The Use of Digital Healthcare Platforms for Chronic Care Management in The Netherlands

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Abstract

In 2019, 44% of the Dutch population aged 65 or above reported having at least one chronic illness, resulting in increasing pressure on the healthcare system to manage the demand for care (OECD, 2019; RIVM, 2018; RIVM, 2020). To manage this, the Dutch government is looking into eHealth solutions such as the personal health environment (Dutch: persoonlijke gezondheidsomgeving [PGO]), a patient portal that allows patients to access their medical information from all healthcare institutions in one location. This study aimed to evaluate how chronic patients experience the use of PGOs to manage their care, using the eHealth Enhanced Chronic Care Model and Technology Acceptance Model 3 as a theoretical framework to assess perceived ease of use, usefulness, and whether PGOs meet users' needs. To do this, eleven semi-structured interviews with Dutch chronic patients using PGOs and a mixed inductive-deductive coding analysis was conducted. Results showed that despite perceiving PGOs as relatively easy to use, participants had concerns about accessibility of PGOs for populations possessing lower (digital) literacy, linked to an absence of user support. Moreover, while participants saw potential added value of the PGO to their chronic care management, issues with interoperability and incomplete information limited the usefulness of PGOs. Furthermore, participants noted the importance of maintaining simplicity, providing explanatory medical information, and improving interoperability in PGOs. These findings suggest that PGO development can benefit from a unified government-supported strategy for implementation and design to increase PGO use and improve user experience.

By 2030, cancer and cardiovascular diseases (CVDs) are expected to bring the largest burden of disease in The Netherlands (RIVM, 2014). In the last century, mortality rates have declined due to the decreasing number of people who die from infectious diseases in the western world. However, the prevalence of chronic diseases continues to grow considerably. Chronic diseases are non-communicable diseases that last over a long period of time (WHO, 2013). These include CVDs, cancers, chronic respiratory diseases, diabetes, as well as mental disorders. In 2019, about 44% of people over 65 reported having one or more chronic illnesses in The Netherlands (OECD, 2019). Most commonly, these included CVD and cancer. As experts predict that the total number of people with chronic diseases in The Netherlands will grow past 7 million people by 2030, further developing and improving chronic disease management is imperative (RIVM, 2014). Moreover, the growing prevalence of chronic diseases has created a higher demand for healthcare services, while the healthcare system has also been experiencing a shortage of available healthcare workers (*Personeelstekort zorg,* n.d.; RIVM, 2018; RIVM, 2020). Due to the growth in healthcare demand, the National Institute for Public Health and Environment (Dutch: Rijksinstituut voor Volksgezondheid en Milieu [RIVM]) has aimed to utilise technology to increase behaviour and self-care in the Dutch population (2014).

eHealth is an overarching term used to describe the use of information and communication technologies to provide and improve health as well as healthcare delivery (Martens et al., 2021). The Dutch healthcare system has become increasingly digitised through the introduction of the National Exchange Point (Dutch: Landelijk Schakelpunt [LSP]), which allows healthcare professionals (HCPs) to safely exchange patients' health information, increasing healthcare communication between HCPs (Patiëntenfederatie, 2024). Additionally, Dutch residents are able to ask health questions or order medicine via online portals (i.e. Mijngezondheid.net). Although these innovations have allowed for more efficient health communication, these platforms are largely managed by the HCP and most healthcare institutions use their own online portal. For chronic patients who often receive care from multiple healthcare institutions, this often results in having multiple accounts on different portals and platforms. A more recent emerging eHealth innovation is the personal health environment (Dutch: persoonlijke gezondheidsomgeving [PGO]). A PGO collects all medical information of an individual from different healthcare institutions on one platform which can be accessed by their HCPs from different institutions with the patient's consent (PGO, 2024). In addition to HCPs being able to add information and results for the patient to see, the patient can add data themselves, such as weight, heart rate, blood pressure, and more, so that their health can easily be monitored remotely.

According to the Chronic Care Model (CCM; Figure 1), a model identifying elements of the healthcare system that are critical for delivering high-quality chronic disease care, self-management support is essential for chronic patients to manage disease symptoms, lifestyle changes, and increase treatment adherence (Austin et al., 2000; Bally & Cesuroglu, 2020; Wannheden et al., 2022; Wagner et al., 1996). The PGO is a participatory health technology that supports self-management and can be a promising platform to manage chronic diseases in The Netherlands. Findings suggest that this type of technology facilitates communication between patients and healthcare professionals, as well as improves patient knowledge about their health (Wannheden et al., 2022). In addition to self-management support, the CCM describes how a patient-centred delivery system design, evidence-based decision support, accessible clinical information systems, and community support are important elements for chronic care. Specifically, these elements contribute to productive interactions between informed, activated patients and their HCPs (seen as ‘prepared, proactive practice team’ in Figure 1). An extension of this model, the eHealth Enhanced CCM (eCCM) has been developed to illustrate how eHealth innovations can add to patients’ self-management through integrating eHealth tools in healthcare (Gee et al., 2015a). The eCCM incorporates a complete feedback loop which Jimison et al. (2008) consider the foundation for impactful eHealth technology and chronic illness outcomes. The eCCM builds on the CCM by emphasising the importance of including patient-provider communication, allowing access to personal health records (PHRs), creating health data visualisations, and creating personalised approaches to health (Gee et al., 2015a). By supplying patients with data, information, knowledge, and wisdom about their health and eHealth use, a complete feedback loop can be formed to create proactive and productive interactions between patients and HCPs. Finally, the eCCM describes the importance of incorporating eHealth education to train patients to use eHealth innovations for their benefit. Several PGOs offer functionalities like health data visualisations, personalised approaches, and patient-provider communication.

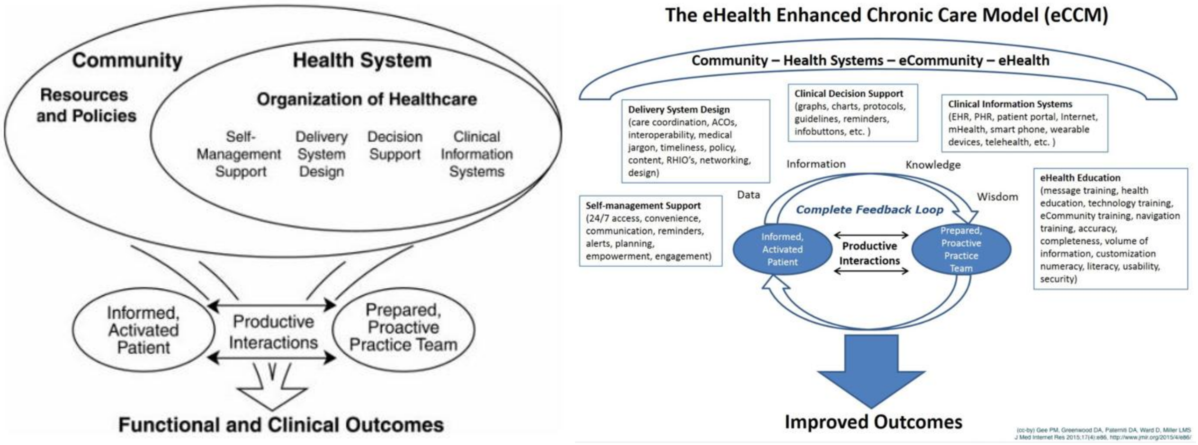

Figure 1. Left: *The Chronic Care Model (Austin et al., 2000).* Right: *The eHealth Enhanced Chronic Care Model (Gee et al., 2015a)*

Although PGOs offer promising features, the adoption of the PGO remains low in The Netherlands, recording less than 500,000 users in 2023 (MedMij, 2024b). Low adoption numbers have largely been attributed to differences in attitudes towards PGO usage from HCPs and patients, as well as disparities in educational background, digital literacy, and cultural background (RIVM, 2022). For example, only 45-50% of the Dutch population possess general digital skills, leaving about half of the population without sufficient skills to adopt eHealth interventions (CBS, 2023). The eCCM highlights the significance of providing eHealth education about using eHealth for chronic disease care (Gee et al., 2015a). Moreover, despite an increase in the use of eHealth products such as patient portals and a general positive attitude from HCPs towards the increased digitalisation of healthcare, about 20-25% of HCPs still have a negative attitude (RIVM, 2022). Their main concerns include user-friendliness, satisfaction, and cost (Doeven & Mol, 2023; RIVM, 2022). These concerns contribute to implementation difficulties for HCPs, as they lack time to assist patients with familiarising themselves with platforms like a PGO (Wannheden et al., 2022; Bally & Cesuroglu, 2020).

In 2022, the RIVM outlined in their Integral Care Agreement (IZA) that they want all Dutch citizens to have access to a "user-friendly and well-stocked PGO that has added value" and possesses "information that is understandable to everyone" by 2025 (Ministerie VWS, 2022). To do this, they aimed to actively support and participate in the development of PGOs in the healthcare sector and create a political environment in which a positive business model for user-friendly and cost-effective PGO development is enabled (Ministerie VWS, 2022). Despite these ambitions, Pluut & Partners found that not enough progress had been made to reach this goal by 2025 (Van der Ploeg et al., 2023). In January 2024, a new plan of how to approach PGO development was outlined by the ministry of health (VWS) in collaboration with important stakeholders, in which they identified that there were generally three barriers to PGO development. First, PGOs are not user-friendly enough yet (De Niet & Brandenburg, 2024). This was also found by the Dutch Patient Federation (Dutch: Patiëntenfederatie) in their user research (Doeven & Mol, 2023). Second, there lacks a general approach to which functions PGOs offer to their users across The Netherlands. Third, not all healthcare providers and institutions are actively participating, preventing the development of a high-quality PGO service (De Niet & Brandenburg, 2024). To tackle these identified barriers, VWS has set the following goals to start implementing in 2024; specify nationally standardised functions for PGOs so that platform differences can be minimised, create PGOs as generally applicable as possible so the majority of citizens can use them, use existing functions and designs that are known to be successful, openly communicate the entire PGO development process, and use user feedback to make improvements (De Niet & Brandenburg, 2024). By implementing these goals, the use of PGOs and digital healthcare platforms may increase, and chronic care management may become more efficient.

To further understand how technological innovations are adopted and can increase acceptance, the Technology Acceptance Model (TAM; Figure 2) outlines elements essential for successful implementation and adoption of technologies (Davis, 1985). The TAM argues that design features trigger cognitive responses, such as perceived usefulness and ease of use. These further lead to an affective response: the attitude towards using. This affective response increases the chance of usage behaviour (Davis, 1985). The TAM was based on the Theory of Reasoned Action, which argues that attitudes and subjective norms influence one’s behavioural intention, and ultimately behaviour (Azjen & Fishbein, 1980; Davis, 1993). This model was later extended several times. The TAM3 extends the original model by describing factors that influence perceived usefulness, perceived ease of use, and the behavioural intention to use (Venkatesh & Bala, 2008). Perceived usefulness can be influenced by subjective norms, image, job relevance, output quality, and result demonstrability. Perceived ease of use can be influenced by anchoring factors and adjustment factors. Anchoring factors like computer self-efficacy, perceptions of external control, computer anxiety, and computer playfulness, influence the initial perception of usability. Adjustment factors such as perceived enjoyment and objective usability, are factors that influence perceived ease of use after users gain more experience using the technology (Venkatesh & Bala, 2008). Finally, experience and voluntariness are involved in one’s intention to use a technological innovation. Using the

TAM3, technological and psychological elements that prevent or promote the use of PGOs amongst patients with chronic illnesses can be identified, which has not been done before.

