Navigating Insights Into the Adoption of Patient Portals

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Chapter 1

General introduction

In the fall of 2023, my son was admitted to a general hospital. This was the start of an extremely stressful period for me. Despite my nursing background, having worked in various hospitals and conducted research in the healthcare field for nearly six years, I found myself struggling to understand much of what was happening and had numerous unanswered questions. My mom, who had worked as a nurse for 40 years, had the same experience. My husband and other family members, who lacked professional healthcare experience, were even less able to comprehend the situation.

After repeatedly asking the professionals about the protocols they were following and for information about my son's admission, but still not getting the answers I sought, I felt that I was not being taken seriously. So, on the third day of my son's admission, I asked for real-time access to his dossier on the hospital's patient portal. The nurse seemed surprised by my request; it felt as if she did not know what I was talking about. However, she told me to fill in a form and assured me that online access would be arranged.

My son stayed in hospital for 11 days, during which time I had to send seven emails asking for access to the portal. The extra burden of repeatedly seeking information on top of caring for my son and my other child at home, became overwhelming. Ultimately, the hospital did grant me access to the portal - but only three days after my son was discharged. At that point, any urgency I had felt to review his dossier had of course diminished.

My recent experience is an example of three views on using a patient portal. First, it shows the patient's perspective, including their information needs that may differ in time. In my case, eHealth technology - real-time access to healthcare information via an online patient portal - could have satisfied my need for information. Second, it illustrates what happens when healthcare professionals are not aware of certain eHealth technology or its benefits for patients. In my case the nurse lacked information of the patient portal and the functionality it offered: online, real-time access. In the process of informing my husband and me about our son's admission, the professionals did not mention the patient portal, which suggests it was not embedded in their work routines. Third, organizing online access for parents to obtain information on their children seemed complicated. The identity verification procedure (the form the nurse gave me) contained a few steps to go through.

This example not only illustrates the challenges that parents encounter but also provides insights into the healthcare professional's standpoint. It underscores the necessity of organizational preconditions for stakeholder cooperation, such as the need for healthcare professionals to be familiar with the portal to effectively engage with parents and the administrative procedures that healthcare professionals and IT specialists must undertake together to ensure online access.

eHealth has been relevant for governments and society at large for many years. Governments view eHealth as having the potential to contribute to the quadruple aim: improve the health of populations, reduce per capita cost of healthcare, enhance patient experience, and improve the working life of those who deliver care [1,2,3]. However, scientific research shows that the promise of eHealth technologies is seldom fulfilled in daily practice [4,5,6]. This can be because eHealth technologies and strategies get developed without due consideration for the complex relationships between people, context and technology [7,8,9] and so technology does not get aligned with the requirements of people [10]. Moreover, eHealth technologies are not well-integrated with existing healthcare processes and electronic health records (EHRs), leading to a lack of interoperability [8,9]. Consequently, healthcare professionals resist change, worried about increased workload and changes to established practices [8-11]. Another reason why eHealth is not fulfilling its promise could be because people lack digital literacy [9,10], which could risk increasing health disparities (digital divide). Patients also express mistrust about the privacy of their sensitive health information when using eHealth technologies [9,10]. Other reasons include problems with financing eHealth technologies [10,11]. The final reason is that although research on eHealth technologies is available, current studies lack multidimensional impact and there are no prospective longitudinal studies with large samples [12]. However, Woods et al [13] recently published a comprehensive study on the impact of digital health on healthcare system outcomes as defined by the four government aims (see above) which found an overall positive or neutral impact on advancing digital health. Nonetheless, more evidence on effectiveness is needed, as well as more insight into the functional elements of eHealth technologies [7].

This raises the following questions: How do we get eHealth technologies to work in daily practice? How do we get care professionals and patients (and their informal carers) to adopt these eHealth technologies? How can we overcome the many challenges patients, healthcare professionals, healthcare organizations and government face on trying to implement and use eHealth? Searching for the answers to these questions, this dissertation is about patient portal adoption by patients and healthcare professionals. This introductory chapter begins by defining eHealth, patient portals and Personal Health Records. Next, it reports on the eHealth technologies adoption process in a Dutch context and discusses the insights obtained from analyzing the concepts and challenges of implementation models. The chapter ends with a summation of the research methodology.

EHEALTH DEFINED

In their systematic review, Oh et al [14] analyzed 51 definitions of eHealth which showed that there is no consensus on the concept of eHealth and therefore no more than a tacit understanding of its meaning. Eysenbach [15] describes eHealth as:

> *"an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology" (p.1).*

Eysenbach [15] suggests that eHealth is a way of thinking and acting to improve various levels of healthcare with digital technologies. After Eysenbach [15], many other scholars tried to describe eHealth in similar terms [15-19]. Meanwhile, Pagliari et al [17] analyzed 36 eHealth definitions, and proposed using Eng's definition [20] combined with an extension of Eysenbach's [15] description:

> *"e-health is the use of emerging information and communications technology, especially the Internet, to improve or enable health and healthcare" [20].*
>
> *"e-health is an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology (adapted from Eysenbach [15])" (p.17).*

There is enormous variation in the terms used, often interchangeably, to describe overlapping functionalities of eHealth, such as mHealth, Telecare and Telehealth [21]. Based on their interview study of experts, Shaw et al [22] developed a conceptual model for eHealth with three overlapping domains: 1) "*Health in our hands: the use of eHealth technologies to monitor, track, and inform health"*; 2) "*Interacting for health: the use of technologies to communicate between stakeholders in health*"; and 3) "*Data enabling health: the collection, management, and use of health data sources"* (p.5) (see Figure 1). Where the three domains overlap in the middle indicates the optimum point for eHealth. Patient portals and Personal Health Records (PHRs) are two eHealth technologies that fit into this central overlap.

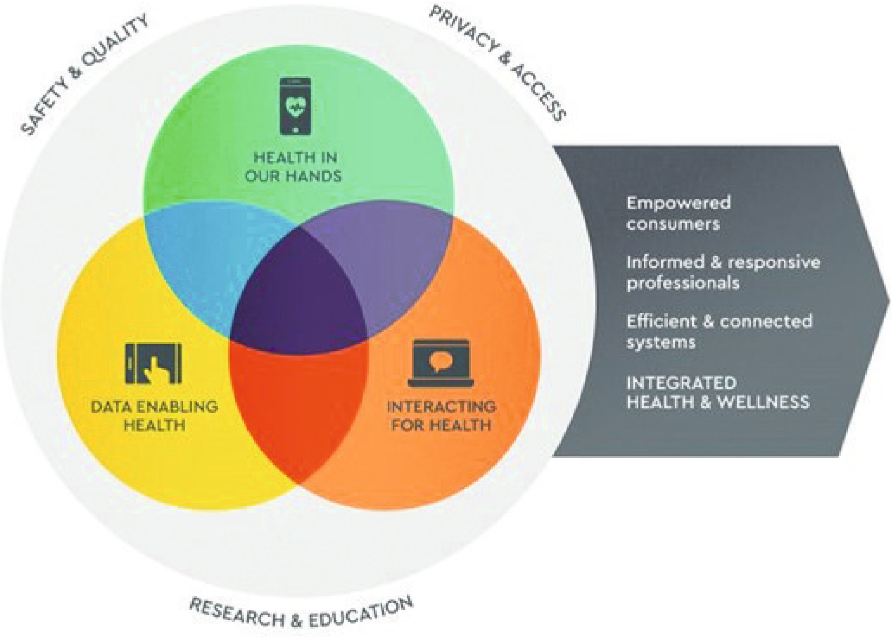

Figure 1. Model of three eHealth domains by Shaw et al. (p.9) [22].

Focused on patient portals, this dissertation follows the Shaw et al model [22] which shows the different categories of eHealth technologies and the optimum point where all three domains overlap. This is helpful for our findings on patient portals, which could be essential for other eHealth technologies that intersect with all three domains identified by Shaw et al. [22]. The overlap of domains covers integrating health data to enhance interactions and the communications that empowering users to be actively involved in their own health (care) [22]. In addition, we argue that the second part of Eysenbach's [15] definition about a new way of working is both a prerequisite for and consequence of implementing and adopting eHealth technologies.

DEFINING PATIENT PORTALS AND PERSONAL HEALTH RECORDS

The literature contains many and varied definitions of patient portals and PHRs that are not coherent. Table 1 summarizes the definitions and shows the differences and similarities between the two concepts and the described functionalities offered to patients. The definitions show that the terms patient portals and PHR are sometimes used interchangeably [23,24]. At other times, portals are seen as a class of PHR [25] or as different applications serving distinctive aims. Most definitions focus on the patient-as-user of the portals and PHRs. Just three definitions explicitly mention the function of sharing data with others [7,26-28].

Table 1. Definitions of Personal Health Records and patient portals.

Definitions	Differences and Similarities	Functionalities
“Personal Health Records (PHR), often known as patient portal, are consumer-centric tools that can strengthen consumers’ ability to actively manage their own health and healthcare” (p.852) [23].	Patient portals and Personal Health Records are used interchangeably.	
“Patient health records (PHR) technology, often known as patient portal, provides patients with online access to their health records, which in turn enables better disease management through tracking of comprehensive health indicators and lower the cost of care” [29,30] (p.588) [24].	Patient portals and Personal Health Records are used interchangeably.	• Online access to EHR • Tracks comprehensive health indicators
“Patient Portals – a class of Personal Health Records (PHRs) that provide access to information in the patient’s Electronic Health Record (EHR) – are becoming a part of the ecosystem of care” (p.47) [25].	Patient portals are seen as a class of Personal Health Records.	• Online access to EHR
The US government defines a patient portal as “a secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection” [31]. The data are managed by the health care organization, and even the most rudimentary portals enable patients to access information like recent doctor visits, discharge summaries, medications, immunizations, allergies, and lab results. More advanced portals enable patients to request prescription refills, schedule non-urgent appointments, and exchange secure messaging (SM) with their provider” [31]. […] *“The ownership of a patient portal distinguishes it from a personal health record (PHR); while the PHR is owned and managed by the patient, a patient portal is owned and managed by the health care organization. A main advantage of the patient portal is that the data are current, while the data in the PHR are current only when the patient updates it. Without a patient portal as an intermediary, the patient would not be able to access the data in the electronic health record (EHR)”* (p.2) [32].	Draws a distinction between patient portals that are managed by healthcare organizations that update information automatically and PHRs which are managed by patients who update their information manually.	Patient portal • Online access to personal health information • Online access to lab results • Online access to discharge summaries, medications, immunizations, allergies • Online access to upcoming appointments • Communication functionalities: secure messages • Administrative functionalities: appointments, prescription refill • Self-management functionalities: schedule non-urgent appointments

Table 1. Definitions of Personal Health Records and patient portals. *(continued.)*

Definitions	**Differences and Similarities**	**Functionalities**
“A patient portal is a secure website through which patients can access personal health information and typically make use of several communication, self-management, and administrative functionalities” [33] (p.162) [34].	Only describe patient portals.	• Online access to personal health information • Communication functionalities • Self-management functionalities • Administrative functionalities
“Patient portals are provider-tethered applications that allow patients to access, but not to control, certain health care information (e.g., their EHR) and provide communication and administrative functions (e.g., secure messaging, appointment booking, and prescription refill requests)” (p.2) [35].	Only describe patient portals as applications owned by healthcare organizations.	• Access (not control) to certain healthcare information (beyond EHR) • Communication functionalities: secure messages • Administrative functionalities: appointments, prescription refill
PHR is “an electronic application through which individuals can access, manage and share their health information and that of others for whom they are authorized, in a private, secure and confidential environment” (p.15) [7].	Only describe Patient Health Records.	• Access and manage health information • Share health information with others in a private, secure, and confidential environment.
“A tethered patient portal is an application build on an Electronic Health Record (EHR) infrastructure of a specific healthcare organization [36]. A tethered patient portal differs from for example a personal health record, in which the patient can collect health data and he/she decides whether to share that data with providers or family members” (p.19) [26].	Draws a distinction between patient portals that are managed by healthcare organizations and PHRs which are managed by patients.	Patient Portal • Builds on EHR Patient Health Record • Collect health data • Share data with others

Table 1. Definitions of Personal Health Records and patient portals. *(continued.)*

Definitions	Differences and Similarities	Functionalities
"Online electronic records such as patient portals and personally controlled electronic health records can be described as online applications that are tethered to the electronic health record system of a healthcare organization [37]*. Through portals, consumers can often access test results, medication lists, upcoming appointments and healthcare information documented by healthcare providers of the organization"* [38]. *"Personally controlled electronic health records can draw information from multiple organisations and sources while being managed, shared and controlled by the consumer"* [27] (p.4) [28].	Draws a distinction between patient portals that are managed by healthcare organizations and PHRs which are managed by patients.	Patient Portal • Online access to healthcare information (EHR) • Online access to test results • Online access to medications • Online access to upcoming appointments Patient Health Record • Access information from multiple organizations • Manage health information • Share and control information
"Patient portals are secure online tools that can stand alone or be tethered to a healthcare organization's health record, through which patients can access their personal health information from anywhere with an Internet connection." [39]. *"PHRs are online applications that are owned and managed by patients or their proxies and allow for patient input of information for greater control of patients' own health information management"* [40] (p.1913) [41].	Draws a distinction between patient portals that are managed by healthcare organizations and PHRs which are managed by patients.	Patient Portal • Online access to personal health information (EHR) Patient Health Record • Manage health information • May include information that is not part of a medical record

Table 1. Definitions of Personal Health Records and patient portals. *(continued.)*

Definitions	Differences and Similarities	Functionalities
"The medical dictionary [42] defined a patient portal as 'a domain in an electronic health record (EHR) that allows patients to access their records or communicate with their healthcare providers.' Patient portals are distinguished from personal EHRs in terms of ownership: a patient portal is mostly tethered to a health care organization, whereas a personal health record is untethered but owned by the patient and may include information that is not part of a medical record [43,44]. *The patient portal provides patients insight into (parts of) their EHR and test results and can also offer a wide variety of other functionalities such as communication with professionals, the possibility to make appointments, and request prescription refills and can also provide patient education"* [44] (p.2) [45].	Draws a distinction between patient portals that are managed by healthcare organizations and PHRs which are managed by patients.	Patient portal • Online access to (parts of) EHR • Online access to test results • Communication functionalities: secure messages, patient education • Administrative functionalities: appointments, repeat prescriptions Personal Health Record • May include information that is not part of a medical record
"Electronic patient portals have emerged as the primary means for patients to gain online access to their health records. A patient portal is defined as a way for patients to view at least some portion of their electronic health records (EHRs), which contain clinical data created by and for health professionals in the course of providing care. Although this information is about the patient, the data are managed by the provider or health system, and typically reside within the health care provider's EHR or as a stand-alone website that sells their services to health care providers. Patient portals also allow patients to interact with their health care providers in some way, often through secure messaging a key distinguishing feature from the conventional personal health record (PHR). Another main advantage of a portal over a PHR is that the data are updated automatically with updates to the EHR, whereas data in the PHR often require manual updates by the patient" [46].	Draws a distinction between patient portals that are managed by healthcare organizations that update information automatically and PHRs which are managed by patients who update their information manually.	Patient portal • Online access to (parts of) EHR • Communication functionalities: secure messages

Table 1 makes three differences between patient portals and PHRs explicit. First, patient portals are initiated, managed and controlled by healthcare organizations/care providers and PHRs are initiated, managed and controlled by patients themselves [26-28,32,38] and, thus PHRs can include information which is not part of an EHR [41,45]. Second, patient portals include health-related information from one healthcare provider/organization while PHRs may include health-related information from multiple healthcare organizations [28]. Third, patient portal data are updated automatically with updates from the EHR while patients can update their PHRs too [32,46].

The most important functionalities of both patient portals and PHRs described in the definition are connected to information: access, manage, control and share information. Also, communication [32,34,35,45,46], self-management [7,27,28,32,34,40,41] and administrative [32,34,35,44,45] functionalities are found in the descriptions. The definition of patient portals by Grünloh et al [35] and the definition of PHRs by van Gemert-Pijnen et al [7] explicitly mention the different functionalities of both. Combining the functionalities from the definitions with Shaw's three domains [22] we can categorize the functionalities of patient portals and PHRs per domain.

The categories of patient portal functionalities in the *Health in our hands* domain [22] help patients monitor, track and be informed about their health [22]. The functionalities include patient education materials made accessible by healthcare organizations [44,45] and patients' access to information on recent doctor visits, discharge summaries, medications, immunizations, allergies on the patient portal [32]. The function of PHRs is to upload health information from various (e)Health technologies (eHealth apps) and organizations (general practitioner, hospitals) [27,28].

The categories in *Interacting for health* [22] help health stakeholders communicate [22]. The functionalities include secure messaging between providers and patients [32,35,44,45], the ability of patients to book appointments [32], check appointment times [28,32,38] and order repeat prescriptions [32,35,44,45]. Also, it allows shared access to portal or PHR data with relatives/family members authorized by the patients [7,26-28].

The categories in *Data enabling health* [22] help to collect, manage, and use health data sources on a broader scale [22]. Patient portal functionalities include giving patients online access to test results (real-time or with a time delay) [28,32,38,44,45] and access to the medical file and EHR [24-26,28,35,38,44,45]. The PHR functionalities upload health information from various (eHealth) technologies or organizations [27,28,41,44,45].

This dissertation distinguishes a patient portal from a PHR. A patient portal is initiated and managed by a healthcare organization and gives access to information in EHRs reported by healthcare professionals. A PHR is initiated and managed by the patient, collects information from multiple providers, and allows the patient to add information.

Aimed at getting the patient to actively manage their own health (care) and support disease management, both patient portals and PHRs can provide self-management tools and administrative support.

ADOPTING PATIENT PORTALS AND PERSONAL HEALTH RECORDS IN THE DUTCH CONTEXT

Many financial and supportive programs are put in place to support the adoption process of eHealth technologies, like patient portals and PHRs. The Dutch Ministry of Health, Welfare and Sport in 2014 formulated eHealth goals [47] as following:

> *"Among the Dutch, at least 80% of the chronically ill and 40% of the rest of the people will have direct access to medical data by 2019."*
>
> *"By 2019, 75% of the chronically ill and frail elderly will be able to use remote monitoring to take measurements independently."*
>
> *"By 2019, anyone who receives care and support at home can, if desired, communicate via a screen with a healthcare provider 24 hours a day" (p.3) [47].*

To achieve these national goals the Dutch government launched a total of nine financial incentive programs known as VIPP (*Versnellingsprogramma Informatie-uitwisseling Patiënt en Professional)* to support information exchange between patients and healthcare professionals through patient portals or PHRs [48]. Commitment to the VIPP program implies that organizations had to achieve certain goals to receive financial compensation, but how they achieve those goals is up to them [48]. Consequently, Dutch healthcare organizations had total freedom in the technology used and the adoption process of patient portals and PHRs. For example, organizations could choose the commercial supplier for their patient portal and which functionalities to offer to their patients. This means portals of different healthcare organizations might differ in their available functionalities. However, based on this financial incentive they all have to offer 1) online access to their personal health information, 2) remote monitoring and 3) screen communication between patient and healthcare provider. Table 2 provides an overview of the nine VIPP programs.

Table 2. Overview of VIPP programs [49,50].

Program	Focus	Duration
VIPP 1	General and teaching hospitals	2017-2019
VIPP 2	Other healthcare organizations for medical specialized care	2017-2020
VIPP 3	Mental healthcare organizations	2018-2020
VIPP 4	Independent mental healthcare professionals	2020-2021
VIPP OPEN	General practitioner care	2019-2022
VIPP Babyconnect	Birth/maternity care	2019-2020
VIPP InZicht	Long-term care	2019-2022
VIPP Farmacie	Pharmacy care	2022-unknown
VIPP 5	General, teaching and academic hospitals, and other healthcare organizations providing specialist care	2020-2023

The first VIPP program for general and teaching hospitals focused on exchanging information between healthcare professionals and patients. Organized by the Dutch Hospital Association, it initiated on January 1, 2017. A few months later, VIPP 2 started for other healthcare organizations providing specialist medical care. The subsequent six VIPP programs also focused on information exchange between professionals and patients. VIPP 3 and VIPP 4 was for mental healthcare care organizations and professionals, VIPP OPEN was for general practitioner care, VIPP Babyconnect for birth/maternity care, VIPP InZicht for long-term care, and VIPP Farmacie for pharmacy care [49].

For general, teaching and academic hospitals and other healthcare organizations providing specialist medical care, VIPP 5 began on February 12, 2020 [50]. This program focused on sharing medical information between healthcare organizations, and standardized information exchange among healthcare organizations and patients via PHRs [50]. Three umbrella organizations - Dutch Federation of University Medical Centers (NFU), Dutch Hospital Association (NVZ) and independent clinics in the Netherlands (ZKN) - worked together to help healthcare organizations implement the VIPP 5 goals, the foundation of standardized digital information exchange with patients via PHRs [51].

Besides these VIPP programs explicitly focused on patient portals and PHRs, other Dutch initiatives also aimed to provide the right (digital) care in the right place, e.g., Program Digital Care by the Dutch Hospital Association, the ‘Vliegwiel’ coalition for digital transformation in healthcare by the Patient Federation of the Netherlands and Digital Aging (District Nursing) by Vita Valley [52].

All these (financial) incentive and supportive programs aimed to stimulate digitalization in healthcare in the Netherlands. A key aspect of healthcare digitalization is the exchange of information between patients and healthcare professionals in organizations. However, Dutch care organizations have not yet fully achieved ‘interoperability’, the ability to exchange digital information. In response, the Minister of Health, Welfare and Sport submitted a legislative proposal in 2021, known as the *Wet elektronische gegevensuitwisseling in de zorg* (Wegiz) [53]. The House of Representatives of the States General accepted this legislative proposal on September 27, 2022. The Wegiz mandates that Dutch healthcare providers and organizations must exchange patient data electronically, a regulation that came into effect on 1 July 2023. [54]. This meant the end of sending patient data on CD-ROMs and by fax [53].

The Wegiz is part of the Integral Care Agreement (IZA), which describes the agreements the Cabinet and healthcare parties made in September 2022, aiming to ensure that healthcare remains high quality, accessible and affordable. Another IZA agreement is that by 2025 all Dutch citizens should have a user-friendly, well-stocked PHR that adds value to the healthcare process and contains comprehensible information [55]. The Minister of Health, Welfare and Sport and IZA-parties signed the IZA implementation agreement on data exchange (IZA *Uitvoeringsakkoord gegevensuitwisseling*) on January 22, 2024 [56]. Additionally, an online platform called DigiZo.nu, initiated by the 14 IZA partners, was officially launched on March 4, 2024 [58]. This platform is designed to help healthcare organizations translate their processes into greater digital integration [58].

Despite all these financially supportive programs and initiatives to enhance the adoption of eHealth technologies, especially patient portals and PHRs, the results in the Netherlands are still questionable. The eHealth Monitor has been studying the situation in the Netherlands annually since 2013 [59]. Its purpose is to obtain an overview of the supply and use of digital healthcare now and in trends over time. In 2021, the monitor showed an increase in usage of eHealth compared to 2019, in part due to Covid-19 pandemic [60]. The rise in eHealth technology use lowered when lockdowns were passed during Covid-19 pandemic [61]. This raises the question of how well eHealth technology was adopted during the pandemic. In the eHealth Monitor of 2023 more patients used eHealth, like patient portals, than in 2022. The most used portal functionality was online access to test results [61]. People with fewer years of education and older people make less use of digital tools [61]. There was no increased use by healthcare professionals [61]. However, eHealth technologies are still seen as ‘add-on’ and should be integrated in care processes [60,61]. Otherwise, new technologies will be used in ‘old’ care processes. Therefore, care needs to be organized differently, digital user skills and financial models should be improved, and eHealth technologies should become more user-friendly [60,61].

IMPLEMENTATION MODELS AND CONCEPTS: INSIGHTS AND CHALLENGES

Implementation models and concepts

The literature features many implementation models for eHealth technologies, often discussing concepts like acceptance, adoption and embedding [62,63,64]. A systematic review of theories informing eHealth implementation reveals models used mostly by researchers: the Technology Acceptance Model (TAM), Unified Theory of Acceptance and Use of Technology (UTAUT), Diffusion of Innovations Theory (DOI) and Normalization Process Theory (NPT) [65]. This section deals with these models and two other broadly, frequently used implementation frameworks, which build on DOI, such as Consolidated Framework for Implementation Research (CFIR) and the Non-adoption, abandonment, scale-up, spread, and sustainability (NASSS) framework.

The TAM states that Attitude toward Using and Actual System Use are affected by an individual's Perceived Ease of Use and Perceived Usefulness [66]. These two determinants are directly influenced by System Design Features [66]. The UTAUT says that Behavioral Intention to use eHealth technologies is affected by individual Effort Expectancy, Performance Expectancy, Social Influence, Facilitation Condition. These direct determinants of user acceptance and usage behavior are moderated by gender, age, voluntariness and experience [67].

The DOI explains how new ideas or technologies spread through a social system over time [68]. Four main elements influence the spread: the innovation, communication channels, time and social system [68]. Rogers [68] identifies five key characteristics that influence an innovation's rate of adoption: Relative advantage, Compatibility, Complexity, Trialability and Observability. The adoption of an innovation occurs in a five-step decision-making process: 1) Knowledge step, 2) Persuasion step, 3) Decision step, 4) Implementation step, and 5) Confirmation step [69].

The NPT is an implementation theory that helps to understand how new technologies, treatments or care practices are embedded and integrated into social contexts. It provides a framework to analyze the factors that facilitate or hinder the normalization of innovations. Given its aims to provide an understanding of how to promote effective integration and sustainment of new practices [69], the NPT focuses on what people do instead of what they believe or intend to do [69,70]. NPT helps to explain how new practices become routinely embedded in everyday work by focusing on the sense-making, engagement, operationalization, and appraisal activities of those involved. For instance, it focuses on how eHealth technology affects human relations such as the doctor-patient relationship [71] and the human factors within organizations [72].

The CFIR can be seen as a broad implementation framework that builds on Rogers' DOI [72] and aims to predict or explain barriers and facilitators for diverse types of implementation outcomes [73-75]. The CFIR contains five main domains: 1) Intervention Characteristics, of the innovation being implemented; 2) Outer Setting, external contexts (economic, political, and social); 3) Inner Setting, including organizational context; 4) Characteristics of Individuals, those involved in the implementation; and 5) Process, covering the implementation stages. Each domain contains multiple constructs that influence implementation outcomes [73].

Another broad framework is the NASSS framework which is not included in the systematic review by Heinsch et al [65]. It should be included because it is one of the most recent implementation frameworks to build on DOI [72]. This NASSS framework considers the influential factors for the adoption, non-adoption, abandonment, spread, scale-up, and sustainability of health and care technologies [71]. It views implementation as a continuous development process that never finishes, and emphasizes that implementing innovation, such as eHealth technology [76], is complex and takes a lot of work. The framework encourages a nuanced understanding of how various elements interact to shape the process of technology implementation. Successful technology implementation requires a holistic understanding of these elements and how they interact within a specific context. These elements exist in the seven domains of the NASSS: 1) Condition focuses on the nature of the health condition or illness being addressed, 2) Technology examines the technology itself, 3) Value Proposition focuses on the perceived value of the technology from both supply-side and demand-side perspectives, 4) Adopters considers the staff, patients, and carers expected to use the technology, 5) Organization examines the organizational context for implementation, 6) Wider System considers the broader context in which the technology is implemented, and 7) Embedding and adaptation over time, focus on the long-term sustainability and evolution of the technology [71].

Table 3 provides an overview of these models and their development over time.

Table 3. Overview of implementation models for eHealth technologies.
(Extended version of Table 1. Theoretical acceptance and adoption models by Hulter et al. [78]).

Model	Developer, year	Theoretical basis	Central constructs	Points of critique	Extended models
Diffusion of Innovations (DOI)	Rogers, 1962 [62]	Diffusion research [78]	Explains the characteristics of innovation. Observability, trialability, complexity, relative advantage and compatibility are the primary determinants which help explain the different rates of adoption [62,80]. Diffusion starts with recognizing the user's need. It spreads by knowledge acquisition, persuasion, decision (adopt or reject), implementation (routine use, reinvention, conformation), promotion and evaluation [79].	Focuses less on the organizational context. [73,76,80].	The unifying theoretical model by Greenhalgh et al [80], the NASSS framework by Greenhalgh et al [71] and the Consolidated Framework for Implementation Research (CFIR) by Damschroder et al [73,78].

Table 3. Overview of implementation models for eHealth technologies.
(Extended version of Table 1. Theoretical acceptance and adoption models by Hulter et al. [78]). *(continued.)*

Model	**Developer, year**	**Theoretical basis**	**Central constructs**	**Points of critique**	**Extended models**
Technology Acceptance Model (TAM)	Davis, 1989 [62-64,66]	Cognitive psychology [81]	Describes elements to predict the degree to which a person plans to perform specific future behavior. It suggests that perceived usefulness, perceived ease of use and attitude (intention to use) can explain user motivation [64]. It is a way to predict the intended use of a technology.	Mainly conceptualized for the acceptance of individuals and is not useful for explaining organization's acceptance of eHealth technologies [63,76].	TAM2 by Venkatesh and Davis [82] and TAM3 by Venkatesh and Bala [83] [62,64]. TAM2 covers social influence processes (subjective norm, voluntariness, and image) and cognitive instrumental processes (job relevance, output quality, result demonstrability, and perceived ease of use) as determinants of perceived usefulness and usage intentions [62,82]. TAM3 extends TAM2 by incorporating determinants of perceived ease of use and perceived usefulness: computer self-efficacy, perception of external control, computer anxiety, computer playfulness, perceived enjoyment, objective usability [62,83].

Table 3. Overview of implementation models for eHealth technologies.
(Extended version of Table 1. Theoretical acceptance and adoption models by Hulter et al. [78]). *(continued.)*

Model	**Developer, year**	**Theoretical basis**	**Central constructs**	**Points of critique**	**Extended models**
Unified Theory of Acceptance and Use of Technology (UTAUT)	Venkatesh et al, 2003 [81,84]	Cognitive psychology [81]	Builds on TAM, focuses on perceptions and assumptions that lead to intended use technology. States that constructs like performance expectancy, effort expectancy, social influence and facilitating conditions influence intention and ultimately behavior [84]. Moderated by gender, age, experience, and voluntariness of use [84].	Does not deal with obstacles to actual use [81]. Excludes users' cognitive, affective and physical ability to use technology and ignores technological factors that might influence the decision to use an application [85].	UTAUT2 by Venkatesh et al [86] adds three constructs: hedonic motivation, price value and habit [62,86].

Table 3. Overview of implementation models for eHealth technologies.
(Extended version of Table 1. Theoretical acceptance and adoption models by Hulter et al. [78]). *(continued.)*

Model	**Developer, year**	**Theoretical basis**	**Central constructs**	**Points of critique**	**Extended models**
Normalization Process Theory (NPT)	May & Finch, 2009 [69]	Sociological theory [69]	NPT helps to understand how eHealth technologies are embedded and integrated into their social contexts [65,69].	Does not include enough organizational context; focus is on generative mechanisms: coherence, cognitive participation, collective action, and reflexive monitoring [70,87]. Overlapping NPT constructs and difficult technical vocabulary [69].	Technology Adoption Readiness Scale (TARS) measures normalization processes in the context of eHealth service interventions [88,89]. It is a ‘sensitizing’ toolkit of 16 statements representing NPT theoretical constructs for individuals planning and implementing complex interventions to think through which aspects of their interventions might affect successful normalization [90]. NoMAD (Normalization Measure Development) is a 23- item tool based on NPT to assess implementation processes from the perspective of professionals involved in implementation [91,92]. It provides a translational framework for researching and evaluating implementation processes, comprising a coding manual to support analysis, aimed at making NPT application easier in qualitative studies [93].

Table 3. Overview of implementation models for eHealth technologies.
(Extended version of Table 1. Theoretical acceptance and adoption models by Hulter et al. [78]). *(continued.)*

Model	**Developer, year**	**Theoretical basis**	**Central constructs**	**Points of critique**	**Extended models**
Consolidated Framework for Implementation Research (CFIR)	Damschroder et al, 2009 [73]	Based on synthesis of Greenhalgh et al [80].	A pragmatic meta-theoretical framework that can be used to complement theories with specific constructs related to five domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation [73].	Sees implementation as a post-design step rather than ongoing development [76] and does not consider how individual, social and organizational constructs might be interrelated or how changes occur [65].	CFIR updated with revisions of constructs and/or domains, contains 48 constructs and 19 subconstructs across five domains (including two subdomains in one domain) [75]. Published separately, the CFIR Outcomes Addendum establishes conceptual distinctions between implementation and innovation outcomes and their potential determinants [74].

Table 3. Overview of implementation models for eHealth technologies.
(Extended version of Table 1. Theoretical acceptance and adoption models by Hulter et al. [78]). *(continued.)*

Model	Developer, year	Theoretical basis	Central constructs	Points of critique	Extended models
Non-adoption, abandonment, scale-up, spread, & sustainability framework (NASSS framework)	Greenhalgh et al, 2017 [71,94]	Complexity theory [71,94]	Highlights aspects explaining the complexity of technological innovations in healthcare, which all described models suggest influence adoption. Model includes the value proposition (i.e., supply-side and demand-side values) as an important factor, unlike many implementation theories that ignore financial/value aspects [71,76]. Other domains are condition or illness, technology, adopter system (staff, patients, caregivers), organization, wider context (institutional and societal). Each domain is assessed as simple, complicated or complex. It also emphasizes the ongoing development process of eHealth technology [76].	Misses a practical tool for planning or managing technology projects, because it is designed for academic analysis [95].	Tools such as NASSS-CAT SHORT and NASSS-CAT LONG help at the stage when there is the idea or broad goal to introduce a technology, but a project has not yet been agreed [95]. NASSS-CAT LONG includes the same questions as the short version but adds a second level of detail (2-5 sub-questions) [95]. NASSS-CAT PROJECT is a 35-item instrument for assessing, monitoring, reducing and responding to the perceived complexity of a technology project over time. NASSS-CAT INTERVIEW is a set of prompts for conducting semi-structured research or evaluation [95].

