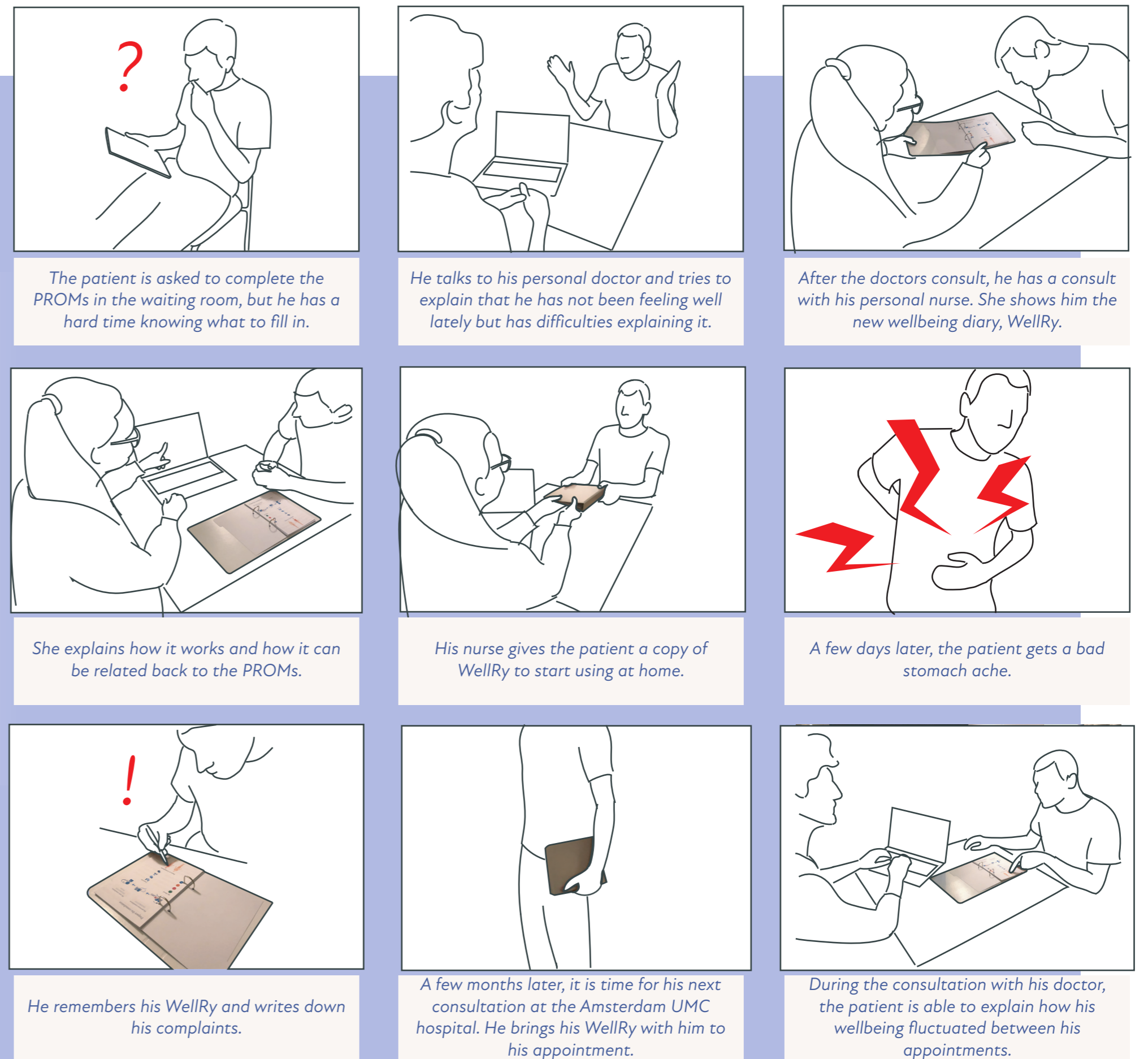


Focus on underserved patients

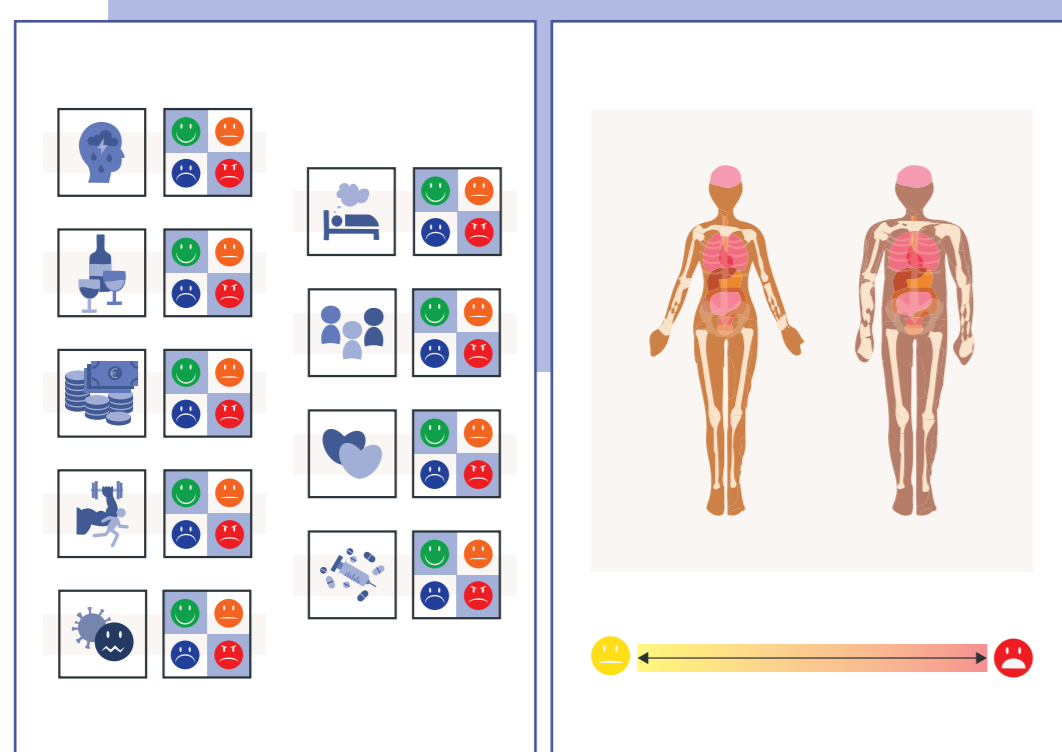
Improving the collection of person-reported outcome measures (PROMs) within the HIV outpatient clinic of the Amsterdam UMC

WellRy The Wellbeing Diary

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.

