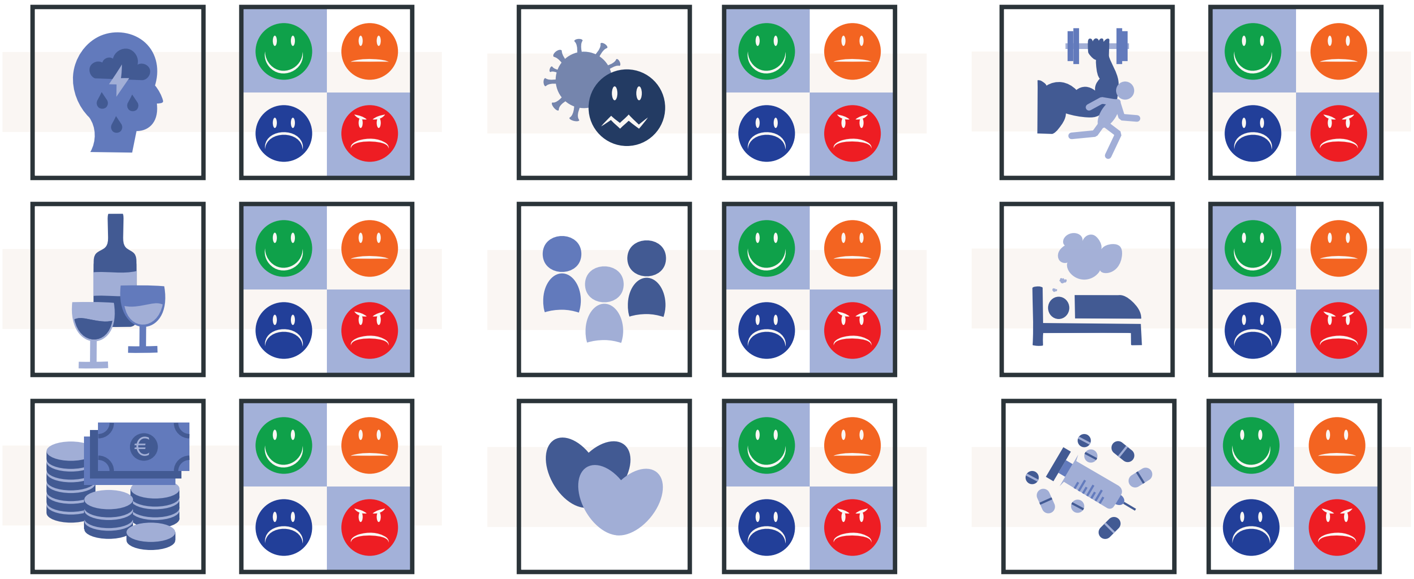


Figure 32 - Mood version 2

6.3.6 Physical shape

Chapter 1, 2, and 3 explained that stigma plays a big part in the life of people living with HIV. Stigma hurts the mental wellbeing of people living with HIV, therefore they prefer to not use a product that has any visible connection with HIV. Their privacy needs to be guaranteed at all times. The physical shape of the wellbeing diary cannot be connected to anything that can be related to living with a positive HIV status. The physical shape of the design should be as subtle and minimal as possible.

Within medical institutions budget will always be tight Therefore, I want to keep the production of the design cheap, to create a feasible final design. There are multiple ways to design the exterior of the diary, it could be a smartphone application that is hidden inside your smartphone, or it could be a neatly printed booklet that looks like any other booklet. Both options ask for financial investment and could therefore be less desirable.

I decided to allow the HCPs to produce the diaries themselves in their offices. I want the pages to be printed on A4 and cut in half, creating an A5 size. Afterwards, the HCPs will make holes in the pages and put them in an A5 folder. The pages can be taken out or added to the folder.

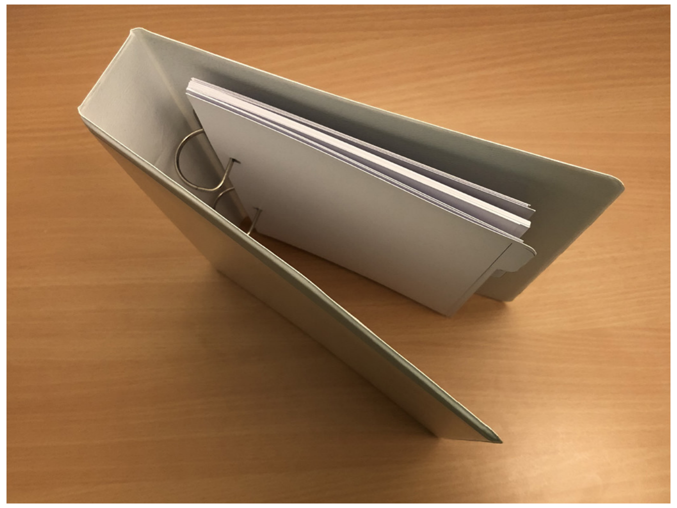


Figure 33a - Physical shape

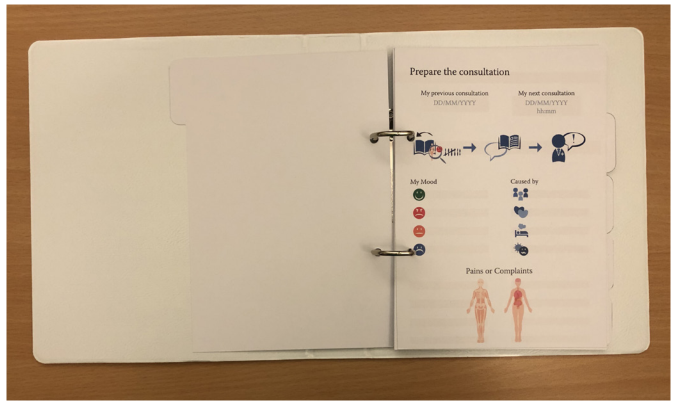


Figure 33b - Physical shape

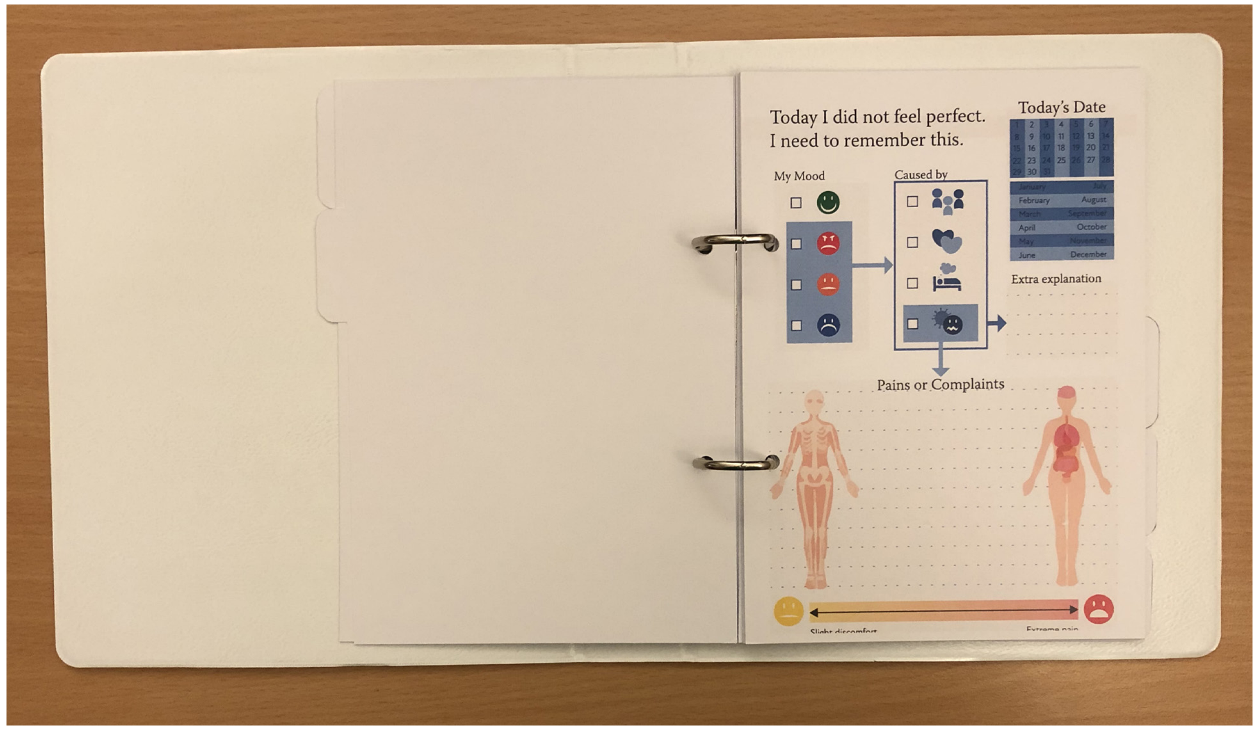


Figure 33c - Physical shape

6.4 Evaluation with Stichting ShivA

6.4.1 Goal

Due to time constraints and the ongoing Covid-19 situation, the decision is made to evaluate with Stichting ShivA, as this minimizes the exposure to different people while being able to evaluate with people close to the target group. The people working for Stichting ShivA are highly involved with the target group or part of the target group themselves. Therefore, evaluating with Stiching ShivA will lead to insights based on relevant expertise.

6.4.2 Method

To gain the most insights from the evaluation, open questions regarding the first impression, perceived usefulness, perceived ease of use, and overall satisfaction were asked. These questions formed the start of an open conversation in which all important topics were being discussed. From the conversation, insights regarding the feeling of privacy, look and feel, and implementation was concluded that will help with the final improvements. See Appendix 12 for the evaluation plan. Two experts from Stichting ShivA were involved in the evaluation.

6.4.3 Results

First impression - Privacy

The experts mentioned agreeing with the decision to keep the outside as neutral as possible as it makes sure that the privacy of the user is maintained. Throughout this research, the topics of "privacy" and "disclosure" have had a clear and recurring role. People living with HIV prefer to keep their positive status private. Therefore, when designing a product or system, it is very important that this cannot be traced back to them having a positive status. During the evaluation with Stichting ShivA, this conclusion was emphasized. During the conversation with the experts, a mutual agreement was made that the diary cannot contain the words "HIV" or "Positive" or anything that relates to living with HIV. In the prototype, the diary is incorporated into a white folder. A white folder is neutral and gives no signal that can be traced back to a specific disease. The content of the diary does refer to mental and physical wellbeing. One of the experts explained that some people are not willing to disclose their positive status to their family, instead, they make up an excuse for their frequent hospital visits and medication use by blaming it on, for example, diabetes or high blood pressure. This excuse can also be used for the diary as long as it does not refer to a specific disease, according to the experts.

Perceived ease of use – look and feel

The white folder gives the user the feeling that his privacy will be guaranteed, but there are also some drawbacks. The white folder is bulky and might not fit in a small bag. That issue can be solved by using another type of folder or binding method, this is a consideration that has to be made.

The visuals are clear and appealing but they work best after a brief explanation of their function. The explanation needs to be included in the implementation plan. The visual of the body including all the organs can be a bit confusing. For that reason, the visual of the body could be simplified into one overarching visual with fewer details. Currently, the body represents a female, the suggestion is made to have a male and female simplified version next to each other.

Within the patient population, there are different levels of literacy. The experts agree that this concept could be relevant for all levels if there are different versions available. The version shown in Figure 32 would be most relevant for someone who is low-literate because it allows them to think about each topic and determine their mood. The version shown in Figure 31 is more interesting for someone literate, as it allows them to add an explanation and keep it global.

Perceived usefulness – Implementation

During the evaluation, the conclusion is drawn by the experts that the concept has great potential to have an added value to the life of someone who is living with HIV with a migration background, if, the implementation is done right. The main concern here is that the user needs to learn how to use the concept and be trained to use it frequently.

When asked how the concept could help someone within the target group, one of the experts who is in care herself, explained that she takes notes of how she has been feeling a few days before she has a consultation at the hospital. She does this on her smartphone in her notes, saying that it would be even better to do this more frequently. Her technique of keeping track helps her to talk to her doctor about how she is doing and what is going in on with her health. Therefore, she thinks that this concept could be really useful for someone who is unable to use a smartphone or feels less motivated to keep track of it by themselves.

Successful implementation of the concept starts by educating the nurses as they will be the ones who will introduce the diary to the user and teach them how to use it. First of all, the diary should not be offered to all patients. The diary needs to be introduced to those who will benefit from the use. For example, someone who frequently has multiple complaints but is unable to clearly explain their situation or someone who never has anything to share with the HCP's because they cannot remember their issues.

During the evaluation session, an informal co-creation started when the experts and I started to brainstorm about how the implementation could be executed. The following plan of action has been devised.

Potential plan of action

The diary will contain an additional page that includes all the information on the use of the product. The nurse will go through the information with the user and explain how to use the diary effectively. Afterwards, a new consultation after two weeks will take place. This will be a consultation in which the use of the diary can be discussed to verify if the user can effectively use the diary. When it turns out that the patient is unable to effectively use the diary after the first explanation, the nurse will give a more elaborative explanation. Another (telephone) consultation can be scheduled if the nurse or user feels like this would be useful. When the user can make correct use of the diary, they will be asked to make use of it throughout the coming months and take it with them at the next routine appointment.

Simultaneously, the Positive Brothers and Sisters will be educated by the nurses on how the diary works and should be used. This way, the peer support will help to improve the use of the diary. During the meetings between Positive Brothers and Sisters, they will be able to informally discuss the diary and help each other where needed.

After six months, the first reflection moment will take place. How is the diary received and how is it used during different consultations. The effectiveness of the visuals needs to be evaluated. And overall feedback needs to be gathered.

One year after the introduction of the diary, the team needs to evaluate and reflect on the diary. In the evaluation and reflection the following question will be addressed: Does the diary needs to be improved or adjusted to better fit the needs of the people? Accordingly, the team will determine whether the diary will be continued and implemented as a standard part of the protocol within the HIV outpatient clinic.

6.5 Key takeaways

The evaluation can be concluded optimistically. The experts agreed that the design has the potential to help people living with HIV with a migration background. For clinical use, the following adjustments should be made:

Terminology
The terminology used cannot be related to HIV and/or AIDS.

Size of the physical product
The large size of the product needs to be reconsidered, allowing easier transportation for the user.

Simplification
Visualization of the human Figure can be simplified.

Meeting different needs
Different versions or modules can be introduced to better fit the variety of literacy skills of the target group.

How to implement
The implementation plan needs to be worked out, including an explanation of the use.

Evaluation
An evaluation moment after a certain period to determine if adjustments are needed within the design or way of implementation.

6.6 Next steps

This Chapter brought the chosen concept to the next level. The first design has been tested on its logic and how people interpret the different elements. The results lead to an improved version of the design. This improved version was evaluated with two experts from Stichting ShivA. The evaluation is described and the final improvement opportunities were described. In the next Chapter, these improvements will be executed and the final design will be presented.

7

Final Design: Bring it together

7.1 Introduction

In this Chapter, the overall thesis will be concluded. A final design will be proposed based on the iterations and evaluation from Chapter 5. The final design will be accompanied by an implementation plan and recommendations for further development. Lastly, gathered insights throughout this project will be reflected to determine if the original goal is reached.

7.2 The Final Design

WellRy is a diary for people living with HIV to better keep track of their mental and physical wellbeing without relying on literacy. Visuals allow the user to indicate their mood and what caused it, and it allows the user to indicate physical complaints. WellRy comes in 3 different variations, depending on the level of literacy of the user, the most appropriate version will be offered.

Figure 34 - WellRy logo

WellRy V1

WellRy V1 relies completely on visual indicators. V1 targets people who are functionally illiterate. Every day that the user notices an abnormality in their wellbeing they can remark their WellRy. V1 does not include the option of a textual explanation. To make sure that the user can take note of all relevant information about their wellbeing, the user can indicate their mood for each topic. Next to that, this version includes larger versions of the human Figures. This version does not include an option to indicate the date, as this might be a challenge for someone who is functionally illiterate and therefore might be unable to write down the date. The decision is made to exclude any written text to best fit the needs of this target group, allowing the threshold to use the WellRy as little as possible and not be a deterrent.

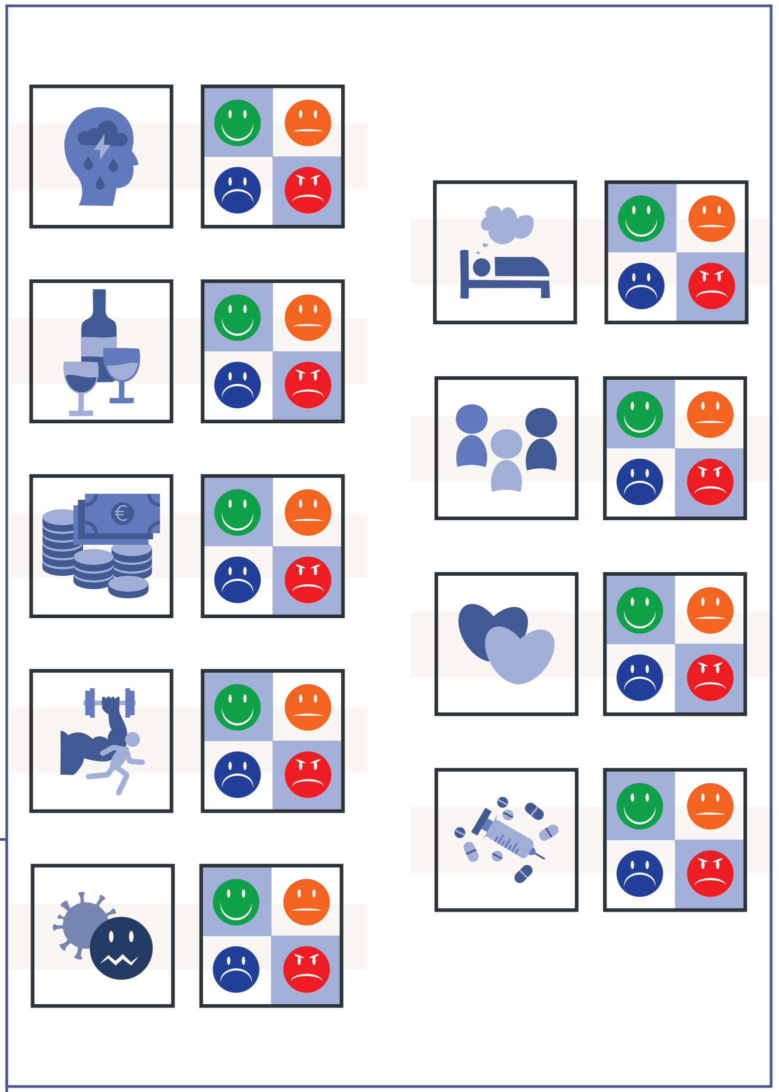


Figure 35b WellRy V1

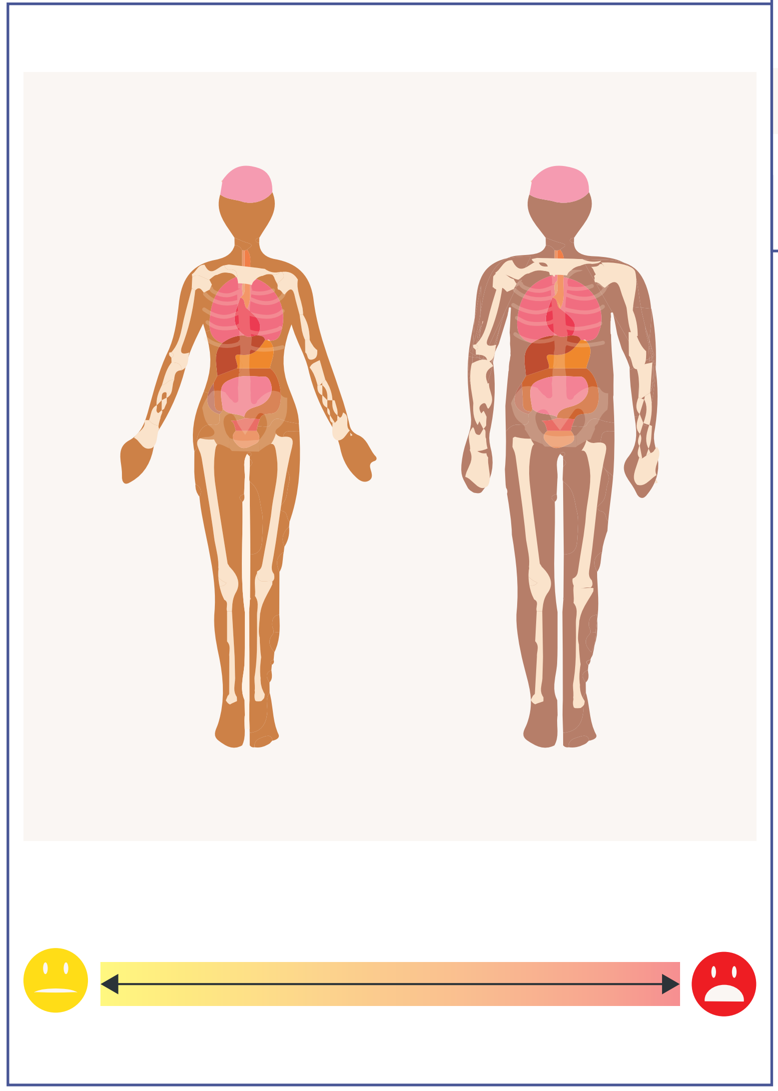


Figure 35a WellRy V1

WellRy V2

WellRy V2 is a balanced combination between visuals and space to write. V2 targets people who are literate but not perse like to write in detail. When the users notice an abnormality in their wellbeing they can note that down in their WellRy and potentially write a short explanation. In V2, the user will note their mood and the cause of it, instead of noting their mood regarding all topics. This decreases the effort of taking note of all topics, which allows the user to have more time to write about their mood more focussed. The human Figures are a bit smaller to allow the user to write about it. This version includes an area where the date can be written down. The space for written explanation should be inviting while being guided in the right direction.

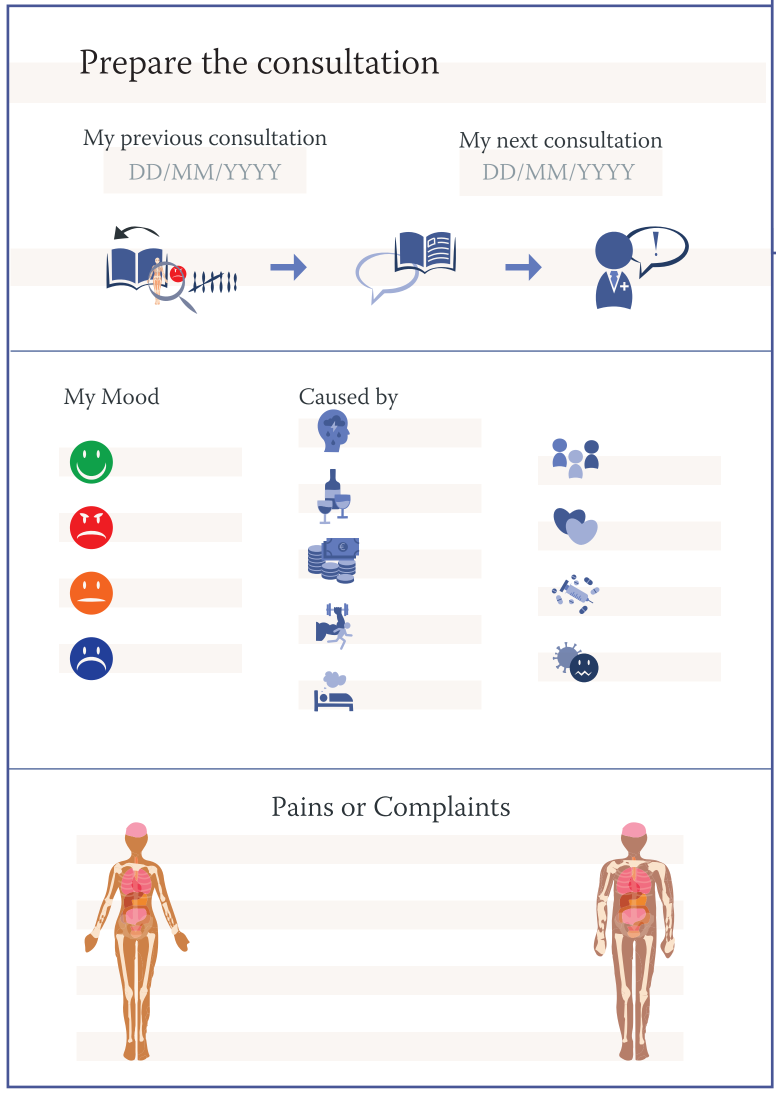


Figure 36a - WellRy V2

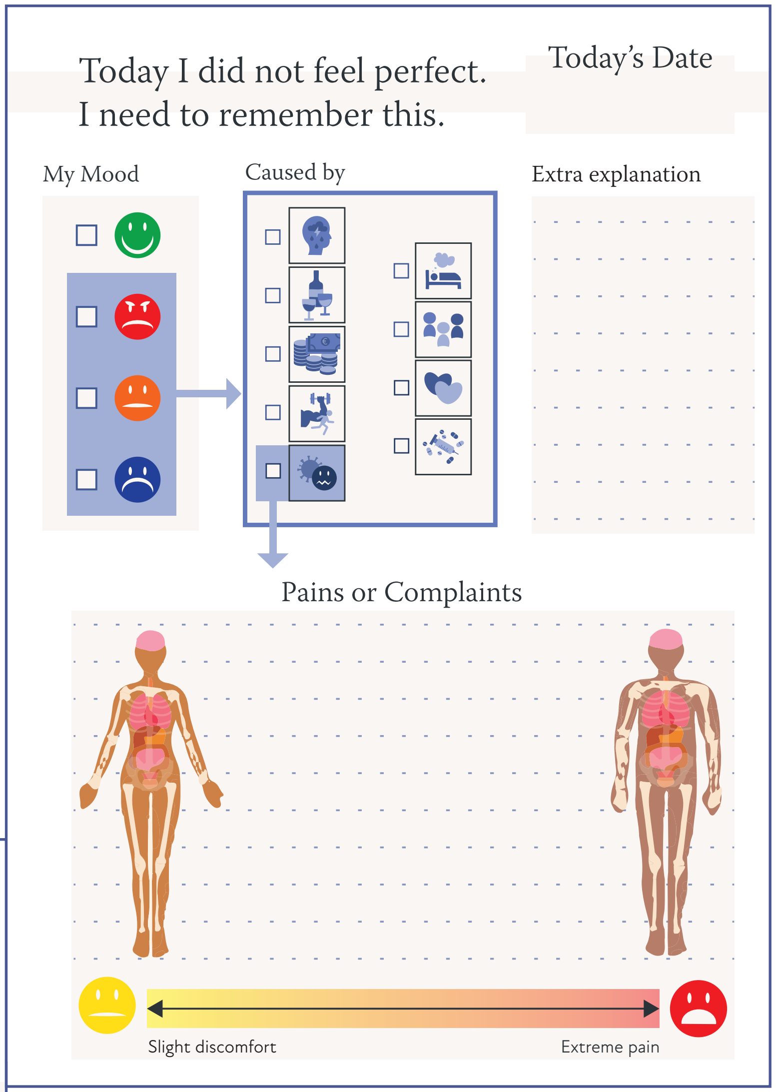


Figure 36b - WellRy V2

WellRy V3

WellRy V3 uses visuals to guide the user during the note-taking of their wellbeing but leaves enough space for the user to write about the abnormalities in their wellbeing. The same visuals are used as in V1 and V2, they create a starting point for the user to take notes of their wellbeing. This version uses less space for the visuals and more space for writing to invite the user to write more about what they are experiencing.