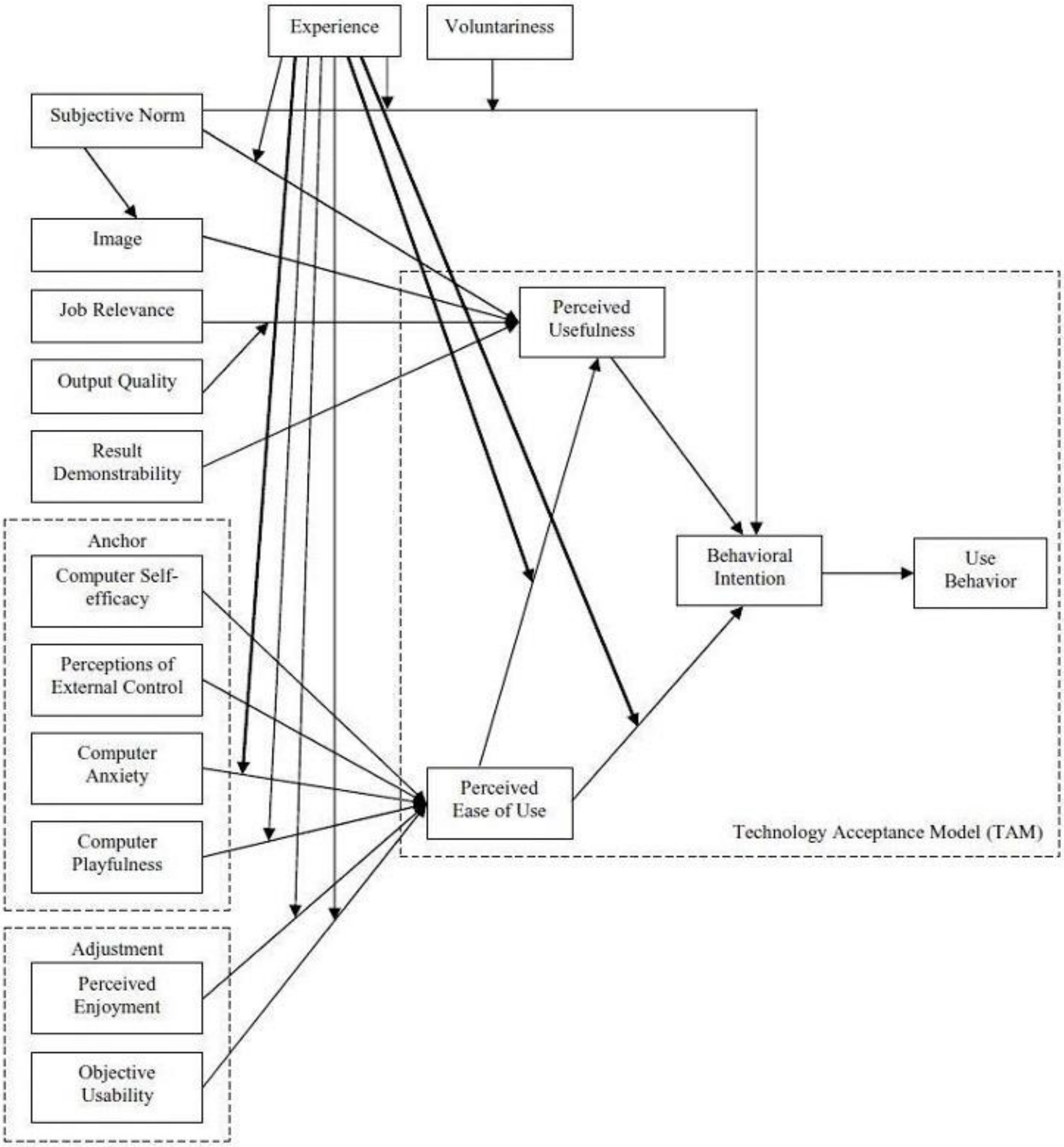

Figure 2. *Extension 3 of Technology Acceptance Model (TAM3; Venkatesh & Bala, 2008)*

With the Dutch government aiming to improve PGO development, the PGOs are in an era of transformation. This research aims to contribute to this transformation by trying to understand how individuals with one or more chronic illnesses experience the use of PGOs in The Netherlands. This contributes to VWS' goals to identify and use existing functions and designs that are known to be successful, as well as use user feedback to identify what improvements need to be made. Additionally, this study aims to investigate whether users believe the PGO adds value to their healthcare management. Investigating this allows eHealth developers of PGOs to refine existing functionalities based on what users consider important and in need of improvement and enhances the development of more user-friendly PGOs. The research question that was investigated is as follows: *How do adults with chronic illnesses in The Netherlands experience the use of PGOs during their chronic care management?*. More specifically, the following sub-questions were defined using elements from the TAM3 and eCCM:

- *How do chronic patients perceive the accessibility and user-friendliness of PGOs?*
- *How useful are PGOs considered for chronic patients' self-management of chronic care?*
- *What are chronic patients' needs for eHealth and are they addressed by PGOs?*

PGOs are still relatively new and unknown. Therefore, individuals are less aware of their existence and PGOs are actively being developed and have not reached their full potential yet (Leijenhorst, 2023). When functionalities are not fully developed yet or are malfunctioning, this may lower perceived ease of use and accessibility. Overall, with regards to the first sub-question, it is expected that chronic patients' experience with PGOs will largely be affected by perceived ease of use. Based on previous literature, PGO users who are older, possess fewer digital skills and health knowledge, will likely experience more barriers in accessing and using PGOs (Bergström and Ekman, 2021; Madanian et al., 2023; O'Connor et al. 2016). In the TAM3, perceived ease of use is seen as a significant factor in behavioural intention, suggesting that chronic patients experiencing PGOs as less user-friendly will use the PGO less (Venkatesh & Bala, 2008). Additionally, it is expected that chronic patients that indicate more concern about privacy will also experience PGOs as less accessible (O'Connor et al., 2016). In previous research, both HCPs and patients have expressed concerns about privacy in PGOs (Heilbron & Koopman, 2018; Mitrovic, 2023). Moreover, privacy concern has been found to have a significant negative correlation with perceived usefulness, perceived ease of use, and behavioural intention (Dhagarra et al., 2020). To continue, with regards to the second sub-question, the TAM3 outlines that perceived ease of use influences perceived usefulness of technologies, suggesting that individuals who will perceive the PGO as less easy to use may also consider the PGO less useful (Venkatesh & Bala, 2008). The eCCM provides a blueprint of eHealth features that are considered useful for chronic care management and self-management (Gee et al., 2015a). It is therefore expected that chronic patients using PGOs that contain more eCCM-mentioned features will be deemed more useful and that those users will experience that the PGO is useful for their chronic self-management. Finally, regarding the final sub-question, it is expected that PGO user needs will include simplicity and well-functioning features, such as access to PHRs, health data exchange for remote monitoring, communication tools with HCPs, tailored interventions, and assistance in the use of eHealth (Gee et al., 2015a). Although PGOs are said to include these features, it is expected that these needs are addressed to a limited extent, as PGO development is still relatively new, and features are continuously being refined.

Methodology

Study design and context

To explore the above-mentioned research question, a qualitative study was conducted, in which adults with chronic illnesses who use PGOs at least once a month were interviewed. Although there has been some PGO user research conducted, this has been limited and largely with questionnaires (Doeven & Mol, 2023). By using semi-structured interviews in this research, platform functionalities that users like and dislike were identified, as well as an understanding of why. The semi-structured nature of this study allowed sufficient structure so that each interview covered the same points while allowing some flexibility to go in-depth if it was considered fruitful and appropriate.

This study was conducted during a highly transformative period for PGOs in The Netherlands. It is important to consider that the creation of PGOs in The Netherlands is largely a private market, despite the government's interests. Whereas other European countries have created a single PGO through their health ministries, The Netherlands did not endorse this in 2011, causing private corporations to put their PGOs on the market for consumers to choose from freely (PGO, 2024). As different corporations have different interest and resources, each PGO slightly varies in the services and functions they offer. To ensure the privacy and safety of patients, the Patiëntenfederatie started the MedMij initiative, which is a quality label given to medical information platforms for the safe and trustworthy exchange of health information (MedMij, 2024a). In Appendix I, all 14 active and MedMij-approved PGOs offered in The Netherlands are outlined, including the services and functions they provide. To remain neutral, these PGOs were not opened or tried by the researcher before conducting or during this study. Finally, during this study, due to the change in subsidies from the Dutch government, some PGOs have become inactive or stopped updating their features. Despite these high-paced changes in the PGO market, the findings of this study are still relevant for PGOs that continue to advance and are subsidised.

Participants and sample

The target population for this research consists of Dutch citizens who have chronic illnesses. As individuals with chronic illnesses are usually more involved with their disease and often require a larger network of care, they are more likely to need to use PGOs more often. Through this experience, they are better able to provide an insight into the functionalities of PGOs than an individual who does not require regular health consults. As a result, this research targeted Dutch citizens with chronic illnesses who use one of the aforementioned MedMij-approved PGOs.

Although some mental disorders are considered chronic, this research focused only on physiological chronic illnesses. At the moment, PGOs have been designed to be used for physiological medical care, as many do not have the option to connect with the GGZ system (Dutch Association of Mental Health and Addiction Care; Appendix I). At first, only lung cancer, diabetes, cardiovascular disease (CVD) and COPD were concentrated on, as the RIVM considers these the most relevant chronic diseases that require the most healthcare (RIVM, n.d.). This was to recruit participants who require a lot of healthcare assistance and would therefore be required to use their PGO more often. However, due to the low number of PGO users in The Netherlands as well as the difficulty of reaching patient groups, this was later expanded to Dutch citizens with a physical chronic illness so that more participants could be recruited. Table 1 outlines the inclusion and exclusion criteria of the research sample. Participants had to be older than 18 at the time that they started to use the PGO to ensure that they voluntarily started using PGOs instead of there being a parental influence in that decision. Additionally, it was required to use the PGO at least once a month so that participants had some experience using the PGO. Finally, participants had to provide their informed consent to participate in this study.

Table 1. *Sample inclusion and exclusion criteria*

Inclusion criteria	**Exclusion criteria**
Resident in The Netherlands	Resident outside The Netherlands
Older than 18 at the time of starting to use PGO	Younger than 18 at the time of starting to use PGO
Uses a Dutch PGO at least once a month	Uses PGOs less than once a month
Uses one of 14 MedMij-approved PGOs	Uses a PGO that is not one of the 14 MedMij-approved PGOs
Diagnosed with a physiological chronic illness	Not diagnosed with a chronic illness or diagnosed with a chronic illness that is not physiological
Informed consent	No informed consent

As mentioned before, semi-structured interviews were conducted. Cobern & Adams (2020) and Vasileliou et al. (2018) argue that determining a sample size for qualitative research with interviews is more complex than quantitative analysis, as it is more limited by available time and resources. Due to limits in time and resources to conduct the study, low use of PGOs in The Netherlands, and specific sample criteria, the targeted number of interviews to be conducted was a minimum of ten until sufficient interviews have been conducted to reach saturation.

Snowball sampling was conducted to collect the sample. Initially, contact was made with several organisations, such as MedMij, Rijnmond Dokters and healthcare centres that offer Combined Lifestyle Intervention (Dutch: Gecombineerde Leefstijlinterventie [GLI]), to ask if they could help contact potential participants based on the criteria. As the previously named organisations could not freely provide contact information of patients or PGO-users, getting in contact with interview candidates via contact persons in the Patiëntenfederatie was considered more fruitful. The Patiëntenfederatie is an organisation that consists of a variety of patient associations which patients can voluntarily join to be actively aware of activities and developments in healthcare relevant to their health condition (Patiëntenfederatie, n.d.). Additionally, the Patiëntenfederatie has worked closely in the past with MedMij and other PGO-user research. Via them, an email was sent to their PGO-panel about this study and the participant characteristics (Appendix II). Panel members could react to this email to show their interest, volunteer to participate and plan an interview. A total of six participants were recruited, which were all compensated €50 by the Patiëntenfederatie for their participation. As there were not sufficient volunteers through this channel, a message was also distributed via Instagram to find more participants (Appendix II). Finally, the same message was posted on the online bulletin boards from the following patient associations: Diabetesvereniging Nederland (for diabetes patients), Longfonds (for lung patients), Nierpatiënten Vereniging (for kidney patients) and Reuma Nederland (for arthritis patients). Due to limits in resources and funding, the researcher was not able to compensate any participants recruited outside of the Patiëntenfederatie. All participants were briefed about the aim and intentions of this research before planning an interview and provided their verbal informed consent via telephone. In total, eleven participants were recruited, after which saturation was met as the same themes started appearing in each interview and no new relevant information was shared in the last interviews.

