Understanding patient perspectives

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Link to publication

Download date: 17 May. 2024

Rosa Ricarda Leni Charlotte Thielmann

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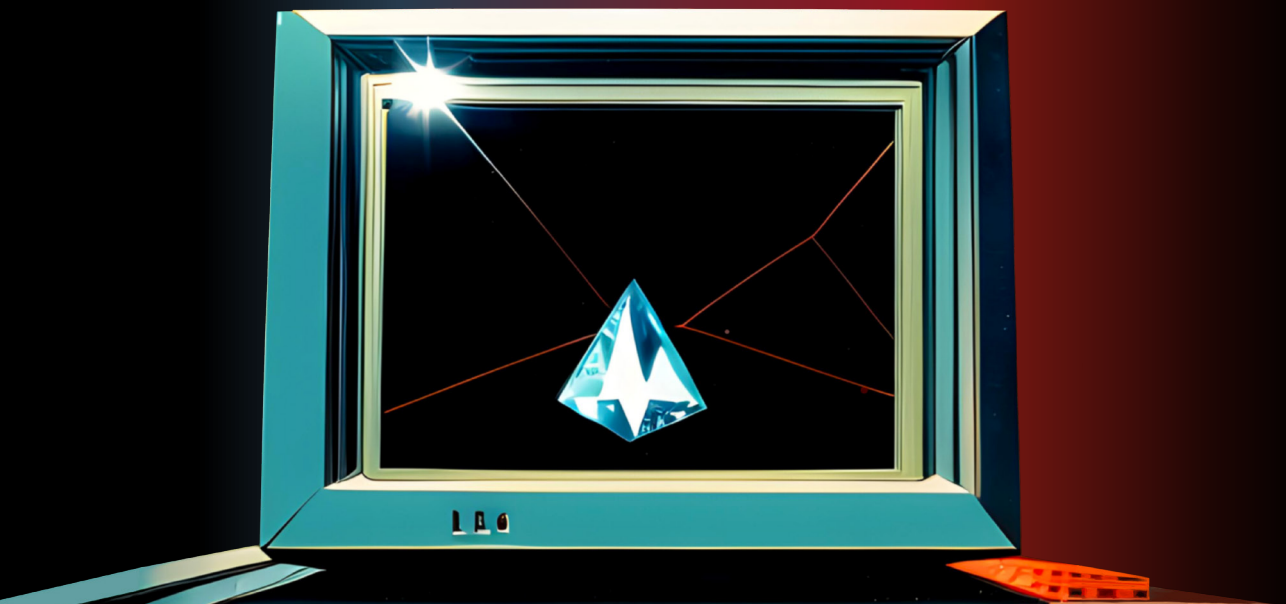
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Online Access to Medical Records

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Colofon

Understanding Patient Perspectives

Online Access to Medical Records

Proefschrift

ter verkrijging van de graad van doctor

aan de Universiteit Maastricht,

op gezag van de Rector Magnificus, Prof. dr. Pamela Habibović,

volgens het besluit van het College van Decanen,

in het openbaar te verdedigen

op dinsdag 5 december 2023 om 16:00 uur

door

Rosa Ricarda Leni Charlotte Thielmann

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General introduction

Paradigm shift

Patient empowerment and patient-centeredness are increasingly recognized as crucial elements for improving the quality of care in healthcare systems (Wolfe, 2001). Conceptualizations of patient empowerment and patient-centered healthcare frequently highlight increased patient participation, patient-provider communication, and respecting the patient's voice as fundamental values (Castro et al., 2016). This focus likely stems from an ideological transformation that has taken place since the 1990s, shifting from a paternalistic model in which healthcare providers held dominant decision-making roles to a model in which patients are empowered with decision-making authority. Especially when it comes to more complex health-related decisions that can have a significant impact on people's lives, many patients want the autonomy to make decisions for themselves and seek information necessary to make informed choices (Bekker et al., 1999). The concept of informed decision-making describes a process wherein a patient reaches a choice that is grounded in relevant and good-quality knowledge (i.e., about their condition, any treatment options and associated risks and benefits), reflects the patient's values (e.g., their preferences and concerns regarding those options and their potential outcomes), and can be subsequently executed (Bekker et al., 1999; Marteau et al., 2001). This kind of decision-making helps mitigate "decisional conflict", which refers to feelings of uncertainty or regret patients may experience in regard to their decisions (Knops et al., 2013; O'Connor, 1995) and can enhance treatment adherence (Sun, 2005).