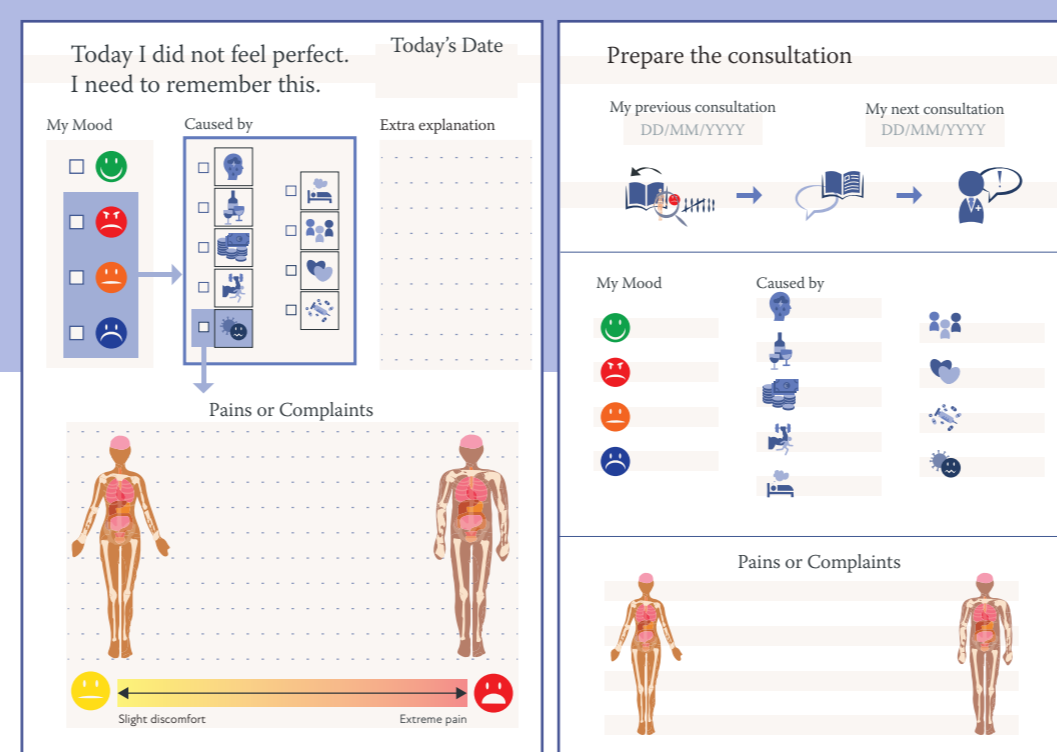


WellRy V1



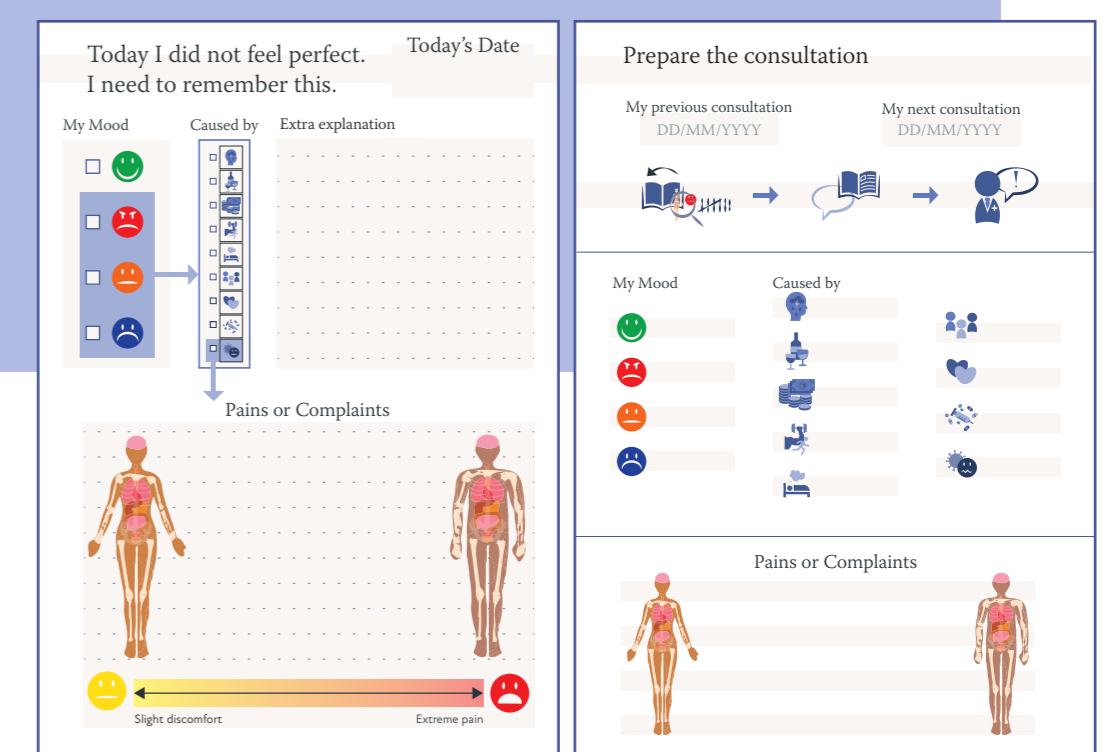
WellRy V1 relies completely on visual indicators. WellRy V1 targets people who are functionally illiterate. Every day that the user notices an abnormality in their wellbeing they can remark their WellRy. V1 does not include the option of a textual explanation. To make sure that the user can take note of all relevant information about their wellbeing, the user can indicate their mood for each topic. Next, this version includes larger versions of the human figures.

WellRy V2



WellRy V2 is a balanced combination between visuals and space to write. WellRy V2 targets people who are literate but not perse like to write in detail. When the user notices 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. This decreases the effort of taking note of all topics, allowing the user to have more time to write about it. The human figures are a bit smaller to allow the user to write about their complaints in words. This version includes a summary page that can be used to reflect on the past period before the next appointment.

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 is visually less elaborative to invite the user to write more about what they are experiencing. This version also includes a summary page that can be used to reflect on the past period before the next appointment.

Why?

To improve the quality of life of all people living with HIV

Since the discovery of HIV, the treatment of people living with HIV has come a long way. The diagnosis of HIV is no longer the death sentence it once was, and the life expectancy is almost similar to the general population (Nakagawa et al., 2013). Still, the life of a person living with HIV looks quite different from someone who has not been diagnosed with HIV. People living with HIV have a significantly higher risk of various comorbidities, such as cardiovascular disease, chronic kidney disease, cancer, and many other conditions (Gallant et al., 2017). 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 normal as possible. To support this focus on improving the QoL, the Amsterdam UMC HIV outpatient clinic recently started a trajectory in which PROMs form an integral part of treatment.

Digital health provides different 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), which creates the risk for the underserved patient group to fall behind.

Most relevant research insights

A strong relationship

People living with HIV are part of the health care system for the rest of their lives. This allows the healthcare professional (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

People living with HIV are often stigmatized and prefer to keep their positive status undisclosed. This is also reflected in the fact that people feel stressed when approaching the outpatient clinic.

Different levels of literacy

The level of health literacy differs greatly within the patient group of the HIV outpatient clinic in the AMC hospital. In some cases, this is caused by the fact that people might be functionally illiterate and unable to read information about their disease.

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. Next, people have difficulties with finding their way around the healthcare system to figure out how to receive the care they might need.

Sharda Wolterink
Focus on underserved patients -
Improving the collection of PROMs within the HIV
outpatient clinic of the Amsterdam UMC
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