The various models and frameworks for implementing eHealth technologies presented in Table 3 provide valuable guidance for organizations. The following section explores the key concepts - as acceptance, adoption, and embedding - highlighting their relevance to these models and their importance in understanding the needs of end-users of eHealth technologies.

Acceptance seems to be a focus of models like TAM [66], UTAUT [67] and seems to be the 'Attitude toward Using' determinant in the TAM influenced by two factors: 1) Perceived Usefulness and 2) Perceived Ease of Use. These two factors represent the user's subjective evaluation of the technology. Acceptance seems to be in the 'Behavioral Intention' determinant in UTAUT which is influenced by four constructs: 1) Performance expectancy; 2) Effort expectancy, 3) Social influence, 4) Facilitating conditions. UTAUT's Behavioral intention is a direct predictor of use. Acceptance seems also to occur in Roger's [68] innovation-decision process for individuals or other decision-making units in two steps: 1) the Knowledge step, when individuals gather information and assess the relevance and usefulness of the innovation to their specific context and 2) the Persuasion step, when individuals form a favorable or unfavorable attitude toward the innovation. Acceptance seems to be about a person's intention to use a technology.

Adoption seems to be a focus of TAM [66], UTAUT [67], DOI [68], CFIR [73], NASSS framework [71]. Adoption is not explicitly defined but seems to occur in TAM's Actual System Use determinant, which is influenced by Attitude toward Using. Additionally, in UTAUT's Use Behavior determinant is directly influenced by Behavioral Intension. In contrast, adoption is explicitly defined in the innovation-decision process, which leads to choose either for adoption or rejection [68]. Rogers [68] defines adoption as *"a decision to make full use of an innovation as the best course of action available"* and rejection as opposition to adoption as *"a decision not to adopt an innovation"* (p. 21) [68]. Adoption in CFIR is seen as one of the implementation outcomes categories and is one of the ultimate goals of implementation efforts. Adoption in CFIR is defined as: *"The extent [to which] key decision-makers decide to put the innovation in place/innovation deliverers decide to deliver the innovation"* (p.4) [74]. This definition aligns with the definition of adoption in the DOI as both emphasize the importance of decision-making. However, the DOI includes 'full use' while the CFIR only says 'put the innovation in place' and 'innovation deliverers decide to deliver the innovation'. In the NASSS framework, adoption is not seen as a simple binary outcome but rather as a process in which all domains contribute to the way technology is ultimately integrated and used. Likewise, Greenhalgh et al [80] define adoption as *"a process rather than an event, with different concerns being dominant at different stages"* (p.600).

Embedding seems to be a focus of the NPT [69], CFIR [73] and NASSS framework [71]. Embedding is explicitly defined in NPT as "*the processes through which a practice or practices become, (or do not become), routinely incorporated in everyday work of individuals* *and groups”* (p.9) [69]. Embedding seems implicitly to occur in one of the five CFIR domains, namely the inner setting. This includes how an intervention fits in according to the structural characteristics of the organization, as well as the communication networks, culture and implementation climate of the organization [73]. Embedding is explicitly mentioned in the seventh domain of the NASSS framework, named Embedding and adaptation over time, but not explicitly defined. It seems that Greenhalgh et al [71] regard embedding as the interaction between the other six domains, which are inextricably interlinked and dynamically evolve in reality of technology implementation.

The challenges for researchers of working with implementation models and concepts

Studying the concepts connected to implementation in conjunction with the models shown in Table 2 reveals some challenges. The first challenge is that the precise meaning of these concepts is often ambiguous in the implementation models or not clearly articulated by researchers. Other researchers have also reported this inconsistency of definitions across sources [74,96,97].

Researchers often apply innovation models for new technologies, treatment and even care practices [76], using concepts interchangeably [97]. For example, researchers use implementation models such as TAM and UTAUT to explore the potential adoption of eHealth technologies [98,99]. However, the intention to use a technology does not automatically mean that the intended users will actually use it. In a literature review on technology adoption, the researchers define adoption as *“the acceptance or the first use of an emerged technology or product”* (p.361) [62]. Several papers see adoption as the same as acceptance. Another example is the definition of ‘embedding’ technology in daily work routines. Specifically mentioned in the NPT, embedding is defined as “*the processes through which a practice or practices become, (or do not become), routinely incorporated in everyday work of individuals and groups* (p.9)*”* [69]. However, in the three stages suggested by Greenhalgh et al [80], embedding is involved in the second, early use stage and the third, adoption stage, where learning to embed technology in daily routines and understanding the consequences of using the technology are central. Furthermore, embedding is one of the domains in the NASSS framework [71], named Embedding and adaptation over time, which emphasizes the continuous nature of implementation, recognizing that technology adoption is not a one-time event but an ongoing dynamic process where all other six NASSS domains evolve and interact over time.

Thus, concepts are either not clearly articulated, ambiguous or used interchangeably. Consequently, researchers study these concepts in widely varied ways. For example, Kruse et al [28] performed a systematic review on the adoption factors of EHRs and Wouters [72] provides a summary of frameworks, theories, models attempting to explain technology implementation in care. Heinsch et al [65] conducted a systematic review to identify theories that inform and explain eHealth implementation and classified these theories for theories of sociotechnical change. These three examples show that using different perspectives on different concepts and models can help in understanding the adoption process more comprehensively. On the other hand, it could make the adoption process more confusing because it creates ambiguities about what is actually being measured and will make replication of interventions and comparison of results difficult.

The second challenge is that while some research theories or models see adoption as a linear process, others see it as an iterative process. For example, the pre-adoption, early use and established user stages of Greenhalgh et al [80] and Rogers' [68] innovation-decision process. If intended users are moving through these steps, then the assumption is that adoption automatically occurs. However, the adoption process is highly complex because its results cannot be established or even predicted [80,81]. Moreover, the focus in theories and models lies on individuals, rather than organizations, which is a well-known criticism [62,73,76, 80]. In other words, there is a difference in the adoption process between end-users - patients and healthcare professionals - and organizations [100]. Individual patients and healthcare professionals can go back and forth through the adoption stages [80]. In contrast, when introducing new eHealth technologies, organizations must deal with an ongoing intertwined process [101], which demands constant effort to stimulate adoption. Furthermore, context influences the process [100] and thus should be taken in account. The scoping review by Nilsen & Bernhardsson [100] shows that implementation frameworks do not describe context consistently, coherently or comprehensively. Still, these authors identify common dimensions of the context based on the frameworks, such as organizational support, financial resources, social relations and support, leadership, and organizational culture and climate.

Earlier research by Dixon-Woods [102] on innovation, such as patient portals, also shows that adoption is not only a 'simple' individual change from A to B, but a complex sociological process involving many actors and factors. Thus, ongoing implementation processes for new technology needs a more holistic view [103]. The Center for eHealth Research and Disease Management Roadmap (CeHRes Roadmap) [103] is a holistic approach that aims to guide the development, implementation and evaluation of eHealth technologies. It is designed to ensure that eHealth applications are effective, user-centered, and sustainable. The roadmap integrates various methodologies and emphasizes a participatory approach involving all relevant stakeholders, which could increase user acceptance. The CeHRes Roadmap consists of five intertwined phases and connecting cycles: Contextual Inquiry, Value Specification, Design, Operationalization and Summative Evaluation. The Operationalization phase focuses on launching the technology and putting organizational procedures into practice, which could relate to the adoption of eHealth technology. The Summative Evaluation cycles ensure that the phases are related to the stakeholder perspective, context, outcomes of previous phases [103]. The evaluation cycles and iterative nature of the CeHRes Roadmap helps to ensure that the technology is well-embedded in the context of use.

Van Gemert-Pijnen [104] emphasizes that frameworks, e.g., CFIR, do not focus on the capacity and characteristics of technologies to change, innovate healthcare or how a technology could be integrated into workflow and care pathways. However, the NASSS framework [71] puts emphasis on the factors and actors that influence the adoption process, e.g., the condition, technology, value proposition, adopters, organization, wider system, embedding and adopting over time. These elements can be seen as either simple, complicated or complex. Simple concerns few predictable components. Complicated involves many components, still largely predictable, while complex involves many components interacting in a dynamic and unpredictable ways [71, 105]. Greenhalgh et al [106] and Dixon-Woods [102] conclude that achieving sustainable positive innovation may be accomplished best through participatory and cooperative approaches. Thus, these models provide no clarity on the pragmatics of efforts in the adoption process of eHealth technologies.

The adoption process of eHealth technologies is an iterative holistic process that should focus simultaneously on the individual and organizational level and their contexts. Therefore, we regard the adoption process as complex. This serves as an important starting point, as recognizing this will provide valuable insights into adoption processes in daily healthcare practice.

RESEARCH OUTLINE

As discussed, various obstacles hinder the adoption of patient portals. Three concepts connected to implementation - acceptance, adoption and embedding - occur in rich implementation models (see Table 3). We elaborated on some of the challenges in working with the concepts used in the implementation models, and we hope that this dissertation will provide more insights into the portal adoption process in daily practice.

Building on the work of other researchers, we demonstrate that the iterative adoption process can be seen as complex, because many factors and actors (multidisciplinary) depend on and are influenced by individual and organizational contexts both. Understanding these aspects requires a holistic view because much of the adoption process of innovations in daily healthcare practices is still unclear. Therefore, our definition of ‘adoption’ stretches beyond actual use in daily practice [80], extending to an interactive process involving multidisciplinary actors and factors and take the context of both individuals and organizations into account [100]. Applying both qualitative and quantitative research methods, this dissertation presents studies based on the rich information produced by the implementation models, linked to the concepts of acceptance, adoption or embedding, to provide new insights into patient portal adoption in daily practice. The overarching aim is to gain actionable knowledge. According to Argyris [107] actionable knowledge is “*knowledge required to implement the* *external validity (relevance) in that world"* (p.390). Useful for both academia and industry (organizations) [108], actionable knowledge is defined by five criteria:

Actionable: describes how people should act [107] through concrete, specific, and detailed actions that are sufficiently practical to implement or to enact [109,110,111].

Contextual: describes the relevance and applicability of the gained knowledge to a specific context or setting [109,110].

Targeted: presents understandable calls for action for the intended audience [109,110], especially decision-makers [109].

Transferable: creates or produces knowledge beyond the initial setting [107] and clarifies the contextual factors of all included settings, e.g., organizational culture and structures [112].

Empirical: based on concrete evidence, real-world experiences, and a deep understanding of the practical realities and constraints, rather than purely theoretical or abstract [110,112]. However, knowledge should be informed by and aligned with relevant theories, frameworks, and existing evidence [112].

Research question

This research aimed to gain knowledge on the adoption of patient portals in daily healthcare practices in the Netherlands. The overarching research question is: **How can the adoption of patient portals by patients and healthcare professionals be supported in the Netherlands?**

Outline

This dissertation is built on qualitative research complemented by a mixed method study. Four distinct but closely connected studies on adopting patient portals in the Netherlands provide insights into elements influencing the adoption process. **Chapter 2** presents a qualitative study of the lessons learned from hospital efforts to adopt a patient portal in order to understand what stimulates or hinders the process. The study found that healthcare professionals play an essential role in the adoption process, emphasizing the necessity of obtaining insight into their thoughts and experiences. **Chapter 3** demonstrates a qualitative study that explores the appraisal work of mental healthcare professionals to assess and understand patient access to their EHRs through a patient portal. **Chapter 4** deals with a sequential explanatory mixed-methods study to understand patients' choices on when their laboratory, radiology and pathology results (per specialty) should be disclosed on the patient portal. **Chapter 5** presents a microlevel discourse analysis conducted to gain a deep understanding of what real-time access to test results means to patients. All four studies discussed in Chapters 2–5 produce actionable knowledge by analyzing the practical implications for healthcare organizations, healthcare professionals and patients. In conclusion, **Chapter 6** provides an overview of the main findings on the adoption of patient portals, and reflects on the research methods used.

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Chapter 2

Adopting Patient Portals in Hospitals: Qualitative Study

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ABSTRACT

Background:
Theoretical models help to explain or predict the adoption of electronic health (eHealth) technology and illustrate the complexity of the adoption process. These models provide insights into general factors that influence the use of eHealth technology. However, they do not give hospitals much actionable knowledge on how to facilitate the adoption process.

Objective:
Our study aims to provide insights into patient portal adoption processes among patients and hospital staff, including health care professionals (HCPs), managers, and administrative clerks. Studying the experiences and views of stakeholders answers the following question: How can hospitals encourage patients and HCPs to adopt a patient portal?

Methods:
We conducted 22 semistructured individual and group interviews (n=69) in 12 hospitals and four focus groups with members of national and seminational organizations and patient portal suppliers (n=53).

Results:
The effort hospitals put into adopting patient portals can be split into three themes. First, inform patients and HCPs about the portal. This communication strategy has four objectives: users should (1) know about the portal, (2) know how the portal works, (3) know that action on the portal is required, and (4) know where to find help with the portal. Second, embed the patient portal in the daily routine of HCPs and management. This involves three forms of support: (1) hospital policy, (2) management by monitoring the numbers, and (3) a structured implementation strategy that includes all staff of one department. Third, try to adjust the portal to meet patients' needs to optimize user-friendliness in two ways: (1) use patients' feedback and (2) focus on optimizing for patients with special needs (eg, low literacy and low digital skills).

Conclusions:
Asking stakeholders what they have learned from their efforts to stimulate patient portal use in hospitals elicited rich insights into the adoption process. These insights are missing in the theoretical models. Therefore, our findings help to translate the relatively abstract factors one finds in theoretical models to the everyday pragmatics of eHealth projects in hospitals.

Key words
patient portal; adoption; adoption processes; eHealth

INTRODUCTION

Electronic health (eHealth) technology is generally considered promising for improving both the well-being and health of patients and the efficiency and effectiveness of the health care organization [1]. However, several studies show that its promise is not always fulfilled [1] and the results on the benefits gained are diverse [1,2]. This also applies to patient portals [2], which have sparked the interest of researchers, government policy makers, and health care organizations.

Previous studies define a patient portal in various ways [3-7]. Some consider them the same as a personal health record (PHR) [3]. Others regard them as a class of PHR [4]: whereas health care organizations own and control patient portals, PHRs are owned and controlled by patients themselves [5]. Grünloh et al [6] define patient portals as "provider-tethered applications that allow patients to access, but not to control, certain health care information (eg, their EHR [electronic health record]) and provide communication and administrative functions (eg, secure messaging, appointment booking, and prescription refill requests)." Wildenbos [7] adds the possibility of authorizing informal caregivers to share access to patient portals.

Despite its technological focus and aim, the success or failure of a patient portal relies on how it is used by patients and staff, such as health care professionals (HCPs), managers, and administrative clerks [1,2,8]. A systematic review shows often-limited use by patients and HCPs for seven nontechnical reasons [2]: (1) patients worry about the confidentiality of their personal health data, (2) patients are unaware of the portal, have no digital access, or think it will not be useful, (3) patients have low health literacy or find using the portal too complicated, (4) HCPs worry about increased workload and disruptions to their usual tasks, (5) HCPs lack the digital skills to interact with patients, (6) HCPs worry that they cannot respond fast enough to patients' questions, and (7) HCPs are concerned that they can be held liable [2]. All seven reasons hinder the adoption of patient portals [2].

Researchers have developed theoretical models to explain or predict the adoption of eHealth technologies, including patient portals. Two systematic reviews on information technology adoption both mention three frequently used acceptance and adoption models [9,10]. Strikingly, these three general models are applied in all societal domains, not just health care [9]. Table 1 details these most-used models to facilitate an understanding of their ideas on the adoption process [9-20]. The table also includes the recently developed NASSS (nonadoption, abandonment, scale-up, spread, and sustainability) framework [21,22].

Table 1. Theoretical acceptance and adoption models.

Model	Developer	Year	Theoretical basis	Central constructs	Points of critique	Extended models
Technology Acceptance Model (TAM)	Davis [9,13,14]	1985	Cognitive psychology [15]	Describes elements to predict the degree to which a person plans to perform specific future behavior. It suggests that perceived usefulness, perceived ease of use, and attitude (ie, intention to use) can explain user motivation [14]. It is a way to predict the intended use of a technology.	Mainly conceptualized for the acceptance of individuals and is not useful for explaining acceptance of electronic health (eHealth) technologies by organizations [13,16].	TAM2 (by Venkatesh and Davis) and TAM3 (by Venkatesh and Bala) [9,14].
Diffusion of innovations (DOI)	Rogers [9]	1995	Diffusion research [20]	Explains the characteristics of innovation. Observability, trialability, complexity, relative advantage, and compatibility are the primary determinants of innovation diffusion, which help explain the different rates of adoption [9,17]. Diffusion starts with recognizing the user's need. It spreads by knowledge acquisition, persuasion, decision (ie, adopt or reject), implementation (ie, routine use, reinvention, and conformation), promotion, and evaluation [17].	There is little focus on the organizational context [16,18,19].	The unifying theoretical model of Greenhalgh et al [18] and the Consolidated Framework for Implementation Research (CFIR) of Damschroder et al [19,20].

Table 1. Theoretical acceptance and adoption models. *(continued.)*

Model	**Developer**	**Year**	**Theoretical basis**	**Central constructs**	**Points of critique**	**Extended models**
Unified Theory of Acceptance and Use of Technology (UTAUT)	Venkatesh et al [9,21]	2003	Cognitive psychology [15]	Builds on TAM and focuses on perceptions and assumptions of people, resulting in the intention to use technology. States that constructs like performance expectancy, effort expectancy, social influence, and facilitating conditions influence intention and ultimately behavior [21]. These four constructs are moderated by gender, age, experience, and voluntariness of use [21].	Does not deal with hindrances to actual use [15]. Excludes users' cognitive, affective, and physical ability to use technology [22] and ignores technological factors that might influence the decision to use an application [22].	UTAUT2 by Venkatesh et al developed in 2012 [9].
Nonadoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS framework)	Greenhalgh et al [11,12]	2017	Complexity theory [11,12]	Points to aspects explaining the complexity of technological innovations in health care, which according to all the described models influence the adoption. Includes the value proposition (ie, supply-side and demand-side values) as an important factor, in contrast to many implementation theories that do not [11,16].	Not found yet.	Not found yet.

All four theoretical models include two key concepts—acceptance and adoption—which are either ill-defined or used interchangeably. The concept of acceptance focuses on if, how, and when intended users would use a technology [23], and adoption is the actual use of an eHealth technology. Different stages in an adoption process can result in the actual use of an eHealth technology [16]. During an adoption process, users of eHealth technology develop feelings about the technology, gain experience, find meaning or do not find meaning in its use, and evaluate the functions of the technology [16]. Thus, there is a difference between intended use (ie, acceptance) and actual use (ie, adoption) [13].

The complexity of the adoption process of eHealth technologies is underexposed in all four theoretical models. The literature reports that adoption is a highly complex process and that results cannot be made or even predicted [13,16]. Greenhalgh et al highlight specific prerequisites for each of the three adoption process stages for innovations [16]: (1) in the preadoption stage, intended adopters should know about the innovation: in this case, the patient portal, (2) in the early use stage, intended adopters should be supported in using the innovation and learn how to fit or blend it into their daily routines, (3) in the adoption stage, established users arise if they gain an understanding of the consequences of using of the innovation and if they have the opportunity to refine and improve it: in this case, a patient portal [16]. The theoretical models provide no clarity on the pragmatics of efforts in the adoption process. For instance, they do not show how hospitals can encourage patients and HCPs to adopt a patient portal. Therefore, we studied the introduction of patient portals in 12 Dutch hospitals, using a multi-actor perspective to gain a broad understanding of the experiences and views on adoption. Our empirical study focuses on the pragmatics of stimulating the adoption of a patient portal. This paper answers the following research question: How can hospitals encourage patients and HCPs to adopt a patient portal?

METHODS

Design and Setting

In this qualitative study, we asked participants from various backgrounds how they encouraged users to adopt a patient portal and what they had learned from their efforts, in order to understand what stimulated or hindered the adoption process. We conducted 22 multi-actor, semistructured group interviews and held four structured focus groups to check, enlarge, and enrich our findings [24-26]. Table 2 lists the different forms of data collection.

Table 2. Data collection.

Type of data collection and participants	Number of participants (N=122), n (%)	Data collection moments (N=26), n (%)
Individual and group interview		
Patients	22 (18.0)	22 (85)
Health care professionals	16 (13.1)	22 (85)
Organizational staff	31 (25.4)	22 (85)
Focus group		
Project leaders and staff	14 (11.5)	2 (8)
Project leaders and staff	28 (23.0)	2 (8)
Patient portal suppliers	5 (4.1)	1 (4)
Macro stakeholders	6 (4.9)	1 (4)

All interviews, both group and individual, and focus group sessions took place in a hospital or online. All the hospitals included in this study are participating in a national program—VIPP (Versnellingsprogramma Informatie-Uitwisseling Patiënt en Professional) [27]—initiated by the Dutch Hospital Association and the Dutch government. VIPP is the Dutch government's financial incentive program to support information exchange between patients and professionals through patient portals. The aim of the VIPP program is to give patients online access to their medical data, either through a patient portal or a PHR [27]. Information technology (IT) suppliers with a commercial interest deliver patient portals and PHRs. Given that Dutch hospitals are free to choose any supplier for their patient portals or PHRs, the hospitals in this study use different patient portals. The portals might differ in their available functionalities, but they all offer patients online access to their personal health information [6]. Additionally, hospitals had different aims for their patient portals; only the VIPP program aims were similar for all Dutch hospitals. Hospitals receive financial support based on their achievement of specific national VIPP aims; for example, "In the past 30 days, 25% of all patients (based on DRG [diagnosis-related group] contacts) logged in to the patient portal or the link to a PHR" [28]. How hospitals achieve these aims is left up to the hospital.

Recruitment and Participants

There are three categories of Dutch hospital: academic, teaching, and general. Academic hospitals were excluded from our study because at the time they were not participating in the VIPP program. We first determined inclusion criteria for general and teaching hospitals, aiming for a diverse study group. Based on user statistics of patient portals (low and high), geographical differences (rural areas and cities), variation in patient portal suppliers, and usage of the patient portal (more or less than one year), the researchers (PH, AMWJ, and BP) made a selection of targeted hospitals.

In total, 15 of 64 Dutch hospitals (23%) were approached, of which 12 (80%: 10 teaching and 2 general) agreed to participate. Reasons for not participating included “already participating in another study” (n=1) and “too busy with implementation and fear of not meeting VIPP deadlines,” which would mean losing financial support (n=2).

At each hospital or via the Zoom online platform [29], the researchers arranged individual and group interviews in close collaboration with the person running the implementation of the patient portal at that particular hospital. Most often, this person was the project leader who selected participants according to a predefined list of three roles:

Patients: patients and client council members (n=22).

HCPs: physicians, Chief Medical Information Officers (CMIOs), nurses, Chief Nursing Information Officers (CNIOs), pharmacists, and outpatient clinic staff (n=16).

Organizational staff: project leaders, project staff, communication advisors, legal policy makers, and managers (n=31).

In total, 69 participants were included (see Table 2) if they were older than 18 years and had experience with developing and/or using a patient portal. The researchers emailed invitations to participants of the individual and group interviews; groups ranged from 2 to 6 participants. In 10 of the participating hospitals, we organized one or two group interviews; in the remaining two hospitals we conducted one individual interview for logistical reasons.

The aim of the focus groups was to check, enlarge, and enrich our results. Two of the four focus groups were held with project leaders and project staff of hospitals. They joined one of two self-selected focus groups organized during an educational meeting of the VIPP program (n=14 and n=28, respectively). For the other two, we used targeted sampling, selecting experts from patient portal suppliers (n=5) for the third group. The fourth group included macro stakeholders: Ministry of Health, NICTIZ (Nationaal ICT Instituut in de Zorg), the center of expertise for eHealth, health insurance companies, and scientific experts (n=6). All focus group members were invited to take part by email.

Data Collection and Analysis

Qualitative data were collected on-site in the hospital (n=59) or online via the Zoom platform [29] (n=10) in the fall of 2018. The Zoom platform enabled the inclusion of hard-to-reach, geographically dispersed participants [30]. Group interviews lasted an average of 72 minutes (range 53-88) and the individual interviews lasted an average of 53 minutes (range 44-65). One researcher (PH) conducted all the interviews, following a predefined topic list (see Multimedia Appendix 1) [31] that was based on a search of the literature and discussed among the research team.

The four focus groups lasted an average of 82 minutes (range 71-88) and were steered by a Microsoft PowerPoint presentation explaining the findings of our study. No revisions were made in the presentation between focus group sessions, ensuring that varying opinions were heard before conclusions were drawn [32]. Each focus group was run by two researchers (PH and BP or PH and AMWJ) complementing each other: one moderating and the other taking notes.

During both group interviews and focus group sessions we encouraged the exchange of heterogeneous views that provided insights into similarities and differences in the opinions and experiences of the various stakeholders [26,30,31]. We also invited the participants to challenge each other's views [33], to explore the implications of their thinking, and to articulate their sometimes-implicit assumptions about the adoption process. This method generated new insights through group interactions.

We audio-recorded the on-site interviews and focus groups and video-recorded the online sessions. All interviews were transcribed verbatim. Analysis, comprising six phases [34], was not linear but a recursive process. First, each individual researcher gave the transcripts a close reading. Second, one researcher (PH) developed codes for the interesting parts of the data. Next, three researchers (PH, AMWJ, and BP) independently developed themes, reaching consensus on a list of relevant themes (eg, communication channel, ambassadors, and patient participation [35]) through discussion. Fourth, one researcher (PH) read the transcripts again. Fifth, using the list of themes, one researcher (PH) performed thematic coding, which two other researchers (AMWJ and BP) checked. In the final phase we (PH, AMWJ, and BP) started writing the results [34].

Ethical Approval

The Medical Ethics Review Committee of Erasmus Medical Center (Erasmus MC) approved our research proposal (MET-2018-1531) and checked if we were General Data Protection Regulation (GDPR) compliant. All participants were asked to sign an informed consent form.

RESULTS

Overview

Our study aims to provide insights into the adoption process of a patient portal by patients and HCPs. The efforts of hospitals to stimulate the use of patient portals can be categorized under three themes: (1) informing patients and professionals about the patient portal, (2) embedding the patient portal in the daily routine of HCPs, and (3) adjusting the portal to patients' needs in the initial and continuous development process. Below we present our empirical findings for each of these themes.

Informing Patients and Health Care Professionals About the Patient Portal

Overview

Participants agreed that communication about the patient portal is very important for the adoption of patient portals. The hospitals require the involvement of communication experts to inform patients and HCPs. We identified four objectives to support patient portal adoption using the informing of patients and HCPs as the basis. Here we explain them one by one. Participants mentioned using 23 communication channels to reach their audiences (see Table 3).

Table 3. Channels (N=23) used to achieve four communication objectives to inform patients and health care professionals.

Channel	**Knowing about the portal**	**Knowing how the portal works**	**Knowing that action is required on the portal**	**Knowing where to find help with the portal**
Pocket tickets	x[a]			
Promotion leaflets	x			
Press releases	x	x		
Posters	x			
Banners	x			
Screen in waiting room	x	x		
Social media	x			
Video on website	x	x		
Explanatory leaflets	x	x		
Students or volunteers in central hall for a week	x	x		x
Physical point with employees and volunteers	x	x		x
Health care professionals	x	x	x	x
Letter with request (before or after appointment)			x	
Text message with request			x	
Mail with request			x	
Staffed desk				xxx
Informative meetings	xx			

Table 3. Channels (N=23) used to achieve four communication objectives to inform patients and health care professionals. *(continued.)*

Channel	**Knowing about the portal**[a]	**Knowing how the portal works**	**Knowing that action is required on the portal**	**Knowing where to find help with the portal**
Interactive meetings	xxx	xxx		
Internal website	xx			
Peer to peer	xx	xx	xx	xx
Training	xx	xx	xx	
Newsletter	xx			
Goodie bag with explanation	xx	xx		

[a]Key: x = patients; xx = professionals; and xxx = patients and professionals.

Objective 1: Knowing About the Portal

First, participants argued that it is obviously necessary to make sure that patients and HCPs know about the patient portal; otherwise, they cannot use it. Meeting this objective means that patients and HCPs will have a general idea of what the portal is and what it looks like. The hospitals used various mass-focused channels most frequently to communicate the existence of the portal to patients and HCPs. These channels include leaflets and posters, banners hung in the corridors, messages on social media, and placing volunteers in the central hall of the hospital to point patients to the portal. Using multiple channels to reach patients is considered important because patients have different preferences, but it is probably a bit inefficient, as these quotes illustrate:

> *I am not inclined to take leaflets from the hospital. If it's really important, I think I will be reminded.*
> *[Participant 0.4, client council member]*
>
> *All those freebies [goodie bags], I don't like them. They won't get me to look at the portal.*
>
> *[Participant 14.2, patient, informal caregiver, and former client council member]*
>
> *Still, it works for others.*
> *[Participant 11.4, client council member]*

Looking at the channels used to reach HCPs, we see hospitals organizing informative presentations for medical and nursing staff and department meetings. Participants felt that informing only the team leaders and managers is not enough; it is important to directly inform the HCPs. According to participants, effective channels that reach broad groups of professionals include department meetings, the hospital intranet, and the staff newsletter. Reaching out by email is considered inefficient because HCPs receive a lot of email and particular messages can be easily missed or skipped.

Objective 2: Knowing How the Portal Works

Second, participants argued that patients and professionals need to know how the patient portal works. Hospitals can meet this objective by (1) using video screens in waiting rooms, (2) putting explanatory videos on the hospital website, and (3) placing volunteers in the central hall of the hospital to teach patients how the portal works.

Hospitals asked professionals who are already successful portal users to explain how the portal works to their peers (ie, peer-to-peer information). One hospital gave their professionals a goodie bag with explanatory flyers during portal training, but only a few hospitals organized training sessions on new functionalities for HCPs. However, the participants said that HCPs need to know how the portal actually works as patients sometimes turn to them for help with portal questions:

> *So often I hear that people can't log in to the patient portal. I think that as staff we should be looking into the portal far more. How does it actually work for the patient in practice?*
> *[Participant 1.2, staff member]*

If the HCP has to tell the patient that they do not know how to help, this can be a disappointment. One participant reflected the following:

> *Lots of patients say, "I'm logged in but then I don't know [what to do]." Many colleagues say, "I don't know either." If you can't help the patient, they'll drop out immediately.*
> *[Participant 5.5, senior doctor's assistant]*

Objective 3: Knowing That Action Is Required on the Portal

A third objective is to entice patients and HCPs to visit the portal. Hospitals did this by sending specific calls to action, including personal letters, text messages, or emails asking the recipient to read through an online brochure on their treatment before their hospital appointment or to fill in a questionnaire:

> *Your appointment letter also asks you to complete the pre-operative screening questionnaire at home.*

> *[Participant 9.1, communication advisor]*

Hospitals encouraged HCPs to use the patient portal by asking them to respond to e-consults (ie, messages sent by the patient) and by showing them functions that will save their time or make their work more efficient. Time-saving functions like preoperative screening questionnaires on the patient portal are easy to embed in the daily routine of professionals. One participant explained the following:

> *We built the pre-operative screening questionnaire in such a way that [the information the patient provides] gets entered directly into the anesthesiologist's outpatient file. [This means] that the moment the anesthesiologist starts the consultation with the patient, the data are already in the system. The outpatient clinic started using the questionnaire right from the go-live.*
> *[Participant 12.1, project leader]*

Objective 4: Knowing Where to Find Help With the Portal

The fourth communication objective is to ensure that patients and HCPs know where to look for help when they have a problem using the portal. Hospitals organized a help desk, publishing its phone number and email address in leaflets, letters, on the hospital website, and on the portal itself. Some hospitals organized a service point clearly visible in the central hall of the hospital, where patients receive face-to-face service. Outpatient clinic staff can tell patients about this service point. HCPs can ask their colleagues for help (ie, peers).

Reviewing these hospital communication strategies, three findings are worth a mention:

1. The texts used to inform patients and HCPs have a promotional tone. Hospitals choose to stress the benefits and hardly mention the potential disadvantages or risks of portal use.

2. Mass communication is preferred because it is less labor intensive. However, it is also less personal and less in line with the needs of an individual. Personal communications, such as letters, text messages, and emails, have the advantage in that they probably make patients and health care professionals feel personally addressed.

3. Hospitals struggle with the timing of starting their communication efforts, for example, having a silent "go-live" or starting a campaign directly after launching the portal.

Our participants explained that most hospitals do not inform patients about the go-live, because this gives them the opportunity to solve start-up problems and technical issues signaled by the first users. After some two to three months they will use a cross-media approach to communicate on the portal. Our participants expressed concern that if a hospital initiated a communication campaign straight after launching the portal, the hospital could be making promises that they cannot keep.

Embedding the Patient Portal in Daily Routines

Overview

In the previous section we showed how communication strategies support patient portal adoption processes. HCPs worry that using the portal is time-consuming and will disturb their daily routine. They regard explaining how the portal works and communicating with patients on the portal as extra tasks and expect that helping non-computer-literate patients (eg, the elderly and people with low literacy) will be especially time-consuming. One participant explained the following:

> *If a patient says, "I don't use the computer," I won't ask if they have a son or daughter who'd like to share their access. I don't start with that, it costs too much time, really.*
> *[Participant 5.5, senior doctor's assistant]*

Our data show three ways to support embedding the patient portal in the daily routine of HCPs and management: (1) hospital policy, (2) management by monitoring the numbers, and (3) a structured implementation strategy that includes all employees in the department, termed a specialism-focused approach. According to our participants, all three ways require changing work processes and routines.