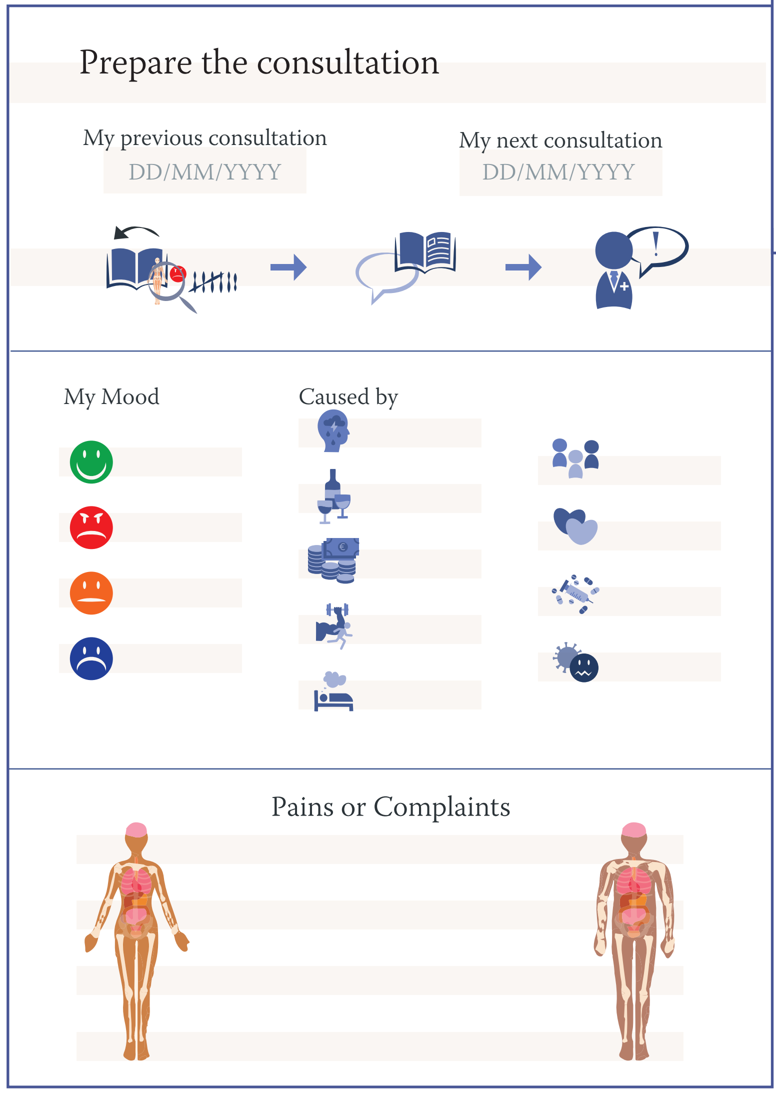


Figure 37a - WellRy V3

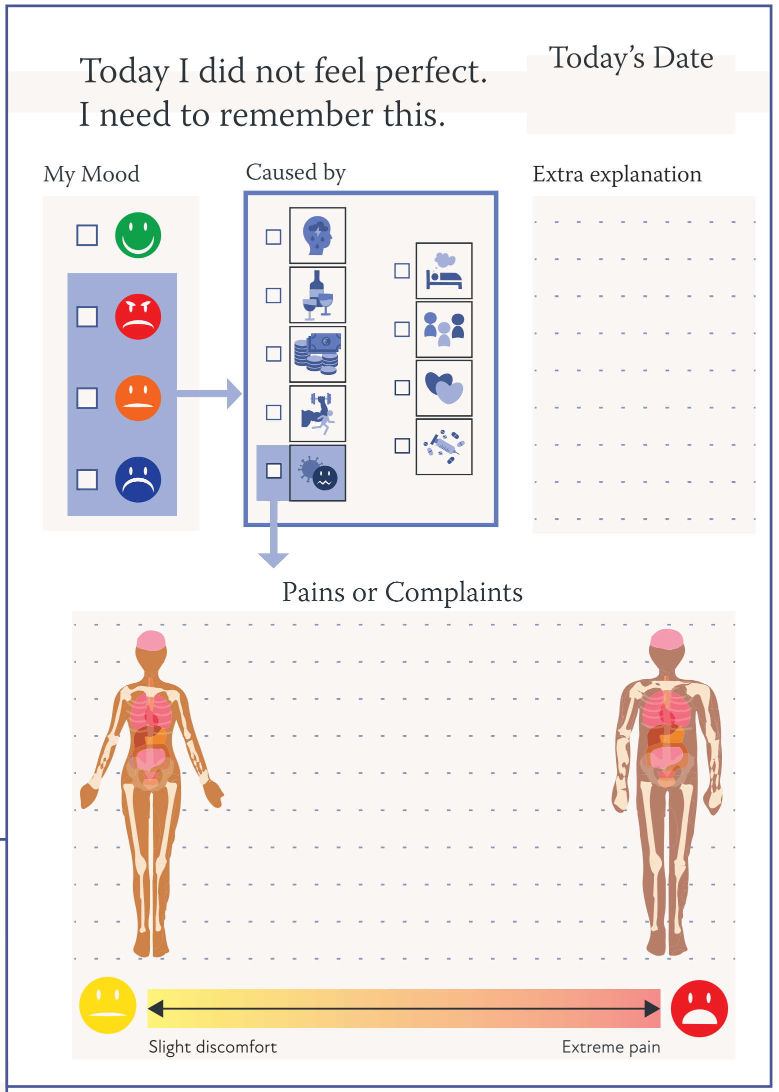


Figure 37b - WellRy V3

7. 3 Use

The HCPs, especially the nurses, will play a crucial part in instructing the users on how to interpret the different visuals. See Figure 39 for the overview of the intended meanings of each visual. The WellRy should be handed out with a separate instruction letter. The nurse will go through the instruction letter together with the user, the user can then keep the instruction letter as a reference or, in the case of low literacy, leave the instruction letter with the nurse.

Once the user knows what is expected, they will take WellRy home. People living with HIV need to take their medication daily, WellRy should be saved near the medication to make sure that the user is reminded of the existence of the diary regularly. Anytime the user notices an abnormality in their wellbeing, they can make a note of this in WellRy. The user scenario is visualized in Figure 40. Version 2 and 3 include summary pages, the user needs to take a moment to reflect on their wellbeing before their appointment at the hospital.

7. 4 Physical shape

WellRy can be printed and bound in-house by the HCPs themselves. Depending on the number of pages the user requires, they can determine to use an A5 folder or a ring binder. The ring binder,as shown in Figure 38, allows the user to easily transport their WellRy as it is a more compact version. The folder allows easier adding or taking away from the pages. The decision can be made by the HCP while taking the preference of the user into consideration.

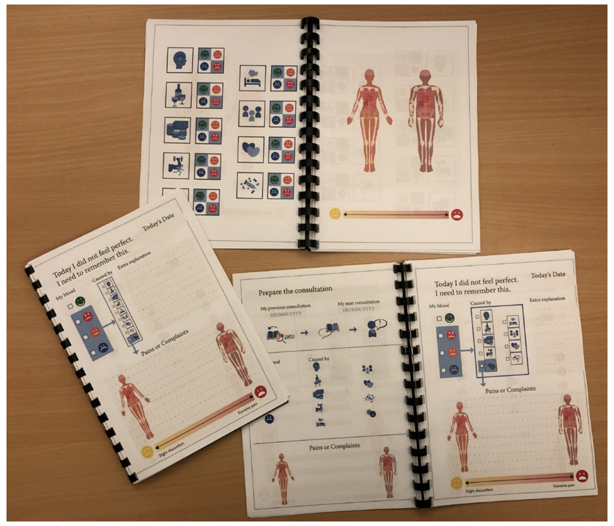


Figure 38 - Physical shape

Negative thoughts
Early detection of potential depression or other mental disorders.

Alcohol consumption
Keeping track of excessive alcohol consumption and how this influences someone's wellbeing

Financial situation
Early detection of financial problems

Physical wellbeing
Exercise and physical wellbeing

Sleep problems
Traumatic events can come back in someone's dreams, keeping track of this can help with the early detection of possible problems

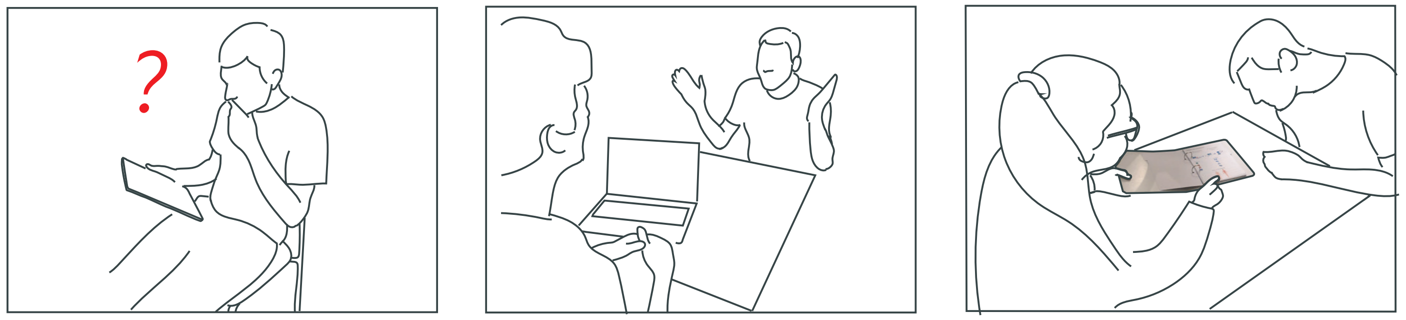
Sickness
feeling unwell due to your chronic disease or other diseases

Social community
Social isolation or a strong social community can influence someone's perceived wellbeing

Love and relationships
Within HIV care this topic reoccurs often as this is a relevant matter to discuss.

Substance use
Similar to alcohol consumption, substance use has a big effect on someone's wellbeing.

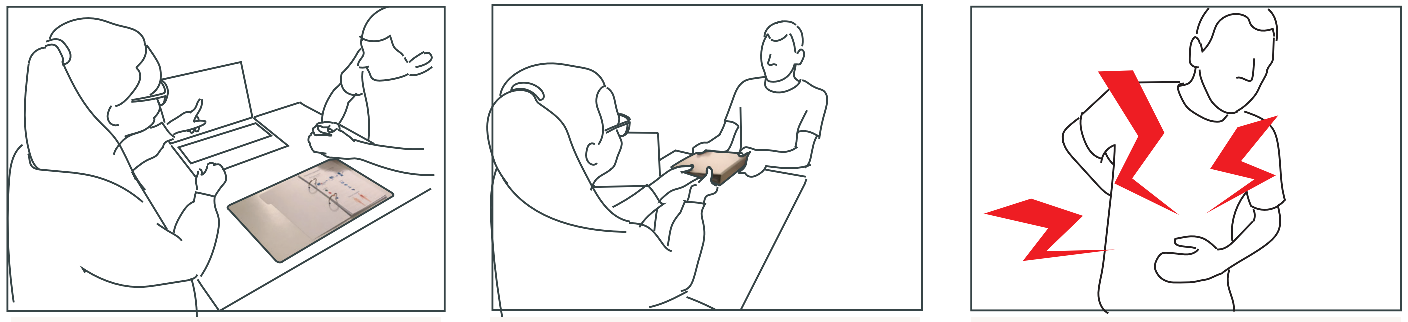
Figure 39 - Intended meaning



The patient is asked to complete the PROMs in the waiting room, but he has a hard time knowing what to fill in.

He talks to his personal doctor and tries to explain that he has not been feeling well lately but has difficulties explaining it.

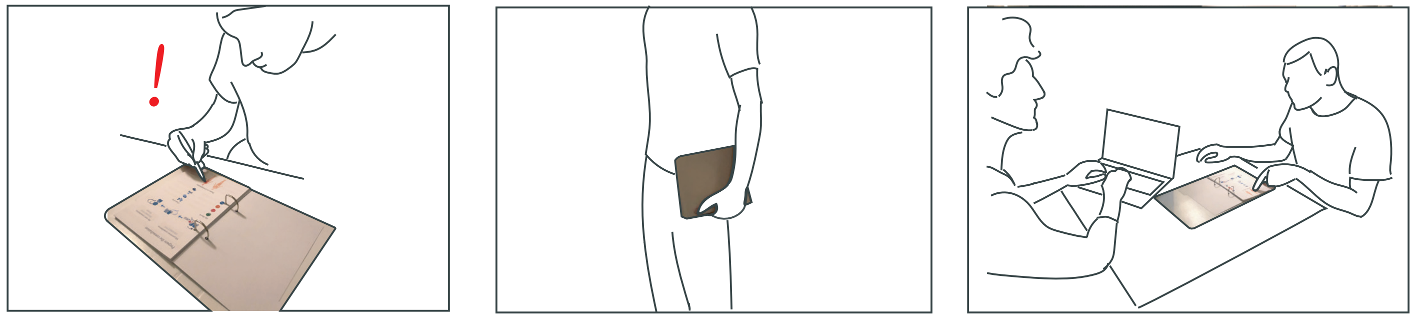
After the doctors consult, he has a consult with his personal nurse. She shows him the new wellbeing diary, WellRy.



She explains how it works and how it can be related back to the PROMs.

His nurse gives the patient a copy of WellRy to start using at home.

A few days later, the patient gets a bad stomach ache.



He remembers his WellRy and writes down his complaints.

A few months later, it is time for his next consultation at the Amsterdam UMC hospital. He brings his WellRy with him to his appointment.

During the consultation with his doctor, the patient is able to explain how his wellbeing fluctuated between his appointments.

Figure 40 - User scenario

7.5 Implementation

Step by step

The implementation of WellRy starts by teaching the HCPs how the diary works and what the desired effect is. This will be done by a presentation in which each element will be explained and discussed with the department. The nurses will be the ones who will determine which patients could benefit from the use of WellRy, they are therefore asked to try WellRy out themselves for one week to be immersed in the usage. This way they will be able to best explain how the end-user should make effective use of WellRy.

Next to the nurses, the ShivA foundation will be involved in the implementation. The existing peer-support community can play a big role when during the informal meetings people can discuss the usage of WellRy. The PB/Ss will be trained to understand the correct usage of WellRy, to make sure that they can guide and help their peers. They will be asked to start using a WellRy as well as a first pilot version and for them to be immersed in the usage too.

The first WellRy will be offered to the first patient that might benefit from the use of keeping track of their wellbeing. The nurse will explain how their version of WellRy works and will explain that the PB/Ss of the ShivA foundation also know about the diary and can help them when needed.

Two weeks later, an extra contact moment is planned. The nurse will check in with the patient to find out if the patient was able to remember the meaning of the visuals and if they had the chance to use their WellRy. If needed, the nurse will schedule an extra appointment to discuss how the diary works more thoroughly.

During the week before the next appointment, the WellRy-user will look back at the notes from the past months to find important matters.

In V2 and V3, the user will have the possibility to create a summary of the past months on the summary page as shown in Figure 36a and 37a. Before their appointment, the user will be asked to fill in the PROMs. Keeping track of their wellbeing allows the user to answer the asked questions easily and truthfully as they are more aware of it now. For V1, the user will not need to create a summary or fill in PROMs, as this does not fit their wishes and needs as discovered in the Chapter 3.

The user will bring their WellRy to the consultation with the HCPs to discuss it, potentially in combination with the answered PROMs.

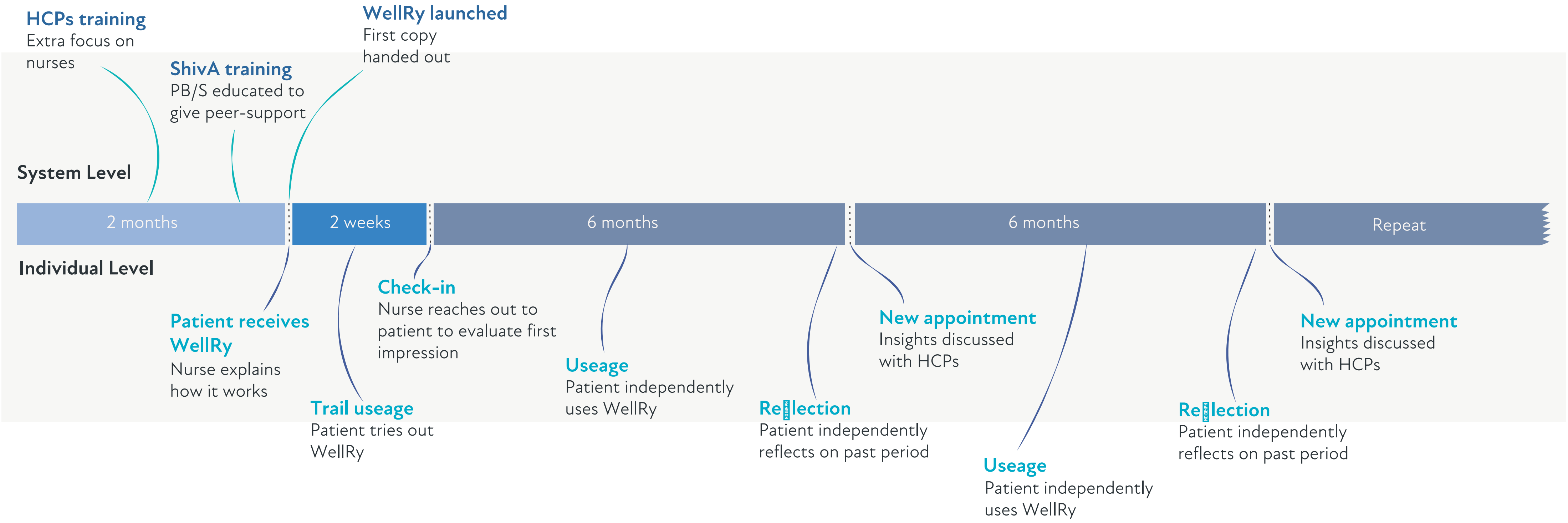


Figure 41 - Implementation plann

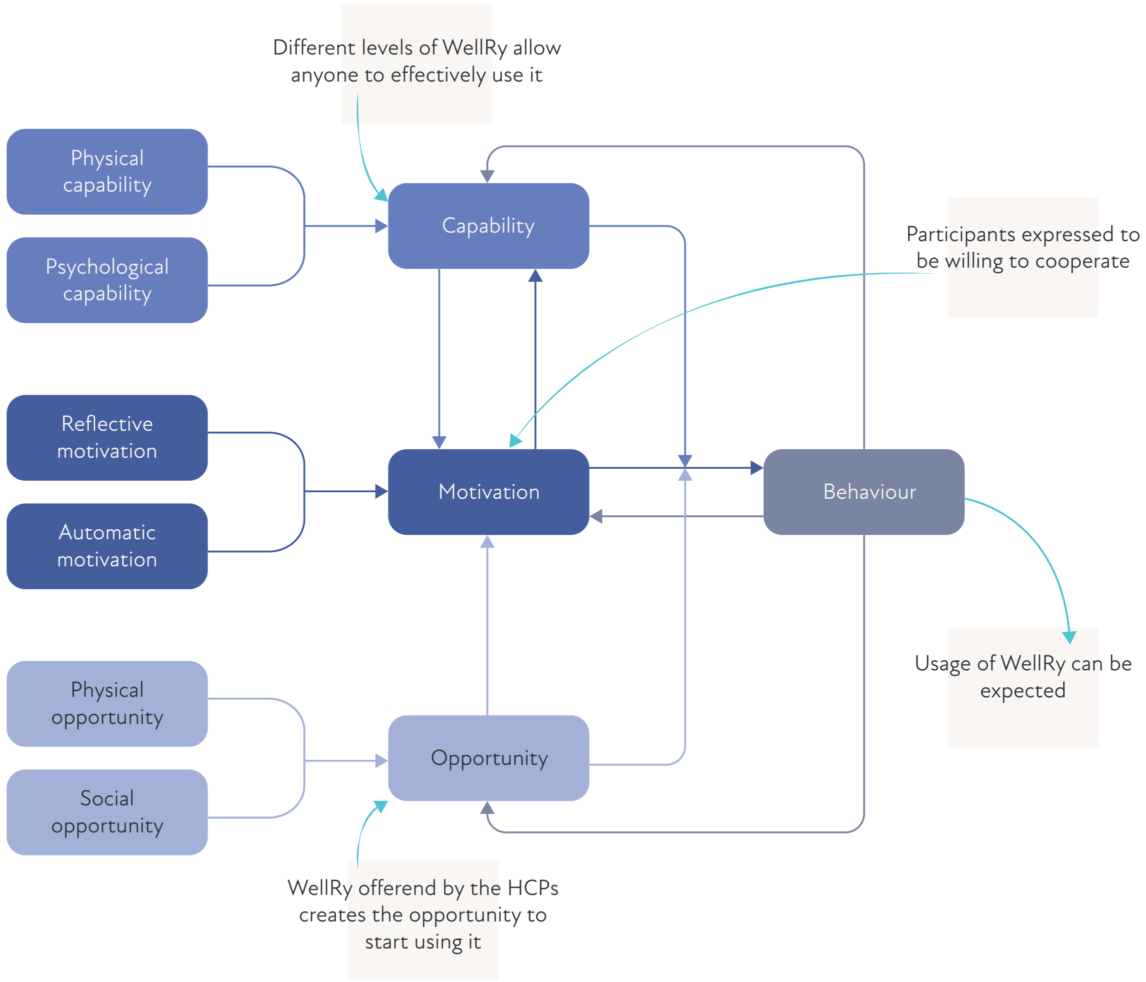


Figure 42 - COM-B model

Will it work?

As stated in the recommendations, how the product will be received is always complicated to predict accurately. The COM-B model shows that behaviour is influenced by a combination of capability, motivation, and opportunity (Michie et al., 2011). In this case, the desired behaviour is that the user will make use of WellRy to keep track of their wellbeing.

Capability; WellRy is built on the capabilities of the target group. This includes people who are digitally inclined and literate, but also people who have no digital skills and are low literate. Therefore, the capability of the user is sufficient.

Motivation; from the research phase it is found that the patients at the Amsterdam UMC are fond of their HCP and like to cooperate when it helps the doctor. If the nurses can explain how this helps the HCPs to better help the patient, the motivation of the patient can be established.

Opportunity; when WellRy is handed out by the hospital the tool is offered and the opportunity to make use of it is there.

8

Discussion: Final Considerations

8.1 Recommendations

8.1.1 Before implementation

Before the WellRy can successfully be implemented, there are three main recommendations to be made. These will ensure the quality of the product and increase the chance of success.

Co-creation

The development process of the final design presented in this report did not include a creative session with the end-users. Insights gathered during the overarching research phase functioned as handles during the ideation phase to find substantiated concepts. The conclusion is drawn, in Chapter 7, based on literature by Michie et al. (2011), that the desired behaviour can be expected as all components of the COM-B model are supported. WellRy is therefore a well-supported design but lacks the voice of the target group. Another iteration of the design could increase the desirability. This iteration should be based on the results of a co-creation session with the end-users and the nurses. The nurses can create the bridge between the intended use and the end-users. Literature states literature states that co-design is an effective tool for the production of technologies (EmERGE, 2020). The end-users are the people who will be using the WellRy regularly, and therefore are the most important stakeholders that stand behind the product. The nurses will be the stakeholders who need to instruct the end-users, therefore they need to advocate the product from full conviction.

Budget and physical shape

One of my personal goals was to design something that could, realistically, be implemented. Therefore, I decided that a cheap final product was of importance to assure that the hospital would be most likely to be able to produce the product. This creates a trade-off between a more expensive version of the WellRy that will be produced in the printing business, or printing the pages in-house and binding it manually. However, the final suggested physical form of the WellRy asks for more manhours as the product will be manually assembled after printing. As investment costs are low when WellRy is printed and bound in-house. Therefore, the physical shape of WellRy is not based on making the product look attractive. More research can be done in finding the best option for the outside of the WellRy. The way that WellRy is shaped, will determine the production technique needed and therefore have a significant effect on the costs. I would recommend starting with the in-house production. If the demand for WellRy increases, the decision can be made to order a larger quantity from a printing office. The physical shape is determined with a low budget in mind while searching for something neutral that could not be linked to a specific disease or condition

Evaluation

This directly leads to a recommendation to plan an evaluation moment, including a go/no-go moment. Despite the claim that the design is well-supported and should be received positively, how a new product is received by the target group is always a gamble. Human behaviour can largely be predicted but is subject to unforeseen outcomes. The patients within the HIV outpatient clinic visit the hospital every six months. After the launch of WellRy, we can expect that within one month the first group of WellRy users is created. Six months later, this first group will be back for their next appointment. During that consultation, the first effect of WellRy can be evaluated. Simultaneously, during these six months, all other patients have the chance to be introduced to WellRy. Therefore, seven months after the launch of WellRy an evaluation moment takes place. During this evaluation, the effect of WellRy should be discussed within the team of the infectious diseases department and potential needed adjustments. Another six months later, all WellRy-users should have been back for an appointment with their HCP, which makes this a good moment for the next evaluation.

Taking all relevant matters into account, an evaluation in which the follow-up plan for WellRy needs to be determined can take place approximately 18 months after the initial launch of WellRy. After 18 months, all patients have had the chance to use the WellRy for at least one year and therefore had the opportunity to learn how to use the product. During this evaluation, the conclusion needs to be drawn if WellRy has the desired effect and therefore the use needs to be continued or stopped. See Figure 43 for the implementation plan, with the evaluation moments included. Eventually, the team needs to be realistic and determine when to pull the plug if the desired effect of the intervention is not achieved.

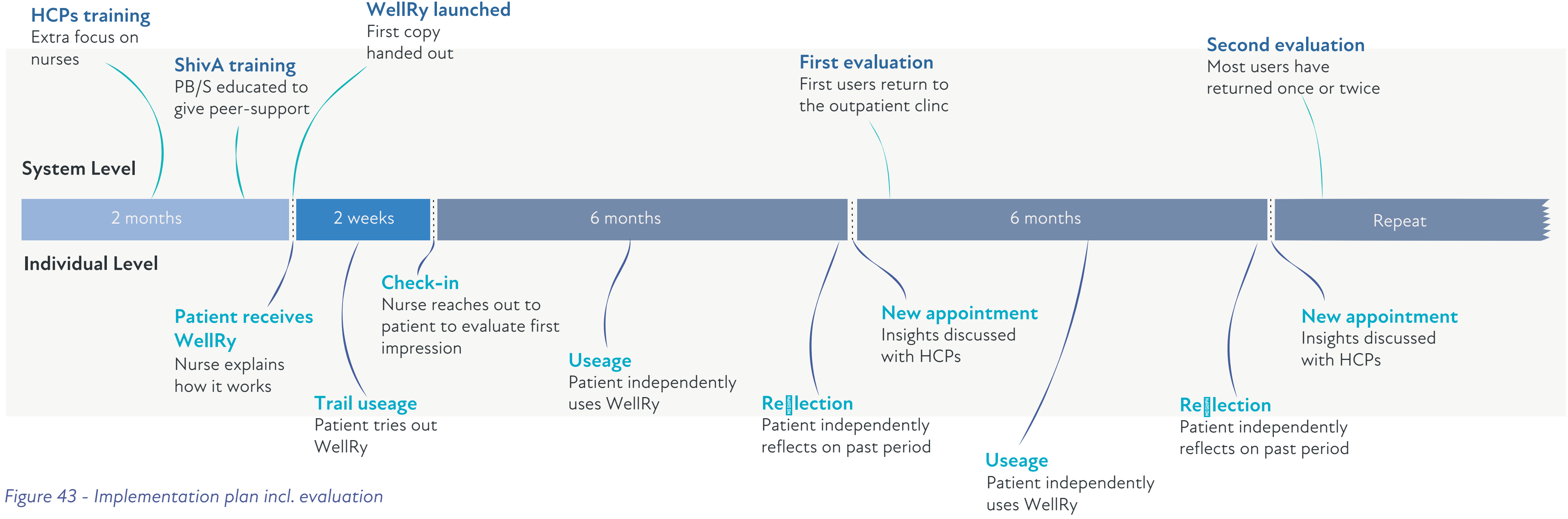


Figure 43 - Implementation plan incl. evaluation

8.1.2 For further research

Evaluation with experts

Many different experts' knowledge has been used to gain more insights throughout this research. For further research, it is recommended to take this to the next level and conduct more co-creation sessions and evaluations with people from different disciplines. For example, making use of the knowledge and wisdom of a psychiatrist can have a great added value for product implantation. They can help with finding the optimal way to meet the needs of the target group. Another example is to involve more of the nurses, the HIV-consultants, and use their expertise and field experience regarding the target group to assure that it fits in their vision of the needs of the target group.

Evaluation of the visuals

In the current design, the visuals are created based on existing tools and tested to verify if they are easy to interpret correctly, in the logic test in Chapter 5. No executive evaluation of the visuals has been executed. To strengthen the design, and be able to officially validate the WellRy diary as a medical tool, conducting an academically supported evaluation needs to be done.

Broadening the target group

The WellRy focuses on people living with HIV with a migration background. These people are known to struggle with reading or interpreting medical information. Therefore it was key to develop a product that is usable without relying on patient literacy. The essence of the product lies in the fact that someone is able to take note of their perceived wellbeing without needing to be able to read or write. Low literacy is an issue that exists in more fields than only the field of HIV care. For further research, it can be an interesting opportunity to broaden the target group and work towards a tool that allows people with low literacy skills who are living with any kind of chronic condition to keep track of their wellbeing.

8.2 Limitations

In Chapter 3.4.3, the initially found limitations of the qualitative research have been discussed briefly. These limitations are mainly the way of recruitment of the participants and the lack of saturation in research data. Apart from these, more limitations can be found that might have a limiting effect on the results of this overall project.

Social-desirability bias

Throughout my entire project, the personal relationship between HCPs and their patients was a topic that kept returning. This was greatly reflected during the interviews as described in Chapter 3, where the patients expressed great fondness for their HCPs. When a person has a personal relationship with someone, they might be under the influence of a social desirability bias and therefore try to give the desired answer instead of honestly answering the question.

Shame

Another reoccurring topic during this project was the effect of stigma and how people living with HIV feel ashamed when talking about their disease. The feeling of shame might have had a negative effect on how open and honest people dare to be when talking to a researcher. This reflects the complexity of the topic of this project and how important it is to build trust an allow the person involved to feel at ease.

Location

The interviews have been conducted in the outpatient clinic of the Amsterdam UMC either via a video or phone call. A limitation can be found in the fact that the participants might associate the setting with an HCP consultation for the interviews that were conducted inside the hospital, . This might have increased the social desirability bias due to the fact that they are physically in the same place as when they are interacting with their HCP. The interviews that virtually took place lacked the element of body language and facial expressions. This made it harder to "read the room" and anticipate in the best manner to maintain a positive atmosphere.

Underserved patient group

Designing for underserved patients can be challenging. As a designer, you need constant validation if the target group is quite distant from you. The target group of this project's scope is extra hesitant to be part of any research since they are often stigmatized. The quality of this research could have been improved if more time was available for reaching out to the target group. The extra time could be used for more contact moments with the target group or more people. Due to the limited time, the decision was made to move forward in the design process instead of investing too much time in the recruitment of a group of representative people.

Interview Participants

From the conducted interviews, four people have been recruited with help from the ShivA foundation. These people are actively part of this peer-support community and people who might be more proactive than the average underserved patient. If the opportunity would have been there to interview more people who are less proactive in their disease management, it might have been that different design directions would have emerged from the research phase.

Larger sample group

In this research, seven interviews with people from the target group were conducted. The decision was made to stop after this number because the first indication of saturation was found when different participants started to share similar experiences, but full saturation cannot be concluded. This decision was made due to the limited time for this project. Next to the interviews, the evaluation was only conducted with two representatives from the ShivA foundation. More improvements could have been found if an evaluation with a larger sample was executed.

Emotional load

On a more personal note, the limitation of the emotional load of this project needs to be discussed. Throughout my life, I have been in touch with people from different backgrounds. Knowing how to behave when interacting with the target group was therefore something that felt quite natural. I had to be aware of the sensitivity of the topics discussed, but I always made sure that the person with whom I was talking was feeling comfortable and I feel like I never crossed any boundary. In my research, I was looking for ways to improve the offered healthcare, I did not need to know any private details about their diagnosis or background. But my approach might have lacked a level of depth.