Data collection and transformation

To collect data for this research, eleven semi-structured interviews were conducted. Interviews were aimed to last around 45 minutes and ranged in duration between 30 and 60 minutes, apart from one which lasted two hours (μ = 70 minutes). For the interviews, an interview guide was created which served to steer the interviews while allowing for some flexibility for follow-up questions relevant to the research and the participant (Appendix III). At the beginning of each interview, all participants were briefed about the research again, re-confirming their informed consent. Each interview discussed the chronic symptoms that the participants experience, their digital literacy and which PGO they use. This was then followed by in-depth questions about the way they familiarised with the PGO, what their first impressions were, how they experience the PGO and whether they believe it has added value to their chronic care management. Furthermore, some demographic information was collected to illustrate participant characteristics. As participants were located across The Netherlands, all interviews were held online, apart from two, which were held in-person at the participants' home. Finally, all interviews were held in Dutch.

All interviews were recorded with permission of the participants. After each interview was conducted, interviews were transcribed for analysis. These transcripts were uploaded to Atlas.ti for coding and analysis.

Data analysis

In line with the qualitative nature of this study, a mixed deductive-inductive coding approach was taken. To begin with, elements from the TAM3 and eCCM models were used as codes to evaluate the experience of PGO-use and its perceived usefulness. Definitions of the deductive codes can be found in Appendix IV. While the TAM3 had straight-forward elements which could directly be used as codes, the codes from the eCCM required more specificity. Using Gee et al. 's (2015a) description of elements in the eCCM, several indicators were established before starting the analysis which could be used to identify whether PGOs encompass the necessary elements to successfully use as an eHealth innovation for chronic care management. First, 'use of eCommunity' was used to identify whether participants were actively involved via online communities about their chronic illness for support. Second, to identify signs of participants having access to or using eHealth education, the codes 'skill-building support' and 'use of educational resources' were used. 'Use of educational resources' was also used as an indication of clinical decision support in addition to 'health data visualisation' and 'health literacy'. These elements could indicate whether participants possessed the knowledge to understand information relevant to their condition, use online resources to understand relevant information and make informed decisions, as well as that their PGO provided visualisations relevant for their condition. To continue, 'patient-provider communication' and 'mobile health applications' were codes used to establish the presence of online interaction between participants and their HCPs and the use of mobile applications to support their healthcare. ‘Personal health records’ was used to identify whether participants had access to their own medical information, test results, records, and whether they monitor this and other measurements. Finally, to indicate a presence of self-management support, ‘confidence building’, ‘customisable features’, ‘tailored interventions’, and ‘monitoring and reporting’ were used.

Although a priori codes from the TAM3 and eCCM were used to gain insights into to what extent participants perceived the ease of use, usefulness, and added value of using PGOs, inductive codes were also established using an explorative fashion. This allowed for a more thorough understanding of participants’ negative experiences using PGOs and their needs. First, each transcript was read through and initial quotes that were considered relevant to the codebook or research questions were highlighted. Afterwards, these quotes were linked to codes in the code book, or a new code was created. This process was repeated several times, highlighting quotes and identifying codes. Subsequently, these codes were refined if needed. During the coding process, two external researchers acted as a second reader for two transcripts to validate and replicate the codes. This was done to ensure that codes are well-defined and correctly identified. These researchers were chosen as they were both actively researching the use of eHealth innovations and were familiar with the models used to guide this analysis. Using the identified initial and refined inductive and deductive codes, themes were established to capture common experiences of PGO-use amongst participants. Finally, the demographic information of each participant was used to see if there were any significant differences between certain demographics such as age, gender, location of residence, educational level, perceived digital literacy, or the diagnosed chronic illness. This comparison was made after the coding process and thematic definition to avoid any bias based on demographic information that could influence the identification and refinement of codes and themes.

Results

To answer the research question “*How do adults with chronic illnesses in The Netherlands experience the use of PGOs during their chronic care management?”*, the accessibility and user-friendliness of PGOs, perceived usefulness of PGOs for self-management, and what needs were addressed by the PGO were evaluated. Using deductive codes from the TAM3 and eCCM and inductive codes derived from an open coding process, participants’ experiences were outlined. In Figure 3, the included codes are visualised including their incidence.

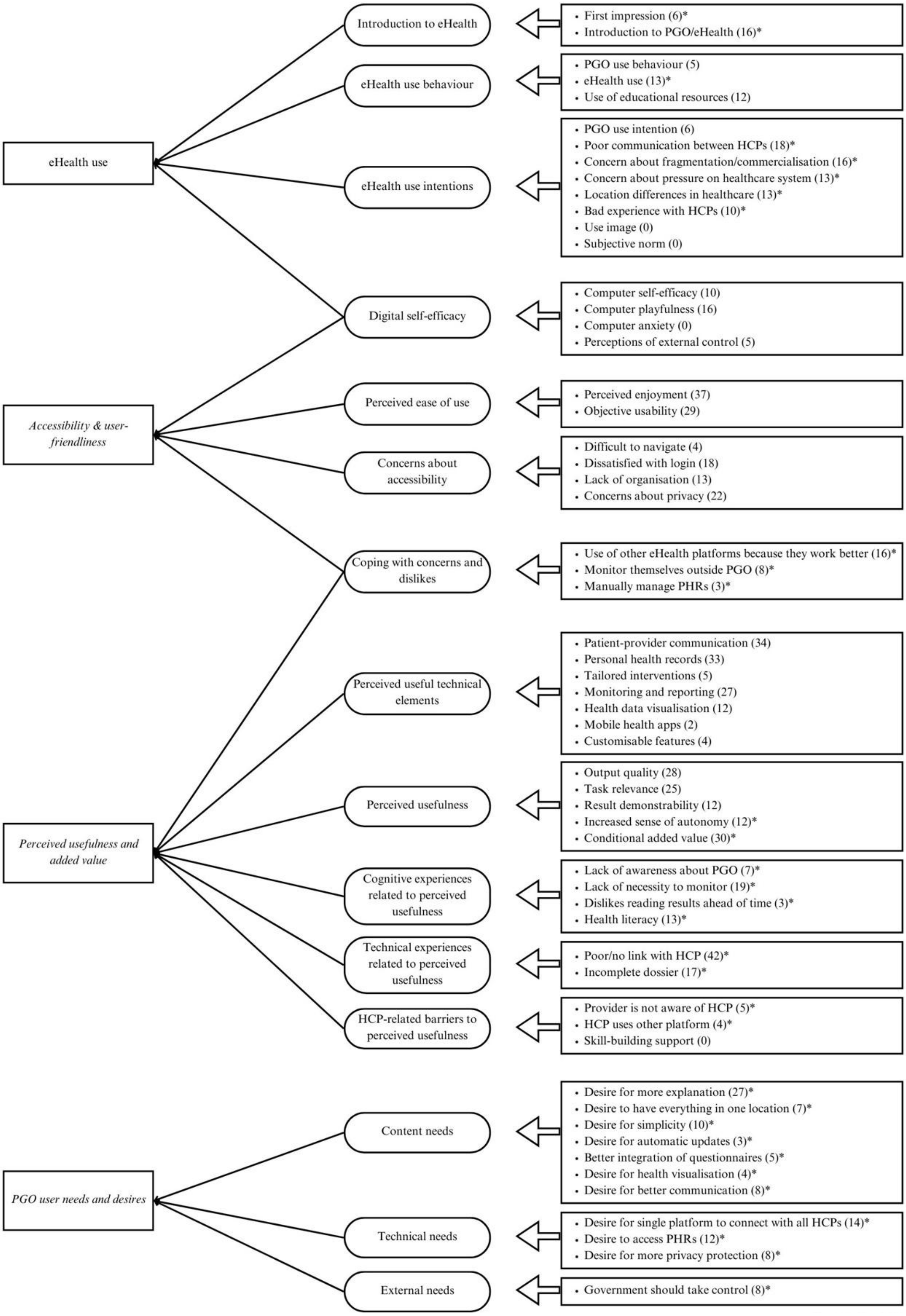

Figure 3. *Inductive and deductive codes (* = inductive codes)*

Participant characteristics

Through snowball sampling, eleven interviews were conducted. Six interviewees were recruited via the Patiëntenfederatie, one was recruited via the Longfonds, and four were recruited via social media (*N* = 11). Each interview lasted between 30 and 60 minutes, apart from one which lasted two hours (μ = 70 minutes).

The sample consisted of five females and six males, and the average age was 55.36 years old (*SD* = 14.52). The sample was relatively highly educated, with everyone completing higher education, and 81.8% completing their higher education at a university of applied sciences or an academic university. Although the sample was distributed across The Netherlands, 45.5% resides in Zuid-Holland. All participants were chronically ill, of which 54.5% had comorbid conditions (Table 2).

Table 2. *Participant characteristics*

	Age (years)	**Sex**	**Province of residence**	**Educational level***	**Chronic illness**	**Comorbidity**
Interviewee 1	46	Male	Overijssel	HBO	CVD**	Yes
Interviewee 2	48	Female	Gelderland	MBO	Diabetes	Yes
Interviewee 3	52	Female	Zeeland	HBO	COPD***	Yes
Interviewee 4	65	Male	Zuid-Holland	HBO	CVD	No
Interviewee 5	81	Male	Friesland	HBO	CVD	No
Interviewee 6	43	Female	Noord-Brabant	WO	Long-COVID	Yes
Interviewee 7	60	Male	Zuid-Holland	WO	Arthritis	No
Interviewee 8	67	Male	Zuid-Holland	MBO	COPD	Yes
Interviewee 9	67	Male	Zuid-Holland	HBO	Long-COVID	Yes
Interviewee 10	28	Female	Noord-Holland	WO	CVD	No
Interviewee 11	52	Female	Zuid-Holland	HBO	Breast cancer	No

**Educational level = highest completed level of education. MBO = secondary vocational. HBO = higher vocational. WO = scientific.*

***CVD = Cardiovascular disease.*

****COPD = Chronic Obstructive Pulmonary Disease.*

Chronic illnesses and care

As mentioned before, all participants were chronically ill, varying in the amount of medical treatment they receive. Most participants had a CVD (36.6%) and some type of lung condition (COPD = 18.2%, long-COVID = 18.2%). Other chronic illnesses included diabetes, arthritis, and breast cancer (Table 2). It is important to note that although participants responded to participate in this research naming a single chronic illness (i.e. COPD), comorbidity was present in 54.5% of the participants. Comorbid conditions included stomach and digestive conditions, nerve conditions, mobility issues, thyroid conditions, urine problems, endometriosis, burnout/chronic fatigue, and genetic conditions including Alpha-1 and Factor V Leiden.

As most participants have medically complex conditions, they utilise care from a multitude of healthcare providers and institutions. All participants had a general practitioner (GP) and pharmacy they reported to and ordered medicine from. Furthermore, 90.9% were also patients at least one hospital. Participants that were patients at multiple hospitals explained that this is partially due to having different specialists for different health issues and that in The Netherlands the system requires you to “first go to the GP, then you go to the regional hospital, and then you can be referred to an academic hospital” (Participant 3). Next to the GP, pharmacy, and hospitals, two participants also receive care at one or more private clinics (18.2%). Finally, five participants receive physiotherapy or manual therapy (45.5%).

eHealth use

All participants use or have used a PGO and other digital healthcare platforms during their patient journey. Table 3 outlines which PGOs are used or have been used by participants, as well as other healthcare platforms/apps. Most use Uw Zorg Online (36.3%) and Ivido (45.5%) as their PGO in addition to digital patient portal(s) from their hospital(s) (81.8%). All participants use one or more digital healthcare platforms, other than a PGO.