1: Hospital Policy

The first way to embed patient portals is by developing hospital policy on digitalization. Our participants revealed that some hospitals lack hospital-wide agreements, resulting in a lack of coherence for the patient. One such hospital-wide agreement could set the maximum time that HCPs have to respond to an e-consult. According to our participants, the CMIO and the CNIO can play an important role in setting hospital-wide agreements and explaining new work routines to their colleagues (ie, peer influence). Our participants also said that some hospitals set no obligation or targets to use the portal:

> *How can we make sure the patient portal lands properly in the outpatient clinic? Good question... Well, it may have landed, but there is still no obligation [to use it] and that's the real problem.*
> *[Participant 1.1, communication advisor]*

For example, it is not clear within which time frame HCPs need to respond to patients' e-consults or how many patients per specialism should be using the portal. Responses to patients should be prompt, and the professionals need time to incorporate their responses into their daily work processes on the portal. One participant explained the following:

> *If you have to explain something to the patient on the portal or send them an email within four hours, then we need to think about how to get that complex planning process in the system. The professionals need time to think about it too. So that's development; and you need even more time to implement. [Participant 13.2, CNIO]*

2: Management by Monitoring the Numbers

The second way to embed patient portals is by ensuring that management monitors information on portal use or response time. Most hospitals lack management control of portal use. Some hospitals, however, monitor the numbers of new patient accounts and users on a dashboard or monitoring system. In one hospital, outpatient clinic employees must ask all patients presenting themselves at the desk if they are interested in opening a patient portal account. Hospital management uses this monitoring information to talk with staff who do not seem to be encouraging enough patients to sign up for the portal. One participant revealed the following:

> *Staff must register whether or not they have asked if a patient is interested in having a portal account. Now we can run reports on the employee level... We do that sometimes and then we can see that, say, Marie scores 100% on "not interested." Of course, ... then you'd have to start the conversation. [Participant 5.4, care and operations manager]*

Our participants said that fear is possibly a reason why HCPs do not motivate patients to sign up for the portal. Professionals need to overcome their own unfamiliarity and prejudices by experiencing the benefits of the patient portal. One participant declared the following:

> *Of course, we do it for the patient, but let's see where it helps the physician. Then you'll get them to at least use the patient portal.*
> *[Participant 8.7, internist]*

3: Specialism-Focused Approach

A third way to embed portals in daily routines is to apply a specialism-focused approach—a structured implementation strategy—that includes all the staff in the department. This involves a multidisciplinary project team (eg, communication advisor and project leader), management, and HCPs temporarily collaborating on changing work processes to benefit the incorporation of the patient portal into daily routines. Not trying to convince just one physician, but the whole department (eg, the outpatient clinic team), makes it easier to embed the patient portal. Working closely with project staff gives the HCPs support that is based on their needs or wishes. This approach requires giving HCPs the time to discuss their problems, share their experiences, and experiment. One participant explained the following:

> *Using this approach, we've really looked in depth at the points where the portal can be embedded better in their work process. For example, we've supported the specialism of rheumatology. They have very clear ideas about using the portal. Now we'll work actively with the health care professionals in the coming period to increase the use of the patient portal within their specialism.*
> *[Participant #11.2, communication advisor]*

According to our participants, using this approach supports giving professionals an understanding of how the portal works and how they can use it in their daily routines. However, they said that it is labor intensive for everyone involved, which slows down the adoption process hospital-wide.

Another implementation strategy is for hospitals to start off the portal adoption processes with keen, intrinsically motivated HCPs. Hospitals put effort into these professionals. They are seen as ambassadors, as game changers, who will convince other HCPs by setting a good example. One participant said the following:

> *I believe that starting out with the enthusiastic specialists is the most successful strategy and that's why we're starting with people who want it. We're not setting out with the difficult ones who don't want it.*
> *[Participant 11.3, CMIO]*

Adjusting the Portal to Meet Patients' Needs

Overview

Our participants said that in the continuous development process, adjusting the portal to meet the patients' needs is important. For example, enhancing user-friendliness ensures repeated use of a portal. As well, asking patients for feedback on the portal can reveal points of improvement that the project staff might not spot, as our participants explained:

> *An example: a patient tests the portal, first on a dummy and later on their own file. Someone remarks: "It's in chronological order, but the most recent is at the bottom. Why don't you put the most recent at the top of the page?"*
> *[Participant 4.2, project leader]*

> *It's as simple as that. You don't notice that when you are so involved.*
> *[Participant 4.1, advisor of functional management]*

According to our participants, another reason they find it important to adjust to patients' needs is because the perspectives of the patient and the communication advisor may differ:

> *I'm against all those abbreviations... Why not explain what they are? I guarantee you that half the patients won't know what the abbreviation means. Add an abbreviation list.*
> *[Participant 10.6, patient and client council member]*
>
> *It's my choice. I can write the term in full, I can explain it the abbreviation. But when I write it out completely, it becomes a very long sentence.*
> *[Participant 10.2, communication advisor]*

Our participants mentioned two methods hospitals use in the effort to optimize portal user-friendliness: (1) patient feedback and (2) focus on optimizations for patients with special needs (eg, low literacy, visually impaired, and low digital skills).

1: Patient Feedback

The first way to adjust to patients' needs in the continuous development of patient portals is to set up a panel of patients to act as a sounding board or to survey patients on their experiences and wishes. One participant reported the following:

> *We have a panel of 150 people. We sent these people a questionnaire on the patient portal and how they would like to use it.*
> *[Participant 3.2, client council member]*

Another way is to organize sessions with patients to test portal functionalities (eg, access to data, an e-consult, and filling in questionnaires). To illustrate, one hospital organized a test session for feedback and observations:

> *We invited a few patients from our patient panel. We gave them a test version of the portal and asked them to do a few assignments and fill in a questionnaire. For example: look at the patient portal and see if you get it. Give as much feedback as possible about the things that could be improved... There was one-on-one guidance. We had a large number of employees involved, so that we could sit next to the patients and get as much feedback as possible. So, we could also see how things went.*
> *[Participant 7.1, project employee]*

Hospitals also asked for feedback and reused questions, comments, and complaints patients express to the helpdesk. One participant said the following:

> *We now actively request feedback from patients. The helpdesk also receives feedback and phone calls and we can use the input obtained.*
> *[Participant #1.1, communication advisor]*

2: Focus on Optimizations for Patients With Special Needs

A second way to adjust to patients' needs is by optimizing the portal for people with special needs. For example, language experts check the language used on the portal and written information on how to use it, removing jargon and abbreviations and simplifying texts for patients with low literacy. They make more use of visuals (eg, icons, pictograms, and infographics):

> *You can summarize in pictograms, which makes it much easier for patients with low literacy. Visuals work better and faster.*
> *[Participant 9.2, patient]*

Another example of optimizing portal use for people with special needs is when hospitals collaborate with organizations offering general computer courses, such as the municipality, community centers, and libraries, for patients with few digital skills. Hospitals ask those organizations to blend the patient portal into their course and teach patients to work with it. Also, hospitals may refer patients to this course if they do not have computer skills and need to learn how to work with the Dutch national identity authentication method (DigiD). Participants report that the DigiD is not easy to use and its log-in process requires many steps:

> *I find the accessibility of the patient portal a real problem. Logging in with your DigiD is difficult.*
> *[Participant 3.3, functional manager]*
>
> *We look for courses on using the DigiD subsidized by the municipality. They organize courses in the community centers for people having trouble with DigiD and then these people can practice logging in on the patient portals.*
> *[Participant 11.2, communication advisor]*

Despite the importance of adjusting to patients' needs in continuous development, hospitals sometimes hesitate to include patients, because they may not be able to act on the patients' feedback. For example, if patients miss functionalities, it can require time and money to add them to the portal and, therefore, this cannot be easily fixed. Participants mentioned the importance of explaining to patients what the hospital does with their feedback and why some feedback points cannot be solved in the near future (eg, technologically impossible or too expensive). Otherwise, patients will feel that the hospital is not taking their feedback seriously. The following quote shows how hospitals struggle to let patients participate in the continuous portal development, even though they find patient input invaluable:

> *If we invite the panel group for testing, then we have to show that we have improved the portal based on their feedback… Otherwise they will think "nothing happens with our input." If we organize patient participation, you can only say "we're too busy" once.*
> *[Participant 4.1, advisor of functional management, and participant 4.2, project leader]*

One of the challenges of acting on patient feedback stems from the collaboration with the suppliers of patient portals. Suppliers will undertake to improve or develop new functionalities when multiple hospitals make the same request. Surprisingly, however, suppliers (n=5) said that they include no patients in their development process. The suppliers see it as the responsibility of their customers—the hospitals—to give voice to patients' wishes.

DISCUSSION

Principal Findings

This qualitative study focuses on patient portal adoption processes by patients and HCPs in a Dutch hospital context. Overall, our results show that the adoption of patient portals is more dynamic than presented in theoretical models and the literature. Greenhalgh et al's linear adoption stages (ie, preadoption, early use, and established users) [16] seem useful in studying adoption by individuals, but hospital patients and HCPs are in different adoption stages. Consequently, an organization cannot simply move through sequential stages; it needs ongoing effort to be put into informing, embedding, and adjusting to patients' needs. Their focus on individuals rather than the organizational context is also a criticism levied at the theoretical models (see Table 1) [14,16,17].

All participating hospitals seem to be experimenting with stimulating adoption of the patient portal. They are trying to create effective communication strategies, looking for the best way to embed the portal in daily routines and adjust to its patients' needs. As yet, they have not found the best way of encouraging portal use by patients and HCPs. Here we explain the implications of our results.

Our study shows that hospitals are experimenting with many communication channels (N=23), mostly ones that are already in use. Despite efforts by communication departments, it seems that portal adoption is still quite a challenge. It seems that hospitals do not know which channels are most effective for which target audiences and what the right timing is for their communication campaigns. Looking at their communication strategies, we found that hospitals choose to emphasize the benefits of portal use and hardly mention the potential disadvantages or risks. According to Greenhalgh et al [16], intended adopters must know the consequences of adopting a patient portal to become established users. If intended adopters are not informed of the potential disadvantages, then they cannot oversee all the consequences of using the portal, for example, the risks. However, the financial incentives of the VIPP program may explain the positive promotion strategy. If hospitals do not attain a certain adoption percentage (ie, 10% or 25%) they will have to repay their VIPP grant.

Our results show that hospitals invest in HCP adoption through peer-to-peer influence. However, focusing on the enthusiastic HCPs can mean that the less-motivated HCPs will lag behind. That a patient portal often does not reduce the burden of HCPs (ie, it only means extra work) and that it is not embedded properly in work routines can hinder adoption. The specialism-focused approach offers a way of encouraging patient portal adoption by HCPs. This experiment with portal embedding would be interesting to study in other contexts to see where and how it could lead to better embedding of the patient portal. A possible disadvantage of this approach could be that patients will not understand why specialisms are in different adoption stages (ie, patients can make an online appointment with one specialism but not for another).

Another principal finding is that hospitals are struggling to adjust the portal to meet patients' needs in their continuous development process, although all seem to find this important. According to Greenhalgh et al [16], it is vital that intended users get the opportunity to refine the portal so that they will not drop out in the early adoption stage. Hospitals are using various ways to adjust to the patients' needs in ongoing portal development, without knowing which one is most effective in which phase and for what purpose. It would be interesting to do more research on how patients can participate in portal development, including efforts to stimulate adoption.

Nonusers of patient portals could be studied further. Previous studies show that nonusers have various reasons for not adopting the portal [36,37], including a preference to speak directly to their HCP, the level of their communication skills [36], and their concern for privacy and information security [36]. Such studies would show that hospitals are taking nonusers' concerns seriously and, at the same time, could produce insights valuable to exploring whether and how the patient portal could be made useful to them.

A remarkable finding is that portal suppliers do not include patients in their development process. The suppliers see it as their clients' responsibility to give voice to patients' wishes, but the focus group discussion did make them rethink this. This means that hospitals must explain to the supplier how they should make the portal more user-friendly for patients. Because of the variation in hospital context and portal suppliers, this could explain the disappointing adoption by patients.

Limitations

Our study has four limitations. The first is that the adoption processes in the hospitals we studied might be somewhat unusual due to the financial incentives of the national VIPP program. Conducting similar research in other countries would, therefore, be interesting and could also teach us more about the contextual, including cultural, factors that influence hospitals' efforts to stimulate adoption.

The second limitation is the way we recruited hospital participants. Using our own research networks may have biased our sample. However, our recruiting process resulted in a good variation in the mix of included hospitals.

The third limitation is that we only included teaching and general hospitals, given that academic hospitals follow another implementation program. Also, during the study period they were not participating in the VIPP program and, therefore, could not be compared. However, the inclusion criteria context of the studied hospitals varied greatly to include different kinds of hospitals and patients.

Last, this descriptive study shows the efforts that some Dutch hospitals have made to stimulate adoption of a patient portal. We did not study whether the undertaken efforts led to an actual increase of the adoption of patient portals. A further study on the effectiveness of these efforts is recommended.

Comparison With Prior Work

In recent years, many theoretical models on the adoption of information technology have been developed [9,10]. These models show which variables are important for the adoption of a technology; for example, perceived ease of use, defined in the Technology Acceptance Model (TAM) as "the degree to which the person believes that using the particular system would be free of effort" [12]. However, these models are not explanatory and do not provide the know-how to stimulate patient portal adoption [9,10]. Consequently, we suggest future research should not focus on models, including new ones, but should deal with actionable knowledge for practice [38]. Action research can be used to study the adoption process and the embedding of patient portals in daily practice [39].

Communication experts support the hospitals' choice to use a cross-media promotion to inform patients and HCPs about the patient portal [40]. Explaining the benefits of using a patient portal is especially important for promotional messages [41]. However, open dialogue among HCPs and project leaders and staff is also vital because it illuminates the professionals' perspectives on portal development [41]. Earlier research shows that ignoring doubts while trying to convince others to use a technology may produce negative energy and a reluctance to use the portal [41,42]. Further research is required to find the most effective hospital communication strategies for encouraging patient portal adoption for patients and HCPs.

Our study showed that embedding a patient portal in the daily routine of HCPs requires changing their work processes. Earlier studies suggest that hospitals need to make extra time available to HCPs so that they can change and learn new work processes [41]. Research shows that portal use by patients may increase when HCPs are active on the patient portal and it is embedded in their work processes [43]. Research suggests training can benefit the adoption process [41], yet only some hospitals organize courses that explain how the portal works. As a result, some HCPs lack familiarity with portal functionalities [42].

The literature reports several ways of using feedback to adjust the portal to patients' needs in the continuous development of patient portals. These studies could help hospitals struggling with this. It is important to include patients at the beginning of ongoing development of patient portals [1,44,45]. Examples include co-design, where patients help identify the project based on personal experiences in collaborating with the clinician [45], and participatory stakeholder co-design, where patients and clinicians are equal stakeholders in the whole project [45]. Vulnerable patient groups, such as disadvantaged older adults, should be given special attention in the process of cocreation and user testing [7]. This is an important issue for future research.

Conclusions

Patient portal adoption processes are not just about implementing the technology. They require human interaction in a multitude of ways. Our study reveals three key findings for the adoption process: (1) informing patients and HCPs about the portal, (2) embedding it in the daily routine of HCPs, and (3) adjusting it to patients' needs in the continuous development of the portal. Our paper provides rich insights into the complexity of the adoption process and gives examples of efforts to stimulate the adoption of patient portals. Our findings help to translate the relatively abstract factors mentioned in the theoretical models to the everyday pragmatics of eHealth projects in hospitals.

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Conflicts of Interest

None declared.

Abbreviations

CMIO: Chief Medical Information Officer
CNIO: Chief Nursing Information Officer
DigiD: Dutch national identity authentication method
DRG: diagnosis-related group
GDPR: General Data Protection Regulation
eHealth: electronic health
EHR: electronic health record
Erasmus MC: Erasmus Medical Center
HCP: health care professional
NASSS: nonadoption, abandonment, scale-up, spread, and sustainability
NICTIZ: Nationaal ICT Instituut in de Zorg
PHR: personal health record
TAM: Technology Acceptance Model
VIPP: Versnellingsprogramma Informatie-Uitwisseling Patiënt en Professional

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MULTIMEDIA APPENDIX 1

Topic list

Setting/context	All participants	Introduce yourself
	Project leader	When did the hospital introduce the patient portal? Description patient portal Functionalities? Who can use it? Aims Intended effects? Target usage percentages?
	Patient	When did you first use the patient portal? Motivation? Extent of use? Reasons for use? Experienced advantages? Example? Experienced disadvantages? Example? When do you think you will use the patient portal again? Why?
	Project manager	User statistics available? Why available, why not? How often are statistics collected? What is done with the statistics? Audit report?
	Healthcare professional	Evaluation Research done? Positive experiences? Negative experiences? How is feedback collected?
Open question	All participants	Promoting use of patient portal? Example per activity Limitations for use of patient portal? Example per limitation
Focused interventions, based on factors derived from the literature	Patient	Communication to you Actions? Resources? Examples? What works well? What is missing?

	Healthcare professional	What are your experiences with communication about the patient portal?
	Project manager	What are your experiences with communication about the patient portal?
	Patient	What can you use the patient portal for? Experiences? Example(s)?
	Project manager	How do you manage the differences in skills among patients? Experiences? Example(s)?
	Patient	What do you want to use the patient portal for? Experiences? Example(s)?
	Healthcare professional	How do you manage the differences in patients' needs/wishes? Experiences? Example(s)?
	Patient	How easy/hard do you think it is to use the patient portal (scale 1-10) Do you understand everything shown in the patient portal? What do you do if something does not work? What do you do when you do not understand? Example(s)?
	Project manager	Is there specific attention for patients with low literacy? Example(s)?
	Patient	"Training" for you? Why (not)? What kind of training was it? Effect(s) of training? Not: would you like training?
	Project manager	"Training" for patients? Why (not)? What kind of training? Effect(s) of training? Have you heard any patients' experiences?
	Patient	Guidance in presented information (written documentation)? How? Example(s)

	Project manager	Guidance in presented information? How? Example(s)?
	Patient	Staffed (help) desk? What works and what does not work? Experiences? Example(s)?
	Healthcare professional	Helpdesk? What works and what do not work? Experiences? Example(s)?
	Project manager	Helpdesk? How is it managed? Who staffs the help desk? What works and what does not work?
	Healthcare professional	Communication to you Actions? Resources? Example(s)?
	Project manager	Communication to healthcare professional Actions? Resources? Example(s)?
	Healthcare professional	“Training” for you? Why (not)? What kind of training was it? Experienced effects?
	Project manager	“Training” for healthcare professional? Why (not)? What kind of training was it? Experienced effects?
	Patient	Encouraged by physician / healthcare professional Yes/No? Why (not)? How? Example(s)
	Healthcare professional	Giving encouragement to patiens Yes/No? Why (not)? How? Example(s)?

	Healthcare professional	What is your experience of working with the patient portal? How have your work processes changed by using the patient portal?
	Patient	Have you authorized anyone to look (share) in your patient portal? Yes/No? Why (not)? Experience(s)?
	Project manager	Shared access Experience(s)?
	All participants	User-friendliness Experience(s)? Example(s)?
Technological factors	Patient	Focusing purely on the patient portal What works well? What could be improved? What does the patient portal lack?
	Healthcare professional	Technical/content-based aspects What works well in the patient portal? What does not work well?
	Project manager	Technical/content-based aspects What works well in the patient portal? What does not work well?
Last question	All participants	Imagine the hospital gets 2 thousand euro for improving the patient portal. What would you recommend? What should the hospital spend the money on? This could be one or more things
End	Healthcare professional or project leader	Are there any healthcare professionals or patients open to joining a focus group in your organization?
	All participants	Is there anything else you would like to tell us?

Chapter 3

Mental Health Care Professionals' Appraisal of Patients' Use of Web-Based Access to Their Electronic Health Record: Qualitative Study

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ABSTRACT

Background:
Patients in a range of health care sectors can access their medical health records using a patient portal. In mental health care, the use of patient portals among mental health care professionals remains low. Mental health care professionals are concerned that patient access to electronic health records (EHRs) will negatively affect the patient's well-being and privacy as well as the professional's own workload.

Objective:
This study aims to provide insights into the appraisal work of mental health care professionals to assess and understand patient access to their EHRs through a patient portal.

Methods:
We conducted a qualitative study that included 10 semistructured interviews (n=11) and a focus group (n=10). Participants in both the interviews and the focus group were mental health care professionals from different professional backgrounds and staff employees (eg, team leaders and communication advisors). We collected data on their opinions and experiences with the recently implemented patient portal and their attempts to modify work practices.

Results:
Our study provides insights into mental health care professionals' appraisal work to assess and understand patient access to the EHR through a patient portal. A total of four topics emerged from our data analysis: appraising the effect on the patient-professional relationship, appraising the challenge of sharing and registering delicate information, appraising patient vulnerability, and redefining consultation routines and registration practices.

Conclusions:
Mental health care professionals struggle with the effects of web-based patient access and are searching for the best ways to modify their registration and consultation practices. Our participants seem to appraise the effects of web-based patient access individually. Our study signals the lack of systematization and communal appraisal. It also suggests various solutions to the challenges faced by mental health care professionals. To optimize the effects of web-based patient access to EHRs, mental health care professionals need to be involved in the process of developing, implementing, and embedding patient portals.

Keywords
patient portals; eHealth; mental health care professionals; mental health; eMental health; mental health care; patient-accessible; electronic health records; Open Notes; normalization process theory; NPT

INTRODUCTION

Background

The number of patient portals is increasing rapidly in all health care sectors. Through these patient portals, patients have gained the ability to access their medical health records on the internet. A patient portal is a form of eHealth that can be defined as "provider-tethered applications that allow patients to access, but not to control, certain health care information (eg, their EHR [electronic health record]) and provide communication and administrative functions (eg, secure messaging, appointment booking, and prescription refill requests)" [1]. Research has shown that, in mental health care, the use of a patient portal can have a positive effect on patient activation, recovery, and organizational efficiency [2]. In the same study, mental health care professionals were involved during implementation and were trained to use the patient portal [2]. Furthermore, the relationship between the patient and their mental health care professional can improve, provided the mental health care professional has an open attitude, and the medical record is unique, individualized, and detailed [3]. Another study showed that mental health care professionals could feel uncomfortable because they experience reduced control over the information flow when patients can access their health information on the internet [4]. Overall consequences can be positive, for example, improved registration (ie, documentation) and consultations (ie, visits) with patients or negative, for example, reduced documentation by mental health care professionals. This suggests that the positive effects of web-based patient access partly depend on the registration practices of the mental health care professional and the ways in which they communicate with their patients [3,4]. Therefore, this study explores the appraisal work carried out by mental health care professionals shortly after the introduction of web-based patient access and sheds light on the challenges mental health care professionals face when trying to make a patient portal work for them and the patient.

To gain insight into the challenges of mental health care professionals, we use the normalization process theory (NPT), which helps to understand how new technologies and practices are embedded and integrated into existing work practices [5]. This theory "identifies, characterises and explains mechanisms that have been empirically demonstrated to motivate and shape implementation processes and affect their outcomes" [6]. NPT includes a model that explains what health care professionals go through when embedding a new technology which, in this study, we have applied to web-based patient access through a patient portal [5-8]. This paper focuses on one of the key constructs of NPT, reflexive monitoring. Reflexive monitoring concerns the appraisal activities that health care professionals do to assess and understand the ways in which a new set of practices affects them and others around them. For patient portals, the focus is on how patients' web-based access to sensitive data in the EHR affects mental health care professionals, their patients, and the relationship between them. Reflexive monitoring sheds light on the individual mental health care professionals' appraisal work shortly after the implementation of web-based patient access. Reflexive monitoring involves four components: (1) systematization, which involves collecting information about formal (eg, research results) or informal (eg, anecdotal examples) evidence; (2) during communal appraisal, individuals work together to evaluate the worth of, in this instance, patient portals and related working routines; (3) through individual appraisal, individuals work experientially to appraise the effects on them and the contexts in which they are set; and (4) reconfiguration involves attempts to redefine procedures or modify practices, and perhaps, here, even to change the shape of the patient portal itself, to make the patient portal work [5].

Little is known about the appraisal work of mental health care professionals during the embedding of a patient portal. We do know that patient access to medical health records in mental health care has always been a sensitive subject. In the early 1990s, researchers raised the question of whether reading psychiatric case–related notes could be considered offensive [9]. Especially in mental health care, doctors' notes often contain sensitive information concerning the mental state of the patient [10]. Research suggests that mental health care professionals think there is a risk that patients disagree with the content of the notes or misinterpret the content, and therefore, patients could be upset [9]. This can cause a patient to become concerned or confused and even to respond angrily. In addition to these specific concerns over sensitive information in mental health care, mental health care professionals share the wider concerns of their colleagues in hospital care [10-12]. In total, 2 studies point to a possible higher work burden caused by increased communication with patients and to a fear of lawsuits or claims for damages [10,13]. However, on the other hand, most mental health care professionals believe that patients will better remember their treatment plans and will be better prepared for appointments [10].

Objectives

This study focuses on appraisal work by mental health care professionals shortly after the implementation of web-based patient access through a patient portal and shows how mental health care professionals try to make sense of this new technology by appraising the effects of the portal and by attempting to modify registrations and consultation practices. Furthermore, our study answers the question of what mental health care professionals do to assess and understand patient access to the EHR through a patient portal.

METHODS

Overview

For this qualitative study, 10 interviews with a total of 11 mental health care professionals and, later, a focus group, were conducted in a Dutch mental health care organization. This organization (2100 full-time equivalents) offers mental health care, well-being, and social services for approximately 32,000 inpatients and outpatients of all ages. In January 2019, the organization implemented a patient portal for patients to access their EHRs. All patients were able to read notes, letters, and other information in their EHRs after a period of 30 days. Mental health care professionals cannot determine whether a patient uses web-based access. Medical notes were not accessible by patients if they were marked as a draft, but drafts would eventually have to be marked as final before a course of treatment could be closed. After implementation, a personal notes tab was added for the mental health care professionals. These notes were not visible to colleagues or patients.

Recruitment and Selection

The objective of recruiting study participants was to include mental health care professionals working in diverse focus areas and with different professions within the same mental health care organization. Recruitment, selection, interviews, and focus group were conducted in the spring of 2019. Participants were selected in two ways: by an open invitation on the intranet (n=6) and then through snowballing (n=5). The latter involved asking existing participants if they knew of others who might be willing to be interviewed [14]. All mental health care professionals who expressed willingness to be interviewed were included in the study (Table 1). During the interviews, it became apparent that both supporters and opponents of the patient portal participated in the study.

Participants in the focus group were identified by the head of the computerization and automation department using purposeful sampling (Table 2). This provided a broader range of professions than the interviewee group and included some who had been involved in the implementation of the patient portal.

Table 1. Characteristics of the participants of the interviews.

Participant (P)	Sex	Age	Profession	Focus area
1.1	Female	43	Clinical psychologist	Development disorders
1.2	Female	38	Nurse practitioner	Hospital psychiatry
1.3	Male	51	Nurse practitioner	Anxiety and mood
1.4	Male	54	Nurse practitioner	Elderly
1.5	Female	49	Psychiatrist	Personality disorders
1.6	Female	53	Psychiatrist	Addiction
1.7	Female	54	Psychiatrist	Personality disorders
1.8	Female	60	Psychiatrist	Elderly
1.9	Female	27	Psychologist	Development disorders
1.10	Male	39	Psychologist	First level health care
1.11	Female	61	Psychotherapist and team leader care	Forensic

Table 2. Characteristics of the participants of the focus group

Participant	Sex	Age	Profession
2.1	Female	53	Functional application manager
2.2	Female	28	Coordinator health care innovation
2.3	Male	57	Team leader anxiety and mood
2.4	Female	52	Team leader specialistic diagnosis and treatment
2.5	Male	50	Functional application manager
2.6	Female	38	Team leader anxiety and mood
2.7	Male	Unknown	Computerization and automation
2.8	Male	37	Client council
2.9 [a]	Female	27	Psychologist – development disorders
2.10	Female	37	Strategic marketing and communication advisor

[a] Also an interviewee (Participant 1.9)

Interviews and Focus Group

Before the interviews and the focus group, participants signed an informed consent form and consented to being audio recorded and the use of the data for research.

One researcher (AMvR) conducted the interviews and the focus group, following a predefined topic list (Multimedia Appendix 1), which was based on earlier research on patient portals [11,15,16]. The topic list for the focus group was also based on the results of the interviews' analysis (Multimedia Appendix 2). During the interviews, participants were asked for their views on and experiences with the potential benefits and risks of patient access to the EHR through a patient portal and possible solutions to reduce the identified risks. The interviews lasted 50 minutes on average (range 30-73 minutes). Most interviews took place in a face-to-face setting. Only one interview was conducted on the internet through Skype because of the geographically distant location of the participant [17].

The focus group was intended to check and enrich the results of the interviews while creating room for elaboration [18]. Participants in the focus group were presented a tentative analysis of the interviews, after which discussion took place according to the predefined topic list (Multimedia Appendix 2). This led to in-depth discussions on the perspectives of mental health care professionals on patient access to their EHR [19]. The focus group lasted 75 minutes and was conducted in a face-to-face setting.

Analysis

The interviews and the focus group were audio recorded and then transcribed verbatim. First, we followed an inductive approach to analyze the data, in which we repeatedly examined which themes emerged from our data [20]. Second, we took a deductive approach, in which we looked at our data through the lens of NPT to analyze the different components of reflexive monitoring by mental health care professionals. Combined, our analysis can be described as abductive [21]. We coded the data in three steps: open, axial, and selective [22]. Keywords were coupled to certain fragments of the transcripts (Multimedia Appendix 3). Using these keywords, connections were made between different fragments of various transcripts. Thereafter, these keywords were regrouped and formed the basis for drawing conclusions from this research. All the interviews were first individually and separately coded by 2 members of the research team (AMvR and BP), after which these codes and themes were discussed, reviewed, and adjusted if necessary until a consensus was reached (AMvR and BP). Subsequently, we discussed and adjusted the outcomes where necessary with the other members of the research team [20]. The analysis was computer-assisted using ATLAS.ti software (version 8; Scientific Software Development GmbH) [23].

RESULTS

Overview

The aim of our study was to provide insights into the appraisal work that mental health care professionals do to assess and understand patient access to the EHR through a patient portal. A total of four interrelated topics emerged from the data analysis: (1) appraising the effect on the patient-professional relationship, (2) appraising the challenge of sharing and registering sensitive information, (3) appraising patient vulnerability, and (4) redefining consultation routines and registration practices.

Our analysis showed that there were both opponents and supporters of web-based patient access among our participants. The following two quotes illustrate the strong differences in opinions among the interviewed mental health care professionals:

> *I must honestly say that I have not thought about the possible benefits. I only saw disadvantages, felt that I have to be very careful. That was my first response.*
> *[P 1.8, psychiatrist]*
>
> *I think it is a greater risk if patients do not have online access.*
> *[P 1.5, psychiatrist]*

Furthermore, our analysis showed that opponents tend to focus on their concerns and have difficulty mentioning the benefits of web-based patient access. When mentioning an advantage, they sometimes immediately denounce the advantages. For example, when asked about the benefit of web-based patient access, one opponent answered:

> *I might forget to write something down, patients can mention this. So that could be an advantage. However, I must say now that I mention it, I am also immediately afraid that this will cause a lot of extra work.*
> *[P 1.8, psychiatrist]*

Appraising the Effect on the Patient-Professional Relationship

One of the effects our participants perceived with patient access to the EHR through a patient portal is that it changes the patient-professional relationship.

The first way in which the patient-professional relationship could be changed by patient access is through feedback provided by patients on the content of the EHR. Participants explained that when patients believe the information they read is incorrect or that information is missing, this can be adjusted, leading to therapeutic gain and a new kind of conversation between the patient and professional. One participant illustrated this as follows:

> *If it [patient access to the EHR] produces complaints, you have to do something about it. If people are correct, they are right to complain and you should not be uncooperative but adjust something. And, it is possible that if you can talk about it with a patient, this could improve the therapeutic relationship.*
> *[P 1.4, nurse practitioner]*

However, participants also mentioned that these extra questions, comments, or even complaints from patients, take time to answer, and mental health care professionals might need to change their records afterwards.

> *I am a little bit afraid that the people that will be looking [in their medical record], are the people that will have a lot of criticism on what I have written. They will say I did not mean this, I meant it like this.*
> *[P 1.8, psychiatrist]*

Second, our participants argued that patients being able to read their EHR both before and after a consultation with the mental health care professional could enable them to be better prepared for their appointments, and therefore enhance the quality of the conversation between patients and professionals.

Third, participants argued that patients who read the information in their EHR could be more aware of their treatment and feel more like an equal to the mental health care professional. Mental health care professionals could also help create a sense of shared responsibility for the treatment by encouraging patients to study their health information in the patient portal. One participant illustrated the following:

> *Very often I hear: "Oh, I do not know where my treatment plan is." You can point it out and mention that it is something that belongs to both of us.*
> *[P 1.7, psychiatrist]*

As the examples above illustrate, our participants believed that web-based patient access could: (1) increase the therapeutic gain, (2) improve the patient's preparation for a consultation, and (3) improve the involvement of patients in their treatment. However, participants also feared that web-based patient access might cost a lot of valuable time and that patients' reading notes could have a negative effect on the patient-professional relationship, which is further described in the next section.