This paradigm shift is in part idealistic, but also necessary given the increasing pressure on healthcare. More than half of the elderly population have more than one chronic condition (multimorbidity) and the prevalence increases continuously (Marengoni et al., 2011). Multimorbidity makes patients' demand for healthcare more complex and may complicate treatments. The demand for healthcare services is expected to increase in the coming years, while the availability of healthcare professionals is projected to decline due to a larger number of retirements compared to new workers entering the field. Consequently, healthcare systems require innovative solutions in order to be able to deliver more complex care with limited resources.

eHealth and digital care

Information and communication technologies, particularly internet-technology, are believed to play a central role to resolve current and future challenges and to redesign the healthcare system (Stroetmann et al., 2006; Wolfe, 2001). When those are used to support or improve health or healthcare, the term eHealth is often used. eHealth innovations enable new ways of patient participation, collaboration, and interactivity and have the potential to improve the quality and enhance the cost-effectiveness and efficiency of care (Shaw et al., 2018; Stroetmann et al., 2006). However, the empirically demonstrated benefits of eHealth innovations often tend to be lower than the initially postulated expectations (Black et al., 2011). Alongside potential benefits, advancements in eHealth also bring forth certain risks and challenges. These include addressing concerns regarding the privacy of sensitive health information (Dong et al., 2012) as well as bridging the digital divide, which refers to the unequal access to technology and varying levels of digital literacy among patients (Neter & Brainin, 2012). Some definitions emphasize that in a broader sense, eHealth is not just referring to technical advancements, but also characterizes a mindset, thinking approach, attitude, and commitment towards interconnected and global thinking (Eysenbach, 2001). This is an important addition, because it implies that the impact of these technologies in healthcare may be dependent on supporting social and cultural values prominent within the implementing community.

The terms eHealth and digital care are often used interchangeably in the literature, but they have distinct meanings. eHealth is an umbrella term referring to the use of digital information and communication to support and improve health and care (Lettow et al., 2019). Digital care specifically refers to the application of eHealth within the healthcare context. Digital care thereby requires a treatment relationship, such as between a doctor and a patient, and the provision of care services. For instance, an independent website offering general health information and resources, such as the in the Netherlands well known website thuisarts.nl, would fall in the category of eHealth, but not into digital care, as it lacks a treatment relationship.

The Dutch Ministry of Health, Welfare, and Sport (VWS) considers digital care a vital solution to the increasing pressure on the Dutch healthcare system (De Jonge et al., 2020). The Dutch College of General Practitioners (NHG) asserts that digital care should be integrated into general practice and implemented alongside non-digital care (Nederlands Huisartsen Genootschap, 2023). The NHG advocates for digital general practice care to adhere to the same quality standards as non-digital care and be used as a supplement rather than a substitute. Furthermore, the NHG emphasizes the importance of collaborative decision-making between caregivers and patients when determining the use of digital means, ensuring that it adds value for both parties.

Patient online access to medical records

One promising digital care innovation to empower patients to be more involved in their own care is patient online access to medical records (hereafter "online access") (Benjamins et al., 2021; Irizarry et al., 2015). In recent years, there has been a growing trend towards implementing patient online access in healthcare systems worldwide (Essén et al., 2018). In many healthcare systems, online access has already become an integral part. For example, in the United States, the "OpenNotes" initiative, which started more than a decade ago (Delbanco et al., 2012), now provides approximately 41 million patients with access to their medical records (Essén et al., 2018). Similarly in the Nordic countries, a majority of patients already has online access to their medical records (Hägglund et al., 2019). Four years after implementation, Swedish patients have reported positive outcomes, specifically that online access makes them feel informed and improves communication with medical staff (Moll et al., 2018).