Table 3. *eHealth platforms used by participants*

Variable	**n** (*N* = 11)
Used PGO*	
Uw Zorg Online	4
Ivido	5
Zorgdoc	1
Gezondheidsmeter	2
Quli	1
Medxpert	1
cBoards Health	2
Other used health platforms/apps	
Beter Dichtbij	3
Luscii	1
CWZ Thuismeten	1
Patient Journey	1
Mijn Gezondheidsnet	2

MedGemak	4
Apple Health	2
Hospital portals	9
Pharmacy app	1

**Some participants use or have used multiple PGOs*

When asked how they were introduced to the PGO, most express coming across it by accident via either their hospital or GP. “I suddenly discovered that I could log in online… I was never pointed towards it” (Participant 1), “I wanted to make an appointment with the GP and saw this [Ivido] at the bottom of MedGemak” (Participant 7). Two participants expressed that their hospital was advertising it or provided a flyer. Another two participants noted that they were searching for ways to get a better overview of their health information and care online. Only one participant had a young GP recommend signing up for a PGO, suggesting to them that it “is nice to get in contact via an app, it is easier” (Participant 2).

eHealth use motivation

All participants were asked how and why they use the PGO or other eHealth to get an idea behind the motivation of using a digital health platform. First, all participants mention that when they signed up for a PGO, they intended to use it to have access to their medical information; “I find it very annoying that, as a patient, while it is about you, you cannot see what is happening” (Participant 10). Second, seven of the eleven participants mention having had bad experiences with HCPs relating to mistakes in reports, wrong medications that were given, or not acknowledging certain symptoms or results. “When I got sick, they totally missed my heart valve…that something strange could be heard, which no one ever noticed again until I became very ill” (Participant 4). These bad experiences were often related to two different observations: the amount of pressure on HCPs and poor communication between HCPs. For example, about half of the participants expressed concerns about the increasing pressure on HCPs due to the rise in demand for healthcare. This concern has motivated some participants to use eHealth innovations like the PGO: “There is a shortage of people, and you can solve that by allowing digitalization to take place” (Participant 3). A similar motivation was mentioned with regards to the poor communication between HCPs. While explaining about taking a beta blocker that was not intended for people with COPD, participant 8 noted that this was prescribed to them because the internist and pharmacist somehow were not aware of their COPD diagnosis.

Third, participants living outside the ‘Randstad’, the Dutch metropolitan region, mentioned experiencing differences in their healthcare due to their location outside this region.

Five of the eleven participants reside outside this area, of which three noted such differences. Differences included needing to travel farther for specialised care, less accessibility to certain care, or experiencing a delay in digitalisation. For example, participant 3 moved outside of the Randstad a few years ago and mentioned that there is a shortage in healthcare employees, they are unable to receive certain necessary lung tests in their area and that they are "10, 15 years behind" with digitalisation. "They have such a shortage in employees and the digital world at your feet, how can you not use it?...Because it is so badly organised here, I started using a PGO" (Participant 3). Despite identifying some differences in access to digital healthcare, no significant differences in PGO-use experiences were identified between participants across different Dutch regions.

PGO use and first impressions

As mentioned before, most participants accidentally came across the PGO or were introduced via a HCP. Not all participants chose a PGO that would fit their needs, as many signed up for the PGO their GP works with. Those that did search for the best-fitting PGO, raised concerns about the amount of existing PGOs: "I think that there are 15 PGOs from which you can choose…Why has The Netherlands made this so complicated?" (Participant 3). This concern was often mentioned in combination with worries about an increasingly commercialised healthcare system: "Now that I see how many PGOs are there, I wonder if [healthcare institutions] can't see the forest for the trees…I actually don't find it good that it is in commercial hands" (Participant 9). In choosing which PGO to use, most participants went with what felt familiar to them, such as what their GP uses (Participant 1), what they have seen advertised in a hospital (Participant 5), or based on what had the most reviews online (Participant 3).

Using the interviews, a general user flow was created to illustrate what participants use the PGO for (Figure 4). Important to note is that this diagram does not include every functionality that PGOs offer, but that it only includes the functionalities that participants mentioned using. Most participants used the PGO to retrieve their medical data and link with multiple HCPs so that they have all their medical information on one platform: "It is a nice idea that when you have an online file, you can just always read things back" (Participant 10). By doing this, participants mention being able to contact their HCP if needed and read back results from tests and other medical examinations. Additionally, some participants use the PGO to order medicine from their pharmacy. To continue, participants mentioned that their PGO offers the possibility to enter and track self-measurements, as well as fill out questionnaires related to their mood or positive health. Moreover, one participant was able to follow care pathways, which provides tasks and activities that the participant can do to monitor their chronic condition and allow their HCP to monitor them at a distance. “There is a COPD module…for example, I use a spirometer for lung function tests, and I can select that in the module, do the test, and it will automatically be sent to the doctor and see the results” (Participant 8). Finally, apart from the one participant recruited via the Longfonds, none of the participants mentioned engaging in an eCommunity with other patients.

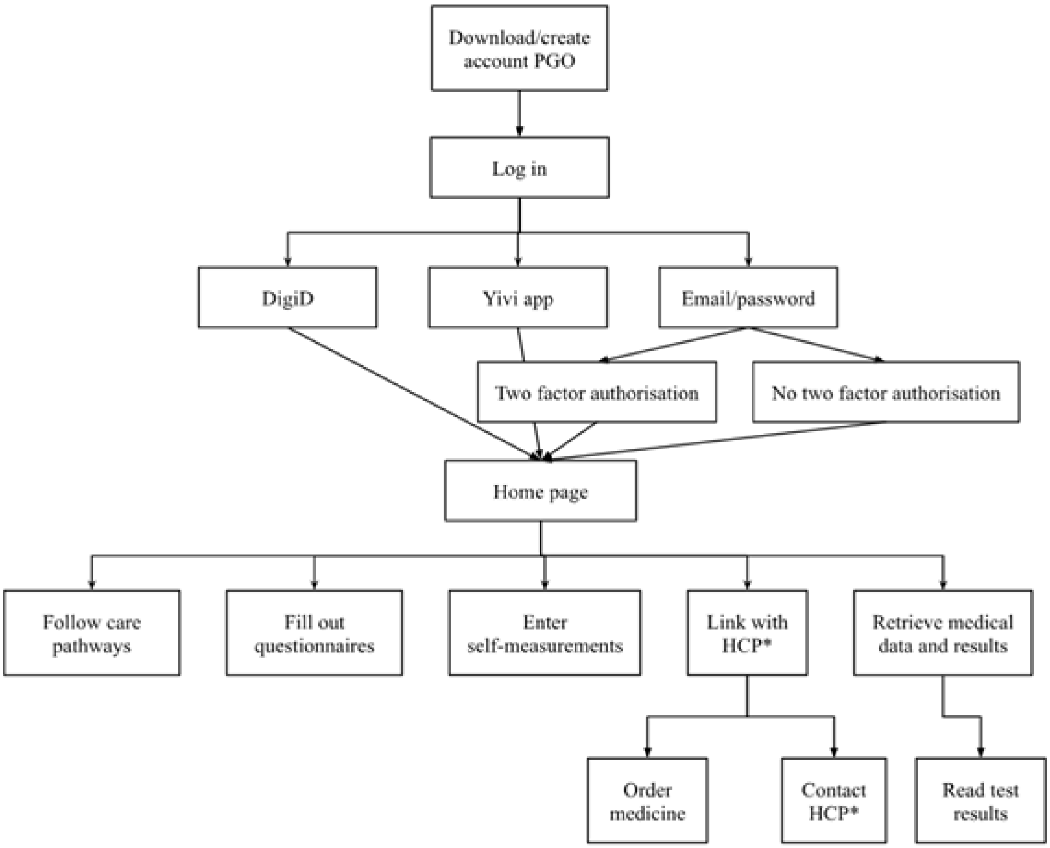

Figure 4. *Flow diagram of mentioned PGO functionalities (*HCP = healthcare provider).*

Accessibility and user-friendliness

Digital self-efficacy

To begin with, anchoring factors for perceived ease of use in the TAM 3 were ‘computer self-efficacy’, ‘computer anxiety’, ‘computer playfulness’, and ‘perceptions of external control’. These elements were used as deductive codes to illustrate the participants’ belief about technology and their digital competencies. No participants expressed any computer anxiety or trouble using technology daily. All participants use technology in their job and/or daily life, believing they can use technology to complete tasks. “I do a lot on the internet, I sit, when I work, often with Teams…so I don’t have a computer fear” (Participant 4). Additionally, they all indicated a level of ‘computer playfulness’, indicating that they explore the eHealth platforms they use by themselves; “I always do everything myself and I press on all the buttons that are there” (Participant 2). Only five participants expressed being aware of existing help desks that they can contact if they experience technological trouble with one of the platforms they use. Finally, only three have contacted a help desk to seek assistance; “it is always up to me to make sure that everything is transferred, so I went to Follow Your Care (Volg Je Zorg)...they looked with me and apparently there was some information missing with the GP what caused some issues in exchanging my information” (Participant 6).

Perceived ease of use

To continue, adjustment factors for perceived ease of us in the TAM3 were ‘perceived enjoyment’ and ‘objective usability’. Participants’ first impressions were relatively divided, some sharing that they were unsure how it worked and “just tried it out” (Participant 4) and others sharing that when they first started using it “it was not working nicely” (Participant 1). Nonetheless, participants noted that it was simple with a “clear layout”, has “clear language”, and “no complicated disclaimers” (Participant 3). All participants felt that the technical aspects of the PGOs were easy to learn how to use and use. “I don’t think these platforms are usually difficult to use because they are pretty obvious with sub-tabs, appointments and summaries, results” (Participant 10). Nine of the eleven participants explicitly expressed enjoying the use of eHealth. “You can look back at your history a bit which is nice, because sometimes you just forget when and which things happened” (Participant 7).

Concerns about accessibility

Despite expressing that the PGO is straight-forward and simple, participants expressed concerns regarding the accessibility and usability for several reasons. First, four participants believed that PGOs are not accessible for individuals with lower literacy, digital literacy, and that speak little to no Dutch. “I think it is quite user-friendly, but I wonder if that is the same for people of my generation or older…there are many people that don’t have those skills…I can imagine that it can be confusing” (Participant 9); “I wonder if the app has been made in another language too, if you can change that. Is that only in English, or also in Arabic, or Turkish, or Chinese?” (Participant 2). Second, while most participants considered the platforms easy to use, three participants shared that there was some difficulty navigating the platform. Namely, two shared that it was hard to find their HCP to connect with because “you have to have the name exactly right to connect, otherwise it won’t find it” (Participant 7). Another participant shared that the PGO was difficult to navigate because some of their data was double, incomplete, or badly organised (Participant 8). While this participant shared that this has improved over time, five participants shared the opinion that their information was poorly organised in the PGO. “The information that is there, is all a bit mixed up”, “it begins with 2019, then comes with 2023, and then goes to 2016” (Participant 1). Third, seven participants shared concerns about their privacy in the PGO. Specifically, two mentioned concerns that there have been other data leaks in public organisations and believe that this could also be possible with their medical information in a PGO. All participants considered privacy protection important, and a few chose their PGO based on the login method. Participant 6 “filtered for two-factor authentication” and most users shared a preference for using DigiD to login. Finally, six participants expressed being unsatisfied with the login method for their PGO. “Just an email address and password…throw DigiD in and you are done” (Participant 4). Two participants shared that to get to their PGO is difficult because they “have to pass many lockets before getting to their medical information” (Participant 7). One participant shared that they were able to log into their PGO but when trying to use the DigiD to connect with HCPs besides their GP, they were asked to do an ID-check, despite not having this problem using DigiD anywhere else. Due to concerns about privacy, this participant does not want to do this; “who knows if a data breach will ever occur?” (Participant 2).