Appraising the Challenge of Sharing and Registering Sensitive Information

Participants admitted that they were struggling with the way they formulated information for the EHR. Medical information in mental health care is often subjective, and writing down a diagnosis is a delicate balance, which is illustrated by one participant's reflection:

> *Especially if one [health professional] did not consider it [web-based patient access], one could have written in a somewhat unsophisticated way in the medical record: "This is typical of borderline behavior.," while not seeing the patient as borderline.*
> *[P 1.7, psychiatrist]*

Some participants were worried that patients might feel insulted, misinterpret the information given, or feel unheard when reading the information in the EHR, which could reduce trust in the treatment or even withdrawal from the care program:

> *[...] people who are attached in an unsafe way will very quickly feel let down, and that is also possible through text, which, getting back to the therapeutic relationship, can of course deteriorate, and that would be a pity.*
> *[P 1.7, psychiatrist]*

On the other hand, participants mentioned that such information is an important part of the psychiatric examination and might be important for colleagues to know. If some information is not appropriate for patients to read in their EHR, then mental health care professionals can be reluctant to write it down. One participant illustrated the following:

> *Let's assume I see someone who looks dirty or with poor hygiene, then I have a hard time writing that down.*
> *[P 1.7, psychiatrist]*

Besides being subjective, information on mental health care is also often sensitive. Participants argued that patients might become overwhelmed and eventually relapse (a deterioration in the mental health of an individual who was controlling their mental illness) because of the amount or content of the information they have at their disposal with access to their EHR. One participant said:

> *[...] there are people who can go backwards over small details, such as "I did not study for seven months but eight" [...]*
> *[P 1.1, clinical psychologist]*

This view was confirmed by the participants in the focus group, where a team leader mentioned that he observed that his colleagues were less detailed in their registration:

> *[...] you also hear that care providers are more aware of what they write in their report, and therefore are more factual and less informative [...]*
> *[P 2.3, team leader anxiety and mood]*

In addition, our participants explained that a mental health care professionals' report of a consultation might reveal that the patient and the professional had experienced their conversation quite differently and felt differently about what was most important or would therefore summarize the highlights and conclusions differently. Our participants stated that this is not unusual with mental health care and occurs less with physical issues. One participant explained the following:

> *I wrote a note in the medical record in a certain way, but maybe the other person (the patient) experienced a different conversation.*
> *[P 1.7, psychiatrist]*

Our participants had various views on entering information that is not yet intended for patients. For instance, collateral history might contain sensitive and possibly offensive information and may not always be suitable for patients or known by them. Our participants experience this ethical dilemma: they are not sure whether they should write down sensitive information and whether this information belongs to the patient's EHR. One participant saw it as a moral dilemma whether to enter certain information or not because it could be beneficial to the treatment but also involves the risk of harming the patient. According to our participants, some information would not be beneficial for patients if they saw it. One participant offered the following example:

> *I have had a patient, […] that girl was sixteen years old and her mother was pregnant through the daughter’s boyfriend, and that was written in her medical record, […] but the girl did not know. […] It was relevant to the background about the girl’s tangled family situation where all kinds of things had occurred, with very unusual relationships.*
> *[P 1.4, nurse practitioner]*

Another example of doubts about entering information that is not yet, if ever, intended for patients is over certain treatment plans, with participants worrying that they might no longer work if patients can read about them. One participant illustrated a situation where a patient’s husband and her general practitioner thought her situation was deteriorating, but the patient herself did not agree and did not want any kind of treatment. The participant called the patient, and the patient made clear that she did not want any treatment. The participant said the following:

> *I will make a note of that: “spoken today, clearly different than yesterday, much angrier today, does not want an appointment, does extensively talk about it, agreed that I will call her again next week to see if there are any possibilities then, otherwise I will ask her husband to come here with her,” that is my plan. I did not tell her all of it […]*
> *[P 1.3, nurse practitioner]*

The issue over treatment plans led to mental health care professionals doubting whether patients should have real-time access to their EHR rather than a 30-day delay. When patients need acute care or are compelled to receive care, for example, in crisis situations, real-time patient access might lead to dangerous situations if patients read what mental health care professionals are planning. One participant stated as follows:

> *It is possible that when he [the patient] reads this and thinks: “Hey, they are on my doorstep tomorrow [for an involuntary admission], you know what, I will end it [his life] before they arrive.”*
> *[P 1.9, psychologist]*

Despite the dangers of disclosing information to patients, our participants were aware that not entering their thoughts in the EHR also carried risks. Information might otherwise be lost or colleagues are no longer fully informed about certain patients. In crisis situations, where mental health care professionals work in shifts, the peer transfer of information is seen as important by our participants. Furthermore, a participant in the focus group mentioned that mental health care professionals are responsible for what they enter, but also if they fail to enter information that might be of importance later:

> *[...] suppose you have seen or recognized something, and you did not want to write it down for whatever reason, but it does have an influence on a future course of the treatment, or possibly a crisis situation, and you say: "well, I did see or spot that earlier on," you are responsible for that.*
> *[P 2.4, team leader specialist diagnosis and treatment]*

This influences the way our participants work individually and together, especially when they disagree about certain issues and have yet to make decisions about how they redefine their registration and consultation practices.

In summary, when sharing and registering delicate information, our participants struggle individually with the way they should write information in the EHR and are afraid that (1) it could reduce patients' trust in their treatment because patients misinterpret the information they have access to, (2) mental health care professionals might enter information that is inappropriate for patients to read, (3) patients might become overwhelmed by the amount or content of the entered information, (4) it might show to patients that professionals have experienced their conversation quite differently than they did themselves, and (5) there is no place to write down information that is not yet, if ever, intended for the patient to read. This shows that our participants, as individuals, have thought deeply about how to make mental health care patients' access to their EHR work. There were disagreements over entering information that was not yet, if ever, intended for patients. Whether or not to enter certain information seemed to be a moral dilemma because it could be beneficial to the treatment but also involves a risk of harm to the patient.

Appraising Patient Vulnerability

Our participants worried that patients could become more vulnerable with web-based access to their EHRs. They were concerned that they had little control over how patients would act on this information in the EHR and are also afraid that patients might, for example, deteriorate after reading their own medical record.

As mentioned in the previous paragraph, information on mental health care is often sensitive. Participants were afraid that this could overwhelm patients and possibly cause a harmful relapse:

> *[...] during meetings we discuss whether an admission to the ward would be an option. If you write down that you consider this, he [the patient] might get upset or deteriorate. [...] The same goes for our considerations, should we write down something else to prevent a patient from deteriorating?*
> *[P 1.9, psychologist]*

When asked what is meant by deterioration, a participant answered as follows:

> *[...] a patient getting completely disordered, mentally stuck, upset, a breach of trust with their mental health care professionals [...].*
> *[P 1.1, clinical psychologist]*

Participants explained that patients could easily print or download their own medical records, after which they could share this with inappropriate people. In this way, sensitive information may fall into the wrong hands. A third party, such as a curious spouse, could also gain access to the EHR for wrong reasons. Especially in mental health care, patients are often vulnerable and easily influenced by relatives. One participant stated as follows:

> *A disadvantage could be that someone else gets access to the password or login codes, that could of course be a risk. With certain treatments, you do not want a partner to know certain things, [...] however they [relatives] can be persuasive and demand access from a patient.*
> *[P 1.10, psychologist]*

Our participants were unsure who would be responsible for the potentially reckless handling of information from the EHR by the patient. They also doubted whether it would be sufficient if mental health care professionals warn patients about the sensitive nature of the information. One participant, however, stated that sharing health data was the responsibility of the patients:

> *The patient has access, so I think it is their responsibility. I think the content and the correctness of the content is the responsibility of the health professional.*
> *[P 1.10, psychologist]*

Another participant mentioned an extreme example of what could happen when patients share their own medical information, for example, to show that they are discontent with their treatment, but emphasized that this is the patient's own responsibility:

> *If the patient thinks: "I will go to Story or RTL boulevard [national media] with my medical record, which sometimes happens, then they can do it."*
> *[P 1.11, psychotherapist and team leader care]*

In summary, our participants were afraid that they had much less control over what patients do with the information in the EHR and wonder who is responsible for sharing information. It seems that patient access raises many uncertainties concerning individual personal relationships with a patient.

Redefining Consultation Routines and Registration Practices

Reflecting on the effects and struggles of entering sensitive information in an EHR, our participants suggested various solutions in terms of modifying their registration practices. However, those who opposed the idea of web-based patient access were not convinced that those solutions would really work, as they often also mentioned the possible disadvantages of the suggested solution.

Solution 1: Draft Notes for Colleagues

The first solution suggested by the participants was to write draft notes for colleagues. This is a temporary solution, in that draft notes will not be immediately visible in the patient portal but will need to be marked as final, and hence become visible, before a treatment can be closed.

Solution 2: Making Personal Notes Visible for Colleagues

The second solution was to make the personal notes tab visible to colleagues. Although this prevents the loss of access to information in, for example, crisis situations, this also reduces the transparency of information for patients because a hidden shadow file is created.

Solution 3: Discussing Information With Patients Before Registration

A third suggested solution was to discuss information with patients before the mental health care professionals register this information. In this way, they can ensure that there is no new information in the EHR should the patient choose to access it. A participant in the focus group explained this as follows:

> *[...] it is quite difficult in that you cannot write down your considerations, but I think it is also a stimulant to share your considerations with the patient a lot more, by which you give a patient more space and influence, which causes the treatment relationship to become more equal [...].*
> *[P 2.6, team leader anxiety and mood]*

However, participants acknowledged that this third option was only workable if they discuss the information directly during a consultation. If not, if mental health care professionals delay registration, this increases the risk of mistakes and lost information because of memory shortfalls. At the same time, our participants commented that they often let a conversation sink in and write the report later:

> *[...] of course it remains difficult, when you walk back into your room and you smell alcohol [lingering from the patient] after the end of a consultation. Where do you record this, as you have not yet discussed it with the patient, but it is important information, these are difficult things.*
> *[P 2.6, team leader anxiety and mood]*

Solution 4: Registering Information Together With the Patient

A fourth solution that is mostly mentioned by supporters is the practice of registering information together with the patient. This collaborative practice could even become a form of treatment. Our participants felt that it depends on the patient whether this would be a workable solution, and two possible obstacles were raised by opponents. First, it was noted by the participants that certain patients (eg, psychotic patients or those with developmental disorders) are not capable of writing notes along with their mental health care professional. For example, an opponent mentioned that patients with a developmental disorder are often overstimulated after a consultation and would not be able to contribute to writing notes:

> *The argument is: "you have to write [in the medical record] together with your patient, use the last ten minutes of your consultation." However, that does not work with our patients. They are completely overstimulated after half an hour, they cannot immediately reflect on what happened.*
> *[P 1.1, clinical psychologist]*

However, when a supporter was confronted with this concern, she responded as follows:

> *It can be an extra effort, but that is also part of the dynamics of that treatment. […] No psychiatrist is made to treat everyone, […], so I guess choose your patient population according to that.*
> *[P 1.5, psychiatrist]*

Second, some participants were concerned that writing notes with the patient would eat into the already limited time for consultation.

Solution 5: Introducing Patients to Web-Based Access at the Beginning of Treatment

The final solution was to introduce patients to web-based access to their EHRs at the beginning of their treatment. Mental health care professionals could then explain the risks and benefits of web-based patient access and decide together with the patient whether the patient would use it. One participant said the following:

> *Sometimes the risks have to be pointed out to a patient, as I just said, you can send a copy of your letter but watch out when you use it in court, so they need to be informed about the risks.*
> *[P 1.6, psychiatrist]*

Our participants would like more support on what kind of information patients can read in the EHR and how they should write sensitive information in the EHR. This could provide them with more knowledge and enable them to experiment with web-based patient access and to evaluate the outcomes together. Our participants said it was unclear to them what kind of information patients could read through the patient portal and on which terms. Furthermore, participants commented that they had only limited experience with the patient portal because it had only just been implemented. Indeed, most participants had no personal experience with patients accessing their EHR at all. However, some participants were able to report on one encounter with a patient who had read their EHR and then regretted doing so:

> *Some patients get overwhelmed by the amount of information, one patient said the following: "I just regret looking because I started and I got so much information, well, I got really upset, then I stopped."*
> *[P 1.7, psychiatrist]*

As illustrated earlier, our participants were individually able to come up with five solutions that they believed could make patient access to the EHR work for them as well as for their patients. However, it would appear that our participants needed more support on how the portal works so that they could actually experiment with their ideas on working with web-based patient access and evaluate these experiments.

DISCUSSION

Principal Findings

This study seeks to provide insights into the appraisal work that mental health care professionals do to assess and understand patient access to their EHRs through a patient portal. By interviewing 11 mental health care professionals and conducting a focus group discussion, we learned that mental health care professionals struggle with how to weigh up the potential benefits and risks they perceive and are trying to work out what they can do themselves to make the portal work for them and for their relationship with their patients.

Our results show that mental health care professionals struggle with various aspects of patient access to the EHR and with entering what they perceive as sensitive information into the EHR. First, we looked at the ways in which mental health care professionals appraise the effect of web-based patient access on their relationship with the patient. Second, we report how mental health care professionals fear that some patients are too vulnerable to handle the new possibility of accessing their medical records. Third, we showed the ways in which mental health care professionals address the challenge of registering and discussing delicate information. Finally, we showed how mental health care professionals individually experiment by redefining consultation routines and registration practices.

Our results show that participants are actively engaged in the NPT terms reflexive monitoring, especially the components related to individual appraisal and reconfiguration [5]. Our participants individually appraised the effects of patient access to the EHR (eg, that mental health care professionals should perhaps no longer write so freely in the medical record) and thought about solutions to modify and redefine their registration and consultation practices. Participants mentioned that notes might become less accurate and less detailed to avoid potential harm to the patient, a concern also expressed elsewhere in the literature [10,13,24]. Although some studies show that, in practice, only very few patients are actually harmed [12,25], another study showed that patients could be surprised or hurt when they read information in the medical record that is incorrect, outdated, or new to them [3]. Such patients are then afraid that this incorrect or outdated information might have a negative impact on their treatment if, for example, other mental health care professionals read and act on this information [3]. Other patients commented that this makes them doubt whether their mental health care treatment is useful [3]. The other two NPT components, systematization and communal appraisal, did not appear to take place. As long as mental health care professionals struggle to engage with these two components of reflexive monitoring, embedding web-based patient access in the work practices of mental health care professionals will be hindered. Consequently, we hope that future research will explore the ways in which systematization and communal appraisal can be stimulated during the implementation of web-based patient access in mental health care. In addition, future research could focus on ways to involve opponents of web-based patient access in the process of communal appraisal and reconfiguration.

Furthermore, our results show that participants worry that certain treatment plans and strategies might no longer work if patients can read them. This is a new concern that has not been mentioned in the literature before and is especially relevant as information in the EHR becomes accessible in real time. However, a study on real-time access through a patient portal in hospital care concluded that the limited negative consequences could be mitigated by instruction, education, and preparation of patients by the mental health care professionals [26]. Further research on this topic in mental health care is recommended and could focus on the cocreation of further development of web-based patient access with patients [27].

NPT suggests that appraisal work needs to include communal appraisal if a technology is to become normalized, that is, for it to become an integrated aspect of the mental health care professionals' work routines. During the interviews, participants suggested various solutions to the struggles they experience with patients having web-based access to their medical health records. Individual mental health care professionals suggesting adaptions to the new service, so that it becomes a normalized practice, is in accordance with the reflexive monitoring component of NPT [5]. Mental health care professionals and the organization as a whole could work on these solutions to eventually embed web-based patient access in their daily work routines. For this to occur, mental health care professionals can discuss their concerns and struggles and cocreate solutions, such as the concerns and solutions expressed and suggested during the interviews [28]. The solutions mentioned in this paper could serve as a starting point but still need to be evaluated in practice.

Limitations

Our study has four limitations. First, our study focused on a specific organization in mental health care with the mental health care professionals involved all having a similar amount of experience with web-based patient access. Furthermore, not all focus areas within mental health care were represented. Therefore, some mental health care divisions, such as forensic psychiatry and primary mental health care, were probably underrepresented. Second, because all the participants actively responded to an open invitation to participate, there is a risk of selection bias. There is also a possibility that only early adopters of the patient portal participated in the interviews, given that the organization implemented the portal in January 2019, and the interviews were conducted in the spring of that year. It might be possible that the participants of this study were not representative of the population of mental health care professionals. However, the interview transcripts show that both proponents and opponents and some mental health care professionals with more neutral views took part in the study. Moreover, it is important to note that, given the very limited time between the implementation of the patient portal and our interviews, most of the worries expressed by the participants were not based on specific personal experiences with web-based patient access. It would be interesting to repeat this study to see whether the mental health care professionals have changed their minds or have experienced the struggles they expected and whether collective experience or evaluations had already occurred. A third limitation is that, apart from one participant in the focus group, the patient perspective was excluded. Further research is needed to explore how the doubts expressed in this study are experienced by patients. Finally, in the topic list, we choose not to explicitly ask participants to reflect on the four different components of reflexive monitoring according to NPT. In contrast, we chose to center the appraisal activities as articulated by the participants themselves. Future research is needed to validate our finding that systematization and communal appraisal are not the predominant components of reflexive monitoring by mental health care professionals.

Comparison With Prior Work

Research shows that patient access through patient portal empowers patients, meaning that patients feel more in control of their mental health care [2,12,29]. A pilot study involving 52 psychiatric patients gaining web-based access to their medical health record found that 82% of the included patients felt more in control of their own treatment because of the possibility of reading their treatment plans and medical notes and knowing what they could expect in their care process [12]. However, our results show that doubts remain as to whether mental health care patients can handle access to their own EHR. For example, our participants were afraid that patients might share their medical records with an unauthorized person or authority, which could make patients more vulnerable to people or institutions with conflicting interests. A recent review similarly raised this concern regarding patients autonomously handling medical information [30]. Another study found that a major barrier to redefining work practices of health care professionals through the use of patient portals in hospital care concerned privacy and security [31]. These examples support our finding that mental health care professionals are struggling to assess and understand the effect of web-based patient access for their patients and their work practices. Further research should confirm our findings and should look for more solutions to reduce the privacy and security concerns of mental health care professionals.

There is a moral dilemma if the benefits of web-based patient access are associated with an increase in patient vulnerability. This has its roots in the normative question of what is good. Is it good to aim for the benefits of web-based access and increasing empowerment, but possibly also resulting in an increase in patient vulnerability, or is it good to prevent an increase in vulnerability that involves withholding possible benefits? And, maybe even more importantly, whose decision is this to make? There are no universal answers to these normative questions, but it is important to recognize and discuss these dilemmas. The thin line between patient autonomy, patient empowerment, and patient vulnerability has been discussed in various studies on patient-centered care, as is evident from a discourse analysis on patient-centeredness, which indeed highlights that there are different views on what is good patient care [32]. Some consider patient-centeredness to be a process of empowering patients, implying that they believe patients should be given the possibility to view their medical data on the web. Withholding web-based access to medical information for vulnerable patients could be considered unethical in this discourse. Risks are recognized, but empowerment also helps patients to appropriately deal with the risks of web-based patient access. In another discourse, which we label caring for patients, people have a more paternalistic view of patient-centeredness and believe that health care professionals should protect patients from risks. Our results indicate that some mental health care professionals doubt that it is their task to protect patients from certain vulnerabilities. However, our participants also commented that not all patients are the same and that patients require tailored care. This reflects the being responsive discourse, which argues that patient-centered care is about meeting the specific and highly differing needs of patients. Individual mental health care professionals and organizations as a whole need to determine what patient-centered care means to them and how they want to deal with the moral dilemmas associated with patient access to the EHR. Communal appraisal can be arranged by organizing a moral deliberation, one of the ways to organize a dialog about the moral dilemmas of patient autonomy versus patient vulnerability [33].

As our results indicate, the protection of vulnerable patients might not only be the responsibility of mental health care professionals through individual appraisals. The literature shows that this can also be achieved through laws and regulations [34]. Patients gaining more control over their own EHR falls under the term informational self-determination, which is defined as “the ability of a person to determine, in principle, to what extent personal data is used and further disclosed, in view of a self-determined life” [34]. With an increase in informational self-determination, the risk of spreading medical information to parties who are not entitled to it increases. A possible solution could be to implement patient confidentiality, in which medical information managed by patients is legally protected [34]. Further research could explore the feasibility of this concept and look at ways to include mental health care professionals and modify their practices.

Research investigating patient access through a patient portal in hospital care has shown that patients’ interests and abilities in using a patient portal are influenced by various factors, including age, health literacy, and level of education [35]. Patients are more likely to use a patient portal if it suits their information needs and has the functionalities they require [35]. Our results show that a possible solution could be to introduce every new patient to web-based patient access with mental health care professionals, discussing with them the possibilities and the possible risks regarding privacy and their responsibilities. This would involve mental health care professionals in (1) collecting information in various ways, such as asking the opinions of patients and colleagues; (2) jointly evaluating how introducing new patients to web-based patient access would work; (3) individually experiencing if introducing every new patient to web-based patient access adds value; and (4) appraising, alone or with each other, if this way of working requires a redefinition of their registration and consultation practices, or even a change in the patient portal itself. In a recent study, some mental health care professionals believed that informing patients about the benefits and risks of reading medical notes was worthwhile [36]. However, in the same study, there were also mental health care professionals who were reluctant to inform patients about this because they feared negative outcomes. The study concluded that clear patient-professional communication about web-based access to medical information would prevent potential harm. However, another study concluded that introducing every patient to web-based access at the beginning of their treatment would be time consuming and might not be feasible [10]. Another option would be a web-based educational program for mental health patients to introduce them to web-based access. Indeed, one study argued that this may help empower patients and increase their active participation in their own care [37]. Another study found that a web-based course for mental health care professionals on web-based patient access in mental health care resulted in a reduction in mental health care professionals’ worries about web-based patient access and an improvement in aspects of patient-professional communication [37]. Further research is needed to explore the feasibility of these solutions as a way to modify the practices of mental health care professionals; researchers should also be open to other possible solutions, such as action research, because this can directly improve the embedding of patient EHR access because improvements can be made during the study [38].

Conclusions

This study provides insights into the appraisal work that mental health care professionals do to assess and understand patient access to their EHRs through a patient portal. Our study explores and describes the effects and struggles that mental health care professionals experience with patients having access to their EHR and how they individually experiment to redefine and modify their work practices. One new insight, not previously reported, is that mental health care professionals are concerned that their treatment plans might no longer be effective. In certain situations, such as when patients need acute care or are compelled to receive care, real-time patient access might lead to dangerous situations because patients act before mental health care professionals can carry out their treatment plan. Furthermore, our study signals a lack of systematization and communal appraisal. Our participants predominantly seem to individually appraise the effects of web-based patient access and how they can modify their registration and consultation practices. Future research is needed to investigate the ways in which systematization and communal appraisal can be stimulated.

In addition, future research could investigate the viability of the modifications in consultation routines and registration practices proposed by our participants. Finally, future research could focus on ways to involve opponents of web-based patient access in communal appraisal. The findings of this study can help researchers, project leaders, project staff, policy officers, and mental health care professionals to understand the process of embedding a new technology and the need for communal appraisal. To further improve working with web-based patient access, mental health care professionals need to be involved in evaluations and the further development of patient portals.

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Conflicts of Interest

None declared.

Abbreviations

EHR: electronic health record
NPT: normalization process theory

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MULTIMEDIA APPENDIX 1

Topic list interviews
Purpose
Risks of online access through a patient portal
Solutions to reduce risks of online access

Introduction
- Erasmus University Rotterdam
- Explanation of the interview (duration, transcript)
- Recording and privacy
- Drop-off
- Introduction on online access through a patient portal

Personal introduction

Patient portals in general
- Definition of a patient portal
- Actual functions of a patient portal
- Required functions according to participants
- Initial reaction on the implementation of online access
- Experience with online access

Performance expectation
- Added value of online access within mental healthcare (therapy adherence, clinical outcomes, communication, patient satisfaction)
- Impact of online access on activities (quality, productivity, efficiency)
- Time-saving due to online access
- Change in responsibility
- Use of online access within treatment, recommending use with patients
- Other concerns on the added value of online access
- Solutions for risks of online access within performance expectation

Effort expectancy
- User-friendliness of online access
- Learning curve
- Impact of online access on workload
- Questions on online access
- Other concerns about using online access
- Solutions for risks of online access within effort expectancy

Social influence

- Opinion colleagues
- Encouraging use of online access
- Attitude management when using online access
- Autonomy in use of online access
- Other concerns about social influence in online access
- Solutions for concerns about social influence

Facilitating Conditions

- Sufficient knowledge to use the patient portal (knowledge of legislation and rules, what should and what should not be written down in patient records, responsibility)
- Resources available to use the patient portal
- Integration with other systems
- Support
- Instructions for use
- Fits work style
- Other concerns about facilitating conditions for online access
- Solutions for concerns about facilitating conditions

Other concerns with online access

- Harming patients through online access
- Writing in the medical record as medical professional
- Positive effect of online access
- Negative effect of online access
- Concerns in practice

Forgotten or underexposed subjects
Experience interview
Focus group
End of interview

MULTIMEDIA APPENDIX 2

Topic list focus group
Purpose
Risks of online access through a patient portal
Solutions to reduce risks of online access

Introduction

- Erasmus University Rotterdam
- Explanation of the focus group (duration, transcript)
- Recording and privacy
- Drop-off
- Introduction on online access through a patient portal

Personal introduction

Patient portals in general

- Definition of a patient portal
- Actual functions of a patient portal
- Experience with online access

Risks of online access known in literature

- Increase in workload
  - Insufficient compensation
- Technical skills
  - Missing important information
- Responsibility
  - Data breach
  - Harmful behavior of patients
- Autonomy

Solutions for risks known in literature

- Way of writing in the medical record
  - Transparency towards the patient
  - Descriptive, non-judgmental and summarizing, emphasizing strengths
  - Psychiatric examination
  - Describe non-pathological qualities
- Involve patients in treatment
  - Involvement in online access, discussion about experience
  - Involvement in documenting in the medical record

Risks of online access experienced by medical professionals

- Workload
  - Fear of increase in workload
  - Spend more time on documenting in the medical record
- Outcomes
  - Doubts about effect on clinical outcomes
  - Harmful for patients
    - Old medical notes are also accessible
    - Overwhelming for patients
  - Treatment plans longer effective
  - No area for personal notes
    - Loss of information
    - Transfer with colleagues
- Therapeutic relationship
  - Psychiatric examination and documentation, interpretation
  - Explanation of notes when viewing a copy on paper
- Patient empowerment
  - Value of self-management
  - Privacy sensitive information
- Instructions and guidelines
  - Writing medical notes
  - Legal responsibility (data breach, harmful for patient)

Solutions to risks experienced by medical professionals

- Workload
- Personal work notes
  - Write information down as soon as it has been discussed
  - Shadow file, concept / final, other terminology “phimosis cerebri”
  - Insightful for colleagues
  - Way of writing notes
- Therapeutic relationship
  - Difference in experience and interpretation of patient / medical professional
  - Writing notes together
    - Difference in patients
    - Settling of information
    - Treatment time
- Patient empowerment
  - Involve in treatment
  - Privacy
    - Information, warning
    - Medical professional indicates what may be viewed by other authorities
- Instructions and guidelines

  - Guideline for writing medical notes from the organization
  - Guideline (legal) responsibility

Forgotten or underexposed subjects
Experience focus group
End of focus group

MULTIMEDIA APPENDIX 3

Analysis of keywords

Adoption process: implemented in consultation with mental healthcare professionals
Adoption process: way of registration
Adoption process: focus on technique
Adoption process: information on patient portal: flawed according to mental healthcare professional
Adoption process: getting used to
Definition patient portal: naming
Higher workload: by registering different
Higher workload: by criticism or questions from patients
Impact on patient-professional relationship: miscommunication
Impact on patient-professional relationship: complaints
Access rights: procedure
Access rights: role of caregivers or family members
Access rights: incapacitated patients
Solution: discuss what is being registered
Solution: delicate information marked as concept
Solution: discuss privacy concerns with patient
Solution: instructions from professional association
Solution: discuss access rights care givers
Solution: writing registration together with patient
Solution: stimulating usage among patients
Solution: further developments patient portal
Solution: sharing personal notes
Reaction patient: no need for online access
Reaction patient: still unclear
Reaction patient: unclear wish
Reaction patient: information was unclear
Reaction patient: varying
Challenges for patient: availability computer
Challenges for patient: digital skills
Challenges for patient: risk of anxiety
Challenges for patient: worries about privacy
Challenges for patient: worries about privacy: family issues
Challenges for patient: worries about privacy: parent-child issues
Change in registration: personal versus business style
Change in registration: linguistic
Change in registration: working hypothesis
Benefits: meeting patient information needs
Benefits: consultation preparation by patient

Benefits: no prospect of potential benefits
Benefits: increase in patient empowerment
Benefits: transparency
Benefits: patient contributes to health record
Benefits: patient is aware of agreements
Benefits: patients completes what professional has forgotten
Benefits: time saving: faster communication
Benefits: time saving
Benefits: therapy adherence

Chapter 4

Patients’ choices regarding online access to laboratory, radiology and pathology test results on a hospital patient portal

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ABSTRACT

The disclosure of online test results (i.e., laboratory, radiology and pathology results) on patient portals can vary from immediate disclosure (in real-time) via a delay of up to 28 days to non-disclosure. Although a few studies explored patient opinions regarding test results release, we have no insight into actual patients' preferences. To address this, we allowed patients to register their choices on a hospital patient portal. Our research question was: When do patients want their test results to be disclosed on the patient portal and what are the reasons for these choices? We used a mixed methods sequential explanatory design that included 1) patient choices on preferred time delay to test result disclosure on the patient portal for different medical specialties (N=4592) and 2) semi-structured interviews with patients who changed their mind on their initial choice (N=7).

For laboratory (blood and urine) results, 3530 (76.9%) patients chose a delay of 1 day and 912 (19.9%) patients chose a delay of 7 days. For radiology and pathology results 4352 (94.8%) patients chose a delay of 7 days. 43 patients changed their mind about when they wanted to receive their results. By interviewing seven patients (16%) from this group we learned that some participants did not remember why they made changes. Four participants wanted a shorter delay to achieve transparency in health-related information and communication; to have time to process bad results; for reassurance; to prepare for a medical consultation; monitoring and acting on deviating results to prevent worsening of their disease; and to share results with their general practitioner. Three participants extended their chosen delay to avoid the disappointment about the content and anxiety of receiving incomprehensible information. Our study indicates that most patients prefer transparency in health-related information and want their test results to be disclosed as soon as possible.

Keywords: patient portals, real-time access, online access, patient experiences, patient choices; mixed methods

INTRODUCTION

Patient portals are "provider-tethered applications that allow patients to access, but not to control, certain healthcare information (e.g., their EHR [electronic health record]) and provide communication and administrative functions (e.g., secure messaging, appointment booking, and prescription refill requests)" (p.2) [1]. Patients may or may not want to access their healthcare information, such as test results, on patient portals. Research has shown that patients' reasons for looking at online test results are 1) more transparent health-related information [2,3], 2) being able to prepare their consultation with a healthcare professional [1,4,5], or 3) reduce their anxiety [5]. Or they may wish to avoid accessing their test results online if they are anxious about the results [5] or if they are concerned about not understanding the results [6]. Despite a few studies on the reasons for accessing and not accessing healthcare information online, patients' preferences regarding when their results are disclosed on patient portals remain unknown [7].

Different healthcare providers disclose test results on patient portals at different time points. Patients may have immediate access to their results or they may need to wait several days. Published time delays for laboratory, radiology, and pathology test results range from immediate disclosure [8,9,10] to a four-day wait [11]. Some studies have reported immediate disclosure [12] or an unknown delay until disclosure [2] of laboratory results while other studies have reported time delays ranging from one to 14 days for the disclosure of radiology results [13, 14]. In another study three working days after the result was finalized was mentioned [15].

Patients' actual preferences on when their test results should be disclosed on patient portals have not been studied yet. This is interesting as these preferences are likely to differ. Victoor et al [16] stressed "There is no such thing as the typical patient: different patients make different choices in different situations." (p.13). While we are aware of the different time delays for disclosure of healthcare information on patient portals, we still do not know what the actual patient choices are and why [17]. Our research question was: When do patients want their test results to be disclosed on the patient portal and what are the reasons for these choices?

MATERIALS AND METHODS

Design and study setting

We used a sequential explanatory mixed methods approach [18] to understand patients' choices per specialty on when their laboratory, radiology and pathology results should be disclosed on a patient portal. The first part of our study was a quantitative study of data from a patient portal that included information on when patients wanted to receive their test results. The second part consisted of a qualitative study including seven semi-structured interviews of patients who changed their choices through the patient portal.

We divided the specialties into the following three categories to provide a structured overview of our results: 1) surgical specialties, 2) medical specialties, and 3) obstetrics and gynecology [19,20]. These categories are described further in Table 1.

Table 1. Categorization of medical specialties

Surgical specialties	Medical specialties	Obstetrics and gynecology
Anesthetics	Allergology	Obstetrics and gynecology
Ear, nose, throat[a]	Cardiology	
Neurosurgery	Dermatology	
Ophthalmology	Gastroenterology	
Orthopedics	Internal medicine	
Plastic surgery	Neurology	
Urology[b]	Pulmonary medicine	

[a] This specialty is not categorized by the OECD [19] and the WHO [20]. In the Netherlands, this specialty is surgical.

[b] We followed the categorization of the OECD [19] instead of the WHO [20]. In the Netherlands, this specialty is surgical.

We used the patient portal of a Dutch teaching hospital as a convenience sample (502,000 outpatient visits, 789 beds, 5,218 employees). The patient portal was launched in March 2018 and offers functions, including online access to medical files and test results, an overview of all hospital appointments, an e-consult service where messages can be sent to healthcare professionals, and a repeat prescription service. Patients can also use the portal to complete questionnaires, give permission for their medical file to be shared with third parties (e.g., their general practitioner), and can make, change, or cancel appointments.