Besides my approach during interviews, the emotional impact on my wellbeing cannot be forgotten. During the first phase of this project, the research phase, I came across stories of people that I resonated with. I knew what I was getting into, but still it was a bit harder than I imagined. I struggled a lot with finding balance between empathizing with the target group and protecting my mental state. The personal investment in this project is much greater than can be reflected in a thesis. As a designer, you need to detach from your target group and step back in the shoes of the designer, but for me, that was quite a hard task as the topic is more complicated than any kind of project I have ever worked on.

9

Conclusion: Final Outcome

9.1 Introduction

This final Chapter describes the general conclusion of this project. All insights will be taken into consideration and a statement will be made about the original goal of this project. Next to the added value within the field of HIV care and the project of improving the QoL of people living with HIV will be discussed.

9.2 WellRy characteristics

Independence from relying on other organisations for implementation

The Amsterdam UMC will be the owner of the final product. A collaboration with the ShivA foundation is recommended as it includes peer support and makes sure that users can help and motivate each other. Eventually, the implementation will stay in the hand of the Amsterdam UMC, allowing them to be in charge of the implementation plan and make the final decisions.

A visual design that can be used independent of literacy level

WellRy comes in three different versions, each contains the same set of visuals but in a different hierarchy. This way each version fits the needs of the user based on their literacy level.

Affordability

Medical institutions are known for their tight budgets. WellRy can be produced with minimal resources, hence will be a cheap product. The affordability of WellRy matched the needs of a non-commercial institute like a hospital.

Low threshold

Because WellRy is a paper diary, the threshold of using a digital platform is removed. WellRy includes PROMs-like experiences that can be discussed during the consultations at the outpatient clinic.

9.3 Reaching the goal

This project started with the assignment goal to improve the collection of PROMs from people living with HIV with a migration background. The assignment goal was translated into the design goal;

> *"I want to design a tool/product/system that will help people living with HIV to take control over their disease management in the comfort of their own homes in between hospital visits to increase the value of the consultation without relying on literacy."*

Based on the evaluation we can conclude that WellRy has the potential to reach this goal. WellRy allows anyone to keep track of their wellbeing. After receiving your WellRy you will be able to keep track of all fluctuations. The user does not need to be literate or own a smartphone to be able to be in control over your disease management. WellRy can be the first step in the right direction.

9.4 Contribution and value

This research contributes to the project of the implementation of PROMs at the HIV outpatient clinic at the Amsterdam UMC. WellRy will act as a support for people that perceive filling in PROMs in the waiting room using an iPad as challenging. WellRy can be the bridge between their personal experiences at home and the translation into information that can be discussed with the HCPs.

The patient journey created in Chapter 3, gives a unique insight into the perception of people living with HIV with a migration background and allows the reader to step in their shoes. After the interviews, while considering the limitations, I can conclude that the PJ can be a great starting point for the infectious diseases department to reflect on its own practice. Although I can conclude that the department does a brilliant job, there will always be room for improvements as long as they stay curious about the experience of others.

WellRy focuses on serving those who need extra tools, those who can be considered as underserved. Existing apps rely on the digital skills and literacy of the user. The unique value of WellRy is its inclusive target audience. PROMs are implemented to improve early signalling of comorbidities and other issues in the personal lives of the patients, WellRy makes sure that those who need it the most are also able to keep track of their wellbeing and be included in the early signalling. Being more aware of your mental and physical wellbeing will ensure that the quality of PROMs.

Within the field of HIV care, there is a lot of ongoing research, but the designer perspective is still relatively new. My research shows that a human-centred approach can contribute in finding opportunities for improvements within the medical context.

> *In conclusion, I hope that my thesis will make a contribution to the field by inspiring fellow researchers.*

10

Personal Reflection

Personal Reflection

Designing in the field of healthcare

In my original project brief (Appendix 0) I have described how I saw this project as the perfect opportunity to explore the field of healthcare as a designer. I wanted to make my first patient journey and see how I, as a designer, could make a contribution to society. My expectations have been met, I made a PJ of which I am really proud of, and it has been confirmed to me that my work has been appreciated. Making the PJ was not an easy task: I received a lot of feedback after my first version, which was an acceptable start but it missed a lot of elements. I really had to dive deeper into reference material and learn new skills. Before starting with this project, I aspired to learn how to create a PJ and I did. If I would get the chance to create more PJ's in my professional career, I assume that I will improve my skills over time as my achieved skills are still not perfect. I enjoyed working on a topic that is important for our society. In a land as wealthy as the Netherlands, I see no reason why "underserved" patients should exist. We have the resources to serve everyone, we just need to make it a priority and continue with projects like this.

Variety in background

During my project, I had the chance to work with many people from different backgrounds. This differs from academic, experience, and cultural backgrounds. It was really interesting to learn from my supervisory team from the Amsterdam UMC, all three members had a unique background with different academic educations and experience in the field. I have learnt a lot of new things that were not common knowledge for an industrial design student. For example, I know exactly how HIV can be treated and how it attacks the human body, and I know a lot more about interviewing techniques. Next, I talked to many people with other cultural backgrounds than my own. It was an interesting challenge to adjust to my conversation partner and make sure that a friendly and open environment was established and maintained. Overall, every person involved during this project was really enthusiastic and happy to cooperate. I had a lot of fun while meeting every single person.

Organizational skills

Throughout my project, there were many stakeholders involved. Especially a supervisory team of five people requires some extra attention as it was my task to keep everyone on board. I really liked that challenge as it forced me to work according to planning and communicate a lot. Working individually is part of a graduation project, but it is not what I prefer, therefore working with this large team was a good alternative. I had a lot of people to spar with to find out what would be the best option.

Co-creation

In my project brief, I mentioned that I want to incorporate co-creation with the target group. Unfortunately, I did not manage to arrange such a session. As a substitute, I have spent extra time to find a fitting analogy that could help someone outside of the target group to empathize with the problem. That analogy helped me to do a creative session with someone else and did lead to useful results. But, in a perfect version of my graduation, I would have loved to host a creative session with the actual target group.

Personality

Lastly, I wanted to showcase my unique personality as a designer. I consider myself a designer who designs for happiness and focuses on adding value to someone's life. During my project, I felt the freedom to act upon my personal style. Eventually, PROMs are being implemented to improve the perceived quality of life of a person living with HIV. My ideologues fit this aim, which made this project and myself a good match.

In conclusion

Overall looking back at my project, I can conclude that I managed to learn quite a lot. I feel a lot more confident about my skills and hope to never stop learning. Throughout the past months, I sat on an emotional rollercoaster with highs and lows as any graduate student probably recognizes, but I do not regret a thing. I really loved working on this project and I hope that my enthusiasm is reflected in my work.

11

References

1. AD, & Van Rootselaar, A. (2021, 18 oktober). Aidsfonds naar aanleiding van uitspraken Baudet: 'Hiv discrimineert niet'. AD.nl. https://www.ad.nl/binnenland/aidsfonds-naar-aanleiding-van-uitspraken-baudet-hiv-discrimineert-niet~aabe6759/

2. Amini, M., Oemrawsingh, A., Verweij, L. M., Lingsma, H. F., Hazelzet, J. A., Eijkenaar, F., & Van Leeuwen, N. (2021). Facilitators and barriers for implementing patient-reported outcome measures in clinical care: An academic center's initial experience. Health Policy, 125(9), 1247–1255. https://doi.org/10.1016/j.healthpol.2021.07.001

3. Artseneed, C. H. & Commissie Herziening Artseneed. (2003). Nederlandse artseneed. Vereniging van Universiteiten (VSNU).

4. Becker, M. H. "The Health Belief Model and Personal Health Behavior." Health Education Monographs, 1974, 2, 324–473.

5. Bil, J. P., Zuure, F. R., Alvarez-del Arco, D., Prins, J. M., Brinkman, K., Leyten, E., Van Sighem, A., Burns, F., & Prins, M. (2019). Disparities in access to and use of HIV-related health services in the Netherlands by migrant status and sexual orientation: a cross-sectional study among people recently diagnosed with HIV infection. BMC Infectious Diseases, 19(1). https://doi.org/10.1186/s12879-019-4477-2

6. Curtis, L. M., Wolf, M. S., Weiss, K. B., & Grammer, L. C. (2012). The Impact of Health Literacy and Socioeconomic Status on Asthma Disparities. Journal of Asthma, 49(2), 178–183. https://doi.org/10.3109/02770903.2011.648297

7. Deacon, H. (2006). Towards a sustainable theory of health-related stigma: lessons from the HIV/AIDS literature. Journal of Community & Applied Social Psychology, 16(6), 418–425. https://doi.org/10.1002/casp.900

8. Devlin, N. J., Appleby, J., Buxton, M., King Edward's Hospital Fund for London, King's Fund Centre (London, E. S., & Office Of Health Economics (London, E. S. (2010). Getting the Most Out of PROMs. King's Fund.

9. Doody, O., & Noonan, M. (2013). Preparing and conducting interviews to collect data. Nurse Researcher, 20(5), 28–32. https://doi.org/10.7748/nr2013.05.20.5.28.e327

10. EmERGE. (2020, February). Policy and practice guidelines: Report on guidelines to support co-design for improved usability, acceptability and patient outcomes in mHealth developments. https://www.emergeproject.eu/_files/d/36a067_04a5cc9ca05646eb9ff5d32a8d649e66.pdf?index=true

11. Erlen, J. A. (2004). Functional Health Illiteracy. Orthopaedic Nursing, 23(2), 150–153. https://doi.org/10.1097/00006416-200403000-00015

12. Gallant, J., Hsue, P. Y., Shreay, S., & Meyer, N. (2017). Comorbidities Among US Patients With Prevalent HIV Infection—A Trend Analysis. The Journal of Infectious Diseases. https://doi.org/10.1093/infdis/jix518

13. Ghaddar, S. F., Valerio, M. A., Garcia, C. M., & Hansen, L. (2011). Adolescent Health Literacy: The Importance of Credible Sources for Online Health Information. Journal of School Health, 82(1), 28–36. https://doi.org/10.1111/j.1746-1561.2011.00664.x

14. Glanz, K., Rimer, B. K., & Viswanath, K. (2008). Health Behavior and Health Education. Wiley.

15. Griffcc D.T. (2005) Research tips: interview data collection. Journal of Developmental Education. 28. 3. 36-37.

16. Hauth, F., Bizu, V., App, R., Lautenbacher, H., Tenev, A., Bitzer, M., Malek, N. P., Zips, D., & Gani, C. (2019). Electronic Patient-Reported Outcome Measures in Radiation Oncology: Initial Experience After Workflow Implementation. JMIR mHealth and uHealth, 7(7), e12345. https://doi.org/10.2196/12345

17. Hernando, V., Alvárez-del Arco, D., Alejos, B., Monge, S., Amato-Gauci, A. J., Noori, T., Pharris, A., & Del Amo, J. (2015). HIV Infection in Migrant Populations in the European Union and European Economic Area in 2007–2012. JAIDS Journal of Acquired Immune Deficiency Syndromes, 70(2), 204–211. https://doi.org/10.1097/qai.0000000000000717

18. HIV.gov. (2021, April 8). What Are HIV and AIDS? Retrieved 13 February 2022, from https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids

19. Hochbaum, G. M. (1958). Public Participation in Medical Screening Programs. .S. Department of Health, Education, and Welfare, Public Health Service, Bureau of State Services, Division of Special Health Services, Tuberculosis Program, 1958.

20. Kirscht, J. P. (1974). The Health Belief Model and Illness Behavior. Health Education Monographs, 2(4), 387–408. https://doi.org/10.1177/109019817400200406

21. Kozak, M. S., Mugavero, M. J., Ye, J., Aban, I., Lawrence, S. T., Nevin, C. R., Raper, J. L., McCullumsmith, C., Schumacher, J. E., Crane, H. M., Kitahata, M. M., Saag, M. S., & Willig, J. H. (2011). Patient Reported Outcomes in Routine Care: Advancing Data Capture for HIV Cohort Research. Clinical Infectious Diseases, 54(1), 141–147. https://doi.org/10.1093/cid/cir727

22. Kreps, G. L., & Sparks, L. (2008). Meeting the health literacy needs of immigrant populations. Patient Education and Counseling, 71(3), 328–332. https://doi.org/10.1016/j.pec.2008.03.001

23. Lambert S.D. & Loiselie C. (2008) Combining individual interviews and focus groups to enhance data richness. Journal of Advanced Nursing. 62. 2. 228-237.

24. Lerner, A. M., Eisinger, R. W., & Fauci, A. S. (2020). Comorbidities in Persons With HIV. JAMA, 323(1), 19. https://doi.org/10.1001/jama.2019.19775

25. Maman, S., Abler, L., Parker, L., Lane, T., Chirowodza, A., Ntogwisangu, J., Srirak, N., Modiba, P., Murima, O., & Fritz, K. (2009). A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings. Social Science & Medicine, 68(12), 2271–2278. https://doi.org/10.1016/j.socscimed.2009.04.002

26. Mayfield Arnold, E., Rice, E., Flannery, D., & Rotheram-Borus, M. J. (2008). HIV disclosure among adults living with HIV. AIDS Care, 20(1), 80–92. https://doi.org/10.1080/09540120701449138

27. Michie, S., Van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implementation Science, 6(1). https://doi.org/10.1186/1748-5908-6-42

28. Nakagawa, F., May, M., & Phillips, A. (2013). Life expectancy living with HIV. Current Opinion in Infectious Diseases, 26(1), 17–25. https://doi.org/10.1097/qco.0b013e32835ba6b1

29. Nall, R. M. (2020, April 24). How Does HIV Affect the Body? Healthline. Retrieved 15 February 2022, from https://www.healthline.com/health/hiv-aids/how-hiv-affects-the-body#:%7E:text=HIV%20destroys%20CD4%20cells%20by,will%20have%20progressed%20to%20AIDS.

30. Nellen, J. F., Wit, F. W., De Wolf, F., Jurriaans, S., Lange, J. M., & Prins, J. M. (2004). Virologic and Immunologic Response to Highly Active Antiretroviral Therapy in Indigenous and Nonindigenous HIV-1???Infected Patients in The Netherlands. JAIDS Journal of Acquired Immune Deficiency Syndromes, 36(4), 943–950. https://doi.org/10.1097/00126334-200408010-00008

31. Rabionet, S. (2014). How I Learned to Design and Conduct Semi-structured Interviews: An Ongoing and Continuous Journey. The Qualitative Report. Published. https://doi.org/10.46743/2160-3715/2011.1070

32. Rath, T., & Harter, J. (2010). Wellbeing (1ste editie). Amsterdam University Press.

33. RIVM, & Van Veen, M. (2010, december). Hiv- en soaepidemiologie bij hoogrisicogroepen in Nederland. https://www.rivm.nl/

hiv-en-soaepidemiologie-bij-hoogrisicogroepen-in-nederland

34. Rosenstock, I. M. (1974). The Health Belief Model and Preventive Health Behavior. Health Education Monographs, 2(4), 354–386. https://doi.org/10.1177/109019817400200405

35. Sanders, L., & Stappers, P. J. (2013). Convivial Toolbox: Generative Research for the Front End of Design (Illustrated ed.). Laurence King Publishing.

36. Scbwandt T.A. (2001) Qualitative Inquiry: A Dictionary Of Terms. Second edition. Sage Publications, Thousand Oaks CA.

37. Schultze U. & Avital M. (2011) Designing interviews to generate rich data for information systems research. Information and Organization. 21, 1, 1-16.

38. Schumacher, J. E., McCullumsmith, C., Mugavero, M. J., Ingle-Pang, P. E., Raper, J. L., Willig, J. H., You, Z., Batey, D. S., Crane, H., Lawrence, S. T., Wright, C., Treisman, G., & Saag, M. S. (2012). Routine Depression Screening in an HIV Clinic Cohort Identifies Patients with Complex Psychiatric Co-morbidities Who Show Significant Response to Treatment. AIDS and Behavior, 17(8), 2781–2791. https://doi.org/10.1007/s10461-012-0342-7

39. Smith J.A., Flowers P., Larkin M., (2009) Interpretative Phenomenological Analysis: Theory, Method and Research. Sage Publications, London.

40. Soa Aids Nederland. (2020, November 19). Hiv-cijfers in Nederland. Retrieved 9 February 2022, from https://www.soaaids.nl/nl/professionals/themas/soa-hiv-cijfers/hiv-cijfers-in-nederland

41. Soa Aids Nederland. (2021, May 4). Hiv. Retrieved 15 February 2022, from https://www.soaaids.nl/nl/alle-soas/hiv

42. Thonon, F., Perrot, S., Yergolkar, A. V., Rousset-Torrente, O., Griffith, J. W., Chassany, O., & Duracinsky, M. (2021). Electronic Tools to Bridge the Language Gap in Health Care for People Who Have Migrated: Systematic Review. Journal of Medical Internet Research, 23(5), e25131. https://doi.org/10.2196/25131

43. Van Boeijen, A., & Daalhuizen, J. (2013). Delft Design Guide (4de editie). BIS.

44. Van den Berg, J., Hak, E., Vervoort, S., Hoepelman, I., Boucher, C., Schuurman, R., & Schneider, M. (2005). Increased risk of early virological failure in non-European HIV-1-infected patients in a Dutch cohort on highly active antiretroviral therapy. HIV Medicine, 6(5), 299–306. https://doi.org/10.1111/j.1468-1293.2005.00304.x

45. Van Weel, C., Noordelijke Centrum voor Gezondheidsvraagstukken, World Organization Of National Colleges, A., & European Research Group on Health Outcomes. (1995). Measuring Functional Health Status with the COOP/WONCA Charts. Noordelijke Centrum voor Gezondheidsvraagstukken.

46. van Winkle, B., Carpenter, N., & Moscucci, M. (2017). Why Aren't Our Digital Solutions Working for Everyone? AMA Journal of Ethics, 19(11), 1116–1124. https://doi.org/10.1001/journalofethics.2017.19.11.stas2-1711

47. West, R., & Brown, J. (2013). Theory of Addiction. Wiley.

48. World Health Organization. (2018, February 22). Health inequities and their causes. Retrieved 8 February 2022, from https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes

12

Appendices

DESIGN FOR our future

TU Delft

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 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 Wolterink
initials S. given name Sharda
student number 4371046
street & no.
zipcode & city
country
phone
email

Your master programme (only select the options that apply to you):
IDE master(s): ○ IPD ● DfI ○ SPD
2nd non-IDE master:
individual programme: - - (give date of approval)
honours programme: ○ Honours Programme Master
specialisation / annotation: ● Medisign
○ Tech. in Sustainable Design
○ Entrepeneurship

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 Marc van der Valk
organisation: Amsterdam UMC
city: Amsterdam country: Netherlands

comments (optional)

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

TU Delft

APPROVAL PROJECT BRIEF

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

chair Marijke Melles date 14 - 09 - 2021 signature MMelles

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: 24 EC
Of which, taking the conditional requirements into account, can be part of the exam programme 24 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 20 - 09 - 2021 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

comments

name Monique von Morgen date 28/9/2021 - signature

Initials & Name S. Wolterink Student number 4371046
Title of Project Improving the collection of PROMS from underserved HIV patients.

Improving the collection of PROMS from underserved HIV patients. 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 13 - 09 - 2021

18 - 02 - 2022 end date

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, ...).

Since the discovery of HIV, the treatment of people living with HIV (PLWHIV) has come a long way. The diagnosis of HIV does not sound like the death sentence it once was, and the life expectancy is almost similar to the general population. Still, the life of a person living with HIV looks quite different than someone who has not been infected. PLWHIV are more likely to suffer from other chronic conditions at a young age and need to pay extra attention to their personal health.

Active self-management and health literacy are therefore essential for the remainder of the patient's life. Because of this, the Amsterdam UMC HIV outpatient clinic focuses on improving the Quality of Life (QoL), intending to provide small-scale and personal care to their patients. Giving them the most healthy and ordinary life possible with a broad focus on other somatic and mental conditions as well as social problems that coincide with HIV.

To support this focus on improving the QoL, the Amsterdam UMC HIV outpatient clinic recently started a trajectory in which Patient Reported Outcome Measures (PROMS) form an integral part of treatment. This trajectory aims to provide an early signaling system to provide individualized care to achieve early intervention where needed. To collect data on PROMS, patients filling in questionnaires before their outpatient visit is essential. These questionnaires give the HIV treatment team insight into a patient's mental situation, treatment compliance, substance use, the burden of HIV stigma, and other important information. To streamline and digitize the collection of this kind of data, a platform is in development.

However, in the collection of this data, the underserved patient groups are at risk of falling behind. A substantial part of HIV patients in care are born outside of the Netherlands and, as a group, were found to have a higher risk of treatment failure. For this project, the focus is on men and women born in Ghana and Nigeria who are living with HIV. Literature shows that this patient group is unsuccessful in filling in the given PROMS. Especially in this group of patients, the information their clinician needs tends to be discovered later than necessary for various reasons.

space available for images / figures on next page

---

introduction (continued): space for images

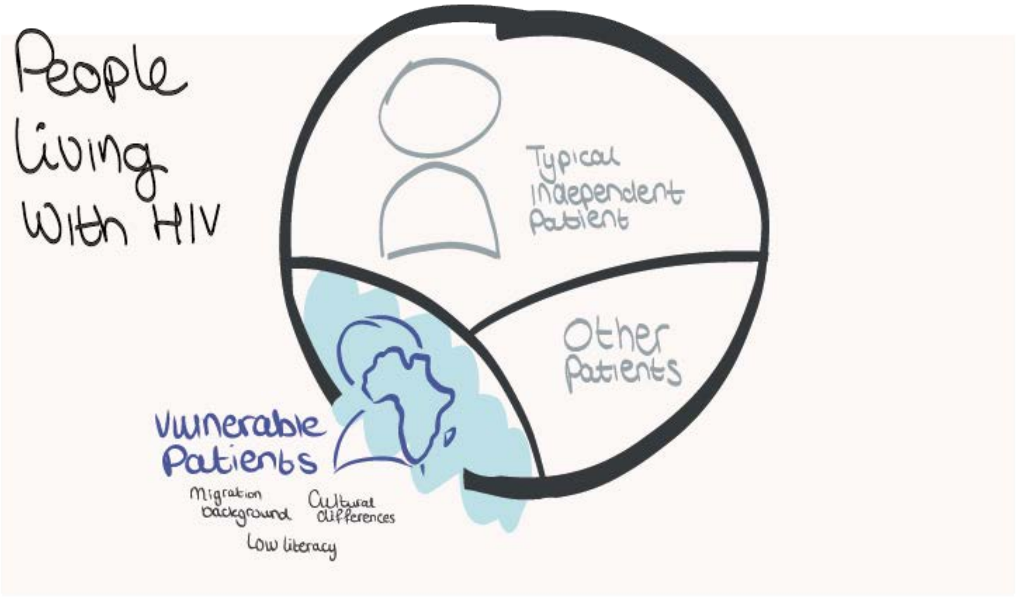


image / figure 1: Patient group within Amsterdam UMC

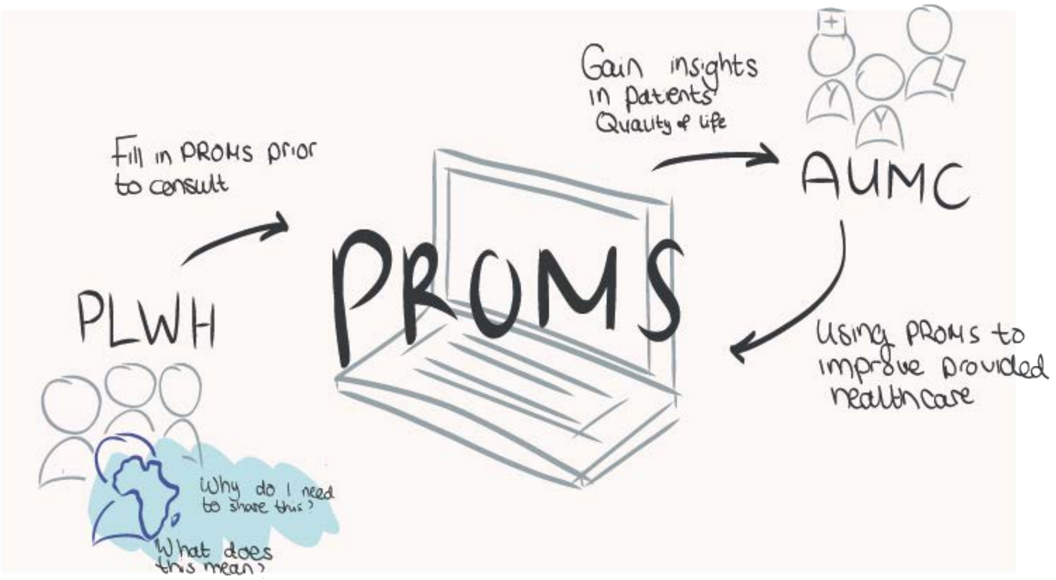


image / figure 2:

Personal Project Brief - IDE Master Graduation

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.

Currently, the Amsterdam UMC is working with PROMS to gather more insights into the quality of life (QoL) of People living with HIV (PLWHIV). The problem arises that the underserved patient group is at risk of falling behind when only standard methods are used. Research has shown that this underserved patient group exists of patients with a migration background, who are not fully skilled with the Dutch languages and come from a different culture with different ways of thinking and values in particular regarding HIV.

The language barrier for PLWHIV with a migration background is primarily cited as the root cause of the PROMS not being responded to properly, but then – on the first view – a simple solution of translating these requires significant time. A PROM needs to meet the "psychometric integrity" and can therefore not be altered in any way. If we wish to translate the PROM, or change or remove even one question, the PROM needs to be validated once again (Moody & EATG PROMise Task group, 2021). When translating the PROM, it is still the question of whether or not you are able to compare the Dutch and translated PROM with each other and draw general conclusions about the entire patient group.
Culture and background play a significant role regarding how open and honest a person wants to be when sharing personal details in the PROMs. Globally we are still seeing a big taboo when it comes to being infected with HIV, and in some countries, it is even seen as a punishment or just what you deserve. "In Tanzania and Zimbabwe, behaviors that led to HIV were often described as "irresponsible", "reckless" and "immoral." As a result, many individuals in these sites felt that PLWHA got what they deserved in terms of being punished for their reckless behavior." Maman et al. (2009).

PROMs are now being implemented via a digital platform, but the digital skills and access to digital tools are not sufficient for all PLWH with a migration background. Therefore, another issue arises when looking at the practical side of the matter of implementing PROMs in this field of healthcare.

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 main goal of this graduation project is to improve the collection of PROMS from PLWH with a migration background. This will be done by researching what the deeper issue is for PLWH with a migration background when it comes to participating in PROMS and investigating how design can have a positive impact on the overall patient journey and engagement with PROMS.

First, I will research the barriers and facilitators for patients with a migration background within the Amsterdam UMC HIV outpatient clinic. The outcome of this research will function as a starting point to design a tool or service and/or a redesign of the patient journey, that will help these patients to feel empowered in their disease management and improve engagement with PROMS. I will perform research through desk (e.g. literature and online available information) and field (e.g. observing patient consults, interviewing patients and medical professionals, and observing and participating in department meetings) research. I want to use as much co-creation as possible, as literature shows that this is an essential element when working with PLWHIV (EmERGE, 2020).

At the end of the research phase, I want to create a patient journey and a vision that concludes the gained information. The patient journey will be a representation of the current situation and the vision will be an inspirational document that will help me to find a design direction. With my design direction, I will be able to find design opportunities leading to concepts. I aim to deliver a product-service combination that is realistic to be implemented. My final design proposal needs to make sure that PROMS are optimal to improve disease management and the QoL of the PLWHIV with a migration background from Ghana and Nigeria.

This project is part of the Medisign specialization as it focuses on improving the quality of healthcare. Looking at what the patient really needs and making this available for the healthcare provider.

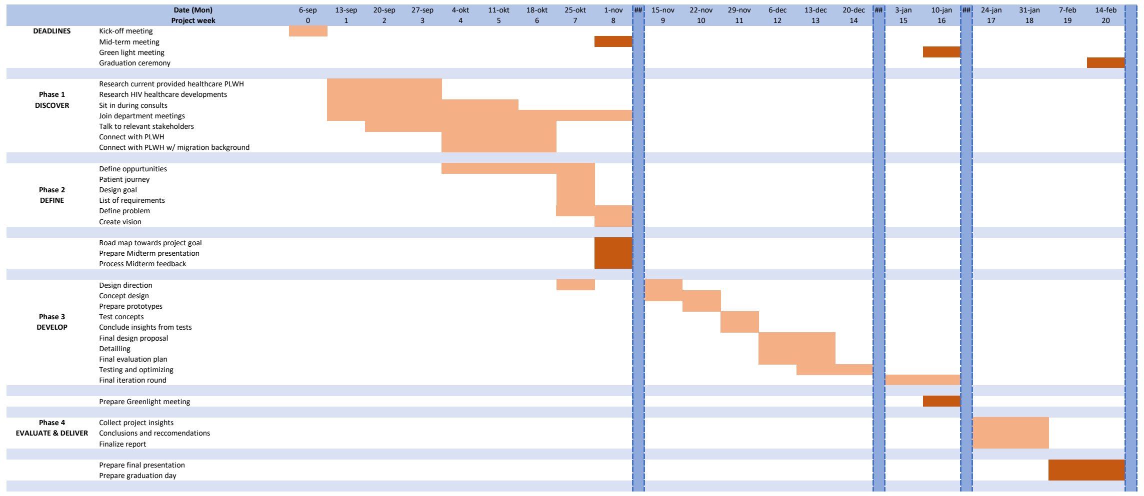
Personal Project Brief - IDE Master Graduation

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 13 - 9 - 2021

18 - 2 - 2022 end date



My overall planning consists of exactly 100 working days and includes 3 weeks of holidays.
I want to spend the first 6 weeks fully exploring the scope and learning all about the patients' lives. As I plan to create a patient journey, I will need to be fully aware of their current experience in order to put this into an overview.
Throughout my discover phase, I need to make sure to write down all the opportunities I come across. This will help me in the next phase. Due to the fact that I expect to need quite some time to discover the field, I want the "define" phase to be quick and efficient. Within one week I expect to be able to conclude all my gathered information. To make sure this is possible, I need to make sure to always document everything I find in the first 6 weeks quite nicely and take time to do so.
After my midterm, I will take a week to recover and reset for the third phase. I expect that the first phase might be emotionally heavy and therefore I want to have some time to relax before going on.