In the Netherlands, patients have been legally granted the right to electronically access parts of their general practice medical record in July 2020. This access is mainly facilitated through online patient portals that are linked directly to the general practice electronic medical record. Presently, patients can view their medication and allergy lists, medical notes, and diagnostic test results through these portals (HealthIT, 2019). The demand for online access among patients is presumed to be high, as 88% of the adult Dutch population considers it important to have online access to their medical data (Netherlands Patients Federation, 2020). However, experiences from pioneering settings in the US indicate user rates of only 15–30% despite high patient interest (Lyles et al., 2020). There are various challenges associated with the adoption of online access for both patients and healthcare providers. These challenges arise from technological aspects, factors related to the medical practice and healthcare providers as well as the characteristics and specific needs of the patients (Niazkhani et al., 2020).

The research described in this dissertation was part of the OPEN program, implemented by the Dutch Ministry of Health, Welfare and Sports. From 2019 until 2022, the program aimed to support general practices in the implementation of patient online access to medical records by offering practical assistance in planning, implementing, and organizing the necessary ICT adjustments. To evaluate the

impact of online access and the OPEN program, three research institutes conducted scientific research on the effect of patient online access. The Scientific Institute for Quality of Healthcare (IQ Healthcare) conducted an in-depth study on the impact of health data sharing on various healthcare users and health workers in general practice. The Netherlands Institute for Health Services Research (NIVEL) explored the perspective of general practitioners (GP) and the possible effects within general practice. The focus of the research presented in this dissertation and conducted by Maastricht University was the perspective of patients and the possible impact of online access to medical records on their care process.

The importance of understanding patient perspectives to fully unlock the potential of online access to medical records has been consistently emphasised in previous research (Crameri et al., 2020; Entzeridou et al., 2018; Fragidis & Chatzoglou, 2018; McGinn et al., 2011). This dissertation reports research on patient needs, expectations, and experienced effects conducted during the early stages of implementation of online access to general practice medical records in the Netherlands. The findings can offer valuable insights for the development and improvement of strategies aimed at supporting the implementation and evaluation of online access in the Netherlands and other countries with similar sociocultural contexts and technical infrastructures, particularly those in similar or earlier stages of introducing online access.

Outline of this dissertation

Patient needs

Studies conducted in different countries and among diverse patient populations have identified several barriers for patients to use online access to their medical records: lack of awareness and insufficient training or instructions on how to use online access (Powell, 2017), a complex and complicated interface of the online environment (McGinn et al., 2011; Ose et al., 2017), concerns related to privacy and security (McGinn et al., 2011; Powell, 2017), and anticipated distress and anxiety when receiving sensitive or incomprehensible medical information through technology without the presence of a healthcare provider (Baun et al., 2020; Jilka et al., 2015).

By contrast, several factors facilitate the use of online access among patients. These facilitators include healthcare provider encouragement (Powell, 2017), the expectation of benefits such as an improved relationship and communication with the provider (Ose et al., 2017; Powell, 2017), and a sense of empowerment and enhanced control over one's healthcare (Crameri et al., 2020; Powell, 2017). Additionally, previous findings indicate that patients with certain characteristics experience more difficulties in using online access than others. Older adults (Logue & Effken, 2012; Lyles et al., 2020), patients with limited health and digital literacy (Emani et al., 2012; Lyles et al., 2020), members of ethnic minorities (Roblin et al., 2009; Yamin et al., 2011), and those with a low socioeconomic status (Emani et al., 2012) are more prone to encounter challenges in accessing and meaningfully engaging with their medical data.