Since October 2020, patients can use the portal to choose the delays for disclosure of laboratory test results (blood or urine sampling) or radiology and pathology results. Patients have the following choices: 1) see their results after one day, 2) see their results after seven days, 3) see their results after fourteen days, 4) see their results after twenty-one days, or 5) see their results after twenty-eight days, or 6) never see their test results. Radiology and pathology results are disclosed after seven days to enable healthcare professionals to discuss results with patients.

When a patient makes a choice, the portal shows a follow-up question: "You have entered X days, are you aware that you might see the results before you have spoken to your healthcare professional?" The portal also gives patients the opportunity to change their initial preferences for each test at any time.

1) Quantitative patient portal usage data on patient choices

The quantitative data set comprised information on all patient portal users who made either one or more choices on the portal regarding their laboratory and/or radiology and pathology results between October 2020 and April 2021. The independent variables collected of all patient portal users were age, gender, and initial preference for each test result. The dependent variable was the number of times the patient changed their mind about their initial choice for blood and urine, radiology and/or pathology test results.

Continuous variables were expressed as means ± standard deviations, medians, and minimums and maximums. Categorical variables were expressed as numbers and percentages. One researcher (WL) performed statistical analyses and differences between groups were deemed significant at a significance level of $p \leq .05$. For normally distributed data (parametric), numerical data were analyzed with an unpaired t-test and categorical data with a chi-squared test. Non-parametric data were analyzed using a Wilcoxon rank-sum test. We compared patients who did not change their initial choice with the group of patients who did change their initial choice. There were no differences found between the groups, so we used descriptive statistics to describe the patient portal users in all groups: 1) all patient portal users, 2) patients who did not change their initial choice, and 3) patients who changed their initial choice. All data were analyzed using R version 4.1.1 [21].

2) Qualitative interview data of patients who changed their choices

One researcher from the hospital (GS) invited 43 purposively sampled patients who changed their initial choice for an interview. Patients were invited by a letter explaining the study combined with an informed consent form. A reminder by telephone or e-mail was send after two weeks. The participants were offered a €20 gift card to participate. Of the 43 invited participants who changed their initial choice, seven (16%; two females, five males) responded, including one participant who changed his preferences more than once. Three of these seven participants changed their preference on laboratory, radiology and pathology results, three on laboratory results only, and one on radiology and pathology results only.

One researcher (PH) conducted semi-structured interviews with these seven participants following a predefined topic list (see S1 Appendix topic list). The interviews were conducted by telephone and took on average 32 minutes (range 24 to 48 minutes). The interviews were audio recorded and transcribed verbatim.

We generated codes using thematic data analysis [22,23]. First, one researcher (PH) became familiar with the data by reading the transcripts in depth and then open coded the transcripts. Next, two researchers (PH, AW) discussed the open codes until consensus was reached. Some codes clearly fitted together into a broader theme, so one researcher (PH) performed axial coding. For instance, the open code 'losing weight when sugar level rises' belongs to the broader theme 'acting on test results'. Finally, three researchers (PH, AMWJ, and BP) reviewed and modified themes until there was consensus on themes among the researchers.

Ethics statement

The Ethical Committee of Erasmus University approved our research proposal (21-027) and checked compliance to General Data Protection Regulation guidelines.

RESULTS

Measurements

Descriptive analysis: characteristics of patients

In total, 4592 patients (1643 males, 35.8% and 2949 females, 64.2%) participated by indicating when they wanted to get their test results. The mean age of male participants was 56.3±15.3 years (median 59 years; range 12–95 years) while the mean age of female participants was 49.5±16.0 years (median 46 years; range 12–92 years). The 50–59-years age category contained the most patients (986 patients, 21%). In total, 4592 patients registered 13,780 choices (including changed preferences).

There was no significant difference in the mean age of portal users who changed their initial preference (N=43; 50.3±15.4 years) and the mean age of portal users who did not change their initial preference (N=4549; 49.6±16.5 years) ($p = .76$). There was also no significant difference in the proportion of male patients between the group that changed their initial choice (40%; N=17) and the group that did not (36%; N=1638) ($p = .23$). Because age and gender distribution were not significantly different between the groups, we did not take these variables into account when inviting participants for interviews.

Patients (initial) preference choices

Patients made choices about test results from at least 16 specialties. To start, all patients (N=4592) made an initial choice, regardless of the specialty. The characteristics of patients making each choice are detailed in Table 2. For laboratory (blood and urine) results, 3530 (76.9%) patients chose a delay of 1 day and 912 (19.9%) patients chose a delay of 7 days for their results, indicating that most patients preferred quick access to their test results. Only a few patients never wanted to see their test results (0.4%) or after 14 or more days (2.8%) (Table 2.1). For radiology and pathology test results, 4352 patients (94.8%) chose the shortest delay of 7 days and only a few patients never wanted to have their test results (0.7%) or have their results after 14 or more days (4.5%) (see Table 2.2).

Table 2. Details of initial test result choices (N=4592).

2.1 Laboratory test results.

Choice	Ave. age (years)	Min. age (years)	Max. age (years)	Male	Female	Total	% of total
1 day	48.5	12	95	1200	2330	3530	76.9
7 days	53.8	12	88	384	528	912	19.9
14 days	56.4	17	86	30	39	69	1.5
21 days	59.6	28	76	3	11	14	0.3
28 days	44.1	20	75	21	26	47	1.0
Never	43.2	20	76	5	15	20	0.4

2.2 Radiology and pathology test results.

Choice	Ave. age (years)	Min. age (years)	Max. age (years)	Male	Female	Total	% of total
1 day	-	-	-	0	0	0	0.0
7 days	49.7	12	95	1157	2795	4352	94.8
14 days	49.8	17	86	46	92	138	3.0
21 days	54.2	28	75	3	11	14	0.3
28 days	44.9	20	81	25	31	56	1.2
Never	49.7	25	82	12	20	32	0.7

Characteristics of patients who changed their preferences

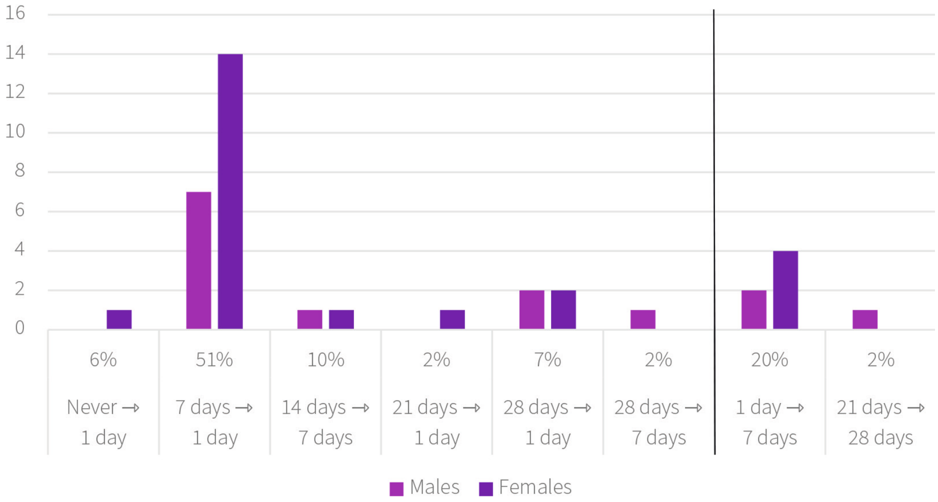
Patients were allowed to change their preference on when they received their laboratory, radiology and pathology results. In total, 37 patients (13 males; 24 females) made 60 changes to their initial preference for laboratory test results for at least 16 specialties (subdivided into surgical, medical, and obstetrics and gynecology) (see Table 3). Two male patients changed their preference twice, namely, for internal medicine (N=1) and for orthopedics (N= 2). Regardless of type of specialty, the results are comparable.

Table 3. Number of changes to laboratory test result preferences per specialty.

Specialty category (total changes)	**Total changes (% of total choices per specialty category)**	**Male**	**Female**
Surgical (2156)	21 (1)	8	11
Medical (2615)	22 (0.8)	9	12
Obstetrics and gynecology (532)	5 (0.9)	1	4
Unknown (1376)	12 (0.9)	4	8
Total	*60*		

Of these changes, 47 (78%) were for a shorter delay, and 31 of these (51%) were from 7 days to 1 day, see Figure 1.

Figure 1. Specific changes of choices for blood or urine test results.



Concerning the time delay for getting radiology and pathology test results, 15 patients (10 males; 5 females) made 38 changes to their preference for at least 14 specialties (including ear, nose and throat, ophthalmology, orthopedics, plastic surgery, surgery, urology, allergology, cardiology, dermatology, gastroenterology, internal medicine, neurology, pulmonary medicine, and obstetrics and gynecology) (see Table 4). There were minimal differences in preference changes between specialties. One male patient changed his preference twice for cardiology (N=1) and one female patient changed her preferences three times for dermatology (N=1); ear, nose and throat (N=1); gastroenterology (N=1);

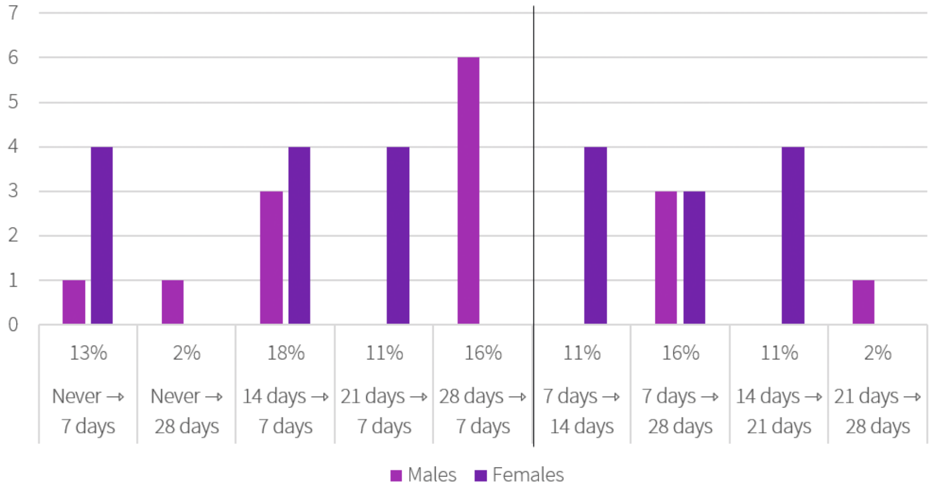
and plastic surgery (N=1). Strikingly, these two patients changed their preferences back to their initial preferences.

Table 4. Number of changes to radiology and pathology test result preferences per specialty category.

Specialty category (total changes)	Total changes (% of total choices per specialty category)	Male	Female
Surgical (1912)	14 (0.7)	6	4
Medical (2671)	20 (0.7)	6	9
Obstetrics and gynecology (532)	1 (0.2)	0	1
Unknown (1372)	3 (0.1)	1	1
Total	*38*		

Figure 2 shows that 23 patients (60%) preferred to get their test results quicker, seven (18%) of whom changed their preferences from 14 days to 7 days. Furthermore, 15 patients (40%) extended their time delay for getting their test results.

Figure 2. Specific changes of choices for pathology or radiology test results.



In sum, figure 1 shows that 47 (78%) changes were made for laboratory results to a shorter delay and 7 (22%) changes to a longer delay. Figure 2 shows that 23 (60%) changes were made for radiology and pathology results to a shorter delay and 15 changes (40%) to a longer delay.

Nine patients (6 males, 3 females, mean age 53.8 years) changed their preferences for both their laboratory and radiology and pathology test results at least once in at least 10 specialties (including surgery, ophthalmology, orthopedics, cardiology, dermatology, gastroenterology, internal medicine, pulmonary medicine, neurology, and obstetrics and gynecology). Table 5 shows how many patients changed their preferences for laboratory, radiology and pathology test results in each specialty category. Some patients changed preferences for both results for several specialties. Specifically, two female patients changed their preferences for both results in four specialties, one male patient changed his preferences for both results in two specialties, and four male patients changed their preferences for both results in one specialty.

Table 5. Changes in preferences for laboratory and radiology and pathology results per specialty category.

Specialty category (total choices)	Total changes (% of total choices per specialty category)	Male	Female
Surgical (2538)	6 (0.24)	4	2
Medical (5102)	8 (0.16)	3	5
Obstetrics and gynecology (1049)	1 (0.1)	0	1
Unknown (2738)	2 (0.07)	1	1
Total	*16*		

Reasons for changing initial preferences

Our quantitative analyses showed that most patients preferred to get their laboratory and/or radiology and pathology test results in the shortest time while a small number preferred to wait longer. We interviewed seven of those participants who changed their preferences to gain more insight into why their preferences changed. First, we describe our participants' experiences in choosing when to receive their laboratory, radiology and pathology results. Second, we describe how our participants' preferences changed. Third, we provide reasons for these changing preferences.

Making a choice

Most participants did not find it hard to choose when they preferred to receive their laboratory and/or radiology and pathology results and did not need any support in making their choices.

> *I didn't think much about it [red: choice option] at all. [R1]*

> *I thought about it for a while […] maybe when I visited the nurse, but I think if I look at things that I don't understand or want to know more about, then I can ask those questions. Again, a longer time, I didn't want that. So, it was easy for me to make that choice. [R2]*

Two participants found the warning before looking at the results helpful in making their decision. One participant said:

> *I think the comment on the portal, 'note you can see results before you have had a medical consultation', I think that's fine. [R5]*

All participants looked at their laboratory and/or radiology and pathology results alone or together with their partner (n=2) depending on the situation. One participant declared:

> *I'm just curious, I want to know as soon as possible. And when I'm reading and my partner happens to be around, he says 'oh let me read it too'. [R7]*

Our participants said that the option to receive radiology results online after 7 days had little value because of how the examination and consultation were organized. Participants explained they had a medical consultation in the hospital discussing the results of the examination on the same day of the examination. One participant said:

> *If you have had an ultrasound or have had an image [red: X-ray] taken, you usually have an appointment with the doctor right away, so you will hear about it anyway. For that kind of result, it doesn't really matter whether you have the option to know it right away or in fourteen days, because you always hear it that same day. [R1]*

Radiology test results are disclosed on the portal as written information. Some participants suggested that the images should be included on the portal to help understand the written results. Participants currently have to ask for their images at the reception desk if they want them. One participant explained:

> *And radiology, usually the text appears later I noticed. You can receive the image [read: X-ray], but you just must ask for it at the desk. They make a printout for you. [R1]*

However, during the COVID-19 pandemic, results were discussed on the phone instead face-to-face with the doctor. In this scenario, the option to receive radiology test results in the shortest time was useful to the participants because this meant they could look at the results during their medical consultation. One participant described the new situation:

> *Before the COVID-19 pandemic, I had an MRI and an examination in the morning and in the afternoon, I discussed these results with the neurologist and neurosurgeon. But during the pandemic, I had to appear for the examination at the hospital, but I only received the results by phone a few days or a week later. I don't like that. I hope that face-to-face consultations return [..] On the phone you are a bit overwhelmed by what you hear, good or bad, and then you don't ask questions so quickly. And if you meet a doctor […] they also show the visual display, and then you sit in front of it and then you keep asking. So, you say 'oh it's so big or small or changed', […] but you don't ask that on the phone. That is why you want to check those results online. [R7]*

The changes made

Our participants changed their preferences from the shortest time delay to longer time delays and visa versa. One participant changed his preferences more than once after experiencing that a longer time delay was not meaningful. He changed his preferences from as soon as possible to a longer delay and then back to as soon as possible:

> *I thought in the beginning, what's the point of it [red: 1 day disclosure for laboratory and 7 days for radiology and pathology], but I actually liked it anyway. You can prepare yourself a bit for the conversation with the physician who prescribed the examinations and otherwise […] you are in suspense of the results […] It was simply a wrong choice to change to the longer time delay. [R1]*

Four participants who had changed their preferences for the laboratory, radiology and pathology results could not remember doing so because it was too long ago. One participant declared:

> *It could be. But I don't know anymore. It's been over a year since I made that choice. [R3]*

Three of these four participants expressed that they would prefer to look at their results as soon as possible, indicating that they changed their initial preferences of a longer time delay to a shorter delay:

> *Well, I actually liked that I could look at the results as soon as possible. I do remember that I could tick that option. Because there was also one option that you could look at your results after you've been for a medical consultation. I deliberately did not choose this option. [R2]*

Reasons for the changes

Our participants had various reasons for choosing the shortest time delay for receiving their laboratory and/or radiology and pathology results on the patient portal. The first reason was the transparency of health-related information and communication about and with patients. For example, one participant explained:

> *It's about you. It's your file. It's not that it [red: information] stayed with 'the white coats' behind closed doors anymore. You can now look at it [red: your file] yourself. It's about you and your results. I'm just someone who wants to know what's going on. [R7]*

Second, choosing the shortest time delay gave the participants time to cope with bad results at home, before consulting the doctor in the outpatient clinic. One participant said:

> *[…] Imagine if I had read, it [red: residual tumor] has grown considerably, then I'm sure the doctor would have said: 'we have to irradiate again'. The moment I know I can already process that for myself in my head. […] Subsequently I can mentally cope with that a bit and mentally prepare myself for that again. And if that's the case, then I can handle it well. Because I can just say to myself, it's for your health, it's just a must, it's not fun and I'm just going to ask for more anesthesia or more this or that and then it will be okay. I'll have to let that sink in and process it for a while. The sooner I know such a result, the better it is. [R7]*

Third, looking at test results sooner reassured those patients who were worried about their results. One participant declared:

> *If you wait for your blood tests then you are damned busy with that, that there is nothing bad or whatever. And when you look at the results and see that the results all marked green, yes, that's a bit reassuring. [R6]*

Fourth, choosing the shortest time delay for laboratory and/or radiology and pathology results gave participants time to prepare for the medical consultation with their doctor. One participant explained:

> *I like that. They [red: doctors] always look at the same thing, I always like to see how the situation is, so then I know, it is neatly indicated whether those values are too high or too low. Then you actually know it prior to the consultation with the doctor, which is a week afterwards. What will happen and what can I do about it. [R1]*

Fifth, choosing the shortest time delay allowed patients to monitor their results and act on them. One participant described how fast online access to his results was preventive. For example, he immediately started to lose weight when he found out that his sugar level had risen:

> *I can now compare my results to the last time. And it [red: the portal] also shows between which values my blood results should be. For example, between what value your sugar level should be, whether the result is on average, below or above it. As a non-medical person, I can follow it myself. […] but I know that if I let go of the reins, those values go up. When I see that my values are rising, I know that I must tighten up the regime. [R3]*

The last reason for choosing the shortest time delay for laboratory and/or radiology and pathology results was to learn more about what the results mean by monitoring and sharing them with the general practitioner. One participant explained that she learned a lot from the values on the patient portal by monitoring the results, asking questions, and taking the results to her general practitioner for more insights:

> *For example, you can study what is changed. There is a graph with it [red: lab results] and you can see if everything is good. But I should also have to do a blood test at the doctor's office for cholesterol levels and then I saw that on the portal of the hospital that the values deviate very much from one and the other. I just learn a lot from it. At the hospital my values were good and at the general practitioner my values were just way too high. And then I could ask all my questions about that. Subsequently you just know and otherwise you don't know those kinds of things. [R2]*

> *I think that's really great, because I can take the test results, e.g., my cholesterol, to my general practitioner, that's nice. [R2]*

Some participants chose a longer time delay for receiving their laboratory and/or radiology results. Two participants changed their preferences from the shortest time to a longer delay (28 or 7 days) for two reasons. First, one participant remembered the first time he looked at the patient portal and felt very disappointed by the lack of profound information on there:

> *At that moment I was very disappointed. You gain access to the portal. You will see some information, where you have appointments and things like that. But there is no profound information. What was discussed with the doctor was not in it [red: the portal]. That is probably contained in a certain note that is not transparent, so to speak. Additionally, what is insightful were my blood results. As time goes by, you also notice that the portal is filled with*

> *old information from the past. This information is nice, but no longer relevant. […] at that moment what I wanted to find; I couldn't find. [R4]*

Second, participants opted for a longer delay because information on the portal was incomprehensible. It was incomprehensible because the text contained a lot of medical jargon and the lab results were not presented with contextual information, such as what is normal. Two participants tried to understand their results by searching on the internet, but did not find any explanations they could understand. In the end, they stopped doing this because the information they found just made them anxious. One participant illustrated:

> *I concluded 'do I want this?' […] I remember looking at a value that was marked red […], then I searched on the Internet and I found a story that I couldn't do anything […] Then I thought, I really shouldn't search anymore, I just have to trust the doctor, who knows hundred times more about this [red: values] than I do, so I just have to wait for the doctor. I was naive about it, and I thought I have a look and then it [red: all the information] was a lot for me to take in. [R5]*

Despite changing their initial choice to a longer time delay, these participants valued that their health-related information was transparent and said that they now preferred to see their results directly after the medical consultation with their doctor.

> *Looking back at your values is nice, because you can look for something specific in terms of values, and compare them to how they were before. [R5]*

DISCUSSION

We studied the choices patients made about receiving their laboratory and/or radiology and pathology test results on a patient portal and their reasons for changing these initial preferences. Our findings show that most patients preferred the shortest time delay for receiving their laboratory and/or radiology and pathology results (Table 2). We also found that a small number of patients preferred a longer time delay for their results (Table 2) and that some patients changed their initial preferences (N=43). Interviews with these patients gave more in-depth insights into these initial choices and why their preferences changed. Our participants did not find it hard to make decisions about when they wanted their test results to be disclosed and did not need or want support in making this choice. Moreover, most of our participants looked at their test results alone.

Our finding that most patients want to see their test results as soon as possible is in contrast to the results of Bruno et al [24], who found that most patients prefer a time delay before receiving sensitive test results (such as a diagnosis of Alzheimer's disease, fetal miscarriage, and cancer) but not for less sensitive test results (such as a diagnosis of high cholesterol, strep throat, genetic disease, and sexually transmitted disease). A possible explanation for the differences between our findings and those of Bruno et al [24] is that Bruno et al [24] asked the participants for their opinion in a survey rather than giving them the option to make the actual choice. In line with our findings, another qualitative study showed that 30 patients with cancer were in favor of real-time disclosure of test results and did not want to wait for their test results because this caused more anxiety than accessing the results [4].

In contrast to our result that patients prefer real-time disclosure of radiology results, Cooper et al [13] showed conflicting findings on patient's views on the real-time disclosure of radiology results. These differences vary from preferring real-time access or preferring looking at results when the medical consultation took longer than 6 days, or even after 11 days waiting for a telephone call from the doctor [13]. These differences may be explained by differences in timing of the medical consultation. This is in line with our finding that patients prefer real-time disclosure of their radiology and pathology results when their medical consultation with the doctor takes place on the same day of the examination.

We identified various reasons why patients prefer the shortest time delay for disclosure of their test results. First, our patients wanted their health information and communication to be transparent, which is in line with the findings of multiple other studies [2,3,5,7,25]. Second, our patients wanted time to process bad results at home, which was also reported in another study [4]. Third, patients want to see their results quickly for reassurance, which was also found in a systematic review on the impact of patient access to medical files [5]. Fourth, our patients wanted to know their results so they could prepare for their medical consultation, in line with the findings of other studies [1,4,5,9]. Fifth, our patients wanted access to their results so they could monitor and act on them if need be, in agreement with the results of a mixed method study on real-time disclosure of test results for increasing engagement and care utilization of patients with diabetes [9]. Finally, our patients wanted to learn about their results and share them with their general practitioner. This learning aspect is in line with findings of Rexhepi et al [4], but our finding that patients want to share results with their general practitioner is novel to our study.

Based on our findings and those of previous studies, we generally recommend that (hospital) policy makers allow laboratory and radiology results to be disclosed on patient portals as quickly as possible. Although some of our participants lengthened their initial preferences. Remarkable four of these could not remember changing their initial choices, so this may not reflect a true change of preference. Some participants described how emotional concerns, such as disappointment and anxiety due to information on the patient portal being incomprehensible, motivated them to extend their initial choices to a longer time delay. In agreement with this finding, other studies have reported that anxiety and incomprehensibility are negative experiences for patients [5,9,10].

Despite these negative emotional experiences, participants who extended their initial preferences to a longer time delay did appreciate that their health-related information was transparent and accessible. Furthermore, these negative experiences can be avoided by informing and instructing patients and by being transparent upfront about real-time disclosure of test results [7,10]. Besides having information, patients need competences to understand the options of the various choices or need help from the healthcare professionals [26].

The negative experiences of real-time disclosure seem to apply to a small number of patients. The same negative emotions also make healthcare professionals reluctant to disclose test results on the portal in real-time. Healthcare professionals in outpatient clinics are concerned about patient anxiety and health-related information on the patient portal being misunderstood [3,6,9]. Previous research has shown that doctors prefer to give patients their radiology results directly at the consultation rather than disclosing them first on the portal [27], probably to avoid these negative experiences.

Our findings support the importance of comprehensible information on the patient portal, because our participants experienced the patient portal as incomplete and incomprehensible as not all health-related information is accessible. For example, patients prefer to see images instead of just text when accessing their radiology and pathology test results. In agreement with our finding, Cabarrus et al [28] found that 85% of respondents wanted access to their images and radiology reports, even though they were difficult to understand [6,13,29]. A recent study showed that plain language definitions and diagrams helped patients to understand their radiology results [29] and Garry et al [15] have called for further research to evaluate how disclosure of test results affects patient understanding of these results. Crameri et al [30] have also called for more research on patients’ preferences and needs because patient portals are still not being used to their full potential.

Conclusions

Our findings show that most patients prefer the shortest possible delay for disclosure of their test results on a patient portal. Reasons for wanting immediate access to test results included a desire for health-related information to be transparent; having time to process bad results at home; reassurance; preparation for medical consultations; monitoring and acting on deviating results to prevent worsening of disease; and learning from the results and sharing them with the general practitioner. A small number of patients preferred a longer delay because they were concerned about the disappointment and anxiety they will feel if the information disclosed on the portal is difficult to understand. In conclusion, our study indicates that most patients want their health-related information to be transparent and disclosed as soon as possible.

Limitations

Our study has several limitations. First, our qualitative analyses involved a small sample (N=7, response rate 16%), and more participants are needed to gain more insights into patient preferences. We only interviewed participants who changed their initial preferences (7/43 of in total 4592 participants) to gain more insight into why their preferences changed. We suggest studying especially participants who made an initial choice for a delay of more than 7 days (laboratory results) or more than 14 days (radiology and pathology results), to understand more about their initial choices in a follow-up study. The participants provided us with rich information on their reasoning and helped us to understand how they chose and why they would like to change their initial choice. We did not study their initial choice, which could add more insights. Non-participants provided reasons for not-participating not connected to the aim of our study, e.g., they had no time, no interest in the topic, or no recollection of their choices. However, our findings should be generalized with caution. Future research would add further valuable insights into for example, patients' opinions on their initial preferences, especially on their reasons for choosing a longer delay. And further research, particularly from other healthcare sectors such as mental healthcare, would probably lead to different results than those reported here, as Van Rijt et al [31] point out at the particular challenges of access to healthcare information in crisis situations. A final limitation is that we only evaluated patient perspectives and not those of the health care professionals.

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S1 APPENDIX

Topic list

Target group: patients who changed their initial preferences on laboratory (blood and urine), radiology and pathology test results and on the patient portal.

Open questions about the patient portal and test results	• How long have you been using the patient portal? • How did you learn about the existence of this portal? • How did you learn about the existence of online access to test results on the portal? • How were you informed about online access to test results through the patient portal? ◦ Informed? What do you think of this way of informing? ◦ Not informed? How would you like to have been informed about viewing your test results? In what way/by whom? • What do you think of being able to view your research results online through the portal? • How often have you used the portal to view your test results? • What are your experiences with viewing your test results online? • What do you think is an advantage? Can you give an example? • What do you think is a disadvantage? Can you give an example? • What did you do with the information that you read on the portal? • Do you remember the first time you looked at your test results on the portal? Can you tell me how that was? Where you alone or with others? Was that a conscious choice? How did you experience that? • How understandable did you find the information you read? ◦ Understandable? What did you do with this information? How did you feel about it? ◦ Incomprehensible? How did that happen? How did you feel about that? What should be done to make the information understandable for you? What have you done with the information you read on the portal?

Open questions about the options of online access

Since October 2020, you can choose within which timeframe you want to view your test results on the patient portal (1,7,14, 21, and 28 days or no access).
What do you think of being able to choose from different options to view your test results?
How do you feel about being able to choose different options for both laboratory results and radiology/pathology results?

- How were you informed about these options on the portal?
  - Informed? What do you think of this way of informing?
  - Not informed? How would you have liked to be informed about viewing your test results? In what way/by whom?

- May I ask what you have entered in terms of delay time for laboratory results? (1, 7, 14, 21, and 28 days or no online access)
- What are your main reasons for choosing X number of days of delay?
- How did you make this choice?
- How did you feel about making this choice?
- Did you think about the choice for a long time or not? Can you explain that?
- Did you receive help/guidance in making this choice?
  - Yes? In what way/how? How do you look back at the help/guidance?
  - No? Did you need help/guidance? And can you tell me what you would have liked?

- What do you think of the options for the laboratory results: 1, 7, 14, 21, and 28 days or no access?
  - Why good? Can you give an example?
  - Why bad? Can you give an example?
  - What needs to be changed or improved?

- May I ask what you have entered in terms of delay time for laboratory results? (7, 14, 21, and 28 days or no online access)
- What are your main reasons for choosing X number of days of delay?
- How did you make this choice?
- How did you feel about making this choice?
- Did you think about the choice for a long time or not? Can you explain that?
- Did you receive help/guidance in making this choice?
  - Yes? In which way/how? How do you look back at the help/guidance?
  - No? Did you need help/guidance? And can you tell me what you would have liked?

- What do you think of the options for the radiology/pathology results: 7, 14, 21, and 28 days or no access?
  - Why? Can you give an example?
  - What needs to be changed or improved?

	Possible questions (depending on whether there is a difference in choices) • *There is a difference in the choices you have made for the laboratory results and radiology/pathology results. I heard that you want to see your laboratory results [as soon as possible] and in radiology and pathology after [14, 21, 28 or not] days. How did you make this choice? / What is this choice based on? Why is there a difference in the number of days?* • *There is a difference in the choices you have made for the laboratory results and radiology/pathology results. I heard you want to see your radiology and pathology results within 7 days (earliest possible) and your laboratory results after [14, 21, 28 or 0] days.* • *How did you make this choice? / What is this choice based on? Why is there a difference in the number of days?*
Open questions regarding to changing preferences	You have changed your preferences. Do you want to tell me which preferences you have changed in the portal? • For laboratory or for radiology/pathology results? • Can you tell me why you changed your choice? • What do you experience as an advantage that you can now view the results after X number of days instead of Y number of days? • Can you give an example? • What do you experience as a disadvantage that you can now view the results after X number of days instead of Y number of days? • Can you give an example?

Chapter 5

Patient discourses on real-time access to test results via hospital portals: a discourse analysis of semistructured interviews with Dutch patients

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ABSTRACT

Objective

Real-time access to test results on patient portals can have advantages and disadvantages for patients. It confronts patients with a complicated decision, namely whether to consult results before the medical consultation. To gain a deep understanding of patients' decision-making processes, we unravelled three discourses about real-time access to test results, each of which articulates a different set of values, assumptions and arguments. Our research question was what patient discourses on real-time access to test results can be distinguished?

Design

We conducted discourse analysis on 28 semistructured interviews.

Setting

Interviews were conducted with patients who had (no) experience with real-time access to test results. Our participants were treated in different hospitals, and therefore, used different portals since Dutch hospitals can choose from suppliers for their patient portals.

Participants

Patients with experience (n=15) and without experience (n=13) of real-time access to test results on a patient portal.

Results

We identified three discourses: (1) real-time access as a source of stress, which highlighted how real-time access could cause stress due to the complexity of deciding whether to access test results, the incomprehensibility of medical language and the urge to repeatedly check if test results were available, (2) anxiety reduction through real-time access showed how real-time access can reduce stress by reducing waiting times and (3) real-time access for self-management showed how real-time access can give patients an opportunity for self-management because they can make informed decisions and are better prepared for the medical consultation.

Conclusion

Our study shows the plurality in opinions on real-time access, which helps in forming different strategies to inform and support patients in order to realise optimal use of real-time access.

Keywords: patient portals, real-time access, online access, patient experiences, patient-centeredness, discourse analysis

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We conducted semi-structured interviews over time with 28 participants who provided a comprehensive overview of opinions and experiences on real-time access to test results.

- Three researchers conducted a thorough theory-informed coding process that led to a deeper understanding of the phenomenon under study.

- Our sample might be biased since we used the snowball method for recruitment.

- However, the sample is well-balanced since we interviewed patients both without (n=13) and with (n=15) experience with real-time access to test results.

- Participants often referred to 'other people' instead of sharing their own views/experiences which might potentially affect the validity of our findings.

INTRODUCTION

Patient portals can be defined as *"provider-tethered applications that allow patients to access, but not control, certain health care information (e.g., their electronic health record) and provide communication and administrative functions [...]"* (p.2) [1]. Accordingly, a patient portal offers three services to patients: 1) health-related information from one provider (eg, a healthcare organization), 2) organizational information of this particular provider, and 3) communication with the healthcare professionals of this provider [2-5].