Perceived usefulness and added value

There were a variety of functionalities which participants enjoy using in the PGO. First, all participants enjoyed having access to their PHRs. “When it is about you…it’s a nice idea that you have an online file somewhere, where you can always find everything” (Participant 10). Second, although not all PGOs or HCPs made this communication line possible, participants enjoyed being able to communicate with their HCPs as it allowed them to easily ask questions and receive advice. “I can just ask questions using the portal when something is not urgent” (Participant 1). Third, the PGO allows participants to monitor certain health data which allows them to be monitored remotely and have insights into their own health. Although not all participants were interested in regularly engaging in self-measurements, having access to this data was positively received, especially if this is coupled with some sort of visualisation of this data, such as a graph. “If I open my PGO weekly and see that my weight increases slowly over time, then I know that I should do something differently…the insight is important to allow people to come to an insight themselves and do something with it” (Participant 3). Fourth, two participants mention being able to customise the PGO slightly to their needs. Participant 1 notes that they can choose whether they want to be able to read their test results before speaking to their HCP or not in their PGO settings. Participant 8 notes how they can choose to connect their PGO with Apple Health so that data measured by Apple Health, such as steps or blood pressure, are automatically available in the PGO as well. Finally, only one participant uses their PGO for a tailored COPD care pathway. This entails being guided through a lung function test via the PGO and using a spirometer and "then it will be forwarded to your doctor, and you will see the results yourself" (Participant 8).

Overall, participants were enthusiastic about the potential of PGOs, expressing positive experiences regarding the output quality and task relevance of PGOs. "I was able to look into my own history…which was also quite extensive" (Participant 5). Specifically, some participants explain that as they get older, it is nice to have a platform with all their medical information that family members can potentially access too in case of an emergency. "You want everything in one file, so that you have that with you and if something happens, someone can say, 'my [parent] has this and that'" (Participant 4). About half of the participants express that they already experience benefits and an increased sense of autonomy from using a PGO. "If you compare this to when I first visited the cardiologist, when I had no idea about what they were saying to me…If that happens to me now, then I can read it back and call if anything is unclear…In that sense, I have some more control over my own health" (Participant 10). Despite these positive experiences, most participants do express that they have not fully been able to adapt and enjoy the PGO yet, due to different technical barriers. However, there was a consensus that the PGO has potential, but currently does not add a lot of value to their care yet, "at least not with what it can do now" (Participant 7).

Cognitive experiences reducing perceived usefulness

Amongst participants, several negative cognitive experiences related to PGO use were identified in the interviews. To begin with, although participants enjoyed having insights into some monitored data overtime, all eleven participants shared a lack of interest in doing self-measurements and constantly monitoring their data. "No, then you'll go crazy…you'll know if something is good and consistent" (Participant 4). Alongside this, a few participants share that they dislike being able to read medical test results in their PGO before speaking with their treating HCP. This was usually mentioned in relation to not always being able to understand the data that is shared and experiencing stress or discomfort in this lack of understanding. Moreover, only five participants indicated feeling capable of comprehending information available to them in their PGO, either through being a patient for an extended period of time or by using resources like books or the internet to understand. Nonetheless, in general, participants felt that additional medical explanation was missing in the PGO and felt that their knowledge was not sufficient to always understand information in the PGO. "It's only data, but I don't have much use for that as a patient, unless I know all the ins and outs" (Participant 7). Lastly, seven participants indicated signs of unawareness about the PGO and its functionalities. Overall, these cognitive experiences indicated doubt about how the PGO operates and the role it plays in their chronic care. “I don’t understand exactly what it’s for” (Participant 11).

Technical problems reducing perceived usefulness

The most common technical problem that participants encountered was having trouble or being unable to link the PGO to their HCP. Some participants explain that they are only able to connect with their GP, but linking with hospitals or specialised HCPs retrieving data does not work. “Every time I try to log in and retrieve data, and every time something gets stuck, or it doesn't work or there is no connection” (Participant 1). As a result, participants note that their PGO is often missing information and is incomplete, therefore limiting its usefulness. When looking at their information with one HCP, participant 6 shares that “it seems like [they are] looking at the medical file of another, because there is nothing right about it”. Most often, the conditional added value that participants expressed was linked to the fact that they were unable to link with all their HCPs and therefore had an incomplete insight into their medical information.

HCP-related barriers to PGO usefulness

In addition to cognitive and technical experiences reducing a sense of perceived PGO usefulness, some external barriers to PGO use and experience were observed. Namely, three participants express that one or more of their HCPs are not aware of PGOs either and are therefore unable to help them when they have questions about it. Participant 9 explained having trouble linking with their GP and called them, but “they did not know the name Ivido”. Another participant, asking about PGOs at their hospital shared that they also responded saying something along the lines of “What are you bothering us with now? We have never heard of this…do not bother us with this” (Participant 6). Besides the lack of awareness amongst some HCPs, four participants also indicated that at least one of their HCPs uses other digital platforms for patients to contact them or have insight into their medical information. “I can find some information in Ivido from my hospital, but in the hospital patient portal I can do much more” (Participant 11). Overall, participants did not share receiving any form of skill-building or confidence building support for using their PGO from any HCPs either. Without the awareness and assistance from their HCPs, participants could not utilise the PGO to its full extent.

Observed coping responses to problems with PGOs

Throughout the interviews, several coping mechanisms have been observed. First, five participants who experienced a lack of organisation in their PGO monitor themselves outside of the PGO without entering their measurements in the PGO. Participant 5 describes themselves as a “do-it-yourselfer”, keeping track of their blood pressure, oxygen levels, fitness, weight, but are not “such a patient” to add everything into the PGO. Second, one participant explains that they have to manually manage their personal health records outside the PGO due to poor communication taking place between their HCPs and being unable to link with all their HCPs in the PGO. “It would be nice for [other HCPs] to have insight into my medical file…so then you have to find some way to get that over to another” (Participant 6). Finally, six participants share that they use other digital health platforms because they work better than their PGO. For example, participant 1 explains that while they can use their PGO to order medicine and link with their GP, they are unable to connect with all their hospitals and the hospitals already have digital patient portals which works better. In the PGO, “the hospital part is more just consulting things…and nothing else really. So, if I want to do something with a hospital [via the PGO], but I don't want to call, then I just do that via the page of the hospital itself. I don't really have the idea with the PGO...not really trusting that everything is going well” (Participant 1).

PGO user needs and desires

Content needs

In terms of content, eight participants shared that they would like the PGO to provide more explanation when data is shared, such as providing guidelines with results if they are “normal or abnormal” (Participant 4). Additionally, three participants shared that this can be done by adding more health data visualisations, as “for many people it is insightful if there is a green middle-line and you can see what happens with yourself in comparison…at some point I can see that my weight is slowly increasing and I’ll know that something needs to change” (Participant 3). A few participants also shared that they’d like their reports about consultations or meetings with HCPs to contain a more understandable summary of what was discussed. “I would like to have a bit more information…then it is clearer for me as the patient” (Participant 5). Second, six participants shared that they want to have all their medical information in one platform, including allergies, medication, treatments, meetings and tests. “That would be the ideal world, that you indeed have one place with the whole nine yards. Meetings, overview, everything” (Participant 3). Third, four participants indicated that it is important to keep the PGO simple, that “it does not need to be mega fancy with spectacular colours and functions. It's basically just about being able to get rid of your data and have them exchange it and you being able to decide [which HCPs] you're adding to it” (Participant 6). Fourth, two participants shared that they would like their medical information to update automatically. For example, both participants explained that “you have to transfer all other data yourself somehow” (Participant 6). One of them related this to being unable to link with the HCP and the other believes that there was no communication between their HCPs, and they were unable to share this themselves via the PGO either. Fifth, three participants explained that they would like patient-provider communication to be improved, whether it is via the PGO or between HCPs. “In terms of communication, being a little nice, a little openness, transparency, that the patient is central and not just the doctors” (Participant 5). Finally, three participants shared that they would like questionnaires to be better integrated into PGOs. These three participants all had comorbid chronic illnesses and a complex medical network of HCPs for which they are required to answer many questionnaires. “Every time you have to repeat [information] and that is quite irritating, and sometimes they send the same questionnaires in a row” (Participant 2); “I don’t know how many questionnaires I had to answer for endometriosis…there are many overlaps too, and I indicate that I have trouble typing, as I am not allowed to type for long due to my shoulder and elbow condition, and then they actually put me in front of the computer almost one day a week just for this” (Participant 6).

Technical needs

In addition to specific needs and desires for PGOs’ content, several technical needs and desires were identified. To begin with, participants shared that having access to their complete personal health record is important and necessary to them. “Because as a patient with a new illness you would like to know what you have…I could barely understand what was happening, so it would’ve been nice to be able to read everything back” (Participant 9). Furthermore, participants noted the importance of protecting their privacy in the PGO, some expressing that PGOs did not feel safe enough yet. Important to note here is that all participants, apart from two, were unaware of what the MedMij-label meant in the PGO. More importantly, participants noted that it was fundamental to be able to connect with all their HCPs in one platform. At the moment, most are forced to use multiple digital platforms.

> *“There is not one yet, I don't think, that really fully covers the load in such situations. So that links extra-regionally, multiple hospitals, people outside the hospital... In my opinion, it is simply not there yet...Especially if you have multiple practitioners, you usually find it nice if they are informed about you... What I then see is that, for example, my PGO is not linked to [my hospital]. And that my specialist at [the hospital] does not have the up-to-date information.”* (Participant 6)

External needs

Finally, four participants believe that externally, the government should take more responsibility and control over the development of PGOs. Some question “why has The Netherlands made it so complicated” with making “15 PGOs which you can choose from” available (Participant 3). One participant was aware that the government is changing their subsidies for PGOs and that there will be less choice in PGOs in the future and says that there should be more government control over the creation of new digital platforms, given that more hospitals are building their own PGO-like platforms. One participant explicitly states that “it is simply time for one PGO to be established by the government” (Participant 4). These participants share that they believe an increased governmental role would help keep personal information exchange safe and controlled and help prevent PGO creation for commercial rather than public health interests.

Discussion

This research studied how individuals with chronic illness(es) in The Netherlands experienced the use of PGOs to manage their care. Specifically, the perceived ease of use of PGOs were assessed, as well as their perceived usefulness for self-management, in addition to exploring whether chronic patients’ needs are addressed in PGOs. By investigating this, the added value and accessibility of PGOs are evaluated as the Dutch government is reassessing their financial support for PGO developers and the role of PGOs in the Dutch healthcare system. Moreover, by evaluating users’ experiences, PGO developers are informed about functionalities and improvements that are needed for chronic patients, who can benefit the most from a well-functioning PGO.

Using semi-structured interviews and a mixed coding analysis, several major themes were identified in the PGO user experience of chronic patients. First, there was consensus that the PGO is easy to use. Nonetheless, participants expressed concerns about its accessibility for people with lower (digital) literacy and of different educational or cultural backgrounds. Second, although participants saw a potential benefit of using PGOs to manage their chronic conditions, they expressed that the PGO is currently not adding value to their healthcare due to certain functionalities not working well. Specifically, this included having trouble linking with their HCPs and the PGO lacking explanatory health information. Finally, participants expressed that PGOs largely already included necessary elements, emphasising the importance of a simple, well-organised layout, and the importance of being able to access their PHR and share their health data easily.