Understanding patients' needs, expectations, and perspectives is consistently emphasized as crucial for unlocking the full potential of online access (Crameri et al., 2020; Entzeridou et al., 2018; Fragidis & Chatzoglou, 2018; McGinn et al., 2011). Those appear to differ across patient populations in different geographical areas, sociocultural contexts, and stages of online access implementation (Prey et al., 2016). **Chapter 2** presents an interview study that identified needs and expectations of Dutch patients regarding online access to their general practice medical record. Insight from such investigations can inform the development of strategies that support patients in the initial use online access.

Estimating the degree of relevance of determinants

Not every patient might wish to access their medical record online. Therefore, it is important to enable patients to make an informed decision about whether they want to access their medical record or not. In line with the findings described above that informed decision-making decreases uncertainty or regret about the decision taken (Knops et al., 2013; O'Connor, 1995) and increases the likelihood of continuation of the chosen option (Sun, 2005), promoting informed decision-making about using online access could lead to more sustained use and thereby facilitate potential benefits such as increased patient engagement in healthcare.

Strategies or interventions to support patients to (decide whether to) use online access should ideally address all factors, commonly labelled "determinants", that seem to be of importance within patients' use of and informed decision-making regarding online access. However, practical limitations, such as time, budget, and staff availability, may pose constraints on content development and delivery for such interventions. Therefore, it is important to identify and address the factors which are most relevant (Crutzen et al., 2017), i.e., have the strongest association with the use of online access and the decision regarding use and offer the greatest potential for improvement. This approach ensures efficiency of efforts to support adoption of online access among patients.

The relevance of determinants for patients' online access use and informed decision-making regarding use were unknown. Informed by the needs patients identified in the interview study described in Chapter 2, a cross-sectional survey study was developed that aimed to identify the most relevant determinants for Dutch patients regarding their room for improvement and their association with 1) use of online access to medical records and 2) decisional conflict regarding use. **Chapter 3** reports on this study.

Effects of online access for patients

Positive effects from online access for patients are thought to arise partly because it enhances patients' personal healthcare knowledge, such as understanding their health condition or treatment options (Han et al., 2019). This increased knowledge can contribute to informed healthcare decision-making by patients (Irizarry et al., 2015). To assess the potential impact of online access, it is essential to monitor the impact on patients. Furthermore, exploring these effects is important for providing accurate information to patients. Patients' interest in using online health information services is strongly influenced by their expectations of the benefits it can offer (Mead et al., 2003). Moreover, having sufficient information about all available options, including their advantages and disadvantages, is a critical prerequisite for making informed decisions (O'Connor, 1995). **Chapter 4** presents the results of a longitudinal survey study investigating the effects patients perceive from online access on patient empowerment, decision-making, and the GP-provider relationship after six months.

Despite ongoing efforts to comprehend the complex process through which online access may affect patients and health systems, previous systematic reviews conclude that the existing evidence is inadequate to draw conclusions regarding its actual impact on patient empowerment and decision-making (Ammenwerth et al., 2019; Antonio et al., 2020; Fraccaro et al., 2018). Results of the study described in Chapter 4 showed very small differences in effect measures between groups of online access users and non-users after six months. To explore whether those small effects had indicated trends that might continue in the future and to better understand the role of online access in healthcare, further insight was warranted into how online access has affected Dutch patients. Therefore, another longitudinal survey study was conducted in which within-person changes in effect measures over a one-

year time period were investigated. This allowed for a comparison of patients that never used online access with those that have used it or recently initiated use. **Chapter 5** presents the results of that study.

2

Patient online access to general practice medical records:
a qualitative study on patients' needs and expectations

Abstract

Background: Patient online access to medical records is assumed to foster patient empowerment and advance patient-centred healthcare. Since July 2020, patients in the Netherlands are legally entitled to electronically access their medical record in general practice. Experience from pioneering countries shows that despite high patient interest, user rates often remain low. How to best support implementation highly depends on patient populations' individual needs and expectations, which are yet unknown in the Dutch context.

Objective: To understand Dutch patients' needs and expectations with regard to online access to their medical record in general practice.