One of the most popular patient portal services is providing health-related information such as test results [6-9]. National digital health patient portals vary by country, as do the requirements for disclosing test results [10]. In the Netherlands, healthcare providers can decide when patients can access test results on the portal. A recent scoping review shows this is still an important topic [11]. Providers can choose to disclose results in real time (immediate release) or after a delay (up to 28 days) [12-17]. This decision presents challenges for patients and professionals. If the provider chooses to disclose test results in real time, the patients can see their results before consulting the doctor, which might cause negative experiences like anxiety and incomprehensibility [14,15,18,19] or positive experiences like reassurance [18], a sense of ownership over their results [7], and better preparation for the medical consultation [1,14,18,20].

Multiple scholars have studied the advantages and disadvantages of real-time access to test results on a patient portal for patients and healthcare professionals. The literature identified three advantages. First, patients are better able to process their test results at home and prepare for the outpatient consultations with their healthcare professional [18,20-22], e.g., by preparing questions [14,21]. Second, patients develop a strong sense of ownership in relation to their results because they can decide for themselves when to access them [12] and become more informed prior the medical consultation [12,14,23]. This enhances shared decision-making with their healthcare professional [13]. Third, patients can review their results and contact their healthcare professional earlier if their results are abnormal, which enhances patient safety [12]. A disadvantage could be that patients may find it difficult to interpret their test results [12-14,24] potentially leading to (unnecessary) anxiety [12,14,15,23,25], stress [22], and confusion [15].

These advantages and disadvantages signal that deciding when to disclose test results is not a simple technological choice made by the healthcare provider and/or the patient. Instead, the possible advantages and disadvantages, which influence patient involvement, patient safety, patient empowerment, patient-centered care, and patient satisfaction, must be considered. Literature has shown that looking at test results before an outpatient consult allows patients to better prepare questions for their consultation [14,18,21]. At the same time, real-time access could cause anxiety if the information shared is misunderstood [15]. Therefore, the timing of test result disclosure is ambiguous and needs careful consideration [26]. A thorough exploration of how patients construct real-time access and how they make their decision is therefore interesting and relevant.

In a systematic review on engaging patients in their own care process using eHealth, researchers concluded that a profound understanding of patients' experiences with eHealth technologies is often not achieved, despite its importance [27]. Similar difficulties have been experienced with research into real-time access to test results. Studies have used questionnaires [15,20], literature reviews [12], discussion papers [12,23], quantitative data from a patient portal [28], reported incidents by healthcare professionals, patients' complaints at the complaint commission and portal helpdesk [15] or mixed methods [11] to investigate this topic. Still, little is known about the expectations, experiences, and emotions of patients in relation to their norms and values [11]. Consequently, we have performed a qualitative study of how patients construct real-time access to test results.

A discourse analysis of scientific publications on patient-centeredness signals how patient norms, values, and constructions of 'good care' influence their attitude toward eHealth technologies [29]. Consequently, we decided to perform a discourse analysis of the in-depth interviews we conducted with patients on their feelings, thoughts, expectations, and experiences of real-time access to test results in relation to their view of patient-centered care. To the best of our knowledge, a discourse analysis of interviews with patients on real-time access to test results on a patient portal has not been conducted. A discourse can be defined as *"an interrelated set of texts and practices that bring an object into being"* (p. 3, Parker, 1992) [30]. This microlevel discourse analysis gave us a deeper understanding of the feelings, thoughts, expectations and experiences of real-time access to test results from a patient perspective. The benefit of a discourse analysis is that it helps us understand patients' perspectives on real-time access by studying them in the broader context of their lived experiences and their views of what patient-centered care entails [31].

Discourse analysis can reveal the differences in patients' experiences, thereby revealing how reality is produced within the patient context, and how this reality influences the patient's understanding and actions [30,32]. In addition, it helps to investigate the practical consequences of different discourses on real-time patient access [33,34] in two ways. First, it highlights the different policy options and their implications during policy development for healthcare providers. Second, it shows how the design of technologies, healthcare processes, and information materials can help patients and healthcare professionals to make decisions about real-time access. Besides investigating practical consequences, the aim of our study was to obtain a deeper understanding of patients' feelings, thoughts, expectations and experiences of real-time access to test results in relation to their view of patient-centered care. Our research question was what patient discourses on real-time access to test results can be distinguished?

METHODS

Study design

We conducted a microlevel discourse analysis to obtain a deep understanding of what real-time access means to patients [30,31,35,36]. A discourse analysis uncovers how social reality is produced, unlike other qualitative methodologies which try to understand or interpret social reality as it exists [30]. Discourse analysis also shows the problems and possibilities created by different discourses, allowing us to weigh their practical consequences [34]. We conducted 28 semi-structured interviews with patients who had or did not have experience with real-time access to test results on a patient portal. We conducted the first interview on 5 March 2018 and the last interview on 2 June 2021. This relatively lengthy data collection period reflects the time frame during which access to test results became increasingly available in the Netherlands.

Patient and public involvement

The principal investigator (BP) of this study was involved in a national program in the Netherlands in which patients articulated their struggles with real-time access to test results [37]. Based upon these results this study was drafted. Patients helped to recruit patients for this study through the snowball method and thereby patients helped us find new participants for this study (also see next paragraph). We plan to disseminate the findings of this study via the Dutch Patient Federation.

Participants and data collection

In the Netherlands, commercial information technology suppliers sell patient portals to Dutch hospitals. The hospitals can choose from suppliers for their patient portals, as long as the supplier complies to national standards (e.g., MedMij) [38]. Our participants were treated in different hospitals so used different portals. These portals had different functionalities, but all offered online access to health-related information and test results.

The inclusion criteria were patients who: 1) had visited an outpatient clinic in a Dutch hospital, 2) were 16 years or older, and 3) had used or not used a patient portal to obtain real-time access to test results.

The researchers involved in this study are trained and experienced (AMJWMW-J, KA and BP) or were in training (PH and MB) in qualitative research. Moreover, the principal investigator of this research (BP) gained her PhD on generative discourse analysis [39]. All researchers are well-informed about patient participation in care processes and (healthcare) organizations.

We used purposive and snowball sampling to find participants. We aimed to select patients with and without experience of real-time access to test results. Three researchers (PH, MB and BP) began by approaching their own networks [40], calling potential participants to explain the study and inviting them to an interview. At the end of the interviews, we asked participants if they knew other patients we could interview (snowball method). In total, we included 28 participants (see supplemental file 1, Table 1 participant characteristics).

Aiming for a broadly inclusive participant sample [31] we included participants both with and without (never accessed) experience of real-time access to test results online. We felt it important to include diverse patients to understand the thoughts, expectations, needs, and wishes of patients without experience. We began interviewing participants without experience in March 2018. At the time, few Dutch healthcare organizations offered real-time access to test results [21]. We stopped interviewing when we reached data saturation (i.e., new data no longer provided new insights) at which point we felt the sample of patients without experience was adequate [41]. Two years later, more healthcare organizations offered real-time access, which in April 2020 enabled us to begin interviewing participants with experience. Again, when we reached data saturation in June 2021, we stopped interviewing. In total, we interviewed 13 participants without real-time access experience (8 females, 5 males) and 15 participants with real-time access experience (10 females, 5 males).

Two researchers (PH and MB) conducted 28 semi-structured interviews with the participants according to a predefined topic list that was based on the literature outlined in the Introduction section. We developed two topic lists: one list for participants without real-time access experience asking about their expectations (see supplemental file 2) and one list for participants with real-time access experience asking about their experiences (see supplemental file 3).

The interviews were conducted at a participants' preferred location or via video or phone during COVID-19 period. At the start of each interview, we introduced ourselves, repeated the information on research aim, research methods, and asked again for informed consent. The interviews lasted 45–60 minutes, were audio recorded and transcribed verbatim.

Data analysis

We analyzed data from participants with and without real-time access experience separately, as two data subsets, and checked for overlap and differences. We found no relevant differences between the two groups with regard to their discourses on real-time access to test results via a patient portal. Therefore, we continued to analyze the whole dataset as one. The analysis consisted of three steps [35,42]. First, one researcher (PH) searched for the three entities that are constructed in a discourse: objects, concepts, and subject positions [35]. Objects are part of a practical order and exist in real life, such as the patient portal, healthcare professionals, and patients in this context [35]. In contrast, concepts exist only as ideas [35] and show how patients construct the concept of real-time access to medical information on the patient portal and what they think about roles and responsibilities. Subject positions are assigned places in the interaction hierarchy and illustrate the power dynamics of relational processes (who was allowed to do what, who determined what, and who did what) [35]. For example, think of a patient who is expert on his or her own disease and who accesses their real-time available test results for self-management purposes, which in turn influences the role of the healthcare professional, namely like a coach [29]. During this coding process, attention was paid to texts about responsibilities, rights, and duties of both patients and healthcare professionals.

Second, two researchers (PH and BP) further coded these codes axially, including the advantages and disadvantages of real-time access described in the literature (see the 'Introduction' section) and the themes described by Pluut [29] (eg, the themes for the discourse 'caring for patients' were 'vulnerability' and 'healthcare professional decides on follow-up'). Any disagreements on codes were resolved by the researchers discussing them until consensus was reached.

Third, one researcher (PH) identified the most common codes for each theme by reading and analyzing the transcripts and codes repeatedly. The coherence among themes was then analyzed and discussed with three researchers (PH, AMJWMW-J and BP). This discussion led to a deeper understanding of the phenomenon under study as we critically examined our own assumptions on the topic during the discussion sessions. In this way, the "interrelated set of text and practices" (p. 3, Parker, 1992) [30] gave meaning to the discourses on real-time access.

RESULTS

We found three discourses on real-time access: 1) real-time access as a source of stress, 2) anxiety reduction through real-time access and 3) real-time access for self-management. Most participants talked from a dominant discourse, which means they explained their construction of real-time access to patient portals based on the main themes and arguments of one discourse. At the same time, patients can draw from different discourses when expressing their feelings, thoughts, and dilemmas about real-time access to test results on patient portals.

Discourse 1: Real-time access as a source of stress

Real-time access as a source of stress frames real-time access as a potential stressor caused by various reasons. First, patients can feel stressed because of the ambivalence they have about the option of accessing their test results before the medical consultation or not. Within this discourse, patients both see the opportunities and risks, and find it difficult to predict whether reading their test results before the consultation will help them or cause more stress. Participants sometimes changed their minds on real-time access during the interview, or simply said they did not know what to do. This is illustrated in the following quotes from one participant, which show how their opinions changed as the interview progressed:

> *Well, I don't know if I should check the results right away or if I should first wait for the conversation with the doctor. Then you see something, but then you don't quite know what it is yet. [...] [R1]*

> *Yes, because that tumor in the bladder: it was huge, and you saw blood. That was all you saw. Of course, they [healthcare professionals], who took the image saw more. No, I think I would just wait for the physician. [...] It doesn't make me any wiser and I think it makes me more anxious. That I know the result and then I can do nothing with it. [...] [R1]*

> *Well, if it's on there [read: the patient portal], I guess I'm curious enough to look anyway. I can't really say that I wouldn't. [R1]*

Another participant who had experience with real-time access, but not with sensitive results, explained her doubts about the opportunities and risks of real-time access. She was quite relaxed about accessing some of her past results but did not know what to think about more sensitive results:

> *I can also read on how my results were a year before. It is not very exciting for me. If I'm waiting for a sensitive result, I would be nervous thus I am going to look at the results real-time or not? Then you want to know, but how are you going to read it? [R27]*

The second stress source mentioned by our participants was the medical language use on patient portals. Within this discourse, medical language was constructed as a source of stress because participants were worried about interpreting texts incorrectly. One participant said:

> *It is good that test results are available, but as laypersons we are not directly aware how to interpret the results. The danger is that if you are in a long process – cancer or something – tumor marker, such a result can put someone on the wrong track. Those results could take on a life of their own. [R24]*

During the interviews, participants commented that test results on the portal are not comprehensible enough. They said that it would be good to add some kind of explanation on the portal to avoid misinterpretation of the test results. One participant with experience in real-time access said:

> *Now, for example, if the result is too high or too low, it is not reported that these values can be interpreted differently. It would be nice if they [read: patients] get a little explanation in the portal and I don't get that now. I'm smart enough to think about it carefully, but I understand that it can be a barrier for other people. [R18]*

Participants also reported that it was quite easy to find information about severe diseases on the internet that could lead them to interpret their test results incorrectly, leading to unnecessary stress. One participant without experience in real-time access said:

> *Because then I think 'oh I don't know something', so I look up (on the internet) what it is. But I do know that can be a big disadvantage. That you often find worse things. [R12]*

The third source of stress was looking repeatedly on the portal to check if the results were already disclosed.

> *It has been said that there will be a result within ten days and then people will check it to see if the results are really on the portal within ten days. And that these people do not do anything with that result, but just check whether they are still receiving attention of the doctor. I get that idea from it. A friend told me about her father: every day I'll check three times because the doctor said, 'within 10 days the result will be on the portal'. So how much unrest can you have in your head for yourself? Looking so dramatically every time if the result is on the portal, how does that affect your life? [R19]*

This quote illustrates how having access to test results can evoke stressful checking behavior that can last for days until the test results are disclosed.

At the same time, patients that constructed real-time access as a source of stress did seem to appreciate the transparency in health information. One participant (who had not had experience accessing their results in real time) identified real-time access as 'a good thing' and said it was nice to be informed about their health, even though the doctor is considered to be the expert.

> *Real-time access is of course good; I am in favor that you can look at such a website and that you then see what is going on. Then you see what's going on, but now imagine that there is something serious. At that moment you cannot ask [the doctor] what it is exactly. It's nice that you can see the result when it's good, but when it's bad and you can't have a conversation with the doctor […] I think you would like to know what the result is, so I think I will look. Only when it's good, then you're relieved. But if it's not good news,*

> *then I think, maybe I shouldn't have done that. But if you have a conversation with the doctor within a short time, they can give the necessary information. Then I would choose to look. [R8]*

Some participants said they would prefer to get their results after their consultation to avoid stress caused by deciding whether or not to look at the portal, by not understanding medical terms, and by the danger of repeatedly checking the portal. These participants would rather use the test results disclosed on the portal as a record of what was discussed with their doctor.

> *Put the results on it [read: portal] if there has been an interpretation of the results in a consultation with the doctor. Then it is an addition to the consultation. [R24]*

Participants also suggested ways to reduce the stress that comes from wondering whether to look at the test results before the medical consultation or not. They argued that informing patients about the advantages and disadvantages of real-time access to test results would help them decide whether to access their test results. They also suggested a conversation about real-time access with a professional could reduce stress. This plea is illustrated in the following citations from participants with experience in real-time access to test results:

> *If the hospital offers this kind of portal, they will also have an intention for a better patient experience or something like that. I also think it would be useful if the hospital informs their patients about this. Otherwise, you might as well not offer a portal. [R28]*

> *Well maybe a conversation before the examinations start, like: 'We have this portal, you can read all of this [on it]. Which do you prefer, that the result is discussed with you first or that it can be read immediately?' [R19]*

This discourse shows that participants appreciate transparency in health-related information. Within this discourse, participants framed the healthcare professional as the expert and the one with the medical knowledge. The disclosure of test results can cause stress for patients in three ways: 1) through the complex decision on whether or not to look at the test results before the medical consultation, 2) through the complex language use on the portal, which may cause misinterpretations, doubts, and unclarity, and 3) through the urge to repeatedly check if the results are already disclosed on the portal. This stress could be reduced by information on the advantages and disadvantages of real-time access and a conversation with the healthcare professional before using the portal. This would better inform patients on the choice they need to make about accessing their test results online.

Discourse 2: Anxiety reduction through real-time access

The first discourse constructed real-time access as a potential stress source. In contrast, this second discourse emphasizes how real-time access may reduce anxiety. The *anxiety reduction through real-time access* discourse is based on the construction of a test being an emotionally charged event. Patients explain how they are very eager to know whether the result of a test is good or bad, and how real-time access can bring relief. This relief comes after the stress of waiting for a result that is constructed as important and impactful. Patients that centered the emotional aspects of accessing text results explained how they were aware of the possibility of bad and good news and how they hoped for the best. One participant, who had no experience with real-time access, said:

> *[…] You can be very relieved, but you can also have a big problem. So that can go both ways. If you're worried about it and the results are not that bad, which will often happen, then that's a relief. [R4]*

In this discourse, patients reflected on how different tests can be more or less emotionally charged. The more worried they are, the more likely they are to access test results before the medical consultation. One participant articulated:

> *If they have done a breast puncture, for example, then I would like to know, because I can prepare myself: it will probably not be a nice conversation and what do I want to know from the specialist? With the Holter monitor it was about arrhythmias, and I wasn't too worried. You can also think of a lot of scenarios, but then I think: I'll hear that from the cardiologist. [R19]*

Some participants compared looking at the test results with sitting an exam, where they have to wait for the result in suspense and, even if they are sensitive, would like to know. One participant without experience with real-time access said:

> *I would look at that moment because I'm curious. That's like taking an exam, so to speak, if you know it's going to be announced, even though you know you've done it badly, then you're curious about how it is now. [R9]*

Another patient without experience with real-time access said they believed it would reduce the stressful waiting:

> *I like real-time access because it gives you your results quicker. Usually, you must wait a few days for the results and now you don't have to wait in stress, so I like that. [R11]*

Other participants talked about how real-time access to test results would help them prepare for their consultation with the healthcare professional, even when getting the result is exciting. They also talked about asking somebody close to them to accompany them to the medical consultation:

> *I would like to see everything, yes. Because it's about me. […] You already know that something is not right when you see those results. You see the deviating values, then you think okay, so apparently something is going on. So, prepare yourself for that. Then you can also think I'll take someone with me during my outpatient visit, because two people always know more than one. [R7]*

Within this discourse, patients seemed to accept that they would not always understand the results they read in the portal, but they also did not expect this to be a problem. Participants with and without experience with real-time access, were willing to ask their healthcare professionals or relatives with medical knowledge for help or use the internet to understand medical terms. To them, the temporary anxiety of not understanding was less problematic than the stress of not knowing at all and having to wait longer for the results:

> *If you know 'it's okay', then I'm relieved. For example, if you don't understand something, I think you can just call the assistant for more explanation […]. [R10]*

> *Last week my sister asked me for help with interpreting her blood test results. She did not know what she should do with these results. Hence, I am able to interpret it. [R23]*

> *[…] And even if you don't fully understand the medical terms, well then I would just look it up. [R7]*

Participants also mentioned that the disclaimer they read before receiving their test results was a good way of informing them that the information could be stressful and misunderstood.

> *You will then receive the disclaimer "with caution" which states the results do not say everything and discussion is needed with your physician before you panic. […] it's fine that the warning is there. [R28]*

Participants talked about how having information on their own health status made them feel responsible for discussing their results and the possible treatment/further action with their healthcare professional. The next citation illustrates the importance of discussing the results with the healthcare professional, who is framed as the expert with knowledge of health conditions and treatments:

> *Of course, I would have a look on the internet, but I would leave it to the doctor... then we can discuss together again, what can we do about it. [R10]*

Although patients were willing to invest time and energy in finding out what the results they read in the portal mean and felt responsible for making decisions on follow-up treatment, they also said they would be appreciate it if healthcare professionals provided interpretations/reassurance in the patient portal to reduce stress:

> *I know, my general practitioner also releases results online. He always adds a comment first: 'Don't worry, nothing to worry about'. Something like that. Now [read: in the hospital portal], you miss that step. [R7]*

In sum, this discourse constructed real-time disclosure as a means of reducing the anxiety that is inextricably linked to waiting for and mentally processing online test results. Participants were more likely to access results that were more emotionally charged before their hospital appointment. Anxiety reduction was especially important to participants, so they were willing to invest time and energy in understanding the information posted on the portal (eg, by asking medically trained friends/relatives or by searching on the internet). Participants also felt the need to be well-informed about their health in order to make health-related decisions and discuss their results with the healthcare professional. Most participants that draw from this discourse perceive the healthcare professional as an expert with invaluable knowledge of health conditions and treatments. Therefore, participants suggested that healthcare professionals could explain test results to patients. This would help them understand their online results and improve their care.

Discourse 3: Real-time access for self-management

The *real-time access for self-management* discourse constructs real-time access as an important facilitator of self-management. Whereas the first two discourses center the emotional aspects of real-time access to test results, this discourse focuses on the practical use of real-time access for self-management purposes and as something that makes the care processes more convenient. Within this discourse, test results are regularly checked to achieve various aims.

The first aim of regularly checking their test results was to become aware of their health status. One participant with experience of real-time access said:

> *I like real-time access very much because I can also read the results. What I like about my hospital is that everything is shown in graphs. No matter what test you open, you can always see how the blood values are rising, or blood platelets, urine tests, etc. [. . .] I find that very pleasant. [R17]*

The second aim of regularly checking the test results was to reflect on their health status and lifestyle. Two participants with experience of real-time access explained:

> *Sometimes, if you tell the doctor 'I am extremely tired'. This could be an iron deficiency. Then I have a blood test and I can immediately see whether my iron level is too low. Then you have confirmation that your assumption is correct. So, I like that. It is also a reassurance of good numbers. [R18]*

> *I recently had a visit to the hospital and we [read: patient and patients' partner] are both curious. I know I can check after one or two days. Then I know and then it's well. I know at that moment; I'm doing the right thing. [R27]*

The third aim of regularly checking their test results was to make the medical consultation more substantive by better preparing them for the consultation. Patients asked more specific questions if they had looked at their test results before the medical consultation. They also felt that they could respond more critically to the physician's explanation of their test results.

> *I like that you immediately can benchmark your reference values, you don't know a lot of those numbers exactly. The most pleasant values are the ones a bit near the limit or just below, especially relevant to ask questions about. My physician tends to say that everything is going well. I believe that too, but it is nice that you have a little more information and are enabled to ask them questions about the values. [R28]*

The fourth aim of regularly checking their test results was to put them more in charge of the conversation with their healthcare professionals during the medical consultation. One participant with experience of real-time access said:

> *I like real-time access because you don't go into the conversation unprepared. I speak to the internist once every six months, three times a year and then you get the results, and I would like to know in advance whether things are going better. Whether it [read: the result] is more stable. So, I can look into that […] I think the internist knows I'm looking at my results before our conversation, but we've never discussed it so emphatically. [R27]*

The fifth aim of regularly checking their test results was to be able to immediately act on the results. This enables patients to obtain quicker treatment and increase their safety by, for example, calling the doctor and asking questions about the test results on the patient portal:

> *I read the report: 'There was nothing unusual in the blood results.' Then I looked at the results and then I saw his [read: my father] hemoglobin (HB) level is much too low and he has high inflammation values. So, I called the doctor and said: 'I don't want to be a smartass, but when I look at the lab results, I see that the HB level is quite low, and the inflammation values are high. Is he on medication for that?' The doctor said, 'I'll have to check that'. Half an hour later he called and said: 'Good that you checked it, indeed he must have medication for that'. Thus, it [read: online access] can also go in the right direction. I found that very striking. I hardly ever look at the results in the portal. But at the time, I was really glad I looked at it. [R19]*

Furthermore, participants constructed another reason for finding real-time access an aspect of good care: their body and health. One participant without experience of real-time access said:

> *I think real-time access is a very good development. Why not? It's about yourself, right. [R7]*

In addition, participants commented on the importance of transparency in health-related information for their own decision-making. The participants framed patients' responsibility in the decision-making process and the right to know their own health-related information. One participant without experience in real-time access stated:

> *I'm positive about it [read: real-time access]. I think that you should also have knowledge of your own medical file. What is known by the doctor and the nurse et cetera, I think that is at least what I should know. [R9]*

Some participants constructed themselves as an expert of their own health and felt that the healthcare professional could not add much new information. This was especially true for patients with a chronic disease:

> *I think I look up or know most of it myself. I am also a member of the diabetes association and then you also receive magazines and newsletters. She [read: nurse] can't really add anything more. The hospital also has information leaflets and things like that. But when I need information, I look it up. [R28]*

Participants become an expert based on the comprehensibility of their test results, which was framed as a learning process. These participants saw their physician as a coach or guide, who explained their test results. For example, one participant with experience of real-time access who checked his ignition values learned over time how he should interpret these values.

> *I'll check the ignition values. I got an explanation from a doctor once: 'The inflammation value is high, but you must see it in relation to that other value, it is low again, so in the end it's not too bad'. You cannot interpret that yourself if you don't have this information. [R25]*

As part of the learning process, participants constructed themselves as being able to easily look up medical terminology they are not familiar with on the internet. One participant with experience of real-time access said:

> *I am always someone who likes to look up everything, because sometimes my healthcare professional has requested to test things, and those [read: test] are far too difficult words and then I will look it up myself to understand 'Gosh what does that mean'. But there is no explanation or anything on the portal. [R18]*

Participants also articulated that, for convenience, they wanted a check mark on the portal that showed whether the doctor had already looked at their test results or not.

> *I don't see a check mark: the doctor has reviewed and assessed and will contact you if treatment is needed. [R25]*

Besides the check mark for convenience, participants also said that they would like to be able to check what is in their patient file and, if necessary, correct any mistakes. They considered it their responsibility to correct this information and look at their test results soon as they are available. Participants mentioned that their whole patient file is not on the portal. One participant with experience in real-time access explained:

> *I have the feeling that there is a lot being written that I don't see on the portal. The patient portal provides a kind of insight, on I don't know what. My new doctor didn't get a file from me, other than a few lines of information. Although I think they have written quite a lot about me. I remember that the diabetes nurse had used 'motivational conversation' methodology to discuss my disease. They also point out things about me that I don't think are right. What kind of image emerges about who I am? [R26]*

Within this discourse, participants had five aims for regularly checking their test results: 1) to be aware of their health status, 2) to reflect on their health status and lifestyle, 3) to prepare questions for their medical consultation, 4) to be in charge of the conversation during the medical consultation, and 5) to act in response to their test results in order to speed up treatment and increase safety. In this discourse, patients are seen as the experts of their own health and real-time access to test results is seen as a natural part of the care process for optimal self-management and convenient care. Healthcare professionals were seen as coaches or guides who explain incomprehensible medical language. Participants also discussed how they cannot completely fulfill their responsibilities because they do not know whether the doctor has looked at their test results (no check mark) and because their entire medical record is not available on the patient portal (incomplete transparency). Participants framed these omissions as missed opportunities for delivering good care with real-time access to test results on patient portals.

DISCUSSION

Principal findings

This study aimed to provide a deep understanding of patient discourses on real-time access to test results on a patient portal. We considered the practical consequences of various discourses [33,34] for 1) policy development by healthcare providers, highlighting the possible implications of policy options, and 2) the design of technologies, healthcare processes, and information to help patients and healthcare professionals make decisions about real-time access. Our research question was what patient discourses on real-time access to test results can be distinguished? We identified three discourses: 1) *source of stress*, 2) *anxiety reduction*, and 3) *self-management.*

Within these discourses, we identified two recurring themes constructed differently in each discourse. The first theme, coming from the patient's perspective concerned the complex language and jargon used in test results. The first discourse, *source of stress* highlights the risk of misunderstanding information and the stress that can arise from searching the internet for information to help understand and interpret test results. The second discourse, *anxiety reduction* emphasized the patient's ability and willingness to ask people with medical knowledge for help when reading complex information or to search for an explanation on the internet. The third discourse, *self-management* framed handling complex language as a learning process, where patients can empower themselves by increasing their knowledge and learning where to look and what to search for on the internet.

The second recurring theme arising in all discourses was the value of transparency, which was also linked to other values and elements of patient-centered care. *Source of stress* emphasized the value of patients being well-informed, not matter if the information was provided before or after the consultation. *Anxiety reduction* related the value of well-informed patients to the emotional relief of knowing the result of a test as soon as possible. Interestingly, *self-management* also linked the value of patient empowerment to the value of transparency, because portal information offered self-management opportunities.

Practical implications

Each discourse has practical consequences for healthcare organizations' policies on real-time access to test results and the ways in which they can embed it into daily practices. *Source of stress* highlighted the importance of reducing possible emotional damage by informing patients about real-time access. A recent study [43] found no link between pre-counseling and reduced patient worry levels, possibly due to the focus on explaining the testing rationale. Pre-counseling could incorporate both technical and socio-technical methods [43]. This discourse suggests that providing real-time access to information can be done in three ways.

First, we showed that patients want to be informed about the advantages and disadvantages of real-time access. Earlier research has shown that patients are not always informed about patient portals [25,44-46] and do not know that they can access their test results before the medical consultation. A recent study confirms that patients should be informed about patient portals in general, and specifically the pros and cons of using them [47]. This has implications for portal design as it should offer explanatory texts or videos for users.

Second, we showed that giving patients real-time access can evoke stressful checking behavior that can last for days until the test results are disclosed. To avoid this, portals could notify patients when their results are published. One study suggests two notification policies: immediate notifications for all results and only for patients who have opted-in for notifications [48]. In this case, however, healthcare providers must uphold promises to deliver test results in real time.

Third, we showed that patients want their healthcare professional's advice on whether or not to access their test results before the consultation. This is in line with the findings of other studies, which conclude that healthcare professionals should anticipate what patients might see at the portal [11], discuss whether real-time access is a good idea, be available to answer questions [15], and have a transparent discussion on the patient's notification preferences for abnormal test results [49]. Further research should focus on how to support healthcare professionals and patients in this shared decision-making process.

Both *source of stress* and *anxiety reduction* show that healthcare providers and healthcare professionals need to think about how patients might interpret test results to avoid misinterpretation. We showed that patients want comprehensible explanations of their test results. This is in line with an earlier qualitative study showing that reference values for test results and doctor's comments helped patients to understand test results on the portal [50]. Also, two other studies demonstrated how the doctor's interpretation alleviated patient anxiety [11, 14]. In a recent study, patients recommended other options, such as a glossary of terms for complex medical results, supplementary follow-up information, and layman's summaries of reports to enhance test result interpretation [51]. This suggests that patient portals should incorporate reference values for test results, health-related information in layman's terms, and open notes from healthcare professionals. Even with reference values displayed, patients want confirmation from healthcare professionals on the accuracy of their interpretation of test results [52]. This also implies that the healthcare professional should give an oral explanation of how to interpret test results is a necessary part of a medical consultation. Healthcare professionals and communication advisers could help portal developers provide the necessary explanations in layman's terms on the portal.

Self-management highlighted possible ways to broaden the functions of patient portals. First, we showed that patients want to know if the doctor has checked their test results, as a study on real-time access to oncology results also reports [51]. Designers of patient portals could consider adding a check mark that lets patients see if the healthcare professional has seen and approved their results. This means healthcare professionals may have to adjust their work processes based on when and how they check results. We also showed that patients want to correct inaccuracies and want more transparent health-related information in their medical file, in line with the findings of earlier studies [7,53].

Healthcare organizations can involve patients in the implementation, integration and evaluation of policies related to real-time access to test results. The evaluation can take the form of action research [54], where patients and professionals co-create, evaluate and improve the processes around access to test results during the research process.

Limitations

This study has limitations. First, the snowball method we used, starting with our own network may have caused bias [55]. Our sample does not represent all ages as the age categories 31–45 and 76–90 are under-represented (see supplemental file 1, Table 1). Therefore, our results should be generalized with caution. However, the 28 people we interviewed provided a good overview of opinions and experiences on real-time access to test results. Second, participants often mentioned 'other people' instead of their own experiences. This may affect the validity of our study because assumptions of others' experiences do not always match what is actually experienced [41]. Speaking of others might also indicate that participants were uncertain of real-time access because they might not have had enough information and were still forming an opinion.

Third, we did not stratify our sample, which could account for the differences among discourses according to gender or type of result (sensitive/not sensitive, routine/diagnostic). Earlier studies on result types and real-time access have mixed findings [20,56]. For instance, in a study of 30 cancer patients, accessing laboratory results in real time reduced anxiety [20]. Another study reported most patients preferred real-time access for less sensitive diagnoses (high cholesterol, strep throat, genetic disease, sexually transmitted disease) but preferred a time delay for sensitive results (Alzheimer's disease, fetal miscarriage, cancer) [56]. Please note, however, that our microlevel discourse analysis aimed to describe discourses, not to explain them. We wanted to examine how individuals socially construct a new technological functionality, namely real-time access to test results via patient portals. Articulating the differences in the social constructs of different discourses invites us to reflect upon the practical implications of each discourse. This in turn could inform the design and embedding process of patient portals. Further research could expand or enrich the three discourses by zooming in on the differences in demographics, such as type of test result, age and sensitivity of the result. For example, one scoping review showed that older patients, those unfamiliar with portals, and those with abnormal results or conditions like cancer, cardiovascular disease or depression use portals less often for radiology results and prefer direct communication with a physician [11]. These patients are likely to frame real-time access as a source of stress.

Fourth, we conducted this study before and during the Covid-19 pandemic. Patient perspectives on receiving test results via the patient portal may have shifted in response to the new and/or temporary online practices that emerged during the pandemic.

Comparison to prior work

Our findings confirm previously observed advantages of real-time access for patients. These include (1) processing their test results better at home and being better prepared for the consultation with healthcare professionals [18,20-22], (2) developing a strong sense of ownership of their results [12,43] and being better informed [12,14,23], and (3) increasing their own safety by checking their results and responding quickly to abnormalities [14]. Our findings also confirm previously observed disadvantages of real-time access. These include difficulties with interpreting test results [12-14,23], sometimes causing unnecessary anxiety [12,14,15,23], stress [22,42], and confusion [15].

We found two disadvantages, not identified in earlier studies: (1) being faced with the hard decision of whether to look at the test results before the medical consultation caused stress and (2) repeatedly checking if results were available evoked stressful checking behavior which could last for days until the test results were disclosed.