To begin with, this research found that participants thought that the PGO was simple and straight-forward to use. Participants reported no computer anxiety and expressed a sense of computer self-efficacy, indicating that they possessed sufficient skills and confidence to use the PGO effectively. Perceived enjoyment' and 'objective usability' were two commonly found TAM3 elements, suggesting that participants experienced using the PGO as enjoyable, regardless of the system's performance, and that it requires minimal effort to use the PGO. These findings correspond to previous research, which emphasised that a user-friendly design is imperative for eHealth adoption (Madanian et al., 2013; O'Connor et al., 2016). Moreover, Doeven & Mol (2023) found that about 62% of users believed the PGO was easy to use. In this research, a larger proportion of participants share this positive perception, specifically emphasising the straight-forward platform structure.

Nonetheless, some participants expressed concerns about the accessibility of PGOs for people with limited digital skills or language barriers. All participants were Dutch natives, completed some form of higher education and expressed being digitally competent, believing that their educational background and digital skills contributed to their positive user experience. Nonetheless, participants identified technical challenges with logging in, linking the PGO with their HCPs, and navigating the platform. Similar findings were reported in previous PGO user research (Doeven & Mol, 2023). Other studies have also identified similar obstacles. For example, studies have highlighted that common problems using patient portals are navigation problems and incomplete information (Hägglund & Scandurra, 2022; Tieu et al., 2016; Yen et al., 2018). Such negative experiences can lead to negative affective responses and discourage PGO use (Venkatesh & Bala, 2008). This raises concerns about the accessibility of PGOs for the larger population, as about half of the Dutch population lacks sufficient digital skills (CBS, 2023). Existing literature reinforces this concern as low (e)health literacy and educational backround are barriers to eHealth adoption (Madanian et al., 2023; O'Connor et al., 2016). Additionally, the RIVM (2022) also found that differences in educational background and cultural background limit PGO usage.

In addition to technical issues posing a challenge for the accessibility of PGOs, participants shared that there was insufficient explanatory content on the platforms. Although some platforms offer health data visualisations, most participants expressed not being able to interpret data, adding an unnecessary stress factor. Madanian et al. (2023) highlighted that limited health literacy is a significant barrier to the adoption of digital health technology. The current study also exhibited that users' lack of understanding health information discouraged the use of their PGO, as it consequently limited its perceived usefulness. These findings reinforce accessibility concerns as about one-third of the Dutch population possesses limited health literacy (RIVM, 2014).

According to the TAM3, perceived ease of use is a positive affective response which increases the likelihood that a technology will be used, but also influences perceived usefulness (Davis, 1993). The high incidence of ‘task relevance’ and ‘output quality’ further suggest that participants generally positively experience the PGO. The most commonly enjoyed features of PGOs that were mentioned included enabling patient-provider communication, having access to their PHR, and enabling monitoring and reporting. The eCCM describes these elements as necessary in a chronic healthcare system to create a complete feedback loop between patients and providers, empowering proactive involvement (Gee et al., 2015a; Jimison et al., 2008). Participants deemed these features relevant and essential for the PGO to be considered a useful addition to their healthcare and contributed to the output quality of the platform, two criteria linked to perceived usefulness in the TAM3 (Venkatesh & Bash, 2008). The findings of this study consolidate previous research supporting that having PHR access makes patients feel informed, improves patient-provider communication, as well aids in understanding their health condition (Hägglund et al., 2022; Moll et al., 2018). Specifically, in a systematic review examining the functions and outcomes of PHR-use among chronic patients found that access to PHRs facilitated self-management, improved patient-provider relationships, as well as higher care quality (Paydar et al., 2021). Moreover, as participants also identified, it is not unusual for patients identify mistakes in their PHRs or noticing incomplete information (Bell et al., 2020). By having access to their PHRs via PGOs, mistakes can be rectified, potential increasing patients’ self-management and safety (Blease & Bell, 2019; Hägglund et al., 2022; Paydar et al., 2021).

Despite these positive experiences with the PGO, result demonstrability and a sense of increased autonomy remained relatively low compared to task relevance and output quality, suggesting that while PGOs’ functionalities are considered useful for patients’ self-management, they have not demonstrated direct benefits. Such result demonstrability is an important motivating factor for the use of technologies (Venkatesh & Davis, 2000). Participants insinuated this as well, describing that PGOs have the potential to be useful, on the condition that certain functionalities are improved. Specifically, this sense of limited usefulness was largely related to the inability to connect with all HCPs in the PGO. Additionally, while monitoring and reporting is considered an essential element in the complete feedback loop illustrated by the eCCM, most participants did not feel the necessity to monitor everything and being able to read results before speaking with their HCP. In previous research, similar findings were found, identifying poor interoperability as a barrier to implementation of PHRs, often leading to patients finding other ways to keep track of their healthcare (Harahap et al., 2021; Li et al., 2024). In Doeven & Mol's (2023) user-research, they also found that about half of the users desired an improvement in medical data integration in PGOs. Additionally, participants did not mention receiving any support from HCPs to build their confidence using the PGO. In line with existing literature, this study emphasises that using PGOs or other PHR accessing platforms can aid the self-management for patients, but that this is contingent upon data interoperability and supporting patient-provider communication (Hägglund et al., 2022).

Finally, through conducting interviews and evaluating the perceived ease of use and usefulness of PGOs by chronic patients in The Netherlands, participants' needs and desires for PGOs were identified. First, participants expressed a need for having a platform containing all their medical information, with which they can connect with all HCPs in one place. Although this is the primary aim of PGO development, in practice, this has shown not to be successful yet due to interoperability issues and consequent incomplete data. Similar issues were identified by previous research, further emphasising the importance of improving this (Harahap et al., 2021; Li et al., 2024). Second, participants expressed that PGOs should integrate explanations for results and medical information to help patients interpret results and understand the consequent health implications. Not only does this make information easier to understand, but this provides an opportunity for patients to expand their health literacy and empowers them to be more informed about their health (Carini et al., 2021; Gee et al., 2015b; Hägglund et al., 2022; Jimison et al., 2008). Third, participants highly valued accessing their PHRs, but emphasised the importance of keeping it simple, much like previous research about technology acceptance (Lazard et al., 2015; Simola et al., 2023). Finally, participants noted a need for more privacy protection, a significant concern that has been identified in existing literature regarding eHealth implementation (Heilbron & Koopman, 2018; Mitrovic, 2023; O'Connor et al., 2016).

Strengths and limitations

Although this research provides support for previous literature suggesting that the PGO can be a promising contribution to chronic care, there are strengths and limitations to keep in mind. To begin with, the sample of this study was small and pose some participant bias. The sample consisted mostly of adults above 50, literate, completing some form of higher education, and possessing sufficient digital competencies. As such, there was limited diversity that could provide sufficient insights into the accessibility of PGOs across groups with different social background, limiting the generalisability of these findings. Furthermore, although all participants in this sample used PGOs, this research only encompassed experiences with seven of the fifteen PGOs that were active at the time. Moreover, most participants rarely used their PGO, ranging from some not using the PGO at all anymore and some only using it once a month. In combination with the small sample size and participant bias, this may pose issues for the internal validity of this study. To continue, this research depended entirely on user experiences from a patient-perspective, not taking into account the perspectives of other end-users like HCPs and healthcare organisations. Additionally, this research relied on self-reported data which is vulnerable to recall bias. Finally, the development of PGOs has been fast-paced and dynamic, resulting in many changes being made during the time this research started and finished. It is therefore important to keep in mind that this research refers to user experiences with PGOs before and during the summer of 2024. Some of the suggestion made in this paper may have already been applied.

Despite these limitations, this research also possesses several strengths. The sample was diverse in terms of geographical location, consisting of individuals living in nearly every province of The Netherlands, contributing to the external validity of the findings. Moreover, the semi-structured nature of data collection in combination with the mixed inductive and deductive analytic method allows for balance theoretical rigour and flexibility. Using semi-structured interviews provided a structured approach for each interview, while leaving room for in-depth questioning if needed. In terms of analysis, a theoretical framework was established while also providing freedom for exploration to build onto the theoretical framework. To establish internal validity and reliability, some interviews were also coded by a second and third coder, to verify that codes are well-defined and to avoid confirmation or personal bias of the researcher in the analytic process.

Implications

This research expands on previous research regarding PGO use and eHealth adaptation by outlining how users experience the PGO as it is now, identifying problems they encounter and functionalities they enjoy. As the Dutch government aims that all citizens have access to a well-functioning and filled PGO by 2025, these findings can be used to enable this by providing insights into user needs (Ministerie VWS, 2022). The findings suggest that developing a unified government-supported approach to implement PGOs is important. At the moment, the government ambitions for PGO use are not met. This can be helped by providing implementation assistance at HCP-level, so that HCPs and patients can use an interoperable, well-filled PGO. Moreover, as the subsidy system for PGO development is changing, the government can set a standard for their requirements for PGOs, emphasising the need for simplicity and explanatory content. Finally, by increasing awareness about PGOs amongst the population as well as providing more eHealth support, patients and HCPs can become more familiar with all possibilities that PGOs can offer, while also feeling supported in adapting the new technology. Providing a unified approach from the government can help meet their goal of implementing well-functioning and filled PGOs in The Netherlands and reduce differences between groups based on location, educational background, and literacy.

Future research

Keeping the previously mentioned implications, strengths, and limitations in mind, several suggestions for future research are made. First, the development of PGOs would benefit from further user research into differences in experiences between social groups to continue evaluating the accessibility of these platforms. Second, future PGO user research would benefit from a larger sample, spread across all Dutch provinces, for greater generalisability and comparison possibilities. Moreover, user research would also benefit from a sample that uses their PGO more often than once a month. Third, this research focused only on patient-perspectives, but PGO development would also benefit from transdisciplinary user research, to take HCP and municipal perspectives into account as well. Including all stakeholders provides a well-rounded evaluation to improve PGOs. Fourth, this study provided a snapshot of self-reported PGO-use experiences, but future research would benefit from collecting observational data as well. For example, a longitudinal observational study of patients and HCPs using PGOs. Finally, it is recommended that future research combines quantitative and qualitative research, to provide statistical insights into PGO use experiences and relationships between specific variables, as well as in-depth explanatory insights.

Conclusion

The results of this study provided a well-rounded evaluation in terms of user-friendliness and usefulness of PGOs in the Dutch chronic healthcare system according to patient end-users. Overall, it was found that educated individuals that possess sufficient digital skills and understanding of the Dutch language perceive PGOs relatively easy to use, despite concerns about accessibility for the general population, and believe that the PGO has the potential to be useful contingent upon certain improvements in content and technical aspects. Taking into account the low (digital) literacy levels of the general population in The Netherlands, these findings indicate concerns about accessibility. Furthermore, the PGO was limited in its added value due to issues with interoperability with HCPs, limiting users with chronic illnesses in benefitting from accessing their PHR via the PGO. Nonetheless, participants expressed enthusiasm about the potential of PGOs in the future of their chronic care. This study outlined needs and desires that chronic patients considered essential to include in the PGO. The present findings indicate that PGO development and use can benefit from a unified government-supported strategy that assists HCPs and healthcare organisations with implementing PGO use as well as providing digital support for end-users.