I expect that I will find motivation and inspiration in my thesis but if at any time, I feel like the emotional baggage of this project gets too heavy, I will reach out to any of my supervisors. Next to that, I have my closest friends with whom I can talk about anything, so I know that my support system will be there for me throughout the entire project.

Once I'm all energized and back after my break, it's time to start ideating in the develop phase. With different brainstorming techniques, I will be able to find my design direction and create concepts. In the best case, I will be able to organize a creative session with my target group to find out all about their ideas regarding the issue. But due to the sensitivity of this topic, I do not want to assume that the target group is willing to participate. I, therefore, need to invest in personal bonds with the target group when I connect to them in the first phase.

Personal Project Brief - IDE Master Graduation

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.

This project feels like the perfect opportunity to combine all my strengths and still learn something new. As a designer, I aspire to work in the field of healthcare and this feels like the final rehearsal before getting there. I have never worked with patient journeys, so I aspire to learn how to create one during my project. My interest in the field of Medisign originates from a small identity crisis where I was asking myself what the point is of being a designer in our current world. I feel a strong urge to contribute to our society and not just come up with new things to make money for myself. Designing for healthcare systems feels like the perfect way to help create a better world with the knowledge I have gained in my academic and personal life.

In my teenage years, I was part of a multi-cultural society within my high school. This taught me valuable things regarding different cultures and how to be respectful to anyone, even when their values differ quite a lot from my own. This project will be a moment to prove to myself that I do have the people skills I think I have.

The past recent years, I have been highly involved in different rowing crews. I always felt motivated to make sure that all the things behind the scenes were well organized and I always had to stay on top of all the things that were happening and changing. I believe that this organizational skill will be put to the test when dealing with all the different stakeholders and making sure that my team stays up to date throughout the entire project. I'm looking forward to improving this skill in this professional field.

Another skill I would aspire to gain is the skill to incorporate co-creation in my design process. I want to learn how to involve the target group and make sure to dive deeper than just find the superficial ideas that will arise initially. I participated in the block course "Creative facilitation" and hope to be able to use the skills gained from this course in practice.

Lastly, this project will be a way to express my unique personality as a designer. I love to design for people and have an impact on their life. Adding value instead of only increasing revenue. In this project I want to show that I can design for happiness and healthcare, designing something that improves the quality of life. I, therefore, think that this project is the perfect opportunity for me to design something that makes me proud.

FINAL COMMENTS

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

Interview guide

Introduction

Hi there, first of all, I want to thank you for taking some time for this interview. My name is Sharda and I am a university student and I'm doing my graduation project for this (Amsterdam UMC) hospital. I am interested in your experiences with the hospital and the way you are receiving care. Other people will be interviewed as well. We will use this information to explore whether we can improve the way we organise health care in any way.

For this interview, I have prepared a set of questions and topics. We will discuss some basic personal information, details about your contact with the doctor and the nurses, and how you experience your hospital visits. Please note that I'm not trying to get information about how your doctor or nurse does their job. I'm interested in your experience only. Before we can start, we will discuss the issue of informed consent. I have prepared a document that indicates your willingness to participate in our research and that you understand what this project is about. I propose we go through the consent form and if you agree to participate you can sign it and then we can start.

[go through the consent form]

As part of the consent form, we discussed making audio recordings of our conversations and to make personal notes. This is important to me as this allows me to listen back to the things we've discussed and to organise what we are discuss during this interview. No one except me will be able to listen to the audio or see these notes. Is it okay for you if I start the recording?
→ start audio record and begin the interview.

Start of the interview

[General questions]

Let's start with some general questions.

- How old are you?
- Where are you from?
- How long have you been a patient here at the AMC Hospital?
- Did you receive any health care in another hospital?
    - Or in another county?

Hospital visit

- How often do you visit to the AMC Hospital?
- When was your last visit?
- How do you know when your appointment is planned? How do you learn when and where you need to be?
- How do you feel when you step into the Hospital building?
- The AMC hospital is quite large, do you feel comfortable when you need to find your way to the outpatient clinic?
- Can you explain to me what steps you need to take during your visit at the AMC hospital?
    - Like, you walk to the clinic and sign in at the counter…. And then?
- How do you experience the waiting time in the waiting room before your consultation?

Disclosure

- Can you tell me a little bit more about how it is to live with HIV in relation to others like your family members, friends and neighbours?
    - {Probe if needed} Do the people in your life know about your positive status or do you feel like you need to keep it a secret?
- How do you feel when you're walking through the AMC Hospital?
    - Are you ever worried that someone will see you in the hospital?

Personal relationship

- Who are your doctor and nurse?
    - *Acknowledge that I know them personally*
    - Have they always been your doctor and nurse or did you ever switch?
    - {If yes} Can you tell me why you switched?
- Can you tell me a little bit about how it is to receive care from Doctor {name doctor}?
    - What makes it this good/difficult/{…given answer…}?
- What topics do you generally discuss with Doctor {name doctor}?
- How do you feel when you talk about these topics?
    - Do you sometimes feel awkward or uncomfortable?
        - {if not} What makes the difference between talking to the doctor or maybe someone outside the hospital?
- And can you tell me a little bit about how it is to receive care from {name Nurse}?
    - What makes it this good/difficult/{…given answer…}?
- What topics do you generally discuss with Nurse {name nurse}?
- How do you feel about these topics?
    - Do you sometimes feel awkward or uncomfortable?
        - {if not} What makes the difference between talking to the doctor or maybe someone outside the hospital?
- Can you give me an example of something you can discuss with the doctor and not with the nurse or the other way around?

Communication

- How do you experience the communication between you and the Doctor?
    - Has it ever happened that the Doctor explains something that is quite complicated?
        - {If yes} How do you feel when that happens?
- Do you sometimes receive information printed on paper?
    - {If no} Would you like to receive information on paper?
        - Why?
    - {if yes} What do you do with the information that you receive on paper?
        - Does it help you to remember the shared information?

Currently the hospital is working on improving the care they offer and want to start with using questionnaires. You can fill this in at home through MyChart or in the waiting room when you arrive for your appointment. When you are waiting for you appointment in the waiting room, they will give you an ipad with the questions. The questions will be for example about how you are feeling, how you are experiencing the medication and if you have any physical complaints. Then the results will be shared with the doctor and the nurse, so when you come in the consultation, they will see an overview of your answers. This should help the doctor to talk about the topics that matter the most.

- How would you feel if you would be asked to fill in this questionnaire in the waiting room?
- And how would you feel when this questionnaire asks you to share extra information?
- After filling the questionnaire in, the doctor and nurse will see your answers and they are able to see what issues should be discussed. How would you feel when the doctor or nurse wants to discuss topics from the questionnaire?
  - Essential point to further discuss!! → Here I will need to start a conversation

The hospital uses this online portal called MyChart (MijnDossier) where you can find your test results and overview of your appointments.

- Do you use MyChart (MijnDossier) ?
  - Is there a specific reason why not?
    OR
  - How often do you use it? How do you feel about this platform?

Health literacy

- What do you do when you have any questions about HIV questions between appointments?
- Are there any sources that you think are trustworthy to get information about HIV?
- When the doctor/nurse explains something about how the treatment works, how do you feel?
- Do you spend time finding more information about living with HIV and the effects on your health?

No Shows

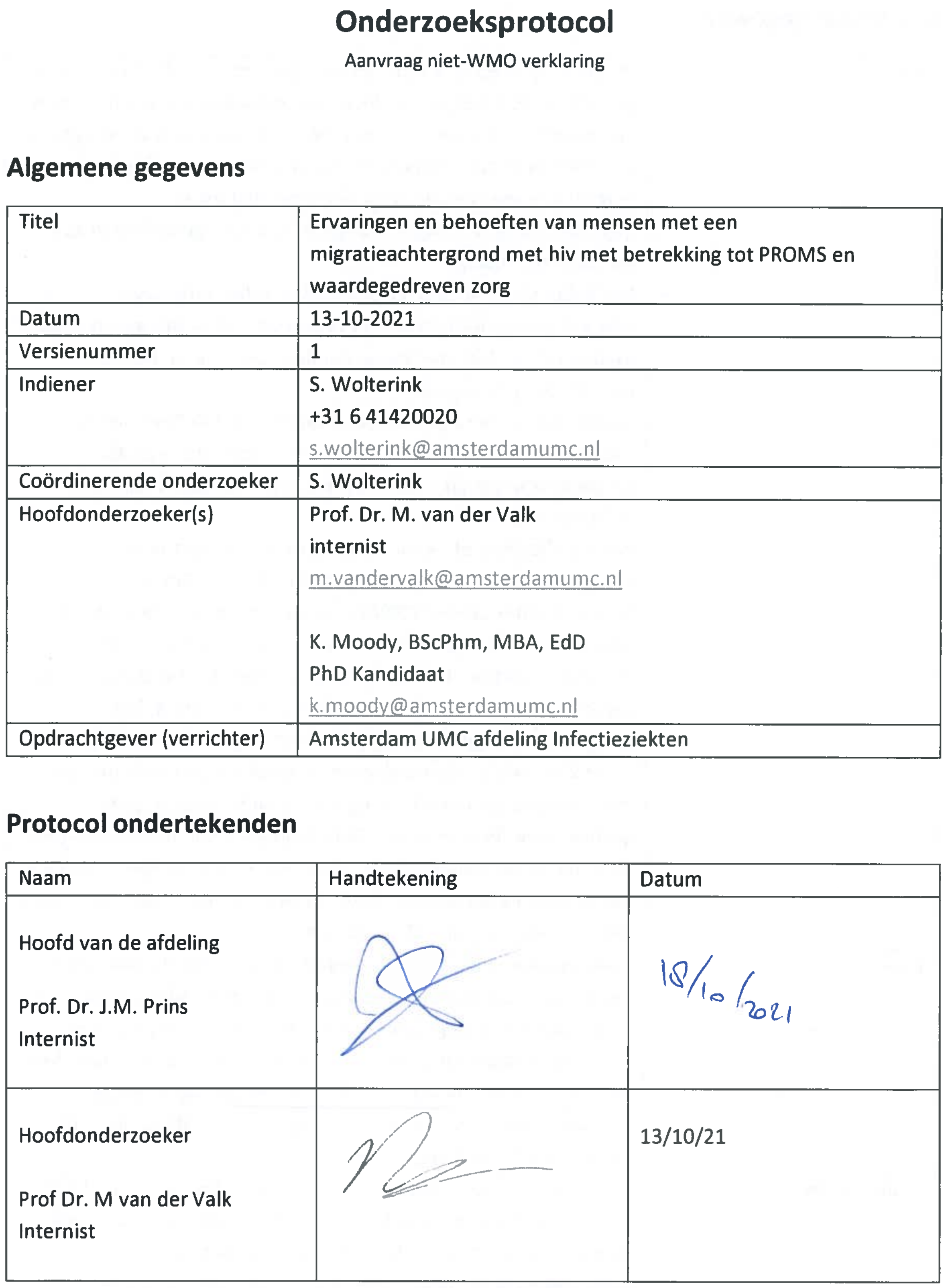
- Do you feel like your appointments at the AMC hospital are important?
  - Why? {Depending on initial response}
- Does it ever occur that you don't want to go to your appointment?
- Have you ever missed an appointment?
  - What was the cause for missing it?
- How do you feel when you know you have an appointment at the AMC hospital?

Wrapping up

I think that for now I have enough information, I want to thank you again for your time.

- Do you maybe have anything else you would like to discuss or share with me?
- How did you think the interview from my side?

Thank you for your time and here is your gift card.



Onderzoeksprotocol

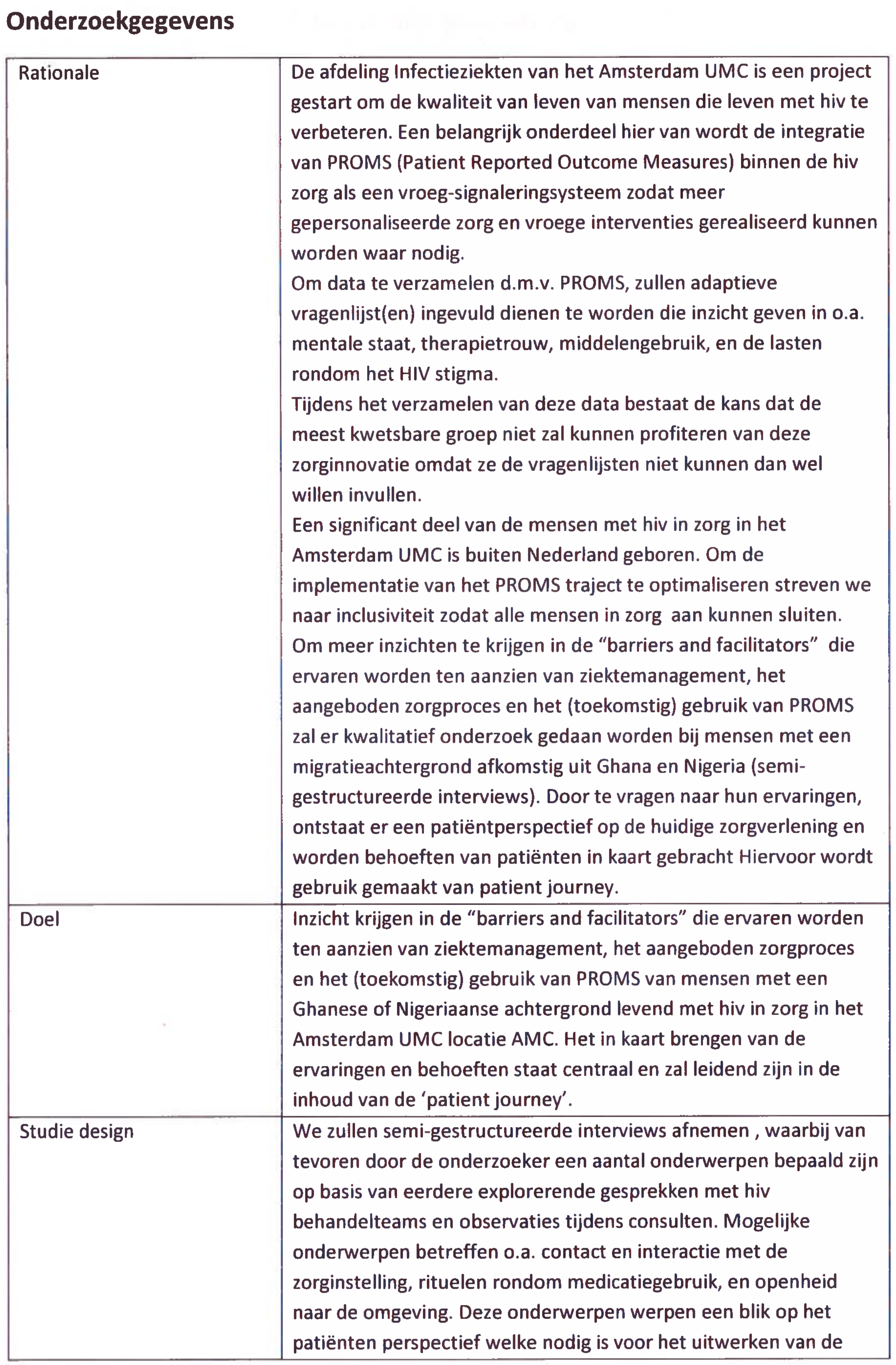
Aanvraag niet-WMO verklaring

Algemene gegevens

Titel	Ervaringen en behoeften van mensen met een migratieachtergrond met hiv met betrekking tot PROMS en waardegedreven zorg
Datum	13-10-2021
Versienummer	1
Indiener	S. Wolterink +31 6 41420020 s.wolterink@amsterdamumc.nl
Coördinerende onderzoeker	S. Wolterink
Hoofdonderzoeker(s)	Prof. Dr. M. van der Valk internist m.vandervalk@amsterdamumc.nl K. Moody, BScPhm, MBA, EdD PhD Kandidaat k.moody@amsterdamumc.nl
Opdrachtgever (verrichter)	Amsterdam UMC afdeling Infectieziekten

Protocol ondertekenden

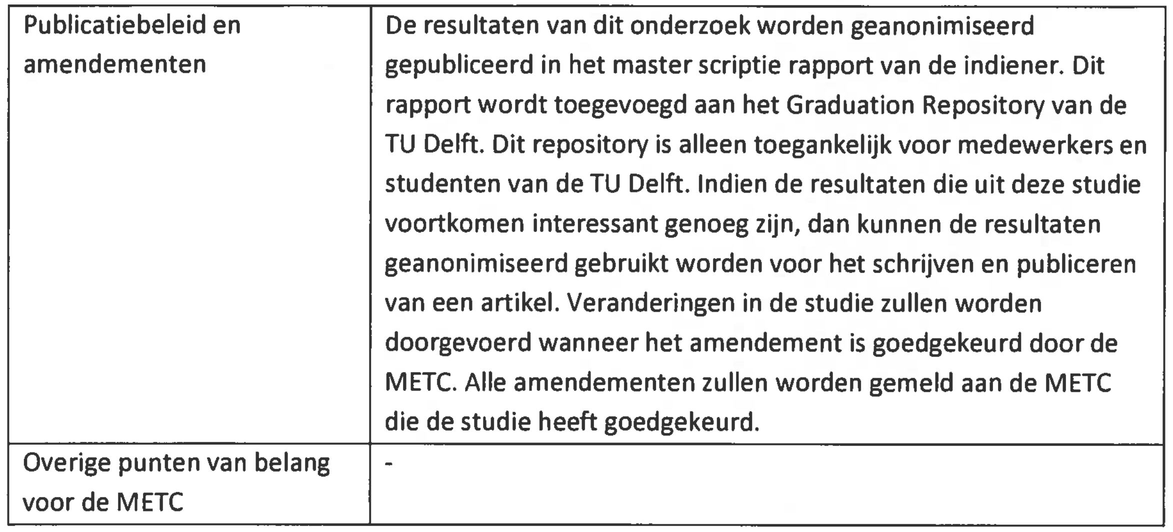
Naam	Handtekening	Datum
Hoofd van de afdeling Prof. Dr. J.M. Prins Internist		18/10/2021
Hoofdonderzoeker Prof Dr. M van der Valk Internist		13/10/21



Onderzoekgegevens

Rationale	De afdeling Infectieziekten van het Amsterdam UMC is een project gestart om de kwaliteit van leven van mensen die leven met hiv te verbeteren. Een belangrijk onderdeel hier van wordt de integratie van PROMS (Patient Reported Outcome Measures) binnen de hiv zorg als een vroeg-signaleringsysteem zodat meer gepersonaliseerde zorg en vroege interventies gerealiseerd kunnen worden waar nodig. Om data te verzamelen d.m.v. PROMS, zullen adaptieve vragenlijst(en) ingevuld dienen te worden die inzicht geven in o.a. mentale staat, therapietrouw, middelengebruik, en de lasten rondom het HIV stigma. Tijdens het verzamelen van deze data bestaat de kans dat de meest kwetsbare groep niet zal kunnen profiteren van deze zorginnovatie omdat ze de vragenlijsten niet kunnen dan wel willen invullen. Een significant deel van de mensen met hiv in zorg in het Amsterdam UMC is buiten Nederland geboren. Om de implementatie van het PROMS traject te optimaliseren streven we naar inclusiviteit zodat alle mensen in zorg aan kunnen sluiten. Om meer inzichten te krijgen in de "barriers and facilitators" die ervaren worden ten aanzien van ziektemanagement, het aangeboden zorgproces en het (toekomstig) gebruik van PROMS zal er kwalitatief onderzoek gedaan worden bij mensen met een migratieachtergrond afkomstig uit Ghana en Nigeria (semi-gestructureerde interviews). Door te vragen naar hun ervaringen, ontstaat er een patiëntperspectief op de huidige zorgverlening en worden behoeften van patiënten in kaart gebracht Hiervoor wordt gebruik gemaakt van patient journey.
Doel	Inzicht krijgen in de "barriers and facilitators" die ervaren worden ten aanzien van ziektemanagement, het aangeboden zorgproces en het (toekomstig) gebruik van PROMS van mensen met een Ghanese of Nigeriaanse achtergrond levend met hiv in zorg in het Amsterdam UMC locatie AMC. Het in kaart brengen van de ervaringen en behoeften staat centraal en zal leidend zijn in de inhoud van de 'patient journey'.
Studie design	We zullen semi-gestructureerde interviews afnemen , waarbij van tevoren door de onderzoeker een aantal onderwerpen bepaald zijn op basis van eerdere explorerende gesprekken met hiv behandelteams en observaties tijdens consulten. Mogelijke onderwerpen betreffen o.a. contact en interactie met de zorginstelling, rituelen rondom medicatiegebruik, en openheid naar de omgeving. Deze onderwerpen werpen een blik op het patiënten perspectief welke nodig is voor het uitwerken van de

	patient journey, en het begrip van de “barriers and facilitators” van de onderzoekspopulatie. De individuele semi-gestructureerde interviews zijn erop gericht om zo veel mogelijk nieuwe kennis te vergaren met betrekking tot de ervaringen, wensen, obstakels en percepties van de onderzoekspopulatie.
Studie populatie	Patiënten die leven met hiv afkomstig uit Ghana of Nigeria, die in behandeling zijn bij de Infectieziekten polikliniek te Amsterdam UMC locatie AMC.
Inclusiecriteria	- Mannen/vrouwen > 18 jaar in zorg op hiv polikliniek - afkomstig uit Ghana of Nigeria
Exclusiecriteria	- Onvoldoende beheersing van de Nederlandse of Engelse taal
Aantal proefpersonen/sample grootte	Het beoogde aantal proefpersonen is tien, of tot thematische saturatie is bereikt. De voornaamste reden van dit aantal is dat het om een kwalitatief onderzoek gaat en daarmee verwacht wordt dat met dit aantal voldoende inzicht wordt verkregen in de ervaringen en behoeften van verschillende type patiënten. Daarnaast biedt kwalitatief onderzoek de mogelijkheid een dieper begrip van de complexiteit van de ervaringen te ontwikkelen.
Werving proefpersonen	De werving van de proefpersonen zal verlopen via de polikliniek Infectieziekten en via de lotgenotenvereniging stichting ShivA. Patiënten zullen door hun behandelaar of contactpersoon vanuit stichting ShivA benaderd worden met informatie over het onderzoek. Hier wordt uitgelegd dat het gaat om een interview van ca. 30 minuten. De behandelaar of contactpersoon zal de patiënt vragen of hij/zij benaderd mag worden door een medewerker van het onderzoeksteam. Wanneer de patiënt hiermee akkoord gaat zal de onderzoeker de patiënt benaderen om een afspraak te maken. De onderzoeker stelt zich voor als onafhankelijk, zonder medische achtergrond en geeft meer informatie over het onderzoek. De patiënt kan dan alsnog besluiten om wel of niet deel te nemen aan het onderzoek. Wanneer de patiënt wil deelnemen zal voorafgaand aan het onderzoek het toestemmingsformulier getekend worden. Het toestemmingsformulier zal beschikbaar zijn in het Nederlands en Engels. Indien de patiënt moeite heeft met het lezen of begrijpen van het toestemmingsformulier zal deze mondeling doorgenomen worden. Na ondertekenen van het toestemmingsformulier wordt er een datum voor het interview afgesproken. Dit kan plaatsvinden aansluitend op de volgende poli-afspraak van de patiënt, of op een ander tijdstip wanneer gewenst door de patiënt.
Interventie	De deelnemers doen mee aan een interview van ca. 30 minuten. In dit semigestructureerd interview worden persoonlijke ervaringen en behoeften besproken met behulp van een themalijst die van tevoren is opgesteld.
Standaardzorg / Standaardbehandeling	Niet van toepassing
Studie parameters	- Ervaringen van patiënten met betrekking tot hun hiv zorg en ziektemanagement. - Behoeften van mensen met betrekking tot hun hiv zorg en ziekte management.
Studie eindpunten	Een patient experience journey; Een visueel, kwalitatief overzicht van welke stappen patiënten doorlopen, hoe ze het hele proces ervaren, de interactie met zorgverleners en informatievoorzieningen en de meest kansrijke ontwerpmogelijkheden om de implementatie van PROMS in het zorgproces van mensen die leven met hiv
Statistische analyse	De gegevens van de semigestructureerde interviews zullen worden getranscribeerd en geanalyseerd door de uitvoerend onderzoeker. Inzichten zullen worden geclusterd door middel van een kwalitatieve, thematische aanpak. Deze thematische aanpak is gekozen omdat er met opzet wordt gekeken naar bredere thema’s die ofwel de huidige literatuur reflecteert, tegenspreekt of aanvult.
Belasting voor de proefpersoon	Interview; ca. 30 minuten
Risico voor de proefpersoon	Er zijn geen gezondheidsrisico’s verbonden voor de patiënten en er zullen geen belastende vragen gesteld worden. Deelnemers kunnen er altijd voor kiezen om vragen niet te beantwoorden of te stoppen met de studie.
Voordelen deelname aan het onderzoek	Er zijn geen directe voorbeelden verbonden aan deelname aan het onderzoek, maar mogelijke voordelen kunnen zijn: - Kwijt kunnen van verhalen, frustraties en zorgen aan een onafhankelijk niet zorg-verlenend persoon - Gevoel van bijdragen aan vernieuwing en verbetering binnen de zorg
Nadelen deelname aan het onderzoek	Een nadeel zou kunnen zijn de investering van tijd in het onderzoek.
Vergoeding voor de proefpersoon	Waardebon ter waarde van €25
Administratieve aspecten	De deelnemers worden genummerd in volgorde van binnenkomst in de studie. Bijvoorbeeld D01, D02, D03 etc. De data zijn verbonden aan dit unieke nummer zonder persoonlijke informatie waarmee de deelnemer geïdentificeerd zou kunnen worden. De anonieme data worden gebruikt voor de data-analyse. De audio data van het interview zullen gecodeerd bewaard worden binnen het AMC op een beveiligde locatie. Hiertoe heeft alleen de indiener en de hoofdonderzoeker toegang. De audio data zal direct verwijderd worden wanneer de audio opnames volledig getranscribeerd zijn.



Publicatiebeleid en amendementen	De resultaten van dit onderzoek worden geanonimiseerd gepubliceerd in het master scriptie rapport van de indiener. Dit rapport wordt toegevoegd aan het Graduation Repository van de TU Delft. Dit repository is alleen toegankelijk voor medewerkers en studenten van de TU Delft. Indien de resultaten die uit deze studie voortkomen interessant genoeg zijn, dan kunnen de resultaten geanonimiseerd gebruikt worden voor het schrijven en publiceren van een artikel. Veranderingen in de studie zullen worden doorgevoerd wanneer het amendement is goedgekeurd door de METC. Alle amendementen zullen worden gemeld aan de METC die de studie heeft goedgekeurd.
Overige punten van belang voor de METC	-

Appendix 3

Non-WMO Approval

Aan de heer prof.dr. M. van der Valk
Infectieziekten
D3-210

Medisch Ethische Toetsingscommissie AMC
TK0-270

Amsterdam, 28 oktober 2021
uw kenmerk:
ons kenmerk: W21_449 # 21.499
betreft:
Uw project: **Ervaringen en behoeften van mensen die met HIV leven met een migratieachtergrond met betrekking tot PROMS en value-driven care**

Geachte heer Van Der Valk,

De brief d.d. 18 oktober 2021 van mw. S. Wolterink betreffende bovengenoemde studie is op 27 oktober jl. besproken in de vergadering van het dagelijks bestuur.

Het dagelijks bestuur is van oordeel dat bovengenoemde studie niet valt binnen de reikwijdte van de Wet medisch-wetenschappelijk onderzoek met mensen, aangezien er geen sprake is van wetenschappelijk onderzoek zoals bedoeld in artikel 1, eerste lid onder b van de WMO, daar alleen een interview wordt afgenomen en wij geen aanleiding hebben te denken dat de psychische integriteit van de proefpersonen in het geding is.

Een formele beoordeling door onze commissie is derhalve niet noodzakelijk.

De commissie attendeert u op de volgende punten:
De commissie heeft alleen de WMO-plichtigheid beoordeeld. Er heeft verder geen inhoudelijke toets van het onderzoek plaatsgevonden. U en uw afdeling zijn verantwoordelijk voor de correcte uitvoering van het onderzoek volgens de geldende wet- en regelgeving. Hierbij vragen wij uw aandacht voor de belangrijkste regelgeving:

- Voor prospectief onderzoek, waarbij gegevens van proefpersonen worden verzameld en verwerkt, is toestemming van de proefpersonen nodig.
- Voor retrospectief onderzoek, waarbij gegevens van proefpersonen gecodeerd worden verzameld en verwerkt is in beginsel toestemming van de proefpersonen nodig. In artikel 458 van de WGBO is vastgelegd onder welke omstandigheden van het vragen van toestemming kan worden afgezien. Bij retrospectief *anoniem* onderzoek is toestemming niet verplicht, hierbij zijn de gegevens nooit meer herleidbaar tot de proefpersonen. Dus ook niet via een code.
- Wanneer in een onderzoek gegevens worden verzameld van proefpersonen, dient hiermee correct te worden omgegaan zoals bepaald in de Gedragscode Gezondheidsonderzoek (Code Goed Gedrag), Algemene Verordening Gegevensbescherming en de Uitvoeringswet Algemene Verordening Gegevensbescherming en, indien het onderzoek van het AMC betreft, de regels die binnen het AMC zijn vastgesteld, zoals de SOP “Reuse of care data for the purpose of research van de CRU (http://kwadraet.amc.nl/iDocument/Viewers/Frameworks/ViewDocument.aspx?DocumentID=8efa33b4-9dfa-4575-a284-03b8fd8c7115&FromLogin=1)
- Voorts dient u zich te houden aan de research code van het Amsterdam UMC.