We also derived new implications for portal design and healthcare processes given the different constructs patients have for real-time access to test results on a patient portal. We can account for these differences by looking at their constructs of 'good care'. All participants seemed to value transparency in health-related information, which agrees with the findings of Leonard et al [57]. Still, not all patients considered real-time access to test results as 'good care'. Some constructed themselves as vulnerable and believed it is the healthcare professional's responsibility to care for them [29]. These patients were more likely to emphasize the emotional aspects of real-time access, such as causing stress or reducing anxiety. Patients who emphasized their own responsibility for 'good care' were more likely to focus on the practical opportunities, such as self-management [29]. A recent study on information transparency through real-time access in oncology suggests a shift in medical decision-making from a paternalistic to a patient-centered approach. This implies that some professionals believe that if given information patients can make informed decisions and thus actively participate in their own care [51]. Real-time access for self-management may increasingly be viewed as exemplary care. Another article [47] underscores that real-time access to their test results and medical file empowers patients in health decision-making. However, our study reveals a diversity of patient expectations and experiences regarding real-time access, suggesting that self-management opportunities represent just one aspect of 'good care'.

Conclusions

Our study provides in-depth insights and highlights practical implications for various stakeholders, such as policy makers and eHealth technology developers. The discourse analysis showed the plurality in patient expectations and experiences. We found three discourses (see supplemental file 4, Table 2 an overview of patient discourses on real-time access to test results) that illustrate the different ways in which real-time access can be constructed and how healthcare providers and patients can make optimal use of real-time access to test results on patient portals from a patient perspective.

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Contributions

The study was conceived by PH, AMJWMW-J, KA and BP. PH and BP were responsible for data collection and PH, AMJWMW-J and BP for data analysis. All authors wrote, read and approved the (final) manuscript. BP acted as guarantor.

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Competing interests statement

None declared.

Ethics approval

The Medical Ethics Review Committee of Erasmus Medical Center (Erasmus MC) approved our research proposal (MET-2020-0843) and checked compliance of our data management plan with General Data Protection Regulation (GDPR) guidelines. All participants gave verbal informed consent which was recorded and transcribed and written consent.

Data sharing statement
Data are available upon reasonable request.

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SUPPLEMENTAL MATERIAL

Supplemental file 1. Table 1. Patient characteristics.

Supplemental file 2. Topic list for participants without real-time access experience asking about their expectations.

Supplemental file 3. Topic list for participants with real-time access experience asking about their experiences.

Supplemental file 4. Table 2. An overview of patient discourses on real-time access to test results.

SUPPLEMENTAL FILE 1

Table 1. Participant characteristics

	Participants (N=28)			
	Female (n=18, 64%)		Male (n=10, 36%)	
Age (years)	Experience with real-time access (n=10, 56%)	No experience with real-time access (n=8, 44%)	Experience with real-time access (n=5, 50%)	No experience with real-time access (n=5, 50%)
16–30	2 (20%)	4 (50%)	2 (40%)	1 (20%)
31–45	2 (20%)	0 (0%)	1 (20%)	0 (0%)
46–60	3 (30%)	3 (37.5%)	0 (0%)	1 (20%)
61–75	3 (30%)	1 (12.5%)	2 (40%)	2 (40%)
76–90	0 (0%)	0 (0%)	0 (0%)	1 (20%)

SUPPLEMENTAL FILE 2

Topic list for participants without real-time access experiences

	Questions
Opening interview	First, I will explain what our study is about. We have just discussed that you, (NAME), give permission for this interview to be recorded and that the data will be used anonymously. The data will only be used for this research. Agree?
Facts (appoint gradually during the interview)	Gender Age Do you use a phone, computer, or tablet? For what do you use it for? Do you use e-mail?
Good care	First of all, I am very curious about how you feel about good healthcare? When was the last time you visited a hospital? May I ask which outpatient clinic you visited? Looking back on that visit, what did you like about the care? How was the conversation with the doctor? Can you give an example of things that you think were not right at that moment? You mention X and Y as starting points for good care – are there any more? A & B did not go well, this means that you value A & B regarding good care? When you visit the doctor at the outpatient clinic, what is the ideal conversation with the doctor? How is the treatment you receive from the doctor? Does the doctor listen to you carefully? How do you know? Do you think your doctor is an expert? Do you think I have a good idea of what you think is good care?
Patient-centeredness	What else do you consider important in your relationship with your doctor? And further? Can you give an example of what you think is patient-centered? Do you think I have a good idea of what you think is patient-oriented?

Patient image	When do you consider yourself as a patient? When do you see someone else, for example a friend or neighbour, as a patient? So when we look at when you consider yourself or someone else as a patient, we can conclude that someone is a patient if … .. (and then let the participant fill this in) A distinction is often made between active patients and passive patients. How do you see yourself? Most people would agree that both the doctor and patient affect the quality of care. What do you think is the responsibility of the patient? Consider your last visit to the hospital. How did you influence the quality of care? What did you think was your responsibility in this? Do you think I have a good idea of your opinion of when you consider yourself a patient?
Most important task of a patient	What do you think is the most important responsibility of the doctor? What is important to you when you visit the doctor in the outpatient clinic from the hospital? How is the treatment provided by the doctor? Do you think that is important? How is the information provided by the doctor? Do you think that is important? How is the doctor’s decision-making? To what extent are you involved? Do you think I know what you think the doctor’s most important task is?

Responsibility for decision-making	Who should make decisions about your treatment? Thinking back to your hospital visit, can you give an example of where a decision had to be made about your therapy? How was it decided, which treatment you received? To what extent did you determine together with the doctor which care you received? To what extent have your wishes been taken into account when choosing the therapy? Do you think I have a good idea of your opinion on decision-making in treatment?
Information	What do you find important about the information you receive? Suppose you have to go to hospital for a day for treatment. What do you do with the information you receive in advance? How would you prefer to receive the information? What do you think is important to see on a website, where you can view data on your own? Suppose you have a chronic illness and therefore have to regularly visit the hospital laboratory for blood tests. Your treatment depends on the results of the blood test. Now it appears that you can see the blood results at the same time as your doctor, before you meet the doctor. What would you do if you could see all of your blood test results before speaking with the doctor? Do you think I have a good idea of what you find important in the information you receive?
Real-time access through a patient portal	What do you think of real-time access to test results via a patient portal? Imagine you have visited the hospital and you have had several tests. The results of those tests will be announced within four business days and you will have an appointment seven business days later with your doctor. What do you think about being able to see the test results at home before you have spoken to your doctor? What would you do? Nictiz, an organization with a lot of knowledge about eHealth, has listed the advantages and disadvantages of direct access to test results. I would like your opinion on these points. An advantage according to Nictiz is that direct access ensures that patients are not unnecessarily stressed and can process the results as soon as they are known. What do you think about this?

	Another benefit that is mentioned is that patients can immediately act based on the results. What do you think about this? Patients can decide themselves whether they want to see the results immediately or not. In case of a bad result, patients can process this in their own environment and are therefore better able to enter into a conversation with their doctor to discuss treatment positions. So, for example, a result about whether you have anemia or cancer. How do you see this? These were the benefits mentioned by Nictiz, do you think there are more advantages of directly viewing data through a website? A disadvantage of looking directly at the test results before talking to the doctor is that there is a greater chance of misinterpreting the result. This can lead to stress and possible disappointment. How do you see this? Another disadvantage is that patients see information even though they have the right to not know. You also have the right not to know something, but it can be difficult to ignore curiosity. What do you think about this? Finally, another disadvantage is that patients may contact the hospital because they have questions about their results. And that takes time for the hospital. What do you think about this? Would you do this yourself? These were some of the disadvantages of directly accessing test results via the website, do you think there are any other disadvantages? Now that you've heard all these advantages and disadvantages, I'm asking again for your answers to the following questions: Imagine you have visited the hospital and you have had several tests. The results of those tests will be announced within four business days and you will have an appointment with your doctor in seven business days. What do you think about being able to see the test results at home before you have spoken to your doctor? What would you do? Do you think I have a good idea of your opinion on direct access to test results?
Closing	Do you want to add or emphasize something? Thank you very much for the interview.

SUPPLEMENTAL FILE 3

Topic list for participants with real-time access experiences

	Questions
Opening interview	First, I will explain what our study is about. We have just discussed that you, (NAME), have given permission for this interview to be recorded and that the data will be used anonymously. The data will only be used for this research. Agree?
Facts (appoint gradually during the interview)	Gender Age
Good care	First of all, I am very curious about how you feel about good healthcare? When was the last time you visited a hospital? May I ask which outpatient clinic you visited? Looking back on that visit, what went well? What did not go well? How was the conversation with the doctor? Can you give an example of things that you think were right at that moment? Can you give an example of things that you think were not right at that moment? You mention X and Y as starting points for good care, are there any more? A & B did not go well, this means that you value A & B with regard to good care? When you visit the doctor at the outpatient clinic, what is the ideal conversation with the doctor? How was the treatment provided by the doctor? How did the doctor listen to you? Do you think your doctor is an expert? How do you know? Do you think I have a good idea of what you think is good care?
Patient-centeredness	What else do you consider important in your relationship with your doctor? And further? Can you give an example of what you think is patient-centered? Do you think I have a good idea what you think is patient-oriented?

Patient image	When do you consider yourself as a patient? When do you see someone else, for example a friend or neighbor, as a patient? So, when we look at when you consider yourself or someone else as a patient, we can conclude that someone is a patient if … (and then let the participant fill in this) A distinction is often made between active patients and passive patients. How do you see yourself? Most people would agree that both the doctor and patient affect the quality of care. What do you think is the responsibility of the patient? Consider your last visit to the hospital. How did you influence the quality of care? What did you think was your responsibility in this? Do you think I have a good idea of when you consider yourself a patient?
Most important task of a patient	What do you think is the most important responsibility of the doctor? What is important to you when you visit the doctor in the outpatient clinic of the hospital? How is the information provided by the doctor? Do you think that is important? How is the decision-making? What is the role of the doctor? What is your own role in the decision-making? Do you think I have a good idea of what you think is the doctor's most important task?
Responsibility for decision-making	Who should make decisions about your treatment? Thinking back to your hospital visit, can you give an example of where a decision had to be made about your therapy? How was it decided which treatment you should receive? To what extent did you determine together with the doctor which care you received? To what extent were your wishes taken into account when choosing the therapy? Do you think I have a good idea of your opinion on decision-making in treatment?

Information	What do you find important about the information you receive? Suppose you have to go to hospital for a day for treatment. What do you do with the information you receive in advance? In what way would you prefer to receive the information? What do you think is important to see on a website where you can view data on your own? Do you think I have a good idea of what you find important in the information you receive?
Real-time access through a patient portal	What do you think of real-time access to test results via a patient portal? Can you give an example of your experience? Imagine you have visited the hospital and you have had several tests. The results of those tests will be announced within four business days and you will have an appointment with your doctor seven business days later. What do you think about being able to see test results at home before you have spoken to your doctor? What would you do? Nictiz, an organization with a lot of knowledge about eHealth, has listed the advantages and disadvantages of direct access to test results. I would like your opinion on these points. An advantage according to Nictiz is that direct access ensures that patients are not unnecessarily stressed and can process the result as soon as the result is known. What do you think about this? Another benefit is that patients can immediately act based on the results. What do you think about this? Patients can decide themselves whether they want to see the results immediately or not. If the result is bad, the patient can process this in their own environment and are therefore better able to enter into a conversation with their doctor to discuss treatment options. So, for example, a result about whether you have anemia or cancer. How do you see this? These were the benefits mentioned by Nictiz, do you think there are more advantages of directly viewing data through a website? A disadvantage of looking directly at the test results before talking to the doctor is that there is a greater chance of misinterpreting the result. This can lead to stress and possible disappointment. How do you see this? Another disadvantage is that patients see information even though they have the right to not know. You also have the right not to know something, but it can be difficult to ignore curiosity. What do you think about this?

	Finally, a disadvantage is that patients may contact the hospital because they have questions about their results. And that takes time for the hospital. What do you think about this? Would you do this yourself? These were some of the disadvantages of directly accessing test results via the website, do you think there are any other disadvantages? You already indicated that you have experience viewing test results in real time – has the discussion of these advantages and disadvantages changed your opinion? How would you like to be informed about direct access to research results? And how would you like to choose how many days you have to wait to access your test results? How would you like to be informed about this? What are the advantages and disadvantages of this choice? How would you like to decide this? Do you think I have a good idea of your opinion on direct access to test results?
Closing	Do you want to add or emphasize something? Thank you very much for the interview.

SUPPLEMENTAL FILE 4

Table 2. An overview of patient discourses on real-time access to test results.

	Discourse 1: *Real-time access as a source of stress*	**Discourse 2:** *Anxiety reduction through real-time access*	**Discourse 3:** *Real-time access for self-management*
Key words	Stress, complexity, and ambivalence.	Stressful waiting period, preparation, and relief.	Facilitator of self-management, frequent checking.
Implications of complex language use	Ambivalence about whether to look at test results and risk of misunderstanding and stress due to searching on the internet.	Willingness to ask healthcare professionals or relatives with medical knowledge for explanation or search for an explanation on the internet.	Learning process: patients can and will learn where to look and what to search for on the internet.
What is the value of real-time access to test results?	The value of transparency. The value of being well-informed as a patient before or after a medical consultation.	The value of transparency. The value of being well-informed as a patient. The value of emotional relief.	The value of transparency. The value of being empowered as a patient.
How to provide patient-centered real-time access to test results on a portal? (practical consequences)	Reducing stress by providing information about the advantages and disadvantages of real-time access, also on the patient portal by texts or videos, and offering patients a conversation with a healthcare professional (pre-counseling).	Reducing anxiety by providing reference values for test results on the portal, health-related information in layman's terms as well as open notes from the healthcare professionals and providing comprehensible explanations on interpretation of test results from healthcare professionals.	Improving self-management opportunities by providing a check mark on the portal that indicates whether the doctor has looked at the test results, more transparency on health-related information in the medical file, and the possibility for patients to correct inaccuracies in their file.

Chapter 6

General discussion

INTRODUCTION

This dissertation describes several studies on the elements influencing the adoption of patient portals. Patient portals are considered key eHealth technologies for patients, healthcare professionals, healthcare organizations, and society at large. Patient portals should support patients to take more self-management and control over their health [1,2] and enable professionals to organize their collaboration with patients more efficiently and effectively through improved information sharing, communication, and administrative support functions [3]. For healthcare organizations and society, patient portals can help address the increasing demand for care in conjunction with staff shortages, thereby mitigating the need for additional financial resources [4].

Since 2017, the Dutch National Government has implemented a range of supportive programs and initiatives aimed at supporting the adoption of patient portals (coined VIPP programs). Various representative organizations, including the Dutch Hospital Association, the Dutch Federation of University Medical Centers, independent clinics, and mental health organizations throughout the Netherlands have executed these initiatives and provided financial and organizational support. However, adoption of portals remains suboptimal despite the availability of financial incentives and the endorsement of organizations. According to the Dutch eHealth Monitor of 2023, only 45% of the patients (n=342-352) had used a patient portal at least once [5]. This monitor indicates that eHealth technologies, including patient portals, continue to be perceived as supplementary tools rather than integral components of care processes [5]. To address this challenge, it is imperative that healthcare delivery systems are restructured to integrate patient portals into routine healthcare delivery. To achieve this, it is necessary to enhance users' digital literacy, and improve the user-friendliness of eHealth technologies [5], which should be part of the implementation and portal adoption process.

Despite an extensive body of literature on implementation and adoption studies, and many models and frameworks to understand adoption processes retrospectively, adoption models or frameworks cannot serve as predictive models [6,7,8]. Scholars have devoted comparatively less attention to the specific activities and actions needed to effectively adopt patient portals in practice. While it is easy to assert that technology should be adopted or embedded in daily practice, it remains unclear what concrete steps should be taken by patients, healthcare professionals, managers, and policymakers.

This dissertation aims to provide actionable knowledge for three primary reasons. First, there is a lack of practical guidance from evaluations of eHealth technology, including patient portals [9,10]. Most studies tend to rely heavily on conceptual frameworks [9,10] and aim to explain the processes retrospectively. Second, to demonstrate that actionable knowledge can assist on two levels: 1) Organizational (patients, healthcare professionals, management, project staff involved in healthcare digitalization) and 2)

Society (IT specialists, vendors, lawyers and policymakers). Third, a holistic overview of adoption processes is needed as a recent scoping review of barriers and facilitators related to the legal, ethical, financial, and technological aspects of successful eHealth implementation explored the complex interplay of these aspects [11].

This dissertation describes case studies in two healthcare sectors: hospitals (Chapters 2,4,5) and mental health (Chapter 3). It incorporates the perspectives of three key groups: 1) healthcare professionals (Chapters 2,3), 2) patients and next of kin, including family or friends (Chapters 4,5), and 3) management, including board members, managers, project leaders and staff, communications professionals, and IT specialists (Chapters 2,3).

It also incorporates diverse eHealth domains as articulated by Shaw et al [12]: 1) *"Health in our hands: the use of eHealth technologies to monitor, track, and inform health";* 2) *"Interacting for health: the use of technologies to communicate between stakeholders in health"* and 3) *"Data enabling health: the collection, management, and use of health data sources"* (p.5). Patient portals intersect with these three domains and could thus serve as focal points for gaining insights into the actionable knowledge. In particular, Chapter 2 emphasizes the role of patient portals in the domains of *"Health in our hands"* and *"Interacting for health"*, as it studied the implementation of patient portals featuring functionalities aimed at enhancing information sharing and communication between patients and healthcare professionals in the Netherlands. Chapters 3, 4, and 5 also concentrate on the role of patient portals in *"Data enabling health"*, specifically examining patient access to test results in the Electronic Health Record (EHR) from the perspectives of healthcare professionals (Chapter 3) and patients (Chapters 4 and 5) in the Netherlands.

Research question

The overarching research question is: **How can the adoption of patient portals by patients and healthcare professionals be supported in the Netherlands?**

Chapter 1 introduces the definitions of eHealth, patient portals and Personal Health Records (PHRs) and the eHealth technologies adoption process in a Dutch context. Furthermore, this chapter presents the insights obtained from analyzing the concepts and challenges of implementation models. The chapters 2,3,4 and 5 present independent studies that together answer the overarching research question. **Chapter 2** offers a qualitative study aimed at understanding the lessons learned during the portal adoption process in hospitals, focusing on factors that either facilitated or hindered the process. The findings indicate that healthcare professionals play a crucial role in portal adoption, and gaining insights into their thoughts and experiences is essential for understanding this process. **Chapter 3** presents a qualitative study that explores the appraisal work of mental healthcare professionals to assess and understand patient access to their EHRs through a patient portal. **Chapter 4** describes the results of a sequential explanatory mixed methods approach aimed at understanding patients' preferences for the timing of the disclosure of their test results (laboratory, radiology, and pathology) on the hospital's patient portal. Furthermore, **Chapter 5** presents the findings of a micro-level discourse analysis designed to gain a deeper understanding of what real-time access to test results signifies for patients. Collectively, these four studies provide actionable knowledge [13] that offers practical implications for the adoption process which we categorized in four phases: **Awareness, Acceptance, Actioning and Assimilation**.

This chapter provides actionable knowledge on the adoption process of patient portals in terms of Awareness, Acceptance, Actioning, and Assimilation. Each phase involves different actors and factors that contribute to the overall adoption process. Although the phases may seem chronological, they are often interrelated in practice, with elements frequently moving back and forth during the adoption process. Thus, these phases should be viewed as a heuristic model. This chapter concludes with a reflection on the research methodology employed.

AWARENESS PHASE

In this phase, intended end-users are made aware of eHealth technology, specifically patient portals in this dissertation. According to Greenhalgh et al [14], this phase is part of the pre-adoption stage. Effective communication regarding the existence of patient portals is necessary; without it, intended end-users will remain unaware of these portals (Chapter 2). The functionalities a patient portal offers must be communicated. Unfortunately, this is especially lacking, as shown in Chapters 2 and 5 and reported by other scholars too [1,15,16,17]. To enhance awareness of eHealth technologies, healthcare organizations should utilize multiple communication channels to inform patients and healthcare professionals. Effective channels found in this study include explanatory leaflets, videos on websites, social media, and screens in waiting rooms (for an overview of channels, see Table 3, Chapter 2).

Chapter 2 emphasizes that hospitals must incorporate the perspectives of multiple stakeholders during patient portal development. On the organizational level, stakeholders include patients and their relatives, healthcare professionals, management, IT specialists, communication personnel, and vendors. Collaboration among these stakeholders is essential, right from the start of the development process. Notably, the patient portal implementation study (Chapter 2) showed that stakeholders hold differing perspectives on the relevance of various patient portal functionalities. Understanding diverse perspectives is crucial, as it facilitates tailored communication with each stakeholder group and supports decision-making in the awareness phase. Our findings resemble those of a recent scoping review on eHealth implementation, which concluded that collaboration among stakeholders is vital for effective decision-making on implementation and aligns with the transition from standalone eHealth technologies to integrated digital health environments [11]. In short, awareness strategies can be enhanced by identifying stakeholders and recognizing their values and interests [11].

Our findings suggest that healthcare professionals play a crucial role in stimulating the use of patient portals (Chapter 2 and 5). Dialogue between healthcare professionals and patients regarding the requirements and use of portals is highly desirable. The manner in which communication about patient portals occurs significantly influences acceptance, as the following section discusses in greater detail.

ACCEPTANCE PHASE

The previous section highlighted the significance of effective communication on the existence and features of patient portals, and the need to understand the perspectives of diverse stakeholders to enhance their cooperation in the awareness phase of the adoption process.

When intended end-users know about patient portals, healthcare organizations can effectively address the potential consequences of utilizing them to ensure that the intended end-users fully comprehend the implications of using portals. This is especially relevant as Chapters 2 and 5 showed that when end-users understand the reasons behind using healthcare technology, they can make informed decisions on whether or not to adopt the patient portal. This is the acceptance phase, which, according to Greenhalgh et al [14], is part of the pre-adoption stage. Addressing the potential consequences of patient portal usage requires vendors, management and IT specialists to provide transparency on the features, not only highlighting the advantages but also acknowledging the disadvantages. Chapter 2 elaborates on the promotional tone of communication materials used to inform patients and healthcare professionals and how this influenced the expectations of end-users who, in turn, could be disappointed by the actual functioning. It is crucial to clearly articulate the disadvantages of using the portal to intended end-users, as also mentioned by others [18,19]. This information can be communicated through the patient portal via texts or videos (Chapter 5) and/or face-to-face by healthcare professionals (Chapters 2 and 5).

Online access to test results is one of the most frequently utilized patient portal functionalities [20-23]. Online access can be offered either in real-time or with a delay of several days. The studies presented in this dissertation explore the perspectives of both healthcare professionals (Chapter 3) and patients (Chapters 4 and 5). Chapter 4 demonstrates that patients prefer the shortest possible time delay for the disclosure of their test results. Patients prefer this for various reasons (Chapter 4) and expect and experience various advantages of real-time access (Chapters 4 and 5). While only a few patients reported negative experiences (Chapter 4), there are disadvantages (Chapters

4 and 5) as noted in Table 1. Both advantages and disadvantages influence the patients' acceptance of portals in their care process.

Table 1. Patients' benefits, disadvantages and experiences of real-time access (Chapters 4 & 5).

Benefits and positive experiences	Patients want transparency about health information and communication, which is in line with the findings of multiple other studies [18,21,24-26].
	Patients have time to process (bad) test results at home, which is also reported in other studies [25, 27-29] and are better prepared for consultations with healthcare professionals, which resembles other studies [25,27-31].
	Patients want to see their results quickly for reassurance; also found in a systematic review of the impact of patient access to medical files [25].
	Patients want access to their results so they can monitor and act on them, if need be. This agrees with a mixed method study on real-time disclosure of test results for increasing engagement and care utilization of patients with diabetes [31].
	Patients develop a strong sense of ownership over their results [32,33] and are better informed [31,32,34].
	Patients want to learn about their results and share them with their general practitioner. This learning aspect is in line with the findings of Rexhepi et al [27].
	Patients want to increase their safety by checking their results and responding quickly to abnormal test results [35].
Disadvantages and negative experiences	Patient experienced emotional concerns, such as disappointment and anxiety due to incomprehensible information on the portal; similarly, other studies have reported anxiety and difficulties with interpreting results [19,25,31,32,34,36] which for patients can be stressful [29,33] and confusing [19].
	Being faced with the complex decision of whether to look at the test results before the medical consultation caused stress in patients.
	Uncertainty over the timing of test results evoked stressful repetitive checking behavior in patients, which could last for days until the test results were disclosed.

In contrast to these advantages and disadvantages, Steitz et al [33] found no association between precounseling - which involves explaining the rationale for a test before testing - and reduced levels of worry among patients who accessed test results via a patient portal, with 92.3% of participants reporting that they received precounseling. The best practices for precounseling need further investigation [33]. Besides explaining the rationale for testing, precounseling could also involve discussions between patients and healthcare professionals about the possible consequences of using patient portals. This approach could help patients make informed decisions about whether to access their test results online and therefore influences the Acceptance phase. Solutions proposed by healthcare professionals to facilitate collaboration between patients and healthcare professionals include: 1) discussing information access procedures with patients prior to EHR registration, with simultaneous display on the patient portal; 2) co-registering information alongside patients; and 3) introducing patients to the benefits and risks associated with online access at the beginning of treatment, allowing for a collaborative decision regarding their use of the portal (Chapter 3). The latter aligns with the perspectives of patients discussed in Chapter 5. These emphasize the importance of reducing stress and anxiety by providing information on the advantages and disadvantages of real-time access, and giving patients the opportunity to talk with healthcare professionals (precounseling).

“What is good care?” is an important question for dialogue in the Acceptance phase (Chapters 2, 3, and 5). Patient portals transform the content and method of communication between healthcare professionals and patients [1,37,38]. Consequently, moral dilemmas regarding the patient-centeredness of care arise. The Institute of Medicine (IOM) describes patient-centered care as responsive to patients’ values and needs and patient preferences guide decision-making [39]. Care provision should: 1) respect patients’ values, preferences, and expressed needs; 2) be coordinated and integrated; 3) offer information, communication, and education; 4) ensure physical comfort; 5) provide emotional support to alleviate fear and anxiety; and 6) involve family and friends [39].

Chapter 3 illustrates the struggle mental healthcare professionals have with the challenges of providing patient-centered care, as they experience a paradox between promoting patients’ self-management through access to their medical records, and patients’ increased vulnerability that may increase when patients read and share this information. Particularly, accessing physicians’ notes can sometimes lead to increased anxiety among patients. To navigate this paradox, physicians are likely to withhold certain information from the EHR, which could ultimately result in patient safety issues and/or interruptions to care continuity.

However, Chapter 5 illustrates that in all patient discourses of real-time access - including those that identify real-time access as a source of stress - the value of transparency through online access to health information is key. In Chapter 4, a study on patients’ choices for accessing their information found that patients primarily preferred real-time access to their test results. Both studies emphasized the importance of a transparent and prompt display of health information to patients. Therefore, it is necessary to clarify what patient-centered digital care entails, specifically how to deliver patient-centered care in a digital context and identify the functionalities that support this objective. This requires dialogue among healthcare professionals (especially physicians) and between healthcare professionals and both management and patients.

Although the value of transparency through online access to health information is significant, Chapter 5 also reveals that not all patients regard real-time access to health information as indicative of “good care”. Some patients believe that it is the responsibility of healthcare professionals to care for them, viewing themselves (the patient) as inherently vulnerable [40]. These patients were more likely to highlight the emotional aspects associated with real-time access, such as increased stress. In contrast, patients who mentioned their own responsibility for achieving good care tended to focus on the practical benefits of real-time access, particularly in terms of self-management [40]. Therefore, the dialogue should cover moral dilemmas such as the tension between patient autonomy and patient vulnerability, as well as the conflict between patient autonomy and patient privacy [41]. Pluut’s [40] three discourses may serve as a valuable framework for initiating discussions about patient-centered care, as they illustrate the differing perspectives and underlying norms and values. The first discourse, caring for patients, constructs patient-centeredness as a process in which the healthcare professional take care of the patient as a whole person. The second discourse, empowering patients, frames patient-centeredness as a process that empowers patients to engage actively in their own care and manage their health. In the third discourse, being responsive, patient-centeredness is characterized as a process of responsive communication [40].

Specifically, the portal functionality of real-time access requires discussion of the advantages, disadvantages, based upon experiences. Engaging in a dialogue about the implications of using real-time access could benefit both the organization and the interaction between patients and healthcare professionals. Chapter 5 shows three discourses that could aid in such a dialogue. These discourses illustrate the different perspectives and arguments regarding real-time access to test results: 1) *Real-time access as a source of stress*, which highlights how real-time access might induce stress due to the complexities involved in deciding whether or not to access test results, the incomprehensibility of the medical language used, and the compulsion to repeatedly check for the availability of results; 2) *Anxiety reduction through real-time access*, which demonstrates how real-time access can alleviate stress by reducing the waiting time of results; and 3) *Real-time access for self-management*, which illustrates how real-time access empowers patients to engage in self-management by enabling them to make informed decisions and better prepare for medical consultations. Using these three discourses in a discussion on “what is good digital care” supports the Acceptance phase of the adoption process.

Lastly, actionable knowledge is gained from the studies (Chapter 4 and 5) on technical features relevant for the Acceptance of patient portals. These features include: 1) providing information about the advantages and disadvantages of real-time access through texts or videos; 2) displaying reference values for test results on the portal; 3) offering health-related information in layman's terms; 4) making healthcare professionals' open notes available; and 5) providing clear explanations for the interpretation of test results. Additionally, healthcare organizations can enhance self-management opportunities by indicating on the portal whether the physician has reviewed the test results, increasing transparency regarding health-related information in the medical record, and allowing patients the ability to correct inaccuracies in their files.

ACTIONING PHASE

In the Actioning phase, users learn how to navigate and utilize the patient portal effectively, with appropriate support provided. According to Greenhalgh et al [14] this is part of the early use stage.

In the Actioning phase healthcare organizations (Chapter 2) encourage patients and professionals (Chapter 3) in various ways to use patient portals, often without a clear understanding of their effectiveness for specific purposes. For instance, hospitals utilize various communication channels without knowing which ones are most effective for a particular target audience or what the optimal timing is for the communication campaign (Chapter 2). Hospitals adopt various strategies to meet patients' needs during ongoing portal development, yet they lack clarity on which strategies were most effective at different stages and for specific purposes (Chapter 2; see also the next phase: Assimilation).

Chapter 3 demonstrates that mental healthcare professionals believe that patients' online access to health information enhances therapeutic gain, improves patient preparation for consultations, and increases patient involvement in their treatment. A study conducted in primary care confirms these findings, indicating that healthcare professionals perceive online access as enhancing therapeutic gain and improving patient engagement in their treatment [21]. However, outpatient clinic studies reveal that healthcare professionals are concerned about patient anxiety due to the potential for misunderstanding health-related information on patient portals [21, 31, 42]. Healthcare professionals or other staff need to address this concern to mitigate the risks, which adds to their already heavy workload. One study shows that nurses often engage in considerable invisible labor to ensure the effective integration of eHealth technologies in daily routines, but this is inadequately recognized at the organizational level [43].

Chapter 3 also shows that mental healthcare professionals worry that patient access to their information on portals might consume valuable time and negatively impact the patient-professional relationship. Specific concerns include: 1) the potential for patients to misinterpret the information they access, which could undermine their trust in the treatment, 2) the possibility that mental healthcare professionals might enter information that is inappropriate for patients to read, 3) the risk of patients feeling overwhelmed by the volume or complexity of the information provided, and 4) the likelihood that discrepancies in the professionals' and patients' perceptions of their conversations could arise. All four concerns should be addressed properly in the Actioning phase.

Hence, hospital communication strategies need to have three additional objectives. End-users should learn to understand: 1) how the portal works, 2) that action is required on the portal, and 3) where to find assistance in case of (technical) problems with the portal.

Ad 1) Chapter 2 discusses the communication strategies hospitals use to inform patients and healthcare professionals on how the portal works. For patients this includes placing video screens in waiting rooms, posting explanatory videos on hospital websites, and assigning volunteers in the hospital's central hall to teach patients how to use the portal. For the professionals, experienced portal users shared their knowledge with colleagues through peer-to-peer information sharing (Chapter 2) and training can facilitate the adoption process [44].

Ad 2) End-users should be made aware that action is required on the portal. One effective strategy to achieve this is to send specific calls to action, such as personalized letters, text messages, or emails requesting that recipients review an online brochure related to their treatment or complete questionnaires prior to their hospital appointment. Another effective strategy is that healthcare professionals were motivated to engage through being encouraged to respond to e-consults and by being shown time-saving functionalities, such as preoperative screening questionnaires (Chapter 2).

Ad 3) End-users should know where to seek help or support when they encounter issues. Hospitals established help desks, publishing phone numbers and email addresses in leaflets, letters, on their websites, and on the portal itself. Some hospitals also set up clearly visible service points in the central hall of the facility (Chapter 2).

In addition to these three requirements, the previously mentioned solution in the Acceptance phase - introducing every new patient to online access and discussing the possibilities and potential risks concerning privacy and responsibilities (Chapters 3 and 5) - will facilitate learning how to work with and experience using a patient portal.

ASSIMILATION PHASE

Finally, the Assimilation phase of the adoption process focuses on integrating patient portals into daily routines and refining its functionalities, based on experiences in daily practice.

Integrating patient portals into daily work processes presents many challenges (Chapters 2, 3, and 5). In Chapter 3, our participants individually assessed the effects of patient access to health information, noting, for example, that mental healthcare professionals may need to be more cautious in their documentation in medical records. Therefore, during the Assimilation phase they found solutions to modify and redefine their registration and consultation practices. This indicates that healthcare professionals can not only identify solutions for embedding the patient portal into their work routines but also play a crucial role in the Assimilation phase, as they can best steer the needed changes in their work processes. It is essential that they discuss, test, and evaluate anticipated solutions with their colleagues. This is referred to as communal appraisal, a component of reflexive monitoring, as defined within the Normalization Process Theory (NPT) [45]. The NPT is an implementation theory that helps to understand how new technologies, treatments or care practices are embedded and into social contexts [45]. Reflexive monitoring, one of NPT's core constructs, focuses on the appraisal activities that healthcare professionals do to assess and understand the ways in which a new set of practices affects them [45]. Chapter 3 concludes that the lack of collaboration resulted in a less effective adoption process.