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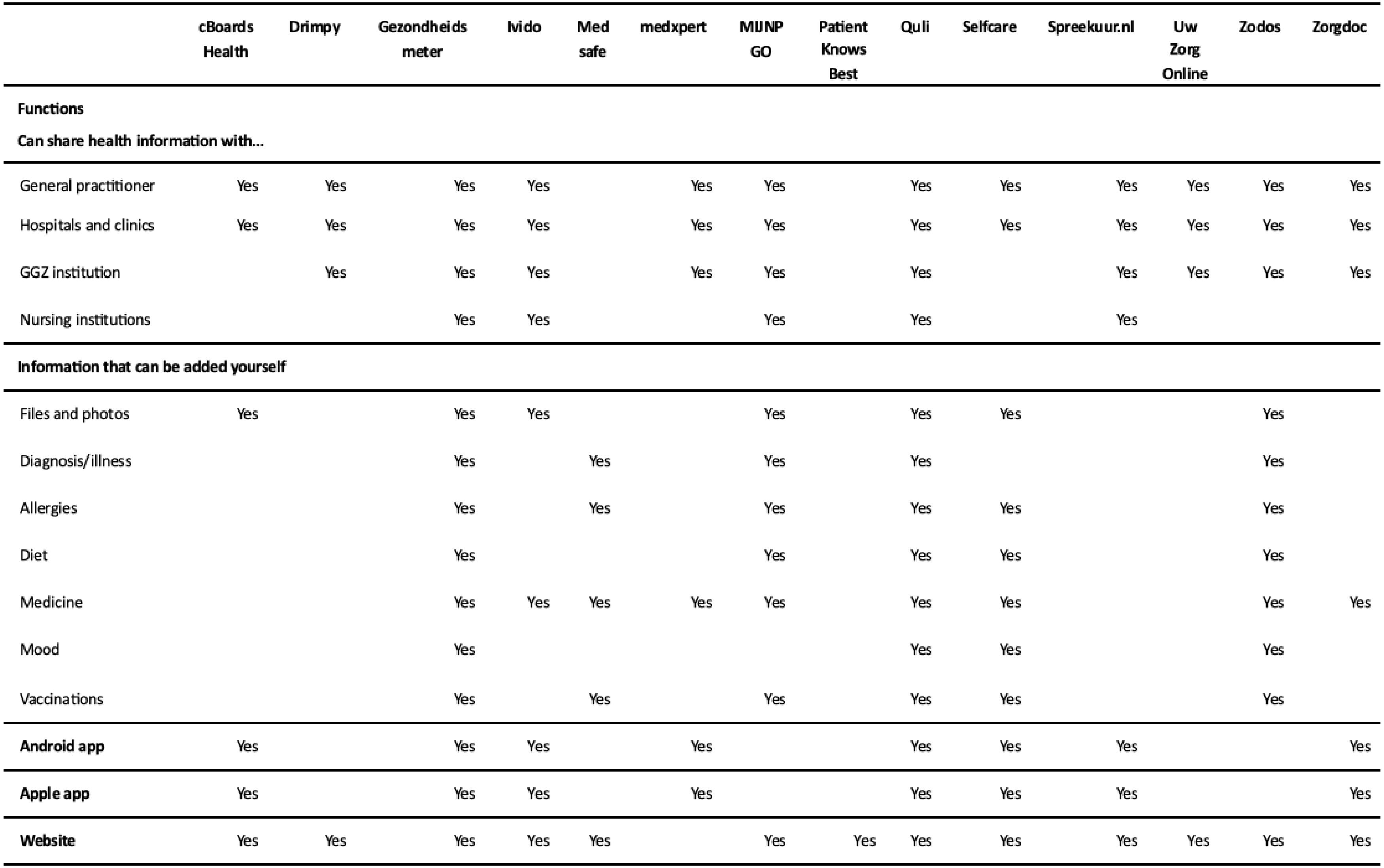
Appendix I: PGO overview

(Patiëntenfederatie, 2024b)



	cBoards Health	Drimpy	Gezondheids meter	Ivido	Med safe	medxpert	MIJNP GO	Patient Knows Best	Quli	Selfcare	Spreekuur.nl	Uw Zorg Online	Zodos	Zorgdoc
Functions														
Can share health information with...														
General practitioner	Yes	Yes	Yes	Yes		Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes
Hospitals and clinics	Yes	Yes	Yes	Yes		Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes
GGZ institution		Yes	Yes	Yes		Yes	Yes		Yes		Yes	Yes	Yes	Yes
Nursing institutions			Yes	Yes			Yes		Yes		Yes			
Information that can be added yourself														
Files and photos	Yes		Yes	Yes			Yes		Yes	Yes			Yes	
Diagnosis/illness			Yes		Yes		Yes		Yes				Yes	
Allergies			Yes		Yes		Yes		Yes	Yes			Yes	
Diet			Yes				Yes		Yes	Yes			Yes	
Medicine			Yes	Yes	Yes	Yes	Yes		Yes	Yes			Yes	Yes
Mood			Yes						Yes	Yes			Yes	
Vaccinations			Yes		Yes		Yes		Yes	Yes			Yes	
Android app	Yes		Yes	Yes		Yes			Yes	Yes	Yes			Yes
Apple app	Yes		Yes	Yes		Yes			Yes	Yes	Yes			Yes
Website	Yes	Yes	Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	cBoards Health	Drimpy	Gezondheids meter	Ivido	Med safe	medxpert	MIJN PGO	Patient Knows Best	Quli	Selfcare	Spreekuur.nl	Uw Zorg Online	Zodos	Zorgdoc
Functions														
Self-measured data that can be added…														
Breathing	Yes		Yes	Yes			Yes		Yes		Yes			
Blood pressure	Yes		Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes		Yes	
Blood sugar	Yes		Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes		Yes	
BMI	Yes		Yes	Yes			Yes		Yes	Yes				
Weight	Yes		Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes		Yes	
Heartrate	Yes		Yes	Yes			Yes		Yes		Yes		Yes	
Height	Yes		Yes	Yes	Yes		Yes		Yes	Yes	Yes			
Body temperature	Yes		Yes	Yes	Yes		Yes		Yes	Yes	Yes		Yes	
Oxygen saturation	Yes		Yes	Yes			Yes		Yes		Yes		Yes	
Burnt calories			Yes				Yes		Yes	Yes			Yes	
Physical activity			Yes				Yes		Yes	Yes			Yes	
Sleep duration			Yes	Yes			Yes		Yes					
Waist circumference				Yes					Yes					
Can be linked to other apps			Yes				Yes	Yes		Yes			Yes	
Pricing	Free	Free	Free	Free	Free	Free	Free	Free	Free	Free	Free	Free	Free	Free

	cBoards Health	Drimpy	Gezondheids meter	Ivido	Med safe	medxpert	MIJN PGO	Patient Knows Best	Quli	Selfcare	Spreekuur.nl	Uw Zorg Online	Zodos	Zorgdoc
Functions														
Extra options														
Diary	Yes		Yes	Yes			Yes	Yes	Yes	Yes			Yes	
Graphs of personal info	Yes		Yes				Yes		Yes	Yes			Yes	
Health questionnaires	Yes		Yes	Yes	Yes	Yes	Yes		Yes				Yes	
Reminders			Yes			Yes	Yes		Yes					
Set personal goals			Yes		Yes		Yes		Yes	Yes			Yes	
Add tasks and appointments			Yes				Yes	Yes	Yes				Yes	
Customer service can be reached by…														
Chat	Yes		Yes	Yes					Yes	Yes	Yes			
E-mail			Yes	Yes		Yes	Yes	Yes	Yes	Yes		Yes	Yes	Yes
Phone			Yes					Yes	Yes	Yes		Yes		Yes
Language options														
	NL	NL	NL, GER, ENG, FR, ITA, TUR,	NL	NL, ENG	NL	NL, ENG	NL, GER, ENG, FR, ITA, POL	NL, ENG	NL, ENG	NL	NL	NL	**NL**

	cBoards Health	Drimpy	Gezondheids meter	Ivido	Med safe	medxpert	MIJNP GO	Patient Knows Best	Quli	Selfcare	Spreekuur.nl	Uw Zorg Online	Zodos	Zorgdoc
Functions														
Log-in methods														
App	Yes	Yes		Yes				Yes	Yes	Yes	Yes	Yes	Yes	
SMS-code	Yes		Yes	Yes	Yes				Yes	Yes	Yes			Yes
Face-ID	Yes								Yes					Yes
Fingerprint	Yes								Yes					Yes
E-mail code			Yes								Yes			Yes
Yivi-app				Yes			Yes							
Ratings														
Number of reviews	106	0	61	95	0	64	3	8	6	0	30	0	30	0
Score	7.7		7.5	7.1		7.4	7.4	4.4	7.3		6.2			

Appendix II: Sample recruitment messages

Patiëntenfederatie email

“Beste panelleden,

Afgelopen jaar gaf je aan mee te willen denken over Persoonlijke gezondheidsomgevingen (PGO’s). Daarom nodigen we je graag uit voor een interview over het gebruiken van een PGO. Met die informatie kunnen PGO’s in de toekomst beter en gebruiksvriendelijker worden gemaakt. Wat vind je vervelend of juist fijn? Wat is er duidelijk en wat niet? Dat soort vragen krijg je in een interview van 30 tot 45 minuten. Je krijgt **50** euro als bedankje.

Een PGO is een website of app waarin je gratis je eigen medische gegevens kunt inzien zoals deze bekend zijn bij je zorgverlener. Zie ook Alles over persoonlijke gezondheidsomgevingen - PGO.nl.

Ellen Burghardt gaat hierover voor Erasmus Universiteit Rotterdam en Healthy’R graag met je in gesprek. Healthy’R is het Rotterdams centrum voor gedragsonderzoek en -ontwikkeling. Haar onderzoek richt zich op mensen die een chronische aandoening hebben omdat PGO’s heel veelbelovende functionaliteiten kunnen hebben voor mensen met zo’n aandoening.

Ellen zoekt mensen die:

- Gebruik maken van een van deze PGO's:
  Ivido, Zodos, cBoards Health, Drimpy, Gezondheidsmeter, Medsafe, medxpert, MIJNPGO, Patient Knowns Best, Quli, Selfcare, Spreekuur.nl, Uw Zorg Online, Zorgdoc
- COPD, longkanker, diabetes of een hart- en vaatziekte hebben (of hebt gehad).

Het interview plannen we (eind) mei 2024, op een moment dat jou het best schikt: datum, locatie en tijdstip worden samen afgesproken. Het kan ook digitaal of telefonisch als je dat liever hebt. Alle informatie wordt vertrouwelijk behandeld, alleen voor dit onderzoek gebruikt en niet gepubliceerd.

We horen graag gauw van je of je met Ellen in gesprek wilt over PGO’s.

Klik hier om je op te geven.

Mocht je vragen hebben over het onderzoek kun je contact opnemen met Ellen via: 556906eb@student.eur.nl”

Instagram

“Help mij afstuderen! Ben jij of ken jij iemand met een chronische aandoening of gebruik maakt van een complex zorgnetwerk en één van de volgende digitale zorgplatforms (PGOs) gebruikt?

- cBoards Health
- Ivido
- Spreekuur.nl
- Zodos
- Zorgdoc
- Gezondheidsmeter
- Quli

- Drimpy
- Medsafe
- Uw Zorg Online
- Medxpert
- MIJNPGO
- Patient Knows Best
- Selfcare

Ik zoek mensen om te interviewen over hun ervaring met een PGO. Kan jij mij helpen?”

Patient bulletin boards (posted to Longfonds, Reuma Nederland, Nierpatiënten Vereniging, Diabetesvereniging Nederland)

“Hallo! Ik ben Ellen en zoek deelnemers voor een gebruikersonderzoek over digitale zorgplatforms voor mijn masterscriptie aan het Erasmus Universiteit (Health Psychology & Digital Interventions).

Uit opdracht voor Gemeente Rotterdam en samen met de Patiëntenfederatie onderzoek ik de ervaringen die patiënten hebben met het gebruiken van persoonlijke gezondheidsomgevingen (PGO’s). Dit zijn digitale zorgplatforms waar de patiënt centraal staat en meer regie zou kunnen hebben over hun eigen zorg. Denk hierbij aan inzicht in hun eigen dossier, maar ook het beijhouden van zelfmetingen en makkelijk gezondheidsgegevens uitwisselen met zorgverleners. Volgens het Integraal Zorg Akkord, wil het Ministerie VWS dat iedereen in 2025 gebruik kan maken van een gebruiksvriendelijke PGO.