Meer informatie over bovengenoemde regelgeving kunt u vinden op internet, waaronder onze intranetpagina. Deze opsomming betreft de belangrijkste regelgeving, maar is niet uitputtend. Mogelijk is nog andere wet- en regelgeving van toepassing op uw onderzoek.

Indien u twijfelt of door amendering of het toevoegen van addenda het onderzoek nog steeds buiten de reikwijdte van de WMO blijft kunt u dit aan de commissie ter beoordeling voorleggen.

Met vriendelijke groet,
namens de Medisch Ethische Toetsingscommissie AMC,

Mw.dr. C.L. van der Wilt
ambtelijk secretaris

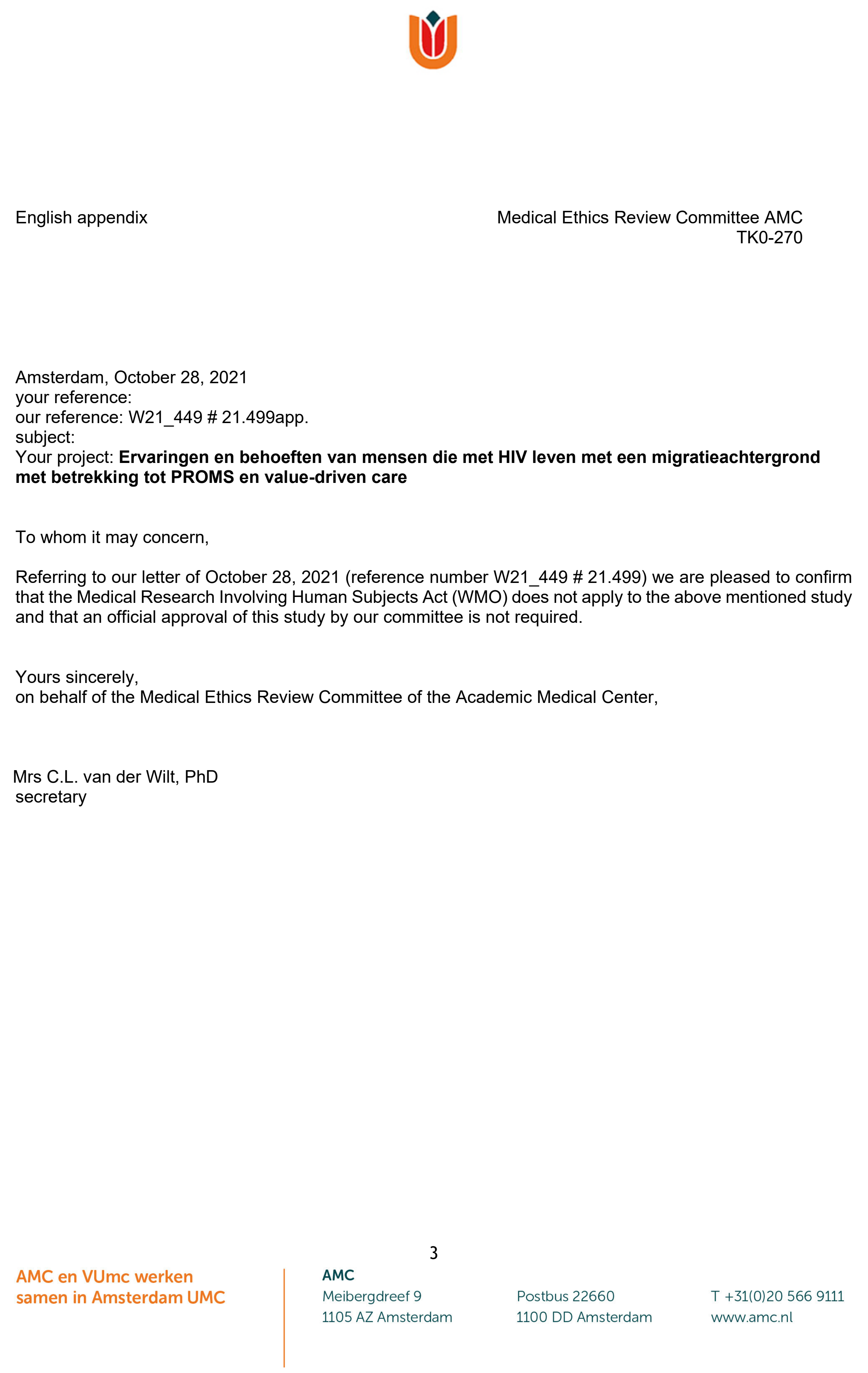
Zo lang de beperkende maatregelen als gevolg van het coronavirus gelden zullen de brieven inzake beoordeling WMO-plichtigheid van de METC niet worden voorzien van een natte handtekening. Deze brieven worden digitaal verstuurd. Indien u na het intrekken van de maatregelen alsnog een ondertekende brief nodig heeft, verneemt de METC dit graag.

Bijlage: verklaring in het Engels

c.c. per email: s.wolterink@amsterdamumc.nl; m.r.d.bedert@amsterdamumc.nl

Appendix 3

Non-WMO Approval



English appendix

Medical Ethics Review Committee AMC
TK0-270

Amsterdam, October 28, 2021
your reference:
our reference: W21_449 # 21.499app.
subject:
Your project: **Ervaringen en behoeften van mensen die met HIV leven met een migratieachtergrond met betrekking tot PROMS en value-driven care**

To whom it may concern,

Referring to our letter of October 28, 2021 (reference number W21_449 # 21.499) we are pleased to confirm that the Medical Research Involving Human Subjects Act (WMO) does not apply to the above mentioned study and that an official approval of this study by our committee is not required.

Yours sincerely,
on behalf of the Medical Ethics Review Committee of the Academic Medical Center,

Mrs C.L. van der Wilt, PhD
secretary

3

AMC en VUmc werken
samen in Amsterdam UMC

AMC
Meibergdreef 9
1105 AZ Amsterdam

Postbus 22660
1100 DD Amsterdam

T +31(0)20 566 9111
www.amc.nl

First interview

The first interview was held with a 69-year-old woman who migrated from Nigeria in 1997 to the Netherlands, she will be referred to as "PI1".

PI1 seems to be a patient who is actively involved in the HIV community, she has been recruited via Stichting ShivA. PI1 mentioned that she is more often present when the experience and opinion of patients are needed for any kind of research. She is not ashamed to talk about the disease, so when she is called she is happy to share her experience.

"I come to these meetings with some people or with many people. I'll be the only one around them talking."

A few years ago PI1 had some issues with the IND (Dutch Immigration and Naturalisation Service) but her Doctor and Nurse helped her by writing letters to help her tell her story. PI1 seems to be extremely appreciative. When she has an appointment at the hospital, she feels happy. She knows that the people at the outpatient clinic are here to help her.

"When I visit my Nurse, sometimes we have a coffee and talk and talk. He loves to talk to someone"

Her personal bond with the healthcare professionals is also reflected in the story she told about the time she was rushed into the emergency room and everybody came to check on her and see how she was doing. Due to the severe side effects of her new medication, she became very ill and had to be brought in. How the medication works and why she would be switching from one to another is something she cannot fully understand. But PI1 repeatedly says "I am not well", and therefore, doesn't question the decisions the doctor makes as he is the one who has studied for many years and knows how to help her.

PI1 is extremely open when she is somewhere to share her experiences and when talking to one of the healthcare professionals. When she is in the waiting room she is not worried about anyone from her community seeing her. But when asked more about disclosure, she mentions that no one knows about her positive status, not even her mother or children, only god.

"People from my country are not good, they talk and talk."

Within her community, no one knows about her positive status as she mentions that people will gossip about it and they will think negatively about it. But when she is in the waiting room of the outpatient clinic, she cannot be bothered with being worried about meeting anyone.

"If someone will tell you that they saw me in the Infectious Diseases clinic, they need to explain what they did there themselves. We all just keep quiet. I'm here for my disease, I am not here to worry"

For PI1, appointments at the Amsterdam UMC are very important as they will make sure she stays healthy. She received her appointment confirmation on paper which she will hang on the wall next to her fridge in her kitchen.
"When you are not an intelligent person, you will forget about the appointment."

When discussing the matter of the (future) PROMs, she claimed to be happy to make use of them as they would help the Doctor. She said that she would be willing to share information in the questionnaire. But she does make the remark that she doesn't have a tablet or anything. She does have a smartphone which she knows how to use. When she was waiting in the waiting room, she used her smartphone to listen to a movie. But once she entered the office she had some struggles to turn it off. This shows that she is digitally inclined but still has some struggles. But for a person who is 69 years old, this is not weird.

Overall PI1 gave me the impression to be a perfect patient. She comes to all her appointments and is very happy with the care she is receiving. When she has a question she feels comfortable calling her Nurse to discuss whatever she needs to discuss.
Due to the fact that she is this happy with her care, the impression is made that that PI1 won't be someone who would complain about the few things that could be improved. In some cases, it might seem like PI1 gives the response she feels is the desired one.

Personal Reflection

Before the first interview, I felt quite nervous, afraid I would say something wrong or end up with only irrelevant information. Fortunately, PI1 was very relaxed and kind-hearted. I right away felt like she was open to helping me with my research, making me feel comfortable which allowed me to make her feel comfortable.

During the interview, I had two moments in which I took a minute to look at my notes and see which topics I had not touched yet. I had tried to let go of the structure in order to let topics flow more naturally. Like in the beginning she told me about her bond with the healthcare professionals and how she had to be rushed into the emergency room. This created an interesting bridge to the topic of communication.
This way of conducting the interview created a positive and a negative effect. The more natural flow of the conversation improved the atmosphere. But the negative effect was that I lost track of the topics I wanted to cover.
Eventually, I did manage to touch all the conversation topics, but I felt uncomfortable.
For the next interviews, I will allow myself extra time to glance over my personal notes to make sure I know what I want to discuss and make myself feel more incharge.

Altogether, I was really inspired after conducting the interview. I loved to gain more insights in the life of someone from the target group. I was also quite surprised by how many of my observations were being confirmed and elaborated by the personal stories.
I hope that the following interviews will be even better.

Appendix 5

Statement Cards

The doctor will help with finding the correct specialist

So when he has to make an appointment for me where they do the bones. SO I went there and they give a operation for that. So anytime something happens like that, he send me to the doctor who can help me for that.

Patient feel happy when visiting the AMC

I feel very happy. I'm very quite happy, especially with Hans.

Patients have to do a blood test every 6 months

the nurse have take my blood

HCP help their patients with problems regarding the IND

So everytime I come to the doctor, nurses, my friends who helped me to bring something, what about me. IND so all of them doctor and Hans, all of them write about me and I'm not a bad person. So they wrote all these things about me to give to IND

Patient hangs appointment invitation on the wall to remind herself of it

hen I have an appointment they give it on a paper and I will hang it on the wall so I know that it is on the 9th. I don't have anything, tablet, anything. So I just put it on the wall. So I won;t forget. The appointments are very long you know, 6 months. So if you are not intelligent person you will forget.

The doctor knows everything best

And if something is not going on, he would ask me what, why is this not good? Then I don't know, you're the doctor.

Patient and Nurse have casual conversations over coffee

I can go and see him and we drink and have coffee and talking too. If there is not plenty patients waiting. Then I tell him to let me go if some people are waiting for you.

The Nurse is able to explain more about the medication treatment

We discuss about my sickness, sometimes I'll ask him questions. Maybe I say Hans if I bring the medicines and it does not do this and this and this, he tells me to go on and try again. And if it doesn't come again I call him. So we sit down and discuss things.

Side effects of medication are hard to understand

sometimes they give me some medicine and the product is not good for mine. That is the dumbest thing to me. Because of the medine i use all my head was like this, I cant see when i my eyes close, I don't see anything.

Patient feels like she is being treated really nicely,

So if I come here if feel very happy. But nobody badly treats me, I have never seen that before.

Patient is open to share information that will help the doctor providing care

I would say anything, I don't care of anything. I am not well, so I need someone who asks me about my sickness and not everybody get's it like that. If somebody would ask me about something, how i am and what is going on I don't care of that.

With the Nurse, also daily life topics are discussed

Even when I went to Afrika in May, I came here for my appointment and we sat down and talked about Afrika.

Patient is not worried about seeing anyone, focus lays on the sickness and meeting the doctor

That is not my problem. When the person is coming, they might be worried. But me, I am not worried of anything. Because if I come and wait outside the poli. My sickness is here and I have to wait for my doctor. All of us here, so if you don't want a problem, keep quiet and I keep quiet.

The HCP also reach out to their patients when they end up in the emergency room

Even when I brought here in the ambulance, with an emergency, they called all of them and they came here to see how I am what it is going on.

HCP are easy to reach by phone calls

If I call them maybe I say I want to talk to Hans, they will direct me to Hans. Teh I will tell Hans what is going on in my life or in the house, what am I going to do? Then Hans tells me I will tell Dr vd Valk, even if he is not there I will cal him and tel him blablabla or he will give me an appointment to come

Appointments are important, because the doctor says so.

Very important! Because if it is not important the doctor wil not give you. It is important to be here.

Patient don't feel the need to search for information about HIV

No, I don't look anywhere for any information. If something worries me. Everything is good, only that one that gives me some symptoms. Apart from that everything is good.

Appointments are never missed

I put it somewhere next to my fridge.So anytime I go to the kitchen I see Oh yeah that is how I do it.

Only people within the HIV community know about her positive status - no family members

Actually, my family doesn't know about it. Sometimes, the hiv, blablabla. But the only people who know are the people I get with then because you go to some place and we share everything but apart from that nobody.

Patient is never nervous as she receives good care

I am not nervous, even if I am not well, I will call and say I am not well.

People from within the community tend to gossip

I don't want anybody to know because our country people are not good

.....

But they talk too much, even my children no body knows. I just keep that secret to me and my God.

Finding your way is easy, a letter was send when they changed location

I know where to go. Before we were at the other place, when they came here it was not hard because they gave me a letter about where to go.

If you meet someone at the clinic, this stays silent.

Even if you come to here to meet me all of us come here to meet our doctor, if you tell someone I saw [Name Pi1] blablabla, what are you coming to do here? This year you are coming, this is the infection diseases yeah.

Patient feels loved by HCP

I would tell everything, you will meet people here who would love you and like you

Patient receives multiple reminders for the appointment

Yeah I have a card and they do send me a letter and I have a reminder on my phone. They send me a reminder because I told them I forget a lot.

...

P2: No I just get an message on my phone, I don't have to do this myself.

The AMC offers guidance when a patient is unable to find their way

I feel good, because when I have a problem or I don't know where to go I know where to ask. I can show them my appointment letter or I show them my card and they check the system and tell me where to go.

The AMC uses an integrated system that allows the patients to check in with their patient card

you need to show your card with your number for them to know you have an appointment

Doctor starts with the open question "how are you" to find out if there is something to discuss right away

If i'm good, I say i'm good, if i'm not good, I will say I am not good. I will not say I am not good if there is not a problem. And then I will begin to explain why I am there in the hospital.

During the semi-annual consultation, a new prescription is made for the medication

He will write me a prescription if I don't have a prescription

The doctor will refer the patient to another specialist when needed

And he will ask me if I have any complaint. And then he will recommend any other appointments for me which another doctor will have to. He will book the appointment in the other department. So they will check my other problem. So everytime that I complain about a problem he will refer me to (for example) oncology and they will look into the tissue, and at the end of the day they did not discover anything

The Nurse will share extra information or explanations when the patient needs this

And if there is any other thing and I need more information the nurse can do that, so he send me to the nurse to talk about that.

The Doctor does the formal and medical things, to guarantee good health for the patient

Doctor Prins is only to administer, check me to see how I am doing and if I am not doing well, if they have to increase my medication if it is not helping. He will do that.

The Nurse shares extra information on a more casual level. Sharing extra information when needed.

Now Frank is not like that [medication and physical checks], he talks a lot. How to give me a particular image. He tells me what to do. Doctor Prins will tell me to go to Frank if I need extra information. And he will tell me anything he needs to tell me.

The HCP speak English with the patients who need that.

he understands English. I communicate in English, I don't speak Dutch very well. He speaks very good English.The communication is very good, it is not difficult at all.

The GP gave the patient Dutch information about the implications of diabetes. She was unable to understand the information

Because the paper she gave me, it was in Dutch. But I don't understand Dutch. I told her, I don't know anything in Dutch. But she still ended up giving me information on paper, in Dutch. This was meaningless and useless to me.

When the patient was informed about the implications of diabetes correctly, she became more careful with her diet

she was giving me an eyeopener then I began very very careful. Then I knew what I was having. She then gave me a paper which I understood very well with what I should be eating.

The GP gave the patient the feeling like she looked down on her.

I spend one hour waiting but this woman did not attend to me. When she came out to attend to me, she did not tell me

When she finally attents to me, she didn't even say sorry. That made me feel bad. So from that moment on I did not want to see her, because she, i think, looked down on me. She is the one who gave me the Dutch paper I did not understand. She is the one who gave me the wrong information, I got offended.

The HCP within the AMC are aware of the language barrier and behave accordingly

I don't have this experience in the AMC. I am very okay with them.

The HCP within the AMC treat their patients with a lot of respect

he other day I thought I had an appointment with the Social Worker but she was not there. And I was worried so I went to the desk and said that I thought I had an appointment. So they check who is this person. But she was not around. They said they were really sorry that this person was not in the office. The other day this woman called me and told me she learned that I was in the hospital and that she was not there. She called to apologize and that it was a mistake. That was nice and much better.

Patient is not occupied with healthcare related questions

I don;t really have a question in between appointments.

Patient know how to reach their nurse when she needs new medication

Only when I have to collect my medication when my medication is finished and my prescription is finished. I try to call the hospital and talk to Frank. I tell him that my medication is finished and I need a prescription. They will write the prescription and forward it to my apotheek.

Hospital visits are important

it is important! You don't send not-sick people to the hospital. If you don't go to the hospital, if you are not sick you don't go to the hospital. So when you have appointment, ofcourse it is important. It is to protect yoursel

The consultation gives the patient insights in their personal health

I really look forward to go and talk to the doctor because I want to know what is going on in my body.

The implementation of PROMs can be frustrating for those with less digital skills who need to be helped by someone else

I think at times they put somebody there who could help but that person don't do all those things. And at times, I saw this and that and I asked how to do it. But at times it is frustrating because they understand it but you don't

Using a device that you don't understand perfectly can be frustrating when you are not in the right mood

If it doesn;t take a lot of my time, I am comfortable with it. But some days somebody can be in a really awkward mood. And maybe you don't have the energy to even do such a thing. It depends on your mood on that day.

No one (outside the HIV community) knows about the positive status

I am okay with keeping it to myself, when I feel like I have to share it with everybody. The ones who are really close to me at work, I told them. And my sisters and brothers. But my friends, I didn't tell it to any of my friends.

Patient is not worried (anymore) when being inside the clinic

I did not go to the market to buy it, it can happen to anybody.

In the waiting room, it does cross her mind that the person next to her might wonder why she is there

when I am seated I am like, the person sitting next to me thinking why I am here, some things do cross my mind.

Statement Cards

Recently diagnosed, feelings of guilt and shame where dominant when entering the AMC building

In het begin van mijn diagnose was het inderdaad wel, ja, schuldgevoel zou ik het ook weer niet noemen misschien is dat een te groot woord maar laten we het op schuldgevoel houden. En dat ik altijd wel het gevoel had van "hier ben ik weer, en ik moet weer die stap nemen en dergelijke"

Over time, the feeling has changed. Now it's a moment to check yourself.

Nu, is het meer van ja ik ben hier om hé mezelf laten controleren, om te checken of alles goed gaat. Nu is het weer een ander gevoel dat ik weer heb.

No one knows about the positive status

In mijn directe omgeving weet niemand van mijn status af, dat ik hiv positief ben.

Patient is afraid to walk into a familiar face

After a few years, you learn to keep your head low while moving through the AMC

In the back of your mind you are still wondering "what if I walk into someone I know?"

Het is wel een tijdje terug maar heel soms als ik het ziekenhuis binnen kom dan heb ik toch nog het gevoel van goh wie kom ik tegen.

Stress levels rise when getting closer to the outpatient clinic. As it gets harder to come up with a credible excuse why you are here.

Throughout the years you will learn ways and tricks to decrease the chances of meeting anyone familiar

HCP need to be emphatic and understand the needs of their patients

The participant needs to feel comfortable with their HCP in order to open up totally

In het begin was het wel even wennen want je komt iets over jezelf er achter wat niet echt prettig is.

The doctor you discuss medical stuff, like medication and the newest developments

The Nurse is there to discuss the daily life issues on a more free and casual tone

bij Hans voel ik me ook vrij maar weer op een hele andere manier. En met Hans kan ik inderdaad wel vrij zijn, met hem kan ik wel bijvoorbeeld over seksualiteit praten, of over gewoon, dagelijkse dingen in het leven. Dat kan ik inderdaad wel gewoon met Hans bespreken.

Talking to the Doctor and Nurse allows the patient to share different stories

omdat ik twee mensen heb, heb ik ook twee verschillende onderwerpen die ik kan bespreken. Ik kan bij de ene mijn verhaal kwijt en kan bij de andere mijn verhaal kwijt.

HCP never demand that the patient shares more details than they want

En ja, ook beide is het nooit van dat ze meer willen weten dan dat ik ze geef. Dat wat ik aangeef en ze vertel, dat is wat ik wil vertellen en dat is het. Ik voel me wel fijner om dit soort gesprekken met hun te kunnen voeren.

The Doctor explains medical information in a understandable and neutral way

All questions regarding medication and the disease can be answered during the consultations

When a specific issue arises and the answer cannot be found online, the Nurse is easy to reach to ask for advise.

Via MyChart you are able to get in touch with the HCP and get quick answers

PROMs miss the aspect of the personal contact. Some delicate issues are rather discussed face to face

PROMs allow the HCP to start the consultation with essential foreknowledge

Aan de ene kant is het super want dan heeft de dokter voorkennis voordat hij de patiënt ontmoet, ook al kent hij deze al een tijdje maar goed dan weet je wat er afspeelt.

Delicate topics are rather discussed with the HCP that are familiar for the participant. A substitute doctor does not have the same bond with the patient

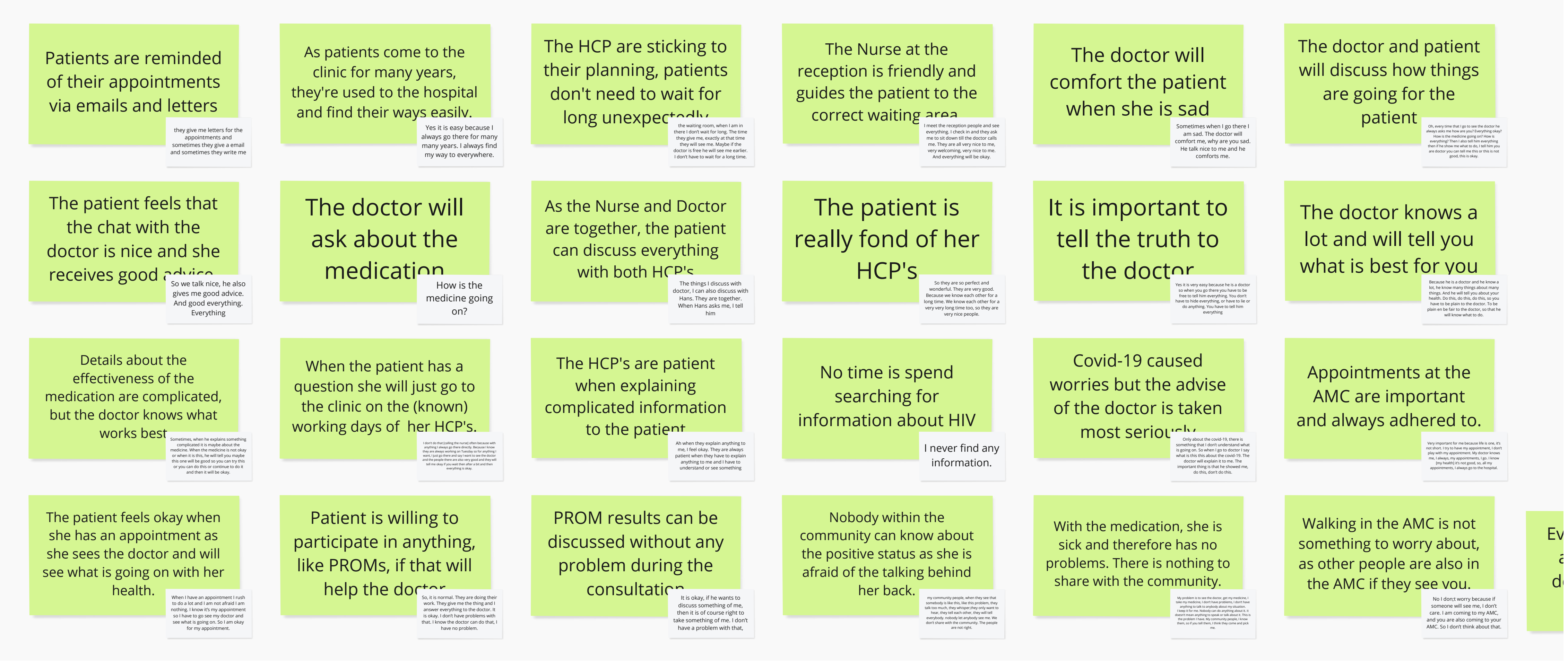
Appointments are important as they remind you to take care of yourself

De afspraken vind ik echt zeer belangrijk. Voor mij zeker wat iedere afspraak herinnert me eraan he let je nog wel op, he denk je aan je gezondheid, heb je aan dit gedacht?

At the beginning of being diagnosed, I did not like to go to the hospital.

Dat was in het begin zeker, maar achteraf, nu dat ik de moed weer heb opgepakt ben ik er wat makkelijker en vrij in. Dus nu ga ik wel elke afspraak die er is ben ik wel aanwezig.

As every patient is unique, it is important to find a good match between patient and HCP to ensure a comfortable relationship



Patients are reminded of their appointments via emails and letters

they give me letters for the appointments and sometimes they give a email and sometimes they write me

As patients come to the clinic for many years, they're used to the hospital and find their ways easily.

Yes it is easy because I always go there for many many years. I always find my way to everywhere.

The HCP are sticking to their planning, patients don't need to wait for long unexpectedly

the waiting room, when I am in there I don't wait for long. The time they give me, exactly at that time they will see me. Maybe if the doctor is free he will see me earlier. I don't have to wait for a long time.

The Nurse at the reception is friendly and guides the patient to the correct waiting area

I meet the reception people and see everything. I check in and they ask me to sit down till the doctor calls me. They are all very nice to me, very welcoming, very nice to me. And everything will be okay.

The doctor will comfort the patient when she is sad

Sometimes when I go there I am sad. The doctor will comfort me, why are you sad. He talk nice to me and he comforts me.

The doctor and patient will discuss how things are going for the patient

Oh, every time that I go to see the doctor he always asks me how are you? Everything okay? How is the medicine going on? How is everything? Then I also tell him everything then if he show me what to do, I tell him you are doctor you can tell me this or this is not good, this is okay.

The patient feels that the chat with the doctor is nice and she receives good advice

So we talk nice, he also gives me good advice. And good everything. Everything

The doctor will ask about the medication

How is the medicine going on?

As the Nurse and Doctor are together, the patient can discuss everything with both HCP's

The things I discuss with doctor, I can also discuss with Hans. They are together. When Hans asks me, I tell him

The patient is really fond of her HCP's

So they are so perfect and wonderful. They are very good. Because we know each other for a long time. We know each other for a very very long time too, so they are very nice people.

It is important to tell the truth to the doctor

Yes it is very easy because he is a doctor so when you go there you have to be free to tell him everything. You don't have to hide everything, or have to lie or do anything. You have to tell him everything

The doctor knows a lot and will tell you what is best for you

Because he is a doctor and he know a lot, he know many things about many things. And he will tell you about your health. Do this, do this, do this, so you have to be plain to the doctor. To be plain en be fair to the doctor, so that he will know what to do.

Details about the effectiveness of the medication are complicated, but the doctor knows what works best

Sometimes, when he explains something complicated it is maybe about the medicine. When the medicine is not okay or when it is this, he will tell you maybe this one will be good so you can try this or you can do this or continue to do it and then it will be okay.

When the patient has a question she will just go to the clinic on the (known) working days of her HCP's.

I don't do that [calling the nurse] often because with anything I always go there directly. Because I know they are always working on Tuesday so for anything I want, I just go there and say I want to see the doctor and the people there are also very good and they will tell me okay if you wait then after a bit and then everything is okay.

The HCP's are patient when explaining complicated information to the patient

Ah when they explain anything to me, I feel okay. They are always patient when they have to explain anything to me and I have to understand or see something

No time is spend searching for information about HIV

I never find any information.

Covid-19 caused worries but the advise of the doctor is taken most seriously

Only about the covid-19, there is something that I don't understand what is going on. So when I go to doctor I say what is this this about the covid-19. The doctor will explain it to me. The important thing is that he showed me, do this, don't do this.

Appointments at the AMC are important and always adhered to.

Very important for me because life is one, it's not short. I try to have my appointment, I don't play with my appointment. My doctor knows me, I always, my appointments, I go. I know [my health] it's not good, so, all my appointments, I always go to the hospital.

The patient feels okay when she has an appointment as she sees the doctor and will see what is going on with her health.