Healthcare organizations play a role in embedding the patient portal and steering change in work processes. First, organizations can develop digitalization policies that establish organization-wide agreement on integrating the patient portal in daily practices (Chapter 2). Chief Medical Information Officers (CMIOs) and Chief Nursing Information Officers (CNIOs) can play an important role by setting hospital-wide guidelines on patient portal use and using peer influence to facilitate new work routines among their colleagues. Next, management can play a crucial role in initiating actual changes in work processes. They need to collaborate with highly motivated healthcare professionals who can serve as ambassadors or 'game changers' to set a positive example for their peers.

Second, management can monitor information on portal usage and response times and use these formative evaluations to engage with healthcare professionals who may not be sufficiently encouraging patient enrollment in the patient portal. Chapter 3 illustrates that gathering both formal evidence (research results) and informal evidence (anecdotal examples) is essential for evaluating patient portal use (referred to as systematization in NPT terms) [45]. Additionally, collaborative efforts to assess the added value of patient portals for end-users should include embedding in related work routines (known as communal appraisal in NPT terms) as this is crucial in the adoption and subsequent refinement process of the patient portal.

Third, management can provide the preconditions (e.g., time, support, allowing experiments) and adopt a specialism-focused approach to encourage healthcare professionals to adapt and learn new work processes (Chapter 2) [44]. A specialism-focused approach is a structured strategy that involves all departmental staff per outpatient clinic and project staff in tailoring the support, based both on the needs of healthcare professionals and disease-specific needs and preferences. However, research indicates that new work routines introduced by eHealth technologies do not always replace existing routines, leading nurses to work in parallel practices with conflicting logics [43]. Decision-makers are not always aware of this, as the intention behind eHealth initiatives is often to make professionals' work easier and more efficient [43].

According to Greenhalgh et al [14], it is essential for end-users to have the opportunity to refine the portal to prevent early dropouts and to improve its fitness for purpose. A recent scoping review supports this finding, suggesting that greater emphasis should be placed on evaluating eHealth technologies during the early design and conceptual phases [46]. Refining the patient portal requires patients' involvement in testing the portal and providing feedback to the healthcare organization. Castro et al [47] define collective patient participation at the organizational level as: *"the contribution of patients or their representing organizations in shaping health and social care services by means of active involvement in a range of activities at the individual, organizational and policy level that combine experiential and professional knowledge"* (p.7). Chapter 2 highlights the importance of involving patients from the beginning of ongoing portal development [48-51]. However, Chapter 2 reveals that portal vendors often do not involve patients in the development process, as they consider it the responsibility of their clients – hospitals - to represent patients' preferences. To incorporate patient feedback, healthcare organizations and vendors can: 1) establish a patient panel to serve as a sounding board or survey patients regarding their experiences and preferences; 2) organize sessions with patients to test portal functionalities, such as data access, e-consults, and questionnaire completion; and 3) solicit feedback by utilizing questions, comments, and complaints voiced by patients to the helpdesk.

Merging all the studies presented in this dissertation provides useful insights into the needed refinements. Chapter 4 underscores the significance of providing clear, comprehensible information on the patient portal, as participants perceived the portal as incomplete and difficult to understand due to limited access to health-related information. For instance, patients expressed a preference for viewing images alongside text when accessing radiology and pathology test results. Additionally, it recommends including plain language explanations and visual aids, such as diagrams. More effort is needed for patients with special needs: 1) employ language experts to review the terminology used on the portal and in written instructions, to eliminate jargon and abbreviations, to simplify texts for patients with low literacy, and to incorporate visuals (e.g., icons, pictograms, and infographics); and 2) collaborate with organizations that provide general computer courses, such as municipal offices, community centers, and libraries, to assist patients with limited digital skills (Chapter 2).

REFLECTION

All studies in this dissertation focus on patient portals. However, the findings and lessons learned are also relevant to the adoption process of Personal Health Records (PHRs) as both eHealth technologies have some overlap. Patient portals and PHRs can provide self-management tools, administrative support, and aim to actively manage health and healthcare by the patient and support disease management [52-59]. Just like a patient portal, a PHR is an eHealth technology which can be seen in the optimum point of the model by Shaw et al [12] where all three domains overlap. The difference between a patient portal and a PHR lies in their management and initiation: a patient portal is initiated and managed by a healthcare organization to provide access to information in EHRs reported by healthcare professionals, while a PHR is initiated and managed by the patient, collects information from multiple providers, and allows for the addition of patient-reported information.

This dissertation presents actionable knowledge on four non-chronological phases in the adoption process of patient portals: Awareness, Acceptance, Actioning and Assimilation. For both patients and professionals, key to this adoption process is embedding the patient portal in daily work processes, and continual refinement of its functionalities based on feedback from its deployment. The latter is especially important as portal refinements influence work processes and vice versa. Therefore, the actionable knowledge this dissertation presents is valuable not only for those using or developing digital or eHealth innovations - such as patient portals and PHRs - but could be interesting for people facing challenges with other types of innovations. The combination of new technology with patients' and professionals' processes offered should be considered [60]. Also, the actionable knowledge presented on adopting patient portals demonstrates that there is substantial knowledge available to translate theory into practice. Rather than a simplified approach, Thouskas [61] advocates a more complex approach to organizational and management theories, as this allows for the recognition of the complexity, ambiguity, and uncertainty inherent in the real world. We contend that developing new theories or models by complicating existing frameworks will not effectively stimulate the adoption of eHealth technologies. More actionable knowledge needs to be developed that acknowledges the complex nature of the adoption process. Our findings indicate that numerous actions play a crucial role in the adoption and continuous development of patient portals. More insights are needed into the actions stakeholders take and the contexts in which they operate.

Strengths and limitations

A strength of this dissertation is that the studies include multiple perspectives. In Chapter 2, various stakeholders were interviewed for the study on adopting patient portals in hospitals. In Chapter 3, mental healthcare professionals and management were involved. Chapters 4 and 5 concentrated on patient perspectives. The different perspectives complement each other. For instance, presenting the perspectives of mental healthcare professionals on online patient access alongside patients' preferences for real-time access helps to unravel assumptions (Chapter 4 on patients' preferences and Chapter 5 on discourses) and provides valuable insights into various experiences.

Another strength is the development of actionable knowledge that suggests the action individuals can take to stimulate patient portal adoption. A significant amount of tacit knowledge resides in people's minds, which is not explicitly articulated. Hollnagel [62] explains this with two concepts: work-as-imagined (WAI) and work-as-done (WAD). "*Work-as-imagined represents how we think work should be done in order to achieve the intended outcomes. Work-as-done covers our ideas about how others do, or should do, their work and also how we prepare our own work*" (p.1). Tacit knowledge refers to personal, context-specific knowledge that is difficult to articulate [63] and plays a significant role in bridging the gap between WAI and WAD. It is important to recognize that this may also apply to the actionable knowledge presented in this dissertation. While the actionable knowledge provides a deeper understanding of the adoption process for patient portals, further investigation to explore tacit knowledge is necessary [63]. This involves examining how the actionable knowledge is applied in practice. For example, exploring tacit knowledge about introducing every new patient to online access and discussing the possibilities and potential risks concerning privacy and responsibilities (Chapters 3 and 5).

A limitation of this dissertation is that the patient portals we studied were mostly in the early stages of implementation or had been recently implemented at the time. Further research is welcome, especially to explore the Assimilation phase and to incorporate and further develop the actionable knowledge we presented. Hence, the findings of this dissertation require validation, as we did not investigate whether our descriptive findings actually lead to increased adoption of patient portals. For instance, Chapter 2 describes how hospitals encourage the adoption of patient portals, but we did not examine whether this effort resulted in increased adoption. Similarly, in Chapter 3, we found that systematization and communal appraisal were not the predominant components of reflexive monitoring, according to mental healthcare professionals, as outlined in the NPT [45]. Our approach focused on capturing the appraisal activities as expressed by the mental healthcare professionals themselves, rather than explicitly asking them to reflect on the four components of reflexive monitoring.

This dissertation demonstrates the necessity for researchers to incorporate patients' perspectives on the development and deployment of patient portals. However, in the studies presented, we treated patients as the study object, rather than including them as active research participants. This might have resulted in bias in the study design, compared to studies that involved patients in jointly creating a research design [64-66].

Towards more actionable knowledge through action research

Throughout this research, I learned that certain data collection methods can serve as interventions for changing processes, particularly in stimulating the adoption of patient portals. For instance, the group interviews conducted in Chapter 2 gave the project leaders involved in implementing patient portals in hospitals the opportunity to engage with multiple disciplines on the subject. One participant, a healthcare professional, mentioned that she found it valuable to speak with a representative of the client council, as she gained insights into his perspective on healthcare - a perspective she typically did not encounter. Another participant, a client council representative realized at the end of an interview that sharing his opinions could influence the implementation process. After the interview, he said he planned to act on this insight. Although we conducted traditional qualitative studies, I learned that research can also facilitate change during the study.

Greenhalgh and Papoutsi [67] conclude that research on complex systems must embrace a richer and more diverse methodological approach. Such richness could be achieved through action research [68,69], in which researchers and co-researchers can develop and utilize actionable knowledge in practice. Action research can be defined as *"an emergent inquiry process in which applied behavioural science knowledge is integrated with existing organizational knowledge and applied to address real organizational issues. It is simultaneously concerned with bringing about change in organizations, in developing self-help competencies in organizational members and adding to scientific knowledge. Finally, it is an evolving process that is undertaken in a spirit of collaboration and co-inquiry."* (p.4) [70]. Thus, action research comprises multiple action research cycles: constructing, planning action, acting and evaluating action [68]. An organizational problem is the starting point of action research, which combines theoretical knowledge and action with the goal of improving organizations. Action research pursues three goals: change, professional development and scientific knowledge [71]. It distinguishes itself from traditional research by involving members and employees of the organization, and the target group of the study, who all become co-researchers in the process.

Co-creation is an essential component of action research and can be defined as *"an all-encompassing principle about collaboration and innovative problem-solving among various stakeholders across all initiative phases (e.g., from problem identification to evaluation)"* (p.723) [72]. This dissertation highlights the need for further action research on three ways of co-creation in portal adoption: 1) the importance of collaboration among stakeholders (patients, healthcare professionals, organizations, vendors) in the four adoption process phases; 2) the lack of collaboration among healthcare professionals when addressing patient access to the EHR (Chapter 3), and 3) the significance of incorporating patient perspectives to challenge assumptions on online (real-time) access to health information (Chapters 4 and 5). The literature on co-creation criticizes researchers for not reporting their co-creation activities and processes in sufficient depth [73] and suggests that co-creation can be complex. Therefore, future action research should precisely document the co-creation steps undertaken by all stakeholders involved in the adoption of eHealth technologies. This would also include a commuting movement between theory and collected data, which fosters other questions: What existing knowledge is available, and how can we adapt it to our specific situation or context? Are all perspectives represented at various levels, and if not, what action can we take to address this? Ultimately, researchers, policymakers, management, healthcare professionals, IT specialists, communication advisers, (eHealth) project staff, patients, and representatives should ask themselves the following questions: Am I doing enough with the knowledge we currently possess and what gaps do we need to study by jointly reflecting on and learning from real-life situations?

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Summary

SUMMARY

eHealth technologies, such as patient portals, can enhance patient experiences in healthcare, improve the workflow of healthcare professionals, reduce costs, and advance population health. However, literature shows that these technologies have not yet been widely adopted by healthcare professionals and patients. Although numerous financial and supportive programs have been implemented to stimulate the adoption of eHealth technologies in the Netherlands, the adoption remains suboptimal. Literature contains many implementation models for eHealth technologies, often focusing on concepts such as acceptance, adoption, and embedding. While these models and concepts can provide valuable insights into understanding the adoption process more comprehensively, they can also make it more confusing. This confusion arises because the use of different concepts and models creates ambiguities about what is actually being measured, making it challenging to study the adoption process of eHealth technologies, such as patient portals. The adoption of eHealth technologies is an iterative, holistic process that should address both individual and organizational levels, as well as their specific contexts. Therefore, we regard the adoption process as complex. This serves as an essential starting point for our research, as acknowledging these factors provides valuable insights into adoption processes within daily healthcare practice. The overall aim of this dissertation is to gain actionable knowledge on the adoption of patient portals in daily healthcare practices in the Netherlands. The overarching research question is: **How can the adoption of patient portals by patients and healthcare professionals be supported in the Netherlands?** We addressed this question through several independent studies presented in different chapters.

We started with a qualitative study on the adoption of patient portals in hospitals (**Chapter 2**). This study aimed to provide insights into the processes of patient portal adoption among patients and hospital staff, including healthcare professionals, managers, and administrative clerks. We examined the experiences and perspectives of stakeholders by conducting 22 semi-structured individual and group interviews (n=69) across 12 hospitals, along with four focus groups involving members of national and seminational organizations, as well as patient portal vendors (n=53). We categorized the efforts made by hospitals to adopt patient portals into three main themes. First, hospitals must inform patients and healthcare professionals about the portal. This consists of four objectives: users should 1) know about the portal, 2) know how the portal works, 3) know that action on the portal is required, and 4) know where to find help with the portal. Second, it is essential to embed the patient portal into the daily routines of healthcare professionals and management. This involves three forms of support: 1) hospital policy, 2) management by monitoring the numbers, and 3) a structured implementation strategy that includes all staff of one department. Third, try to adjust the portal to meet patients' needs to optimize user-friendliness in two ways: 1) use patients' feedback and 2) focus on optimizing for patients with special needs, e.g., low literacy and low digital skills.

Inquiring with stakeholders about their experiences in stimulating patient portal use within hospitals provides rich insights into the adoption process, which were previously absent from existing implementation models. Consequently, the findings of this study contribute to translating the relatively abstract factors found in implementation models into the everyday pragmatics of eHealth projects in hospitals.

As indicated by the findings in Chapter 2, healthcare professionals play a crucial role in the adoption of patient portals. Consequently, we conducted a qualitative study focusing on mental healthcare professionals' appraisal work of patients' use of web-based access to their electronic health records (EHRs) (**Chapter 3**). This study aimed to provide insights into the appraisal work performed by mental healthcare professionals to assess and understand patient access to their EHRs through a patient portal. This study included 10 semi-structured interviews (n=11) and a focus group (n=10). Participants consisted of mental healthcare professionals from diverse professional backgrounds, including staff employees such as team leaders and communication advisors. We collected data on their opinions and experiences regarding the recently implemented patient portal and their attempts to modify work practices. The data analysis revealed four main topics: 1) appraising the effect on the patient-professional relationship, 2) appraising the challenges of sharing and registering delicate information, 3) appraising patient vulnerability, and 4) redefining consultation routines and registration practices. Mental healthcare professionals face challenges related to patient access to EHRs and are actively exploring strategies to modify their registration and consultation practices. Our findings suggest that mental healthcare professionals tend to appraise the effects of web-based patient access individually, indicating a lack of systematization and communal appraisal. Additionally, various solutions to the challenges faced by mental healthcare professionals emerged from this study. To optimize the effects of patient access to EHRs, it is essential for healthcare professionals to be involved in the development, implementation, and embedding of patient portals.

In **Chapter 4** we present a mixed-methods study on patients' choices regarding online access to laboratory, radiology, and pathology test results on a hospital patient portal. The disclosure of online test results (i.e., laboratory, radiology, and pathology results) on patient portals can vary from immediate disclosure (in real-time) to delays of up to 28 days or non-disclosure. We aimed to gain insights into patients' actual preferences. To achieve this, we allowed patients to register their choices on the hospital patient portal. We applied a mixed-methods sequential explanatory design that included 1) patient choices regarding their preferred time delay for test result disclosure on the patient portal across different medical specialties (N = 4592) and 2) semi-structured interviews with patients who changed their minds about their initial choices (N = 7). For laboratory (blood and urine) results, 3530 (76.9%) patients chose a delay of 1 day, while 912 (19.9%) patients opted for a delay of 7 days. For radiology and pathology results, 4352 (94.8%) patients selected a delay of 7 days. A total of 43 patients changed their minds about when they wanted to receive their results. Interviews with seven patients (16%) from this group revealed that some participants did not remember the reasons behind their changes. Four participants preferred a shorter delay to enhance transparency in health-related information and communication, to have time to process bad results; for reassurance; to prepare for a medical consultation; monitoring and acting on deviating results to prevent worsening of their disease; and to share results with their general practitioner. In contrast, three participants extended their chosen delay to avoid disappointment regarding the content and to mitigate anxiety about receiving incomprehensible information. Our study indicates that most patients prefer transparency in health-related information and wish for their test results to be disclosed as soon as possible.

Next, in **Chapter 5** we present the findings of a microlevel discourse analysis designed to gain a deeper understanding of what real-time access to test results means for patients. The aim of the study was to explore patients' feelings, thoughts, expectations, and experiences regarding real-time access to test results in relation to their views on patient-centered care. We conducted a discourse analysis based on 28 semi-structured interviews with patients who had experience (n=15) and those without experience (n=13) of real-time access to test results via a patient portal. We identified three discourses that illustrate the ways in which real-time access can be constructed: 1) *real-time access as a source of stress* shows how real-time access might cause stress due to the complexity of deciding whether or not to access test results, the incomprehensibility of the medical language used, and the urge to repeatedly check whether test results are already available, 2) *anxiety reduction through real-time access* shows how real-time access can reduce stress by reducing waiting times, and 3) *real-time access for self-management* shows how real-time access can give patients an opportunity for self-management because they can make informed decisions and are better prepared for the medical consultation. This study reveals the plurality of patients' opinions on real-time access. These insights can inform the development of various strategies to educate and support patients, thereby optimizing the use of real-time access to test results.

In the final chapter (**Chapter 6**) we present the main findings of this research and answer the main question by combining the insights from the different independent studies. We categorized the actionable knowledge that offers practical implications for the adoption process of eHealth technologies, such as patient portals, into four phases: **Awareness**, **Acceptance**, **Actioning**, and **Assimilation**. Each phase involves different actors and factors that contribute to the overall adoption process. This can be viewed as a heuristic model, because these phases may appear chronological, they are often interrelated in practice, with elements frequently moving back and forth during the adoption process. In the awareness phase, intended end-users become aware of eHealth technologies, such as patient portals. The acceptance phase involves healthcare organizations effectively addressing the potential consequences of utilizing patient portals to ensure that intended end-users fully understand the implications. In the actioning phase, patient portal users learn how to navigate and utilize the portal effectively, with appropriate support provided. The assimilation phase focuses on embedding patient portals into daily routines and refining the functionalities of the portal based on experiences in daily practice. Further research on the adoption process of eHealth technologies can be conducted through action research, in which researchers and co-researchers collaborate to develop and apply actionable knowledge in practice.

Samenvatting

SAMENVATTING

EHealth technologieën, zoals patiëntportalen, kunnen de ervaringen van patiënten en het werkproces van zorgprofessionals verbeteren, de kosten verlagen en de volksgezondheid bevorderen. Uit de literatuur blijkt echter dat deze technologieën nog niet op grote schaal worden toegepast door zorgprofessionals en patiënten. Hoewel er tal van financiële en ondersteunende programma's zijn geïmplementeerd om de adoptie van eHealth technologieën in Nederland te stimuleren, wordt het tot op heden niet optimaal gebruikt. In de literatuur bestaan implementatiemodellen voor eHealth technologieën, vaak gericht op concepten als acceptatie, adoptie en/of inbedding. Deze concepten worden op verschillende manieren toegepast. Aan de ene kant verrijkt dit de literatuur, maar aan de andere kant maakt dit het onderzoeken van het adoptieproces van eHealth technologieën, zoals patiëntportalen, uitdagend. De adoptie van eHealth technologieën is een iteratief, holistisch proces dat zich moet richten op zowel individuele als organisatorische niveaus, evenals de context. Dit is een belangrijk uitgangspunt voor dit onderzoek, omdat het erkennen van deze factoren waardevolle inzichten opleveren voor de adoptieprocessen binnen de dagelijkse praktijk van de gezondheidszorg. Het doel van dit onderzoek is om toepasbare kennis te verzamelen over de adoptie van patiëntportalen in de dagelijkse zorgpraktijk in Nederland. De onderzoeksvraag is: **Hoe kan de adoptie van patiëntportalen door patiënten en zorgprofessionals in Nederland worden ondersteund?** We hebben deze vraag onderzocht aan de hand van verschillende onafhankelijke studies.

We zijn gestart met een kwalitatieve studie naar de adoptie van patiëntportalen in ziekenhuizen (**Hoofdstuk 2**). Het doel van deze studie was om inzicht te verkrijgen in de adoptieprocessen van patiëntportalen onder patiënten en ziekenhuispersoneel, waaronder zorgprofessionals, managers en administratief medewerkers. We hebben de ervaringen en perspectieven van deze belanghebbenden onderzocht door 22 semigestructureerde individuele en groepsinterviews (n=69) in 12 ziekenhuizen, evenals vier focusgroepen met leden van nationale en semi-nationale organisaties en leveranciers van patiëntportalen (n=53) te houden. We categoriseerden de inspanningen van ziekenhuizen om patiëntportalen te stimuleren in drie thema's. Ten eerste is het van belang dat ziekenhuizen patiënten en zorgprofessionals informeren over het portaal. Hierbij onderscheiden we vier doelstellingen: gebruikers moeten 1) weten dat het portaal bestaat, 2) begrijpen hoe het portaal werkt, 3) weten dat actie op het portaal vereist is en 4) weten waar ze hulp kunnen vinden met het portaal. Ten tweede is het essentieel om het patiëntportaal in te bedden in de dagelijkse routines van zorgprofessionals en management. Deze inbedding omvat drie vormen van ondersteuning: 1) ziekenhuisbeleid, 2) management door het monitoren van de cijfers, en 3) een gestructureerde implementatiestrategie waarbij alle medewerkers van een afdeling betrokken waren. Ten derde proberen ziekenhuizen het portaal aan te passen aan de behoeften van patiënten met als doel de gebruiksvriendelijkheid te optimaliseren.

Dit kan op twee manieren: 1) door gebruik te maken van de feedback van patiënten en 2) door het portaal te optimaliseren voor patiënten met speciale behoeften, zoals laaggeletterdheid of beperkte digitale vaardigheden. Het bevragen van belanghebbenden over hun ervaringen met het gebruik van patiëntportalen binnen ziekenhuizen levert rijke inzichten op over het adoptieproces. Deze bevindingen dragen bij aan de vertaling van de relatief abstracte factoren in implementatiemodellen naar de dagelijkse praktijk van eHealth projecten in ziekenhuizen.

Uit de bevindingen in hoofdstuk 2 blijkt dat zorgprofessionals een cruciale rol spelen bij de adoptie van patiëntportalen. Om die reden hebben we een kwalitatieve studie uitgevoerd dat zich richt op een evaluatie door professionals in de geestelijke gezondheidszorg (GGZ) over het gebruik van online inzage door patiënten in de elektronische patiëntendossiers (EPDs) via een patiëntportaal (**Hoofdstuk 3**). Het doel van deze studie was om inzicht te geven in het evaluatiewerk dat GGZ-professionals verrichten om de online inzage via een patiëntportaal te begrijpen. Deze studie omvatte 10 semigestructureerde interviews (n=11) en een focusgroep (n=10). De deelnemers aan zowel de interviews als de focusgroep bestonden uit GGZ-professionals met verschillende achtergronden, waaronder stafleden zoals teamleiders en communicatieadviseurs. We verzamelden data over hun meningen en ervaringen met betrekking tot het onlangs geïmplementeerde patiëntportaal en hun pogingen om werkwijzen aan te passen. Onze analyse onthult vier thema's: 1) het evalueren van het effect op de patiënt-professionele relatie, 2) het evalueren van de uitdagingen van het delen en het registreren van gevoelige informatie, 3) het evalueren van de kwetsbaarheid van patiënten en 4) het herdefiniëren van consultatieroutines en registratiepraktijken. GGZ-professionals rapporteerden worstelingen met de implicaties van de online inzage door patiënten via het patiëntportaal en waren actief op zoek naar effectieve methoden om hun consultatie- en registratiepraktijken aan te passen. Onze bevindingen suggereren dat GGZ-professionals de effecten van online inzage voor patiënten individueel waarderen, maar dat er een gebrek is aan systematisering en gezamenlijke evaluatie (in termen van de Normalization Process Theory (NPT)). Daarnaast worden er verschillende oplossingen aangedragen over de uitdagingen waarmee GGZ-professionals worden geconfronteerd. Om de online inzage via een patiëntportaal te optimaliseren, is het essentieel dat professionals betrokken zijn bij de ontwikkeling, implementatie en inbedding van patiëntportalen.

In **Hoofdstuk 4** beschrijven we een mixed-methods studie naar de keuzes van patiënten met betrekking tot online inzage in laboratorium-, radiologie- en pathologieresultaten op een patiëntportaal van een ziekenhuis. Het ontsluiten van testresultaten (d.w.z. laboratorium-, radiologie- en pathologieresultaten) via patiëntportalen kan variëren van directe openbaarmaking (in realtime), vertragingen tot maximaal 28 dagen of het niet openbaar maken van de resultaten. We wilden inzicht krijgen in de werkelijke voorkeuren van patiënten. Om deze reden lieten we patiënten keuzes registreren op het patiëntportaal van een ziekenhuis. We hebben een sequentieel verklarend mixed-methods design gebruikt dat bestond uit 1) keuzes van patiënten met betrekking tot hun voorkeur voor het tijdstip waarop testuitslagen op het patiëntportaal worden gepubliceerd voor verschillende medische specialismen (N = 4592) en 2) semigestructureerde interviews met patiënten die van gedachten waren veranderd over hun aanvankelijke keuzes (N = 7). Voor laboratoriumresultaten (bloed en urine) kozen 3530 (76,9%) patiënten voor een vertraging van 1 dag, terwijl 912 (19,9%) patiënten voor een vertraging van 7 dagen kozen. Voor radiologie- en pathologieresultaten kozen 4352 (94,8%) patiënten voor een uitstel van 7 dagen. In totaal veranderden 43 patiënten van gedachten over wanneer ze hun resultaten wilden ontvangen. Door interviews met zeven patiënten (16%) uit deze groep leren we dat sommige patiënten zich de redenen voor hun veranderingen niet herinnerden. Vier patiënten gaven de voorkeur aan voor een kortere termijn om verschillende redenen: om de transparantie in gezondheidsgerelateerde informatie en communicatie te vergroten, om tijd te hebben om slechte uitslagen te verwerken, om gerustgesteld te worden, om zich voor te bereiden op een medisch consult, om afwijkende uitslagen te controleren en daarnaar te handelen, om verergering van hun ziekte te voorkomen, en om uitslagen met hun huisarts te delen. Het omgekeerde was van toepassing op drie patiënten die de door hen gekozen termijn verlengden om teleurstelling over de inhoud te voorkomen en om de angst voor het ontvangen van onbegrijpelijke informatie te verminderen. Deze studie wijst uit dat de meeste patiënten de voorkeur geven aan transparantie in gezondheidsgerelateerde informatie en dat ze willen dat hun testresultaten zo snel mogelijk bekend worden gemaakt.

Vervolgens presenteren we in **Hoofdstuk 5** de bevindingen van een discoursanalyse op microniveau. Het doel van deze studie was om de gevoelens, gedachten, verwachtingen en ervaringen van patiënten te onderzoeken ten aanzien van realtime inzage in testresultaten in relatie tot hun opvattingen over patiëntgerichte zorg. We hebben een discoursanalyse uitgevoerd op basis van 28 semigestructureerde interviews met patiënten die ervaring hadden (n=15) met realtime inzage en patiënten zonder ervaring (n=13) met realtime inzage in testuitslagen via een patiëntportaal. We identificeerden drie discoursen: 1) *realtime toegang als bron van stress* laat zien hoe realtime inzage stress kan veroorzaken door de complexiteit van de beslissing om al dan niet gebruik te maken van realtime inzage, door de onbegrijpelijkheid van de gebruikte medische taal en door de drang om herhaaldelijk te controleren of testresultaten al beschikbaar zijn, 2) *angstreductie door realtime inzage* laat zien hoe realtime inzage stress kan verminderen door de wachttijden van de bekendmaking van resultaten te verkorten, en 3) *realtime inzage voor zelfmanagement* laat zien hoe realtime inzage patiënten in staat kan stellen tot zelfmanagement, doordat ze beter voorbereid zijn op het medische consult en geïnformeerde beslissingen kunnen nemen. Deze studie toont de pluraliteit van meningen van patiënten over realtime inzage. Dit draagt bij aan de ontwikkeling van verschillende strategieën voor zorgorganisaties om patiënten voor te lichten, te ondersteunen en te kunnen informeren. Hierdoor kan het gebruik van realtime inzage in testresultaten geoptimaliseerd worden voor patiënten en zorgorganisaties.

In het laatste hoofdstuk (**Hoofdstuk 6**) presenteren we de belangrijkste bevindingen van dit onderzoek en geven we antwoord op de hoofdvraag door de inzichten uit de verschillende studies te combineren. De opgehaalde toepasbare kennis over het adoptieproces van eHealth technologieën, zoals patiëntportalen, delen we op in vier fasen: **Bewustwording, Acceptatie, Actie en Assimilatie**. Verschillende actoren en factoren spelen hierin een rol. Hoewel deze fasen chronologisch lijken, zijn ze in de praktijk met elkaar verweven, waarbij elementen in het adoptieproces heen en weer bewegen. Daarom moeten deze fasen worden gezien als een heuristisch model. In de bewustwordingsfase worden beoogde eindgebruikers zich bewust van eHealth technologieën, zoals patiëntportalen. De acceptatiefase houdt in dat zorgorganisaties de mogelijke gevolgen van het gebruik van patiëntportalen effectief aanpakken om ervoor te zorgen dat de beoogde eindgebruikers de implicaties van het gebruik volledig begrijpen. In de actiefase leren eindgebruikers hoe ze effectief door de portalen kunnen navigeren en deze kunnen gebruiken, met de juiste ondersteuning. De assimilatiefase richt zich op het inbedden van patiëntportalen in dagelijkse routines en het verfijnen van de functionaliteiten van portalen op basis van ervaringen in de dagelijkse praktijk. Verder onderzoek naar het adoptieproces van eHealth technologieën kan uitgevoerd worden door middel van actieonderzoek, waarbij onderzoekers en medeonderzoekers samenwerken om toepasbare kennis te ontwikkelen en toe te passen in de praktijk.

Dankwoord

DANKWOORD

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Er zijn meerdere (persoonlijke) gebeurtenissen geweest gedurende het promotietraject waarbij ik heb gedacht: wat fijn dat ik deel uit mag maken van dit promotieteam en wat ben ik dankbaar voor jullie betrokkenheid.

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PhD portfolio
&
About the author

PHD PORTFOLIO

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Department: Erasmus School of Policy Health & Management
PhD period: 2018-2024
Promotors: Prof. dr. ir. C.T.B. (Kees) Ahaus
Prof. dr. J.W.M. (Anne Marie) Weggelaar-Jansen, MCM
Co-promotor: Dr. Bettine Pluut

Courses

June 2024	Dissertation writing three-days
May 2024	Action research (network group)
February 2024	Action research (network group)
January 2023	Action research (network group)
October 2022	Action research (network group)
July 2022	Action research (network group)
July 2022	Speak up dear!
April 2022	Communicating your research: lessons from Bitescience
April 2022	Maximise your visibility as a researcher
January 2021	The focus group method
November 2020	Self-presentation: focus, structure, interaction and visualization
May 2020	Workshop management skills 'leren vergaderen'
February 2020	Group dynamics
November 2019	Basic didactics
November 2019	Academic writing
2018	Coaching and peer feedback for ESHPM thesis supervisors

Presentations

September 2019	Science Club HSMO
April 2019	ScienceWorks; research patient portals
March 2019	Ministry of Health, Welfare and Sport; research patient portals
January 2019	Client councils Dutch Hospital Association; research patient portals
November 2018	V&VN symposium eHealth; research patient perspectives patient portal

Attending congresses / seminars

November 2020	EHMA (European Health Management Association) conference
October 2019	Symposium Value Based Healthcare and affordable care

Teaching activities

2022 – 2023	Thesis supervision Master students Health Care Management
2021 – 2022	Thesis/internship supervision Bachelor students Health Sciences
2021 – 2022	Working groups course Health Services Innovation Master Health Care Management
2018 – 2022	Examination Health Services Innovation Master Health Care Management
2018 – 2020	Thesis supervision bachelor students Health Sciences

ABOUT THE AUTHOR

Pauline Hulter was born on January 21, 1992, in Coevorden, the Netherlands. She has been a nurse since 2014. She worked as a nurse in the cardiology and neurosurgery wards at Medisch Spectrum Twente in Enschede. In 2016, she completed a pre-master's in Health Sciences at the Erasmus School of Health Policy and Management, Erasmus University Rotterdam. She graduated her Master's in Health Care Management from Erasmus School of Health Policy and Management in 2018.

Pauline's Master's thesis marked the beginning of her role as a junior researcher in Health Services Management & Organisation at Erasmus University Rotterdam, which led to this PhD thesis. During her PhD, she coordinated the development of the Advanced Training Program in Value-Based Health Care (a blended learning program) on behalf of the Netherlands Federation of University Medical Centres (from June 2019 to October 2020). Alongside her PhD research, she supervised bachelor's students in Health Sciences with their final internship/thesis projects and participated in the Master's Health Services Innovation course (Master's in Health Care Management), where she facilitated working groups and contributed to examination.

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