Met dit onderzoek krijgen we een beter idee van de huidige ervaringen die gebruikers van PGO’s hebben. Wat werkt geod, wat mist er, wat werkt niet goed? Op basis van interviews zal een advies gemaakt worden zodat de eisen en ebnodigdheden van patiënten meegenomen worden in verdere ontwikkelingen van digitale zorgplatforms, zoals de PGO. Hier heb ik u voor nodig!

Ik zoek kandidaten die 45 minuten met mij een interview willen doen (online of face-to-face). Hierin zullen we uw ervaring met een PGO/andere digitale zorgplatforms bespreken, en de toegevoegde waarde dat dit wel of niet geeft gehad voor uw zorg. Alle besproken informatie wordt uiteraard vertrouwelijk en anoniem behandeld.

Wanneer kunt u meedoen? U kunt deelnemen als u een chronische aandoening hebt en ouder dan 18 bent. Daarnaast is het een vereiste dat u een PGO gebruikt of hebt gebruikt in het verleden. Zie de lijst aan PGO’s hieronder:

- Ivido
- cBoards Health
- Gezondheidsmeter
- Uw Zorg Online
- Drimpy
- Quli
- MIJNPGO
- Zodos
- Zorgdoc
- Patient Knows Best
- Medsafe
- Medxpert
- Selfcare

- Spreekuur.nl

Wilt u mij helpen? Reageer op dit bericht of stuur een email naar 556906eb@eur.nl!”

Email GLI-provider

“Beste,

Mijn naam is Ellen en ik ben gestart met mijn scriptie om mijn master Health Psychology & Digital Interventions aankomende zomer af te ronden. In samenwerking met Healthy’R, een onderzoeksbureau van het Erasmus Universiteit en Gemeente Rotterdam, doe ik onderzoek naar het gebruik van persoonlijke gezondheidsomgevingen (PGO’s) door mensen met chronische aandoeningen in Nederland.

Alhoewel PGO’s nog niet heel actief gebruikt worden door de algemene Nederlander, biedt het al veel aan voor mensen met chronische aandoeningen op het vlak van gezondheidsinformatie opslaan van verschillende zorginstellingen en eigen metingen bijhouden. Om de ervaring van PGO gebruik te evalueren, wil ik graag PGO-gebruikers met chronische aandoeningen interviewen.

Nu mijn vraag aan u. Via het internet kwam ik erachter dat u Gecombineerde Leefstijlinterventie (GLI) aanbiedt waardoor u hoogstwaarschijnlijk met mensen werkt die diabetes hebben. Ik zou graag in contact willen komen met diabetespatiënten die een PGO gebruiken om te vragen of ik ze zou mogen interviewen.

Ik hoor graag of u mij hierbij zou willen helpen. Mocht u meer vragen hebben, neem dan gerust contact op!

Met vriendelijke groet,

Ellen Burghardt”

Appendix III: Interview guide

Welkom! Ik wil u graag bedanken voor uw deelname. Voordat we beginnen met het interview zelf, wil ik graag nog samen wat praktische dingen bespreken. Zoals u al eerder was geïnformeerd, gaat mijn onderzoek over de ervaring van PGO-gebruikers met chronische aandoeningen. Hiermee hoop ik een beter beeld te schetsen voor PGO-ontwikkelaars over wat er verbeterd moet worden, vanuit de ervaring van de gebruiker zelf. Tijdens dit onderzoek zal ik meerdere mensen interviewen en de uitkomsten vergelijken om te zien of er overeenkomsten zijn in deze ervaringen. Ik zal beginnen met vragen naar wat informatie over u en uw chronische aandoening. Daarna zullen we de PGO die u gebruikt bespreken. Uw inzichten worden vertrouwelijk behandeld en blijven anoniem. Om te bevestigen, geeft u toestemming voor het gebruik van uw inzichten in dit onderzoek?

Ik zou het interview graag willen opnemen zodat ik het later kan terugluisteren. Dit zal uiteraard niet met anderen gedeeld worden en alleen gebruikt worden in dit onderzoek. Is dat goed?

Dank u wel voor uw toestemming en deelname. Mocht u zich toch bedenken of een onderwerp niet willen bespreken, kunt u dit altijd aangeven. Voordat we beginnen, heeft u nog vragen voor mij?

Demografische informatie:

1. Hoe oud bent u?
2. Waar komt u vandaan? / Waar woont u nu?
3. Wat is uw hoogst voltooide onderwijsniveau?
4. Wat doet u voor werk?

Chronische aandoening:

5. U geeft aan dat u [chronische aandoening] hebt. Ik zou graag meer willen weten over hoe dat voor u is. Wanneer kreeg u deze diagnose? Welke symptomen heeft u het meeste last van?
6. Hoe ziet uw chronische zorg eruit?

Digitale zorg:

7. Gebruikte u voor de PGO ook andere digitale zorgplatformen?
   a. Welke?
   b. Waar gebruikte u deze voor?
8. Welke PGO gebruikt u? Hoe lang al? Hoe vaak?
9. Hoe kwam u in aanmerking met deze PGO?
10. Wat was uw eerste indruk van de PGO?
11. Toen u de PGO tegenkwam, voelde het veilig om te gebruiken i.v.m. privacy?
12. Waar gebruikt u de PGO het meeste voor?
13. Hoe leerde u om de PGO te gebruiken?
    a. Was dit moeilijk? Heeft u hierbij hulp gehad?
    b. Heeft u hier hulp voor opgezocht?
14. In hoeverre vindt u de PGO gebruiksvriendelijk? Waarom wel of niet?
15. Welke functionaliteiten werken goed?
16. Welke functionaliteiten werken niet goed? Waar loopt u het meest tegenop?
17. Zijn er functies die u mist?
18. Vergeleken met uw zorg vóór de PGO, vindt u dat u uw zorg beter kan beheren? Heeft de PGO toegevoegde waarde voor u?
19. Naar mate uw gebruik, hoe is uw indruk van de PGO veranderd?

Appendix IV: Codebook

Table 1. *Deductive and inductive codebook including code definitions*

Code	Definition
Demographic information	
Age*	Age of participant
Educational level*	Highest level of completed education
Location of residence*	Where interviewee lives/resides
Chronic illness symptoms *	Symptoms that user experiences and needs treated
eHealth use	
First impression*	First impressions of PGO expressed by users
Introduction to PGO/eHealth*	How user was first introduced and familiarised with the PGO
PGO use behaviour (TAM3)	How PGO is used by user
eHealth use*	Use of eHealth (other than PGO) by participant
Use of educational resources (eCCM)	Expressed use of online educational materials or resources to manage their conditions and/or use the PGO
PGO use motivations	
PGO use intention (TAM3)	Users’ subjective probability that they will use PGO
Poor communication between HCPs*	User expresses that communication between different healthcare providers about their health is not sufficient/absent, or in the PGO
Concern about fragmentation/commercialisation*	User expresses worry about the privatisation/commercialisation of healthcare, or the consequent fragmentation of the system
Concern about pressure on healthcare system*	Expressed concerns about the pressure on healthcare workers/system
Location differences in healthcare*	User expresses that their residential location affects their medical care
Bad experience with HCPs*	Experienced feeling invalidated by HCP / mistake made by HCP / not helped sufficiently by HCP
Use image (TAM3)	Degree to which use of a technology is considered to enhance status in one’s social circle
Subjective norm (TAM3)	User’s perception that most people who are important to them think they should use a PGO
Digital self-efficacy	
Computer self-efficacy (TAM3)	Belief that participant can perform a specific task/job using the computer
Computer playfulness (TAM3)	Expressed curiousness and intrinsic motivation to use computers
Computer anxiety (TAM3)	Expressed apprehension/fear when faced with possibility of using computers
Perceptions of external control (TAM3)	Belief that organisational and technical resources exist to support the use of the PGO

Perceived ease of use	
Perceived enjoyment (TAM3)	Extent to which activity of using the PGO is considered enjoyable, regardless of the system’s performance
Objective usability (TAM3)	Actual level (rather than perceptions) of effort required to complete specific tasks using the PGO
Concerns about accessibility	
Difficult to navigate*	User expresses difficulty navigating the PGO, i.e. struggling to find things
Dissatisfied with login*	User expresses dissatisfaction with login method because it does not work, it is complicated, or does not feel safe, etc.
Lack of organisation*	User expresses that PGO needs more organisation
Concerns about privacy*	Expressed concerns about the privacy of their online personal information/data
Coping with concerns and dislikes	
Use of other eHealth platforms because they work better*	Participant uses other digital health platform because it works better for certain things
Monitor themselves outside PGO*	User monitors their health but does this outside of PGO either due to not being possible in PGO or not feeling need to do it in PGO
Manually manage PHRs*	User feels compelled to manually forward health information from their PHR as PGO/HCP does not do it for them
Perceived useful technical elements	
Patient-provider communication (eCCM)	Use of PGO/eHealth to communicate with healthcare providers, including messaging, telehealth consultations, and feedback on health status
Personal health records (eCCM)	Access and use of electronic health records to manage health information
Tailored interventions (eCCM)	References to receiving personalised advice or interventions through PGO
Monitoring and reporting (eCCM)	Instances where users track and report their health data using eHealth/PGO
Health data visualisation (eCCM)	Use of charts, graphs, or other visual tools to understand health trends and outcomes via eHealth/PGO
Mobile health apps (eCCM)	Use of mobile apps for tracking symptoms, medication adherence, or lifestyle changes
Customisable features (eCCM)	Use of customisable features in eHealth applications to suit individual needs and preferences
Perceived usefulness	
Output quality (TAM3)	Degree to which user believes that the PGO performs their job tasks well
Task relevance (TAM3)	Perception regarding the degree to which the PGO is applicable to its job/task

Result demonstrability (TAM3)	Clear/tangible results from using the PGO
Increased sense of autonomy*	User expresses that PGO helps take some control of their medical processes
Conditional added value*	User considers PGO useful but on the condition that features/characteristics/processes are improved
Cognitive experiences related to perceived usefulness	
Lack of awareness about PGO*	Lack of awareness about what a PGO is, what it offers, how it is used, etc., expressed by user
Lack of necessity to monitor*	User expresses a lack of necessity to monitor their health constantly and uploading this to PGO
Dislikes reading results ahead of time*	User expresses concern about ability to read lab results ahead of speaking with HCP
Health literacy (eCCM)	Indications that participant comprehends health information provided through eHealth tools
Technical experiences related to perceived usefulness	
Poor/no link with HCP*	User expresses that PGO cannot be linked, or link is not working well with a HCP
Incomplete dossier*	User expresses that PGO shows incomplete health information
HCP-related barriers to perceived usefulness	
Provider is not aware of HCP*	User expresses that their HCP was/is not aware of PGO
HCP uses another platform*	User expresses that HCPs already use other non-PGO platform, preventing them from using PGO
Skill-building support (eCCM)	Instances where healthcare professionals help participant develop skills for using eHealth tools
Content needs	
Desire for more explanation*	User expresses need to have health data be better explained in PGO so they can better understand it
Desire to have everything in one location*	User expresses wanting to have all their health information in one location
Desire for simplicity*	User expresses that PGO is too complex, needs more simplicity and conciseness (i.e. simple layout, only necessary functions, nothing complicated)
Desire for automatic updates*	User would like PGO to automatically update their health data/information
Better integration of questionnaires*	User expresses that health questionnaires should be better integrated/improved
Desire for health visualisation*	User expresses desire that health data gets visualised (i.e. graphs)
Desire for better communication*	Participant expresses that more needs to be communicated between patients & healthcare

Technical needs	
Desire for single platform to connect with all HCPs*	User expresses wanting a single platform where they can connect with all providers from different institutions
Desire to access PHRs*	Participant expresses wanting access to their personal health records
Desire for more privacy protection*	User expresses that they want a safe and private log-in
External needs	
Government should take control*	User expresses thinking government should take control and responsibility over eHealth platform development

**= inductive codes*