When I have an appointment I rush to do a lot and I am not afraid I am nothing. I know it's my appointment so I have to go see my doctor and see what is going on. So I am okay for my appointment.

Patient is willing to participate in anything, like PROMs, if that will help the doctor

So, it is normal. They are doing their work. They give me the thing and I answer everything to the doctor. It is okay. I don't have problems with that. I know the doctor can do that, I have no problem.

PROM results can be discussed without any problem during the consultation

It is okay, if he wants to discuss something of me, then it is of course right to take something of me. I don't have a problem with that,

Nobody within the community can know about the positive status as she is afraid of the talking behind her back.

my community people, when they see that somebody is like this, like this problem, they talk too much, they whisper,they only want to hear, they tell each other, they will tell everybody. nobody let anybody see me. We don't share with the community. The people are not right.

With the medication, she is sick and therefore has no problems. There is nothing to share with the community.

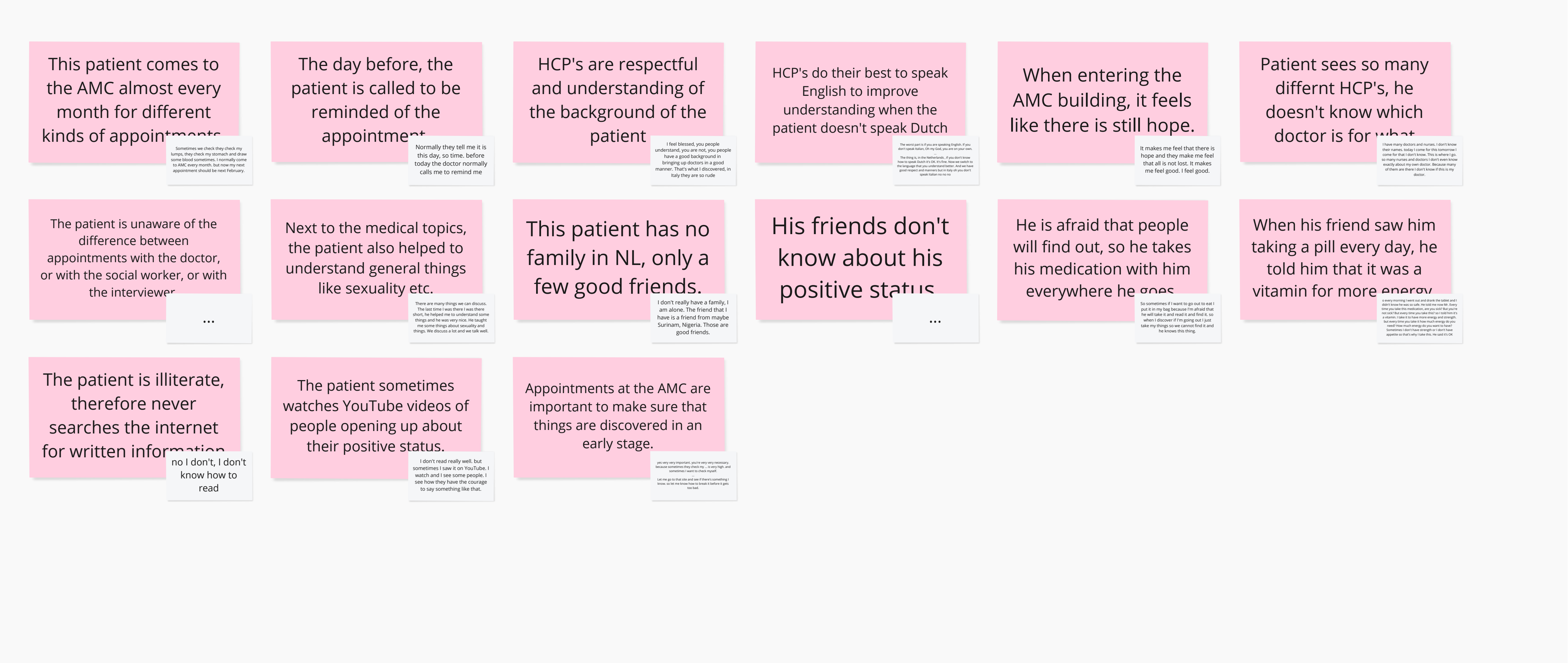
My problem is to see the doctor, get my medicine, I take my medicine, I don't have problems, I don't have anything to talk to anybody about my situation. I keep it for me. Nobody can do anything about it. it doesn't mean anything to speak or talk about it. This is the problem I have. My community people, I know them, so if you tell them, I think they come and pick me.

Walking in the AMC is not something to worry about, as other people are also in the AMC if they see you.

No I don;t worry because if someone will see me, I don't care. I am coming to my AMC, and you are also coming to your AMC. So I don't think about that.

Appendix 5

Statement Cards



This patient comes to the AMC almost every month for different kinds of appointments

Sometimes we check they check my lumps, they check my stomach and draw some blood sometimes. I normally come to AMC every month. but now my next appointment should be next February.

The day before, the patient is called to be reminded of the appointment

Normally they tell me it is this day, so time. before today the doctor normally calls me to remind me

HCP's are respectful and understanding of the background of the patient

I feel blessed, you people understand, you are not, you people have a good background in bringing up doctors in a good manner. That's what I discovered, in Italy they are so rude

HCP's do their best to speak English to improve understanding when the patient doesn't speak Dutch

The worst part is if you are speaking English. If you don't speak Italian, Oh my God, you are on your own.
...
The thing is, in the Netherlands , if you don't know how to speak Dutch it's OK. It's fine. Now we switch to the language that you understand better. And we have good respect and manners but in Italy oh you don't speak Italian no no no

When entering the AMC building, it feels like there is still hope.

It makes me feel that there is hope and they make me feel that all is not lost. It makes me feel good. I feel good.

Patient sees so many differnt HCP's, he doesn't know which doctor is for what

I have many doctors and nurses. I don't know their names. today I come for this tomorrow I come for that I don't know. This is where I go. so many nurses and doctors I don't even know exactly about my own doctor. Because many of them are there I don't know if this is my doctor.

The patient is unaware of the difference between appointments with the doctor, or with the social worker, or with the interviewer

...

Next to the medical topics, the patient also helped to understand general things like sexuality etc.

There are many things we can discuss. The last time I was there I was there short, he helped me to understand some things and he was very nice. He taught me some things about sexuality and things. We discuss a lot and we talk well.

This patient has no family in NL, only a few good friends.

I don't really have a family, I am alone. The friend that I have is a friend from maybe Surinam, Nigeria. Those are good friends.

His friends don't know about his positive status

...

He is afraid that people will find out, so he takes his medication with him everywhere he goes

So sometimes if I want to go out to eat I put it in my bag because I'm afraid that he will take it and read it and find it. so when I discover if I'm going out I just take my things so we cannot find it and he knows this thing.

When his friend saw him taking a pill every day, he told him that it was a vitamin for more energy

o every morning I went out and drank the tablet and I didn't know he was so safe. He told me now Mr. Every time you take this medication, are you sick? But you're not sick? But every time you take this? so I told him it's a vitamin. I take it to have more energy and strength. but every time you take it how much energy do you need? How much energy do you want to have? Sometimes I don't have strength or I don't have appetite so that's why I take this. He said it's OK

The patient is illiterate, therefore never searches the internet for written information

no I don't, I don't know how to read

The patient sometimes watches YouTube videos of people opening up about their positive status.

I don't read really well. but sometimes I saw it on YouTube. I watch and I see some people. I see how they have the courage to say something like that.

Appointments at the AMC are important to make sure that things are discovered in an early stage.

yes very very important. you're very very necessary. because sometimes they check my ... is very high. and sometimes I want to check myself.
...
Let me go to that site and see if there's something I know. so let me know how to break it before it gets too bad.

The patient is fond of the HCP's

yes he is very sweet, very nice. Anything I can ask from him, he did for me. Especially, I don't know how I can explain. Hans and especially the doctor are very very good for me.

With the doctor you can talk about the medication and does a physical check

I talk about medication and always want to check my sugar and my older problems he said everything is fine. because I take my medicine good. so every day that I come here, if I am 40 it is still 40 it's not like it's going up. always down. so I can do anything I want.

After talking to the Doctor, she can discuss more personal matters with the Nurse

same thing, if doctor finish I go to Hans, Hans also we talk nice today I explained I am very tired. I want to rest in Ghana for six months. OK you can go. no problem. Because you don't have any problem.

The patient doesn't always sees the nurse as she is familliar with the system and has few problems.

sometimes I don't see Hans, because he is busy and I know my routes already because I stay here for long time. it's not that I always see Hans.

The doctor tries to help with issues outside the HIV-related care

He's serves me also nice. If I miss something, even different medication, I ask him to give it to me. that's why I like the man so much

The doctor knows what is best for the patient.

no it's not difficult for me, he is the doctor he knows what is good for me.

Patient feels like she has to listen en adhere to the advise of the doctor

so I have to listen to him

The advise of the doctor is extremely important

especially when I'm going to take the vaccination I come here I said no I'm not taking it doctor. the doctor was not here so he phoned me home and advised me, it's good for you, take it . but everybody told me that I should take it, even my house doctor told me to take it. I didn't take it, the vaccination

When the doctor's advise is adhered, the patient is happy that the doctor is happy to hear she listened.

so today I come show to him, doctor, see I taken them both. he said I am happy this is very good. so anything when he will say it if I did it's good for me. he's very happy that I did it.

Nobody knows about the positive HIV status

no nobody knows.

Before the appointment the patient feels normal about seeing the doctor

I come to the doctor for just two times a year, so it's normal

When the patient has complaints that are not HIV-related, she will go to her GP

but if the sickness is something different like asthma or blood pressure, I will go to my house doctor.

The trust between patient and HCP is build over time

I didn't trust him but now I did, because the sickness too much people forget that they die and they have problems. with kidneys blablabla, but I take care of myself. anything he said I do it. I know that I have a good medication and I like that very much.

Patient is illiterate, written information is therefore worthless

I can't read. even to English I cannot read English. I cannot read Dutch

Patient doesn't like it when some one else needs to read things to her [illiteracy]

so if I get it I need to give it to somebody to read for me, but I didn't like that.

The patient feels very stressed at the clinic because people might see her. Her blood pressure rises drastically.

especially when I come here I don't like it. when I come here my blood pressure rises. today you see the lady told me my blood pressure is 159, at this morning I checked it and it was 120.

If the medication is finished, the patient is able to call the doctor for a new prescription to be send to the pharmacy

my medication finished, I phone, they sent. if I want my medication in the apotheek, I call them, they sent it. so I don't have problems too much.

The people from the reception are friendly and willing to help solve issues

but this time I couldn't find my card, that's why I came last month and the lady said, even if you give me a new one I want to go home for two weeks time to come, but the lady said no problem I can check it. so that's why I check it and I go home. so today everything is fine. he told me everything is great.

HCP's are highly respected due to the bond of trust, but other people are rather avoided

I respect him and anything I need I talked to him or Hans. I even told him that I didn't want to come to here because I only know him [this is about the interview].

PROMs will not make sense due to the illiteracy

no I don't want that, only talk.

Patient is convinced of the effectiveness of her African home made medicine against Covid - despite the disbelief of the Doctor

I stayed home and then make my African medication. I have some ginger. I drew my own medicine. and now I am better. I tell my doctor but he says no it's not true, you didn't get corona because you didn't come to the hospital. because my nervous system is not good, because this sickness and this sickness, I say because of that I didn't come because if they see I have this sickness and I have to corona maybe they will kill me

The patient does not want to worry her children with the disease.

yeah my daughter don't know. I don't want to give them stress. if I die I die, it's simple. I don't want to give my children stress, so anybody didn't know. Except myself.

Finding your way around the AMC is easy

I always know it is the first floor. I've born my two children here.

Provided healthcare in NL is very good in comparison with Ghana.

I like it very much. because in my country we don't get it like that. there is a big big difference.

Appendix 5

Statement Cards

At the end of an appointment the following appointment is scheduled. The patient receives a confirmation/ reminder letter at home

they send me a letter, or they give me [a new] appointment that day I come here. Or they do both. They will give me an appointment when I am there and then send me a letter.

Participant feels welcome in the AMC

I feel welcome.
...
yes I'm always welcome everywhere.

Finding your way in the AMC is easy

...

The waiting time before the consultation is short

...

Only the husband knows about the positive status

Only my husband knows about it. Next to that, nobody knows about it.

Despite the fact that the participant doesn't know anyone, she still thinks about people seeing her. But she feels okay.

S: and when you are at the hospital, do you sometimes think about people seeing you?
Pi7: yeah I do think about that but because I'm new here I don't know anyone. so I feel OK with that.

After 8 months of care, the patient doesn't have a strong personal connection with the HCP's

Observed by the way she talks about the HCP's, doesn't know their names etc.

Communication is easy due to mutual English understanding

It is easy to communicate, she understands good. And Hans also

The doctor shows intrest in the well-being of the patient, broader than just the medical picture

S: what kind of topics can you discuss with the doctor?
Pi7: how am I feeling? how is home? Taking care of the children and the environment? I am with people. normally I don't go outside I'm always indoors.

The nurse overlaps with the doctor, but also shows intrest in the more personal daily life topics

The same thing, normally do ask about my husband. he has not had a chance to meet him. because he wanted him to come, but he didn't get the chance. He came last too many months, but Hans wasn't around

The participant feels comfortable when talking to the HCP's

I feel good, I'm always good when I talk to them. I feel fine.

The participant never receives written information

No, we just talking

The participant calls the AMC when her medication is finished

when my medication is finished, I do call for advice, and they tell me to get the receipt and I can go for it.

When calling the AMC, it can be hard to get a hold of the right person

the calling is sometimes difficult. I don't always get them. the time you can call him this is not the time. the calling is difficult

It's hard to understand online information when it is not English

the Internet because of the language, I have a problem with the language, if it is in English I can do it easily. but the Dutch I'm not good, I haven't learned anything about it.

During the pregnancy, she felt the urge to take triple the amount of pills as prescribed. The doctor had to interfere.

my medication I do take a lot, I take 3 tablets when I was pregnant, morning and evening, so it was too much for me and they had to encourage me to take it.

The medical advise and explanations of HCP's are understandable.

S: and is it easy to understand all the medical things?
P7: it's easy it's OK.

S: and do you feel like the doctor is good at explaining why you need to do something?
P7: yeah they explain everything to me before. if I go to the lab they tell me they have to check the kidney and liver. they do that.

If PROMs are offered in English, there is no problem

...

Participant is open to participate in PROMs if that will help her receive better care

if it will help me then it's OK for me.

The idea of early detection of issues sounds good to the participant

I wish I can do that I think it will be very nice. it makes it easy, because I don't have contact with my GP so if I problem, I can just tell them I don't have to be refer to the GP. and come here I wish I get the doctor here I, if I come if I'm not feeling well take care of everything for me.

As appointments in the AMC are important to the participant, she will make sure remember them in her plan for the month

yes, it's always important I make sure it's in my plan for the month. I have appointment for this, so I keep them in my mind. and make sure I don't miss them very important. for this month I do have a lot. also this appointment for my son. I come here. yes to come for his vaccination. so I make sure everything is in my mind I don't mistake them.

New in the Netherlands, it's hard to find your way in the Dutch care system

I just wish if I want to see this doctor I know this process. for instance and I want to see a gynecologist, I don't know the process I really don't know who I have to call how to have a book a appointment. this is really confusing. I really need to gynecologist for the family planning. it's really confusing time for me.

As her husband has been living in NL for >30 years, he had to help her and talk on her behalf. Which is not ideal due to his own schedule

my husband had to step in talk on my behalf. that everything is in process before, it was really difficult
...
He is very busy I cannot help me with everything.

The midwife helped her arrange an appointment at the AMC

eah it was the midwife who did it for me. and by then, I didn't have insurance I didn't have anything two it was difficult in the beginning. I had to deliver two months before they start to take care of me

Appendix 6

F&Bs process

Personal connection with HCP

A good realtionshop between patient and HCP has a big added value to the QoL of the PLHIV

The trust between patient and HCP is build over time

The participant needs to feel comfortable with their HCP in order to open up totally

HCP's are highly respected due to the bond of trust, but other people are rather avoided

Patient sees so many different HCP's, he doesn't know which doctor is for what

As every patient is unique, it is important to find a good match between patient and HCP to ensure a comfortable relationship

The patient is really fond of her HCP's

The HCP also reach out to their patients when they end up in the emergency room

Patient feels like she is being treated really nicely

PROMs miss the aspect of the personal contact. Some delicate issues are rather discussed face to face

The patient is fond of the HCP's

Patient feels loved by HCP

After 8 months of care, the patient doesn't have a strong personal connection with the HCP's

Talking to the Doctor and Nurse allows the patient to share different stories

Expectations from HCP

HCP need to be emphatic and understand the needs of their patients

Appointments at the AMC are important to make sure that things are discovered in an early stage

Details about the effectiveness of the medication are complicated, but the doctor knows what works best

PROMs allow the HCP to start the consultation with potential foreknowledge

The consultation gives the patient insights in their personal health

The doctor will help in finding the correct specialist

The doctor knows what is best for the patient

All questions regarding medication and the disease can be answered during the consultations

Participant is open to participate in PROMs if that will help her receive better care

The doctor will refer the patient to another specialist when needed

PROM results discussed without any problem during the consultation

The doctor knows a lot and will tell you what is best for you

Adaptability of HCP

The HCP speak English with the patients who

Communication is easy due to mutual English understanding

HCP's do their best to speak English to improve understanding when the patient doesn't speak Dutch

The HCP within the AMC are aware of the language barrier and behave accordingly

The medical advise and explanations of HCP's are understandable.

The HCP's are patient when explaining complicated information to the patient

The Doctor explains medical information in a understandable and neutral way

Inspiration and peer-support

Appointments are important as they remind you to take care of yourself

This patient has no family in NL, only a few good friends.

The patient sometimes watches YouTube videos of people opening up about their positive status.

Attitude of HCP

The doctor shows intrest in the well-being of the patient, broader than just the medical

The HCP within the AMC treat their patients with a lot of respect

HCP never demand that the patient shares more details than they want

HCP's are respectful and understanding of the background of the patient

The reception are friendly and willing to help solve issues

Remembering appointments

Patients are reminded of their appointments via emails and letters

As appointments in the AMC are important to the participant, she will make sure remember them in her plan for the month

Patient receives multiple reminders for the appointment

Patient hangs appointment invitation on the wall to remind herself of it

Appointments are never missed

At the end of an appointment the following appointment is scheduled. The patient receives a confirmation/reminder letter at home

Doctor specific interaction

The doctor and patient will discuss how things are going for the patient

The doctor you discuss medical stuff, like medication and the

Doctor does the and medical things, garantee good health for the patient

Doctor starts with the open question "how are you" to find out if there is something to discuss right away

With the doctor you can talk about the medication and does a physical check

During the consultation prescription is made for the medication

The doctor will ask about the medication

Knowing where to go for which issue

When the patient has complaints that are not HIV-related, she will go to her GP

Non-healthcare related help from HCP

The doctor will comfort the patient when she is sad

HCP help their patients with problems regarding the IND

The day before, the patient is called to be reminded of the appointment

The doctor tries to help with issues outside the HIV-related care

Next to the medical topics, the patient also helped to understand general things like sexuality etc.

Side effects of medication are hard to understand

Attitude towards HCP

Patient is open to share information that will help the doctor providing care

Patient is willing to participate in anything, like PROMs, if that will help the doctor

As the Nurse and Doctor are together, the patient can discuss everything with both HCP's

Appointments at the AMC are important and always adhered to.

It's important to tell the truth to the doctor

Covid-19 caused worries but the advise of the doctor is taken most seriously

The idea of early detection of issues sounds good to the participant

The advise of the doctor is extremely important

The doctor knows everything best

Every appointment is adhered to, as the doctor is waiting for you.

Patient feels like she has to listen en adhere to the advise of the doctor

Appointments are important, because the doctor says so.

Delicate topics are discussed with the HCP that are familiar for the participant. A substitute doctor does not have a good bond with the participant

The patient feels that the chat with the doctor is nice and she receives good advice

The participant feels comfortable when talking to the HCP's

Hospital visits are important

When the doctor's advise is adhered, the patient is happy that the doctor is happy to hear she listened

Interaction with hospital building

The AMC offers guidance when a patient is unable to find their way

As patients come to the clinic for many years, they're used to the hospital and find their ways easily.

Finding your way is easy, a letter was send when they changed location

The AMC uses an integrated system that allows the patients to check in with their patient card

Finding your way around the AMC is easy

Finding your way in the AMC is easy

Nurse specific interaction

The Nurse is able to explain more about the medication treatment

The patient doesn't always sees the nurse as she is familiar with the system and has few problems.

The nurse overlaps with the doctor, but also shows intrest in the more personal daily life topics

Patient and Nurse have casual conversations over coffee

After talking to the Doctor, she can discuss more personal matters with the Nurse

The Nurse shares extra information on a more casual level. Sharing extra information when needed.

The Nurse is there to discuss the daily life issues on a more free and casual tone

The Nurse will share extra information or explanations when the patient needs this

With the Nurse, also daily life topics are discussed

Emotions during visits

Over time, the feeling has changed. Now it is a moment to check yourself

Participant feels welcome in the AMC

Recently diagnosed feelings of guilt and shame where dominant when entering the AMC

Patient feel happy when visiting the AMC

In the back of your mind you are still wondering "what if I walk into someone I know?"

When entering the AMC building, it feels like there is still hope.

The patient feels that she has an appointment as she sees the doctor and will see what is going on with her health.

The patient is never nervous as she receives good care

Before the appointment the patient feels normal about seeing the doctor

Information

Patient doesn't like it when some one else needs to read things to her (illiterate)

Patient don't feel the need to search for information about HIV

The patient is illiterate, therefore never searches the internet for written information

The participant never receives written information

It is hard to understand online information when it is not English

Patient is not occupied with healthcare related questions

The GP gave the patient much information about the complications of diabetes. She was unable to understand the information

Patient is illiterate, written information is therefore worthless

When the patient was informed about the implications of diabetes correctly, she became more careful with her diet

No time is spend searching for information about HIV

Interaction with HCP outside consultations

When the patient has a question she will just go to the clinic on the (known) working days of her HCP's.

If the medication is finished, the patient is able to call the doctor for a new prescription to be send to the pharmacy

HCP are easy to reach by phone calls

When calling the AMC, it can be hard to get a hold of the right person

Patient know how to reach their nurse when she needs new medication

Via MyChart you are able to get in touch with the HCP and get quick answers

When a specific issue arises and the answer cannot be found online, the Nurse is easy to reach to ask for advice

The participant calls the AMC when her medication is finished

The Dutch healthcare system

Provided healthcare in NL is very good in comparison with Ghana.

The midwife helped her arrange an appointment at the AMC

The patient is unaware of the difference between appointments with the doctor, or with the social worker, or with the interviewer

Her husband has been in NL for >30 years, he had to help her and talk on her behalf. Which is not ideal to his own schedule

This patient comes to the AMC almost every month for different kinds of appointments

New in the Netherlands, it's hard to find your way in the Dutch care system

Visit related steps

The HCP are sticking to their planning, patients don't need to wait for long unexpectedly

Patients have to give blood every 6 months

The waiting time before the consultation is short

The Nurse at the reception is friendly and guides the patient to the correct waiting area

Attitude towards privacy inside AMC

Walking in the AMC is not something to worry about, as other people are also in the AMC if they see you.

In the waiting room, it does cross her mind that the person next to her might wonder why she is there

If you meet someone at the clinic, this stays silent.

Patient is afraid to walk into a familiar face

Patient is not worried (anymore) when being inside the clinic

Stress levels rise when getting closer to the outpatient clinic. It gets harder to come up with a credible excuse why you are here.

The patient feels very stressed at the clinic because people might see her. Her blood pressure rises drastically

Despite the fact that the participant doesn't know anyone, she still thinks about people seeing her. But she feels okay

Patient is not worried about seeing anyone, focus is on the doctor

Understanding & using PROMs

The implementation of PROMs can be frustrating for those with less digital skills who need to be helped by someone else

PROMs will not make sense due to the illiteracy

If PROMs are offered in English, there is no problem

Using a device you don't understand perfectly can be frustrating when you are not in the right mood

Negative experiences with other HC providers

The GP gave the patient the feeling like she looked down on her

In Italy, the doctors did not bother to try to speak English

Dealing with it

After a few years, you learn to keep your head low while moving through the AMC

Throughout the years you will learn ways and tricks to decrease the chances of meeting anyone familiar

At the beginning of being diagnosed, I did not like to go to the hospital

(Mis)use of (alternative) medication

During the pregnancy, she felt the urge to take triple the amount of pills as prescribed. The doctor had to interfere

Patient is convinced of the effectiveness of home made medicine against Covid - despite the disbelief of the Doctor

Disclosure

No one knows about the positive status

With the medication, she is sick and therefore has no problems. There is nothing to share with the community.

People from within the community tend to gossip

When his friend saw him taking a pill every day, he told him that it was a vitamin for more energy

He is afraid that people will find out, so he takes his medication with him everywhere he goes

Nobody within the community can know about the positive status as she is afraid of the talking behind her back.

Only the husband knows about the positive status

Patient does not worry her children with the disease.

Nobody within the HIV community know about her positive status - no family members

Nobody knows about the HIV status

Her friends don't know about his positive status

No one (outside community) knows about the positive status


Personal connection with HCP
Patient feels loved by HCP
tations from
Adaptability of HCP
Non-healthcare related help from HCP
Inspiration and peer-
Attitude of HCP
Remembering appointments
Doctor specific interaction
towards HCP
Knowing where to go for which issue
Interaction with hospital building
Nurse sp interac
Emotions during visits
Information
ction with HCP outside consultations
The D system
Visit related steps
Attitude towards privacy in
Understanding & using PROMs
Negative experiences with othe
Dealing with it
(alternative)
Disclosure

Appendix 6

F&Bs process

Patient are in care for the rest of their lives. Allowing the HCP's to build a relationship

PROMs give the doctor foreknowledge and make the consultation more efficient.

HCP's are able to talk in English when the patient cannot understand Dutch

Consultations give insights in your physical well-being.

Appointments at the hospital allow for early stage discovery of diseases

HCP's do their best to explain information in an understandable way

Patient feels loved by HCP's

The patient receives phone calls from the hospital to remind him of his appointments.

HCP's come across as patient

The doctor is seen as someone who knows everything best

All necessarily information can be retrieved from the HCP during the consultations

Over time, patients find their own ways of dealing with the situation.

Patients feel welcome in the hospital

As the doctor knows everything, I don't need to learn anything about the effects of HIV

PLWH find support within the HIV communities

Appointments at the hospital remind you to take care of yourself.

When offered in English, PROMs can be understood and answered.

HCP's respect the boundaries of the patients and what they want to share, or not.

Watching videos with inspirational content about living with HIV [illiteracy]

Patients are willing to fill in questionnaires if that helps the doctor

Entering the hospital gives a feeling of hope. Not all is lost.

The HCP offer a listening ear for anything that can be seen as (slightly) HIV related

MyChart allows you to send a email to your HCP and receive an answer within 1-2 days

HCP's show intrest in the personal lives of their patients

The doctor can tell me what to do regarding any medical related matter.

Consultation appointments are reminded via letters and/or text messages

The quality of healthcare in NL is highly appreciated

Friendly people at the reception will help you when someone misses their cards or something went wrong with the appointment

The doctor checks the physical well being of the patient.

Hospital visits are important

Reminding yourself about the appointment by hanging the letter on the wall next to the fridge

HCP won't let their patients wait for long. Sticking to the schedule.

Gentlemen agreement between patients who see each other and stay silent about this

Routes in the hospital al clear and easy to find

Nurse tries to stay up to date with the personal lives of the patient.

The host near the entrance can help you when you need guidance finding your way

The Nurse has a more casual relationship with the patient, allowing to discuss daily life

The Midwife made the initial appointment at the hiv clinic

HCP's help patient with extra things in daily life outside of the job description of being a doctor/nurse

Doctor helps to find the right specialists when patient needs extra medical treatments

The nurse can be reached via the phone for things like a new prescription

41
facilitators

Getting the right person on the phone can be hard

Patients are afraid to meet someone they know who will discover their positive status

Patients have a hard time accepting their positive status

Feeling anxious and suspicious when walking through the hospital.

While waiting you are wondering what people might think of you and why you are there

When you recently moved to the Netherlands it is hard to figure out where you can find the medical help you need.

Only information shared by HIV-HCP can be trusted completely

Pregnant patient overdosed on HIV medication because she thought that would be better

An appointment includes multiple steps. The patient sees many people

How can you book an appointment for a certain specialist

Being afraid to bump in to a familiair person who will then know about the infection

Refugee has no family members in NL

Living with HIV brings extra issues to your private life that HCP's like to discuss. These topics can be seen as sensitive. E.g. sexual contact, substance abuse

Stress levels rise when coming closer to the outpatient clinic

Within the cultural communities, people tend to gossip

Things that can comfortably be discussed with your personal HCP's, are not the same with a substitute

The inability to speak, understand, read Dutch

Low digital skills can be the cause of frustration when trying to fill in PROMs on a digital platform.

PROMs take away the face-to-face element. Making it less attractive to answer personal/private questions

Out of fear of negative reactions, PLWH keep their positive status a secret from (almost) every one

You need to be in a good mood when you are going to use a new device your not used to, or it will be frustrating.

When you are illiterate, it will not make sense to answer a written questionnaire

I want to see an gynecologist but I have no idea how to get in touch with the right person

Bad past experiences might influence how a patient views the healthcare system

As a "migrant" you can get in trouble with the IND when something goes wrong what you don't understand

Using MyChart is hard with low digital skills

Patients have experiences with being treated badly at other falicities

Illiteracy.

I cannot read Dutch

When seeing many different specialists, it's hard to remember which one is for what.

Even regarding COVID-19, the only doctor that will be listened to is the HIV-HCP

31
barriers

Patients believe in the effectiveness of alternative medications/treatment

1 random
statement

HCP take their time to make sure the patient is able to understand everything

- HCP's come across as patient
- HCP's do their best to explain information in an understandable way
- HCP's are able to talk in English when the patient cannot understand Dutch

Patients are willing to co-operate with PROMs if this helps the HCP

- Patients are willing to fill in questionnaires if that helps the doctor
- When offered in English, PROMs can be understood and answered.
- PROMs give the doctor foreknowledge and make the consultation more efficient.

Via different ways patients can reach out to their HCP

- MyChart allows you to send a email to your HCP and receive an answer within 1-2 days
- The nurse can be reached via the phone for things like a new prescription

Mutual respect and understanding within the HIV communities

- Watching videos with inspirational content about living with HIV [illiteracy]
- Gentlemen agreement between patients who see each other and stay silent about this
- PLWH find support within the HIV communities

HCP are willing to help find the correct specialist

- The Midwife made the initial appointment at the hiv clinic
- Doctor helps to find the right specialists when patient needs extra medical treatments

HCP are good at time management

- HCP won't let their patients wait for long. Sticking to the schedule.
- The quality of healthcare in NL is highly appreciated

The doctor gives the best advise and makes sure the physical things are in order

- The doctor checks the physical well being of the patient.
- The doctor is seen as someone who knows everything best
- As the doctor knows everything, I don't need to learn anything about the effects of HIV
- All necessarily information can be retrieved from the HCP during the consultations
- The doctor can tell me what to do regarding any medical related matter.

HCP's do their best to create a personal connection and build a bond of trust over time

- Nurse tries to stay up to date with the personal lives of the patient.
- The HCP offer a listening ear for anything that can be seen as (slightly) HIV related
- The Nurse has a more casual relationship with the patient, allowing to discuss daily life
- Patient are in care for the rest of their lives. Allowing the HCP's to build a relationship
- HCP's respect the boundaries of the patients and what they want to share, or not.
- HCP's show intrest in the personal lives of their patients
- Patient feels loved by HCP's
- HCP's help patient with extra things in daily life outside of the job description of being a doctor/nurse

Arrangemens are made that people are reminded of their appointments and guided to the right locations

- The host near the entrance can help you when you need guidance finding your way
- Routes in the hospital al clear and easy to find
- Friendly people at the reception will help you when someone misses their cards or something went wrong with the appointment
- The patient receives phone calls from the hospital to remind him of his appointments.
- Consultation appointments are reminded via letters and/or text messages

Patients find their own ways to deal with different elements

- Reminding yourself about the appointment by hanging the letter on the wall next to the fridge
- Over time, patients find their own ways of dealing with the situation.

Patients see their hospital visits as important

- Appointments at the hospital allow for early stage discovery of diseases
- Hospital visits are important
- Consultations give insights in your physical well-being.
- Appointments at the hospital remind you to take care of yourself.

Patients feel welcome and hopeful when entering the hospital building

- Entering the hospital gives a feeling of hope. Not all is lost.
- Patients feel welcome in the hospital

HCP take their time to make sure the patient is able to understand everything

Via different ways patients can reach out to their HCP

The doctor gives the best advise and makes sure the physical things are in order

Patients see their hospital visits as important

HCP are willing to help find the correct specialist

Arrangemens are made that people are reminded of their appointments and guided to the right locations

Patients are willing to co-operate with PROMs if this helps the HCP

Mutual respect and understanding within the HIV communities

HCP's do their best to create a personal connection and build a bond of trust over time

Patients feel welcome and hopeful when entering the hospital building

HCP are good at time management

Patients find their own ways to deal with different elements

Appendix 6

F&Bs process

Getting in touch with the right person

- Getting the right person on the phone can be hard
- When you recently moved to the Netherlands it is hard to figure out where you can find the medical help you need.
- How can you book an appointment for a certain specialist
- I want to see an gynecologist but I have no idea how to get in touch with the right person

Only the HIV-HCP's are fully trusted

- Only information shared by HIV-HCP can be trusted completely
- Even regarding COVID-19, the only doctor that will be listened to is the HIV-HCP

Misunderstanding the rules within the Netherlands can get you in big problems

- As a "migrant" you can get in trouble with the IND when something goes wrong what you don't understand

Feeling uncomfortable when using digital platforms or systems

- Using MyChart is hard with low digital skills
- You need to be in a good mood when you are going to use a new device your not used to, or it will be frustrating.
- Low digital skills can be the cause of frustration when trying to fill in PROMs on a digital platform.

Different faces of different HCP within and outside Q1

- An appointment includes multiple steps. The patient sees many people
- When seeing many different specialists, it's hard to remember which one is for what.

Negative responses from peers/family

- Out of fear of negative reactions, PLWH keep their positive status a secret from (almost) every one
- Patients have a hard time accepting their positive status
- Within the cultural communities, people tend to gossip

The inability to read and write

- When you are illiterate, it will not make sense to answer a written questionnaire
- I cannot read Dutch
- Illiteracy.
- The inability to speak, understand, read Dutch

Sensitive topics can only be discussed with the personal HCP's, after building a trust-bond

- Things that can comfortably be discussed with your personal HCP's, are not the same with a substitute
- Living with HIV brings extra issues to your private life that HCP's like to discuss. These topics can be seen as sensitive. E.g. sexual contact, substance abuse
- PROMs take away the face-to-face element. Making it less attractive to answer personal/private questions

Building a new network as a refugee

- Refugee has no family members in NL

Stress and anxiety arise when being near Q1

- Patients are afraid to meet someone they know who will discover their positive status
- Feeling anxious and suspicious when walking through the hospital.
- Stress levels rise when coming closer to the outpatient clinic
- While waiting you are wondering what people might think of you and why you are there
- Being afraid to bump in to a familiair person who will then know about the infection

Past (negative) experiences

- Patients have experiences with being treated badly at other falicities
- Bad past experiences might influence how a patient views the healthcare system

Personal beliefs can get in the way of the prescribed treatment

- Patients believe in the effectiveness of alternative medications/treatment
- Pregnant patient overdosed on HIV medication because she thought that would be better

Getting in touch with the right person
Different faces of different HCP within and outside Q1
Building a new network as a refugee
Misunderstanding the rules within the Netherlands can get you in big problems
The inability to read and write
Past (negative) experiences

Only the HIV-HCP's are fully trusted
Negative responses from peers/family
Stress and anxiety arise when being near Q1
Feeling uncomfortable when using digital platforms or systems
Sensitive topics can only be discussed with the personal HCP's, after building a trust-bond
Personal beliefs can get in the way of the prescribed treatment

Which barriers and facilitators do PLWH with a migration background experience regarding disease management, the current offered healthcare and the (future) use of PROMS.

Stress and anxiety arise when being near Q1 ☆
Negative responses from peers/family
Building a new network as a refugee
Misunderstanding the rules within the Netherlands can get you in big problems
Past (negative) experiences

Getting in touch with the right person ☆
Personal beliefs can get in the way of the prescribed treatment
Different faces of different HCP within and outside Q1
Only the HIV-HCP's are fully trusted ☆

Feeling uncomfortable when using digital platforms or systems ☆
Sensitive topics can only be discussed with the personal HCP's, after building a trust-bond
The inability to read and write ☆

Appendix 6

F&Bs process

Which barriers and facilitators do PLWH with a migration background experience regarding disease management, the current offered healthcare and the (future) use of PROMS.

PROMs will be implemented via MyChart, which is a digital platform.
Only 1 out of 7 interviewees is currently using this platform.

One participant mentioned that she doesn't like it when someone has to ready something to her

Building a new network as a refugee

Misunderstanding the rules within the Netherlands can get you in big problems

HCP take their time to make sure the patient is able to understand everything

Via different ways patients can reach out to their HCP

Patients feel welcome and hopeful when entering the hospital building

HCP are good at time management

Patients are willing to co-operate with PROMs if this helps the HCP

Patients see their hospital visits as important

HCP are willing to help find the correct specialist

Arrangemens are made that people are reminded of their appointments and guided to the right locations

(The lack of) Skills and the effect

Getting in touch with the right person ☆

Feeling uncomfortable when using digital platforms or systems ☆

The inability to read and write ☆

The doctor will refer the patient to another specialist when needed

The midwife helped her arrange an appointment at the AMC

eah it was the midwife who did it for me. and by then, I didn't have insurance I didn't have anything two it was difficult in the beginning. I had to deliver two months before they start to take care of me

Using a device that you don't understand perfectly can be frustrating when you are not in the right mood

Patient doesn't like it when some one else needs to read things to her [illitera

so if I get it I need to give it to somebody to read for me, but I didn't like that.

Patient don't feel the need to search for information about HIV

No, I don't look anywhere for any information. If something worries me. Everything is good, only that one that gives me some symptoms. Apart from that everything is good.

New in the Netherlands, it's hard to find your way in the Dutch care sy

The doctor will help with finding the correct specialist

The patient is illiterate, therefore never searches the internet for written infor

no I don't, I don't know how to read

Making use of the knowledge provided

Only the HIV-HCP's are fully trusted ☆

Personal beliefs can get in the way of the prescribed treatment

The doctor gives the best advise and makes sure the physical things are in order ☆

Patients find their own ways to deal with different elements ☆

When the doctor's advise is adhered, the patient is happy that the doctor is happy to hear she listened.

During the pregnancy, she felt the urge to take triple the amount of pills as prescribed. The doctor had to interfere.

my medication I do take a lot, I take 3 tablets when I was pregnant, morning and evening, so it was too much for me and they had to encourage me to take it.

Throughout the years you will learn ways and tricks to decrease the chances of meeting anyone familiar

The doctor knows everything best

And if something is not going on, he would ask me what, why is this not good? Then I don't know, you're the doctor.

Patient is convinced of the effectiveness of her African home made medicine against Covid - despite the disbelief of the Doctor

At the beginning of being diagnosed, I did not like to go to the hospital.

Dat was in het begin zeker, maar achteraf, nu dat ik de moed weer heb opgepakt ben ik er wat makkelijker en vrij in. Dus nu ga ik wel elke afspraak die er is ben ik wel aanwezig.

Covid-19 caused worries but the advise of the doctor is taken most seriou

Personal connection with HCP

HCP's do their best to create a personal connection and build a bond of trust over time ☆

Sensitive topics can only be discussed with the personal HCP's, after building a trust-bond

Different faces of different HCP within and outside Q1

Patient feels loved by HCP

I would tell everything, you will meet people here who would love you and like you

The patient is really fond of her HCP's

PROMs miss the aspect of the personal contact. Some delicate issues are rather discussed face to face

After 8 months of care, the patient doesn't have a strong personal connection with the

Observed by the way she talks about the HCP's, doesn't know their names etc.

The patient is fond of the HCP's

As every patient is unique, it is important to find a good match between patient and HCP to ensure a comfortable relationship

The participant needs to feel comfortable with their HCP in order to open up to

In het begin was het wel even wennen want je komt iets over jezelf er achter wat niet echt prettig is.

Patient sees so many differnt HCP's, he doesn't know which doctor is for

Stigma

Stress and anxiety arise when being near Q1 ☆

Negative responses from peers/family

Past (negative) experiences

Mutual respect and understanding within the HIV communities

With the medication, she is sick and therefore has no problems. There is nothing to share with the community.

Nobody within the community can know about the positive status as she is afraid of the talking behind her back.

Only people within the HIV community know about her positive status - no family mem

No one (outside the HIV community) knows about the positive status

I am okay with keeping it to myself, when I feel like I have to share it with everybody. The ones who are really close to me at work, I told them. And my sisters and brothers. But my friends, I didn't tell it to any of my friends.

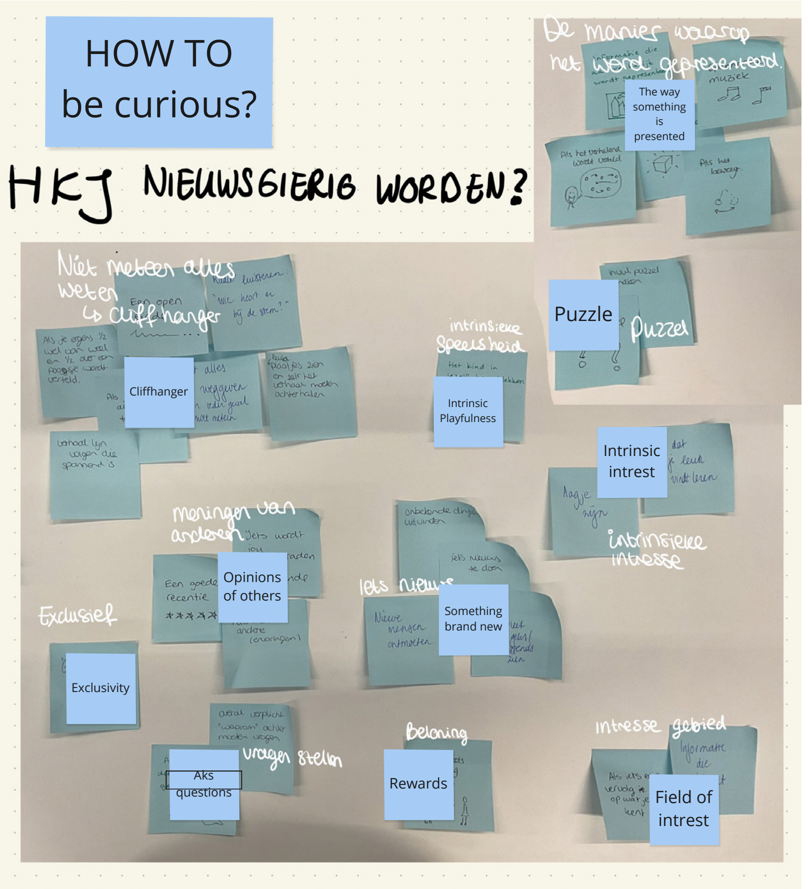
The GP gave the patient the feeling like she looked down on her.

In Italy, the doctors did not bother to try to speak English

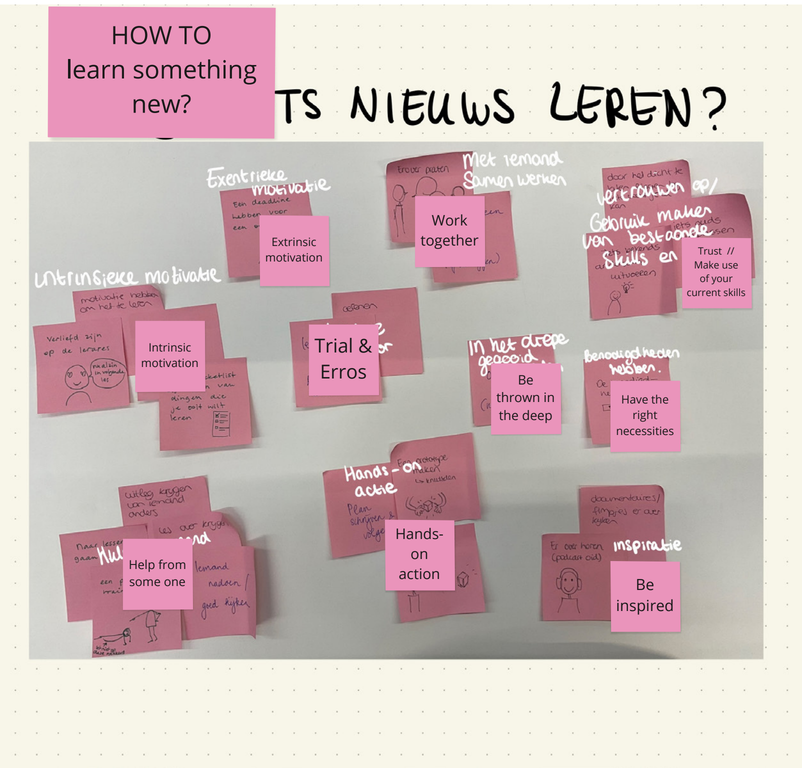
People from within the community tend to gossip

The patient does not want to worry her children with the disease.

yeah my daughter don't know. I don't want to give them stress. if I die I die, it's simple. I don't want to give my children stress, so anybody didn't know. Except myself.


HOW TO be curious?
HKJ NIEUWSGIERIG WORDEN?
De manier waarop het wordt gepresenteerd
The way something is presented
Niet meteen alles weten ↳ cliff hanger
Cliffhanger
Puzzle
Puzzel
intrinsieke speelsheid
Intrinsic Playfulness
Intrinsic intrest
intrinsieke interesse
meningen van anderen
Opinions of others
Iets nieuws
Something brand new
Exclusief
Exclusivity
vragen stellen
Aks questions
Beloning
Rewards
interesse gebied
Field of intrest


HOW TO understand something which you do understand (yet)?
TS BEGRIJPEN WAT JE (NOG) NIET BEGRIJPT?
Juiste taal
The correct language
Sometimes this is not possible -
oefenen & trainen
Practice and train
Visually work it out
Visueel uitwerken.
Verdiepen op een andere manier
Use another method to deepen your knowledge
uitleg/hulp van een ander
Ask for an explanation or help from some one else
Samen bespreken
Discuss it with some one


HOW TO learn something new?
TS NIEUWS LEREN?
Extrinsieke motivatie
Extrinsic motivation
Met iemand samen werken
Work together
vertrouwen op/ Gebruik maken van bestaande skills
Trust // Make use of your current skills
Intrinsieke motivatie
Intrinsic motivation
Trial & Erros
In het diepe gegooid.
Be thrown in the deep
Benodigdheden hebben.
Have the right necessities
Help from some one
Hands-on actie
Hands-on action
inspiratie
Be inspired


HOW TO have the feeling of privacy?
T GEVOEL HEBBEN DAT PRIVACY HEBT?
ervaringen van anderen
How other people experienced it
Beschermen met sleutels/ wachtwoorden
Protect with keys or passwords
Have secrets
Randomizer
Contracts
Fysiek/visueel afschermen/ verbloemen
Physic/Visually protect or disguise
Alleen zijn zonder geluid van externe bronnen/factoren
Being alone without any stimulus from external sources/factors
Anoniem
Anonymously
Asking for a friend
"Asking for a friend"
Consciously ignore eachother
Elkaar bewust negeren


HOW TO have trust in something/someone?
N IETS/IEMAND VERTROUWEN HEBBEN?
Afhankelijk
Depend on someone
Wederzijds vertrouwen
Mutual trust
Goede kwaliteit
Good quality
Positieve ervaringen (peers of zelf)
Positive experience from the past or peers
wetenschappelijk bewezen en onderbouwd
Scientifically proven or grounded
Zwart op wit vast gelegd
Official promise
vertrouwen opbouwen
Build trust

Appendix 7

How To - Brainstorm

I want to design a tool that helps PLWH to feel in control over their personal disease management.

HOW TO be curious?

- The way something is presented
- Puzzle
- Cliffhanger
- Intrinsic Playfulness
- Intrinsic intrest
- Opinions of others
- Something brand new
- Exclusivity
- Aks questions
- Rewards
- Field of intrest

HOW TO understand something which you do understand (yet)?

- - Sometimes this is not possible -
- Practice and train
- Visually work it out
- Use another method to deepen your knowledge
- Ask for an explanation or help from some one else
- The correct language
- Discuss it with some one

HOW TO have the feeling of privacy?

- How other people experienced it
- Protect with keys or passwords
- Have secrets
- Randomizer
- Contracts
- Consciously ignore eachother
- Being alone without any stimulus from external sources/factors
- "Asking for a friend"
- Physic/Visually protect or disguise
- Anonymously

HOW TO have trust in something/someone?

- Good quality
- Positive experience from the past or peers
- Scientifically proven or grounded
- Official promise
- Build trust
- Depend on someone
- Mutual trust

HOW TO learn something new?

- Work together
- Trust // Make use of your current skills
- Intrinsic motivation
- Trial & Erros
- Be thrown in the deep
- Be inspired
- Have the right necessities
- Help from some one
- Extrinsic motivation
- Hands-on action

Duidelijke taal met visualisaties

Conclusies in het dagboek - andere kleur. Makkelijk terug bladeren

Buddies? Elkaar herinneren en helpen tijdens het consult --> rationeel + niet altijd de patiënt zijn, ook steun geven. Waardevoller zijn

onthouden wat er is besproken

App met foto momenten --> herinneringen dagboek

Invul dagboek vóór consulten

Weten wat je moet vragen

Online vragenlijsten vóór consulten

Overzicht met vragen die in de 6 maanden naar boven zijn gekomen

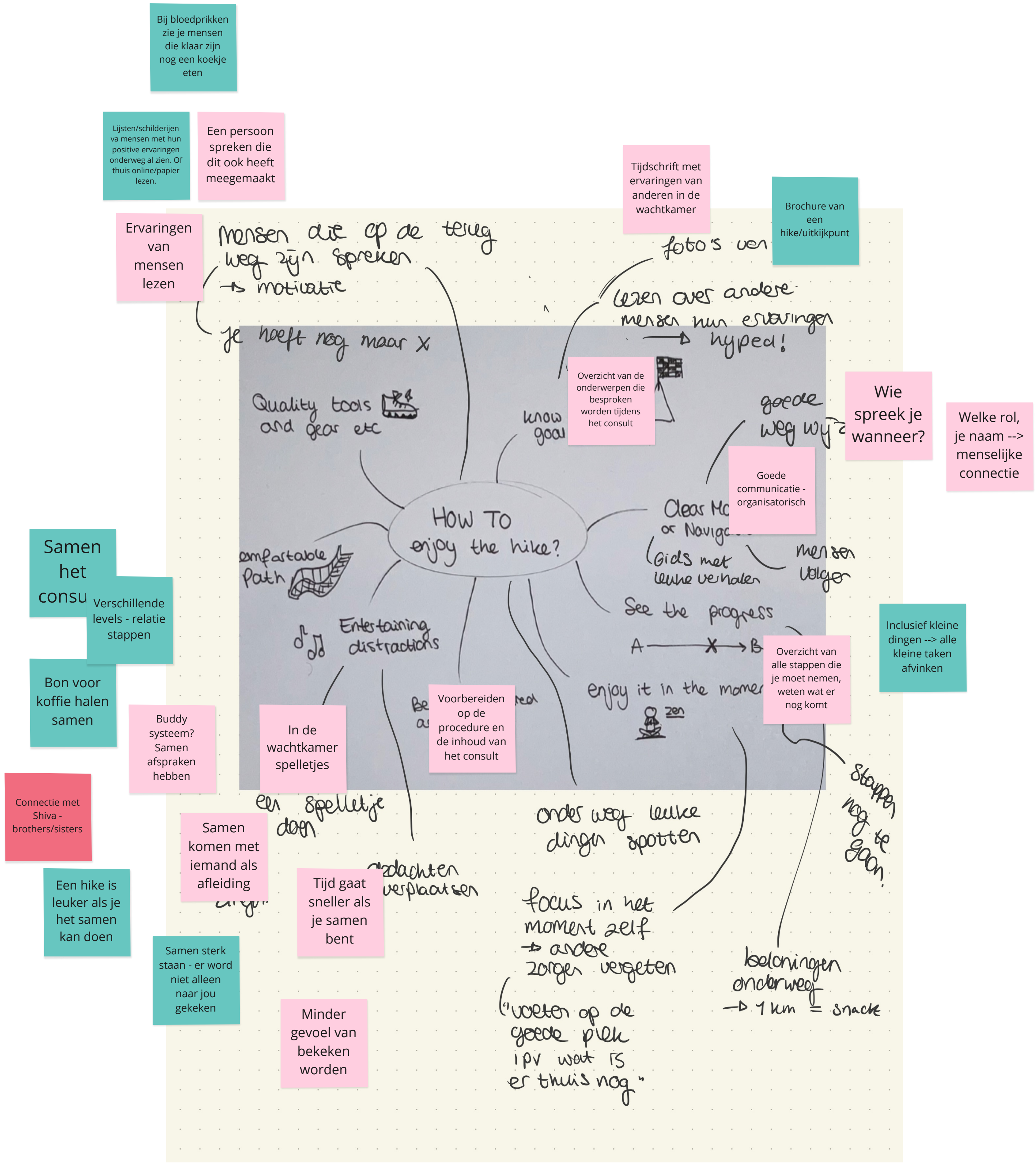
Overzichts pagina.

Data bij vragen en wat is er nog meer gebeurt in die periode?

Nieuwe losse paginas

Mooi geheel, medicatie en boekje samen houden

Geen "verdacht" uiterlijk, geen stigma



Bij bloedprikken zie je mensen die klaar zijn nog een koekje eten

Lijsten/schilderijen va mensen met hun positive ervaringen onderweg al zien. Of thuis online/papier lezen.

Een persoon spreken die dit ook heeft meegemaakt

Ervaringen van mensen lezen

Tijdschrift met ervaringen van anderen in de wachtkamer

Brochure van een hike/uitkijkpunt

Overzicht van de onderwerpen die besproken worden tijdens het consult

Wie spreek je wanneer?

Welke rol, je naam --> menselijke connectie

Goede communicatie - organisatorisch

Samen het consu

Verschillende levels - relatie stappen

Inclusief kleine dingen --> alle kleine taken afvinken

Overzicht van alle stappen die je moet nemen, weten wat er nog komt

Bon voor koffie halen samen

Buddy systeem? Samen afspraken hebben

In de wachtkamer spelletjes

Voorbereiden op de procedure en de inhoud van het consult

Connectie met Shiva - brothers/sisters

Samen komen met iemand als afleiding

Een hike is leuker als je het samen kan doen

Tijd gaat sneller als je samen bent

Samen sterk staan - er word niet alleen naar jou gekeken

Minder gevoel van bekeken worden

Appendix 8

Synectics

IDEE 1

Buddies? Elkaar herinneren en helpen tijdens het consult --> rationeel + niet altijd de patiënt zijn, ook steun geven. Waardevoller zijn

Bon voor koffie halen samen

Samen sterk staan - er word niet alleen naar jou gekeken

Een hike is leuker als je het samen kan doen

Samen het consult?

Verschillende levels - relatie stappen

Buddy systeem? Samen afspraken hebben

Connectie met Shiva - brothers/sisters

Tijd gaat sneller als je samen bent

Samen komen met iemand als afleiding

Minder gevoel van bekeken worden

IDEE 2

App met foto momenten --> herinneringen dagboek

Nieuwe losse paginas

Geen "verdacht" uiterlijk, geen stigma

Overzicht met vragen die in de 6 maanden naar boven zijn gekomen

Mooi geheel, medicatie en boekje samen houden

Overzichts pagina.

Conclusies in het dagboek - andere kleur. Makkelijk terug bladeren

Invul dagboek vóór consulten

Data bij vragen en wat is er nog meer gebeurt in die periode?

Online vragenlijsten vóór consulten

IDEE 3

In de wachtkamer spelletjes

Een persoon spreken die dit ook heeft meegemaakt

Tijdschrift met ervaringen van anderen in de wachtkamer

Ervaringen van mensen lezen

Bij bloedprikken zie je mensen die klaar zijn nog een koekje eten

Brochure van een hike/uitkijkpunt

Lijsten/schilderijen va mensen met hun positive ervaringen onderweg al zien. Of thuis online/papier lezen.

IDEE 4

Goede communicatie - organisatorisch

Wie spreek je wanneer?

Welke rol, je naam --> menselijke connectie

Overzicht van alle stappen die je moet nemen, weten wat er nog komt

Overzicht van de onderwerpen die besproken worden tijdens het consult

Weten wat je moet vragen

Voorbereiden op de procedure en de inhoud van het consult

Inclusief kleine dingen --> alle kleine taken afvinken

Duidelijke taal met visualisaties

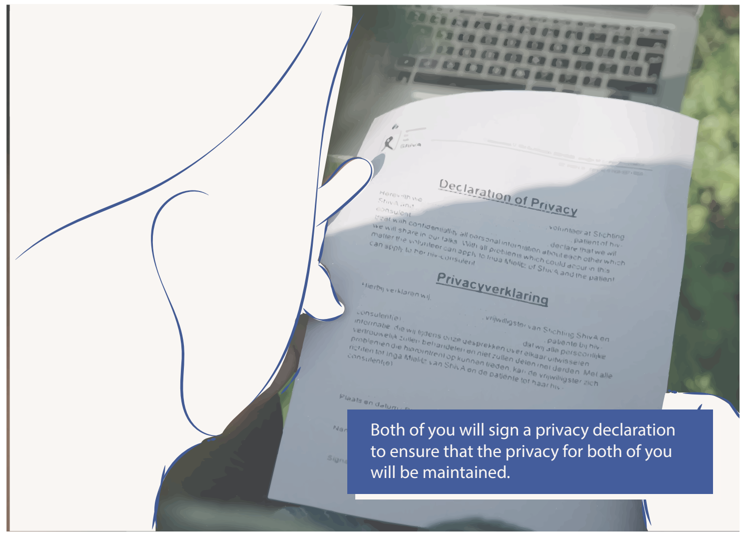
Appendix 9

Storyboard Concept 1

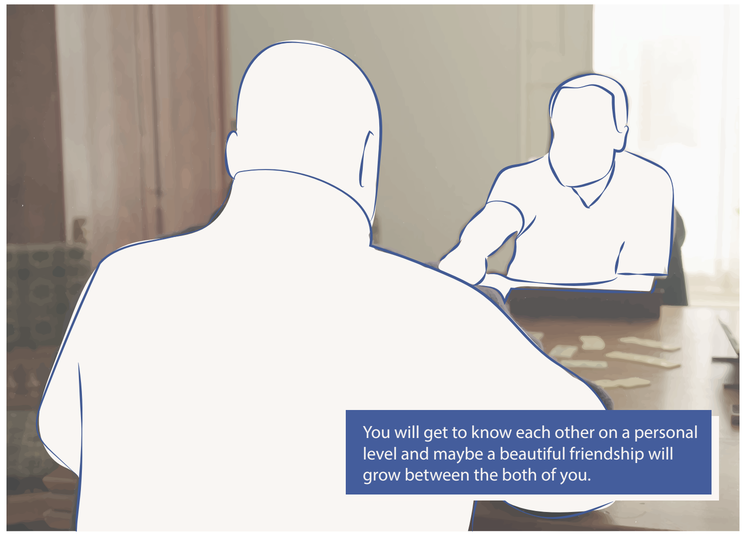

The diagnosis of a positive HIV status can be hard to deal with when you are on your own without someone to talk to.


Stichting ShivA can help you to get connected to a Positive Brother or Sister. This is someone who is also living with HIV. They will be your role model and help you with your struggles and worries.

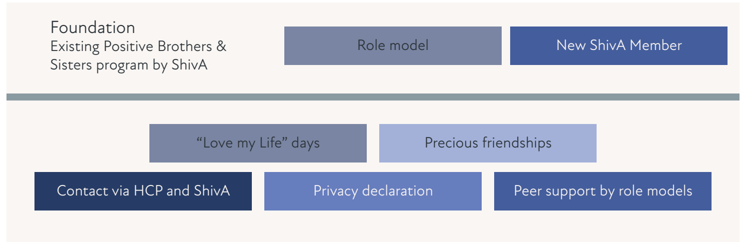

Many different people are part of the ShivA community, you will be connected to the perfect match. Someone who has the same ideas and values as you.



Both of you will sign a privacy declaration to ensure that the privacy for both of you will be maintained.


You will get to know each other on a personal level and maybe a beautiful friendship will grow between the both of you.


During the "Love My Life" days you will meet other people from the ShivA community.


Foundation
Existing Positive Brothers & Sisters program by ShivA

Role model

New ShivA Member

"Love my Life" days

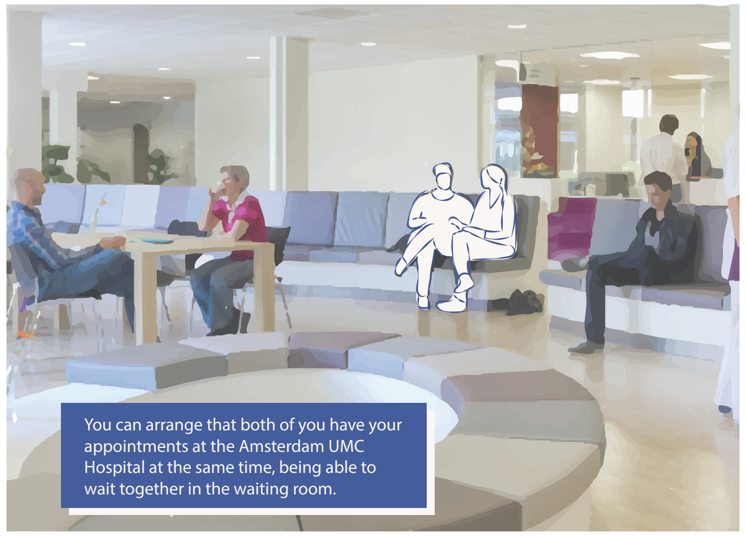
Precious friendships

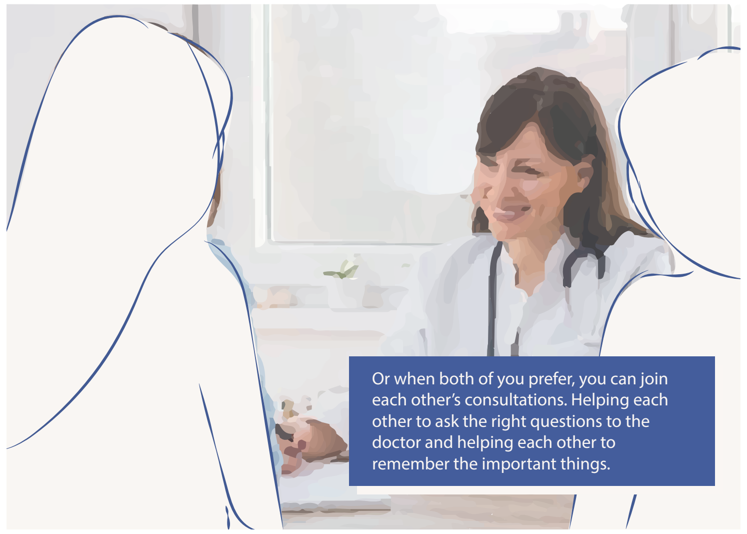
Contact via HCP and ShivA

Privacy declaration

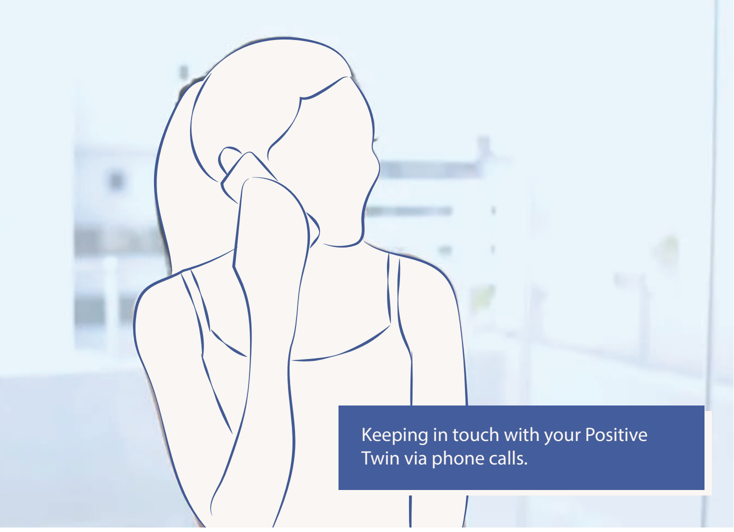
Peer support by role models

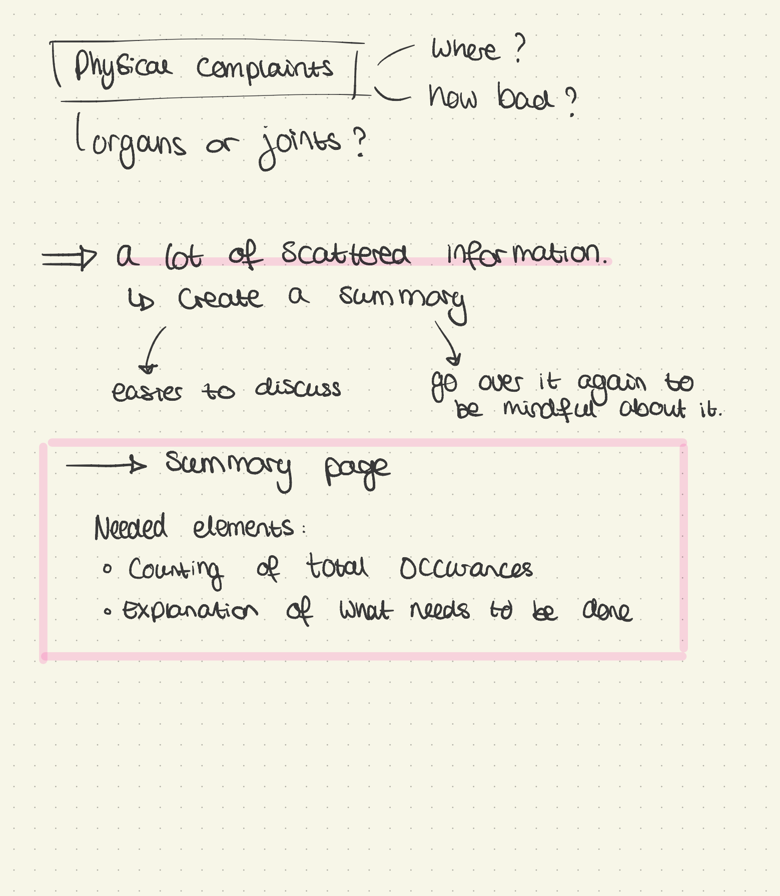
Next to the connection with your Positive Brother or Sister, you can also decide to get in touch with a Positive Twin. This is someone who is just like you. Someone who is in the same stage as you with whom you can find out new things together.


You can arrange that both of you have your appointments at the Amsterdam UMC Hospital at the same time, being able to wait together in the waiting room.


Or when both of you prefer, you can join each other's consultations. Helping each other to ask the right questions to the doctor and helping each other to remember the important things.


After the consultation with the Doctor you are able to have a cup of coffee to discuss your health and help each other with the daily struggles.


Keeping in touch with your Positive Twin via phone calls.

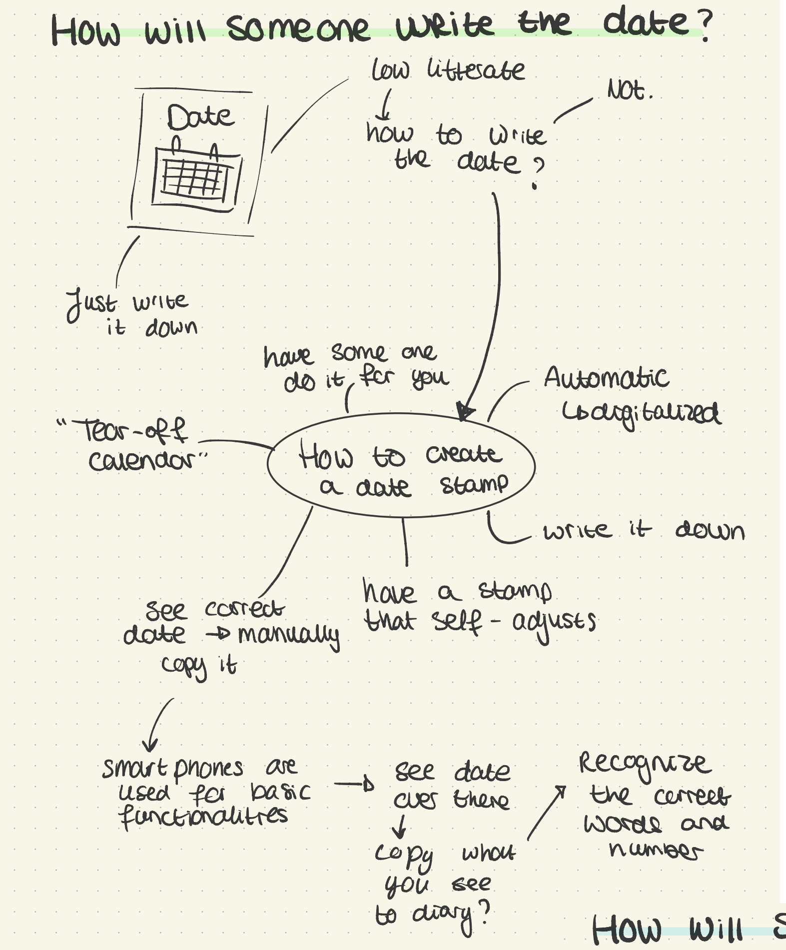


Physical complaints
- where ?
- how bad ?
- organs or joints ?

⇒ a lot of scattered information.
↳ Create a summary
- easier to discuss
- go over it again to be mindful about it.

→ Summary page

Needed elements:
- Counting of total occurances
- Explanation of what needs to be done



How will someone write the date?

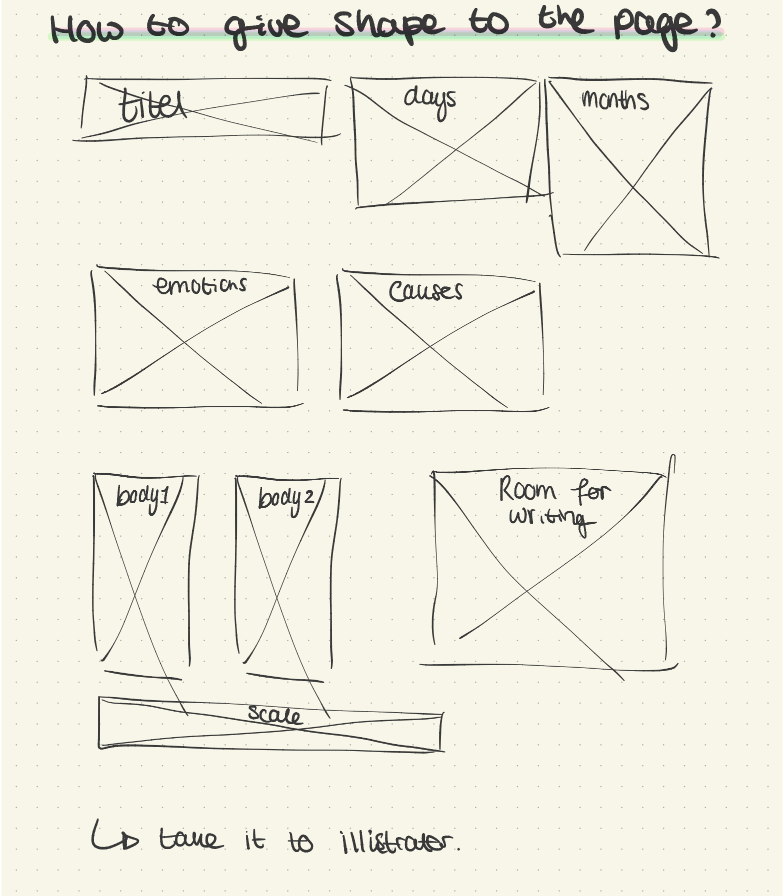
low litterate
↓
how to write the date ?
Not.

Just write it down

How to create a date stamp
- have some one do it for you
- Automatic
  ↳ digitalized
- "Tear-off calendar"
- write it down
- have a stamp that self-adjusts
- see correct date → manually copy it

↓

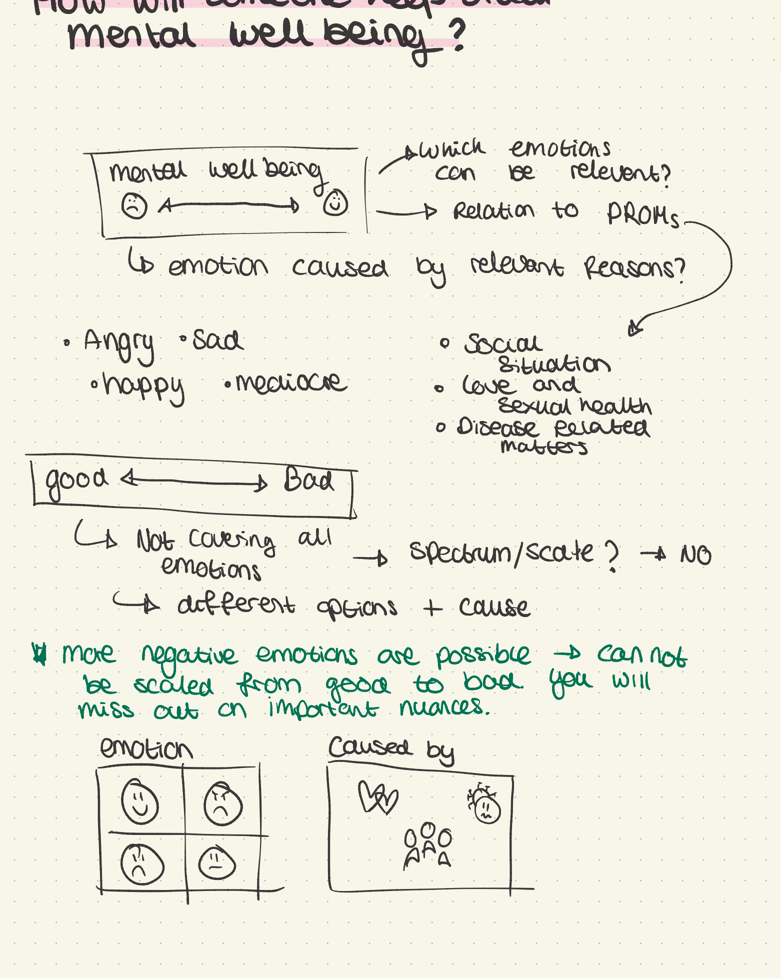
smart phones are used for basic functionalitres → see date over there
↓
copy what you see to diary? → Recognize the correct words and number



How to give shape to the page?

↳ take it to illistrater.

How will someone keep track mental well being ?



→ which emotions can be relevent?

→ Relation to PROMs

↳ emotion caused by relevant Reasons?

- Angry
- Sad
- happy
- mediocre

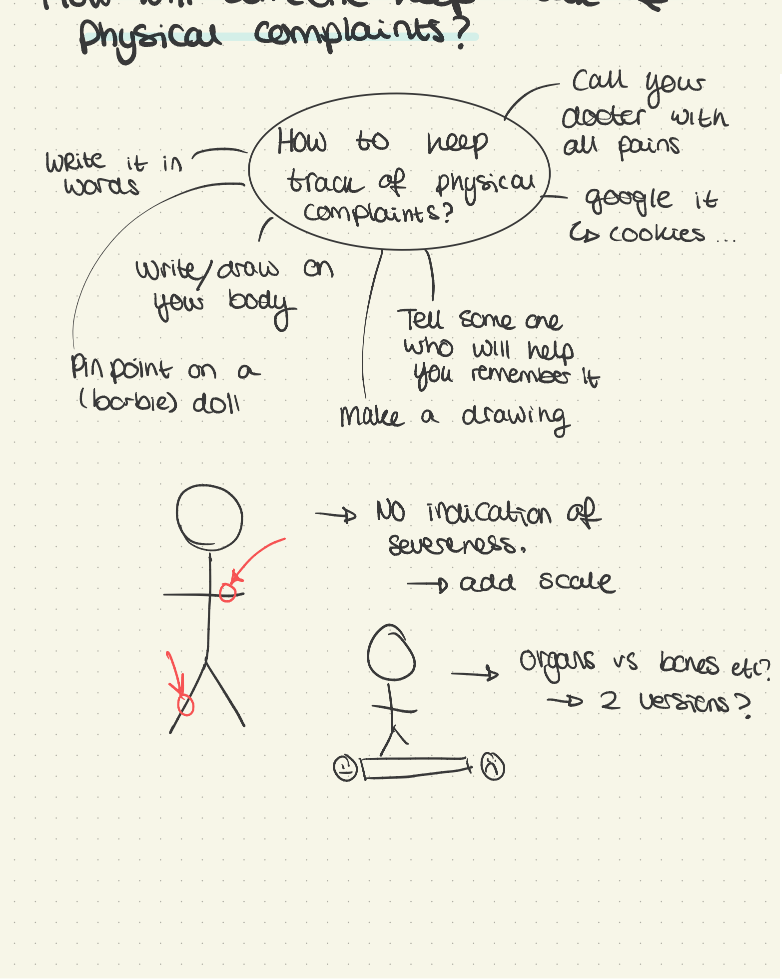
- Social situation
- Love and sexual health
- Disease Related matters

↳ Not covering all emotions → Spectrum/scale ? → NO

↳ different options + cause

* more negative emotions are possible → can not be scaled from good to bad. you will miss out on important nuances.

How will someone keep track of Physical complaints?



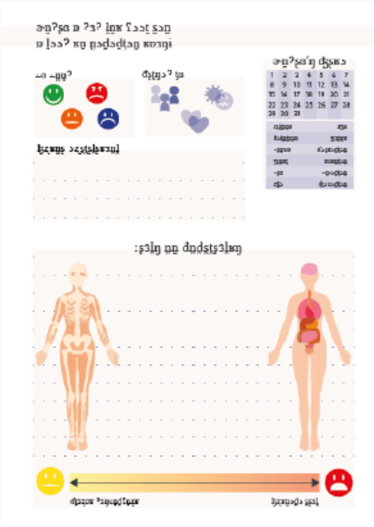
How to keep track of physical complaints?
- Call your doctor with all pains
- google it
  ↳ cookies ...
- Write it in words
- Write/draw on your body
- Pin point on a (barbie) doll
- Tell some one who will help you remember it
- Make a drawing

→ NO indication of severeness.
→ add scale

→ Organs vs bones etc?
→ 2 versions?

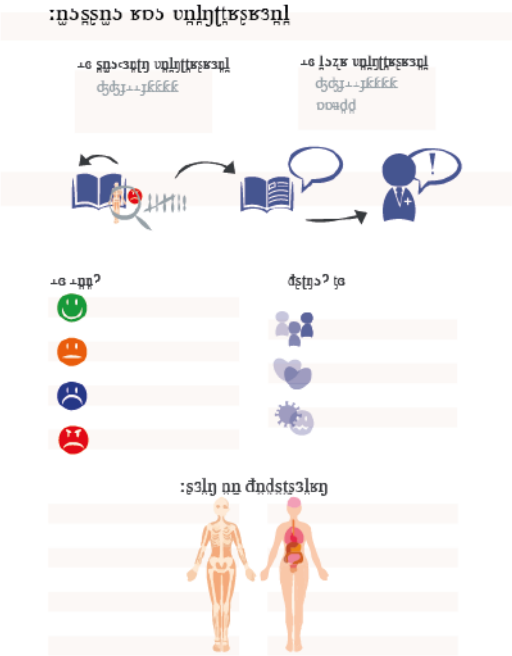
Appendix 11

Results from Logic Test



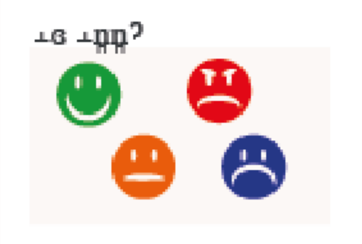
What is the first thing that pops up in your mind when looking at the entire page?

Confusion	20
Clear	14
Attention	5
Recognition	3
Panic	3
Biology	1



What is the first thing that pops up in your mind when looking at the entire page?

Summary	9
Call for action	8
Recognize elements	7
Manual	6
Confusion	6
N/A	5
Organized	2
Research	1
Chaotic	1
Complex	1



What do you think that this element is meant for?

Emotion	33
Wellbeing	7
Rating	5
N/A	1

What emotion do you think this represents?

Angry	31
Bad, Sick, Ill	12
Frustraded	3

What emotion do you think this represents?

Below good	20
Neutral	15
Mentally unwell	7
Okay	3
Unclear	1

What emotion do you think this represents?

Happy	30
Good	10
No pain and happy	2
Healthy	2
Stable	2

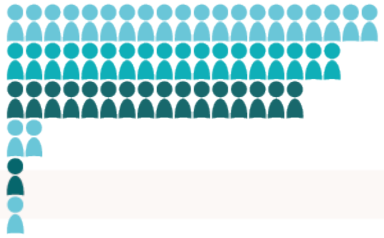
What emotion do you think this represents?

Sadness	30
Hurting	2
Depressed	2
Pain	2
Physically not good	1
Other negative emotions	9

What do you think that this element is meant for?

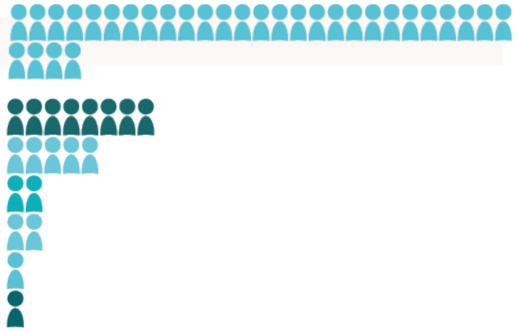
Daily topics	23	
N/A	17	
Interactions	6	

What do you think this image represents?



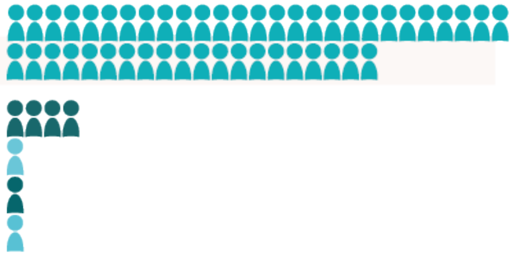
Frieds/Family	16	
Social contact	14	
Group of people	12	
Unclear	2	
Social contact needed	1	
Busy	1	

What do you think this image represents?



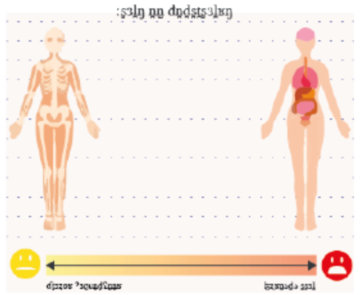
Love	27	
Relationships	8	
Sexual activities	5	
(Mental) Health	2	
Heart issues	2	
Extra care needed	1	
Inner feeling	1	

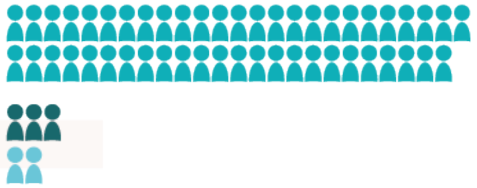
What do you think this image represents?



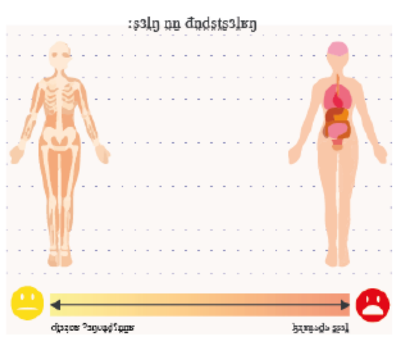
Disease related matters	39	
Corona	4	
Unclear	1	
Scared of health	1	
Feeling depressed	1	

How would you fill this in if there is anything in your body hurting?

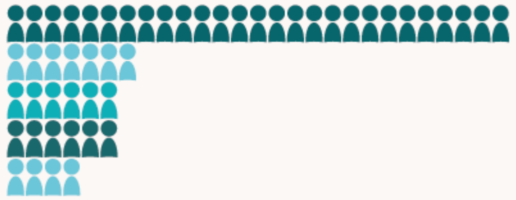




Correct, as intended	41	
Participant was unsure	3	
Wrong, not as intended	2	

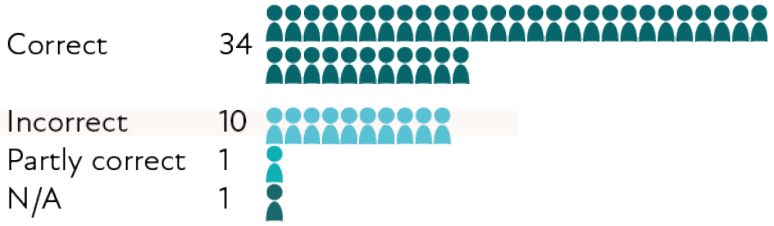


What do you think that this element is meant for?

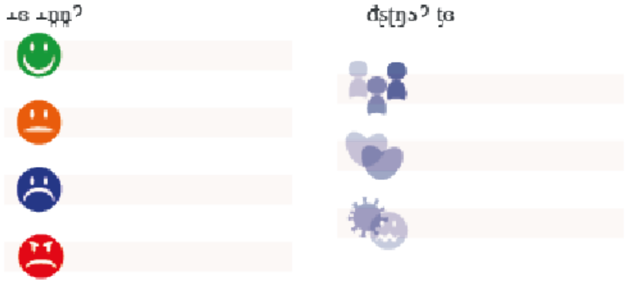


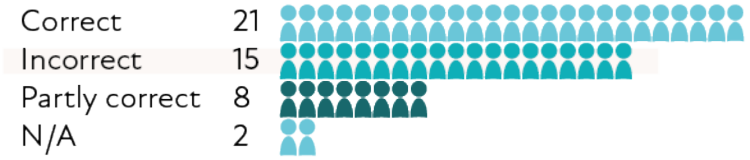
Indicate pain	23	
Health check	7	
Unclear	6	
Locate complaints	6	
Other	4	

How did the participants interpret the element?

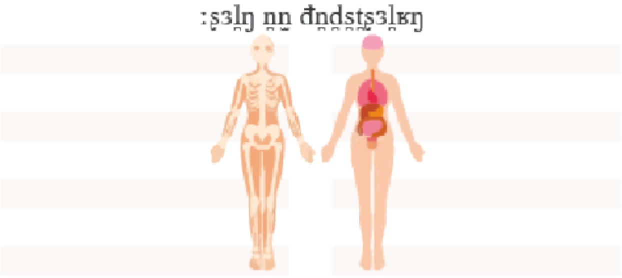


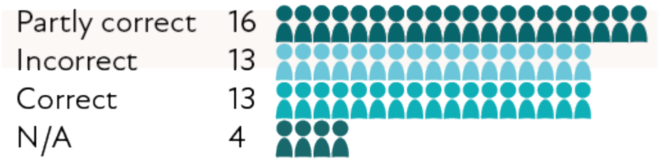
How did the participants interpret the element?





How did the participants interpret the element?





Evaluation with ShivA

Main research question:
How does ShivA receive the concept?

Introduction

- Introduction of who I am (if there are new people)
- Recap of the project and what I did for the AMC
- Explain the concept and storyboard
- Explain that I am here today to evaluate the concept and find possible improvements. This is not the permanent final version but if we want to be able to help the people who go to the hospital, I want to give them the best possible advice. I would love to hear your personal opinion and also what you think that other people might think.
- Ask permission to make a voice recording

First impression?

- So, is there anything unclear about the concept?

I tried to make the outside as subtle as possible, anyone who sees the folder should not be able to know that this has something to do with a sickness or disease.

- If you would have a folder like this, how would you feel about that?
- How do you think that someone will feel when they have a folder like this?
    - Do you think that someone will feel safe when they have this? Or will it make them insecure?

Perceived usefulness

- Do you think that this concept will help you?
    - No – How can we make it more useful, what is missing?
    - Yes – Why, how will this help you?
    - And someone else?
- Could you imagine a situation where this concept could help you?
- In what ways can this concept help someone?
- Do you think that this will give you a feeling of control? You are in control of your disease?
- Do you think that this concept can help you to better talk to their doctor about your health?

Perceived ease of Use

- Do you think that this concept is easy to use?
    - No – How can we make it easier?
- What aspects of the concept are easy to understand or which are harder to understand?

Now I'll show a few of the variations of the modular idea of the concept, different options.

- Which of these modules would be most easy to use? Which would be hardest?

Satisfaction

- Would you recommend this to one of your friends?
- Do you like the concept?
- Do you think that other people will like this concept?