Method: Twenty participants completed semi-structured individual interviews via video or telephone call. Transcripts of interviews underwent template analysis combining deductive and inductive coding using Atlas.ti software.

Results: Patients' needs and expectations ranged across three overlapping areas: 1) prerequisites for getting online access, 2) using online access, and 3) the impact on interaction with healthcare providers. Patients expected benefits from online access such as better overview, empowerment, and improved communication with their general practitioner, but identified needs regarding technological difficulties, data privacy, and complex medical language in their record.

Discussion: The concerns and obstacles participants identified point towards the need for organisational changes in general practice, for example adjusted documentation practices, and the key role of the general practitioner and staff in promoting and facilitating online access.

Conclusion: Implementation strategies addressing needs identified in this study may help to unlock the full potential of online access to achieve desired outcomes of patient involvement and satisfaction.

Chapter 2

Introduction

Patient empowerment and patient-centeredness are increasingly regarded as critical quality attributes in healthcare (Wolfe, 2001). While there is no widely accepted definition of those terms, conceptualizations often illustrate an ideological shift from paternalistic to increasingly participation-based health care in which communication and respecting the patients' voice become key values (Castro et al., 2016). A promising mechanism to enable patient participation in healthcare is patients' online access (hereafter "online access") to medical records (Irizarry et al., 2015).

Online access to medical records was ascribed the potential to facilitate patient informed decision-making (Irizarry et al., 2015) by improving the patients' health knowledge (Han et al., 2019). Informed decision-making is the process resulting in decisions that the patient makes based on relevant and good quality knowledge, that reflect the patients' values, and that are behaviourally implemented (Bekker et al., 1999; Marteau et al., 2001). Involving patients more in decisions about their health has the potential to improve affective-cognitive patient outcomes such as patient satisfaction (Shay & Lafata, 2014).

Recently, in July 2020, patients in the Netherlands became legally entitled to access parts of their medical record electronically in primary care (mainly care delivered through the general practitioner [GP]). Access is mainly facilitated via online patient portals which are directly tethered to the medical record held by the GP. Access is safeguarded by two-factor authentication. In patient portals, patients can view medication and allergy lists, medical notes, and diagnostic test results (HealthIT, 2019).

Patients' demand can be assumed high, as 88% of the adult Dutch population finds it important to have online access to their medical data (Netherlands Patients Federation, 2020). However, experiences from pioneering U.S. settings show user rates of only 15 to 30% despite high patient interest (Lyles et al., 2020), as well as long lists of challenges in the adoption of online access for both patient and health care provider. These challenges are attributable to technological aspects, factors related to the medical practice and provider, and characteristics and according needs of the patient (Niazkhani et al., 2020).

Research on patient needs in various countries among diverse patient populations point towards the following barriers in the use of online access: lack of awareness and insufficient training or instructions regarding use of online access (Powell, 2017), a complex and complicated interface of the online environment (McGinn et al., 2011; Ose et al., 2017), privacy and security concerns (McGinn et al., 2011; Powell, 2017), and anticipated distress and anxiety when receiving sensitive or incomprehensible medical information through technology without the presence of a healthcare provider (Baun et al., 2020; Jilka et al., 2015). Further, facilitators for the use of online access include encouragement from the healthcare provider (Powell, 2017), expecting benefits from use (Crameri et al., 2020; McGinn et al., 2011) - especially the benefit of improved communication and relationship with the provider (Ose et al., 2017; Powell, 2017) - and the feeling of empowerment and enhanced control (Crameri et al., 2020; Powell, 2017).

Further, previous findings indicate that patients with certain characteristics experience more difficulties in using online access than others. Older adults (Logue & Effken, 2012; Lyles et al., 2020), patients with limited health and digital literacy (Emani et al., 2012; Lyles et al., 2020), low socioeconomic status (Emani et al., 2012; Roblin et al., 2009; Yamin et al., 2011) and members of ethnic minorities (Roblin et al., 2009; Yamin et al., 2011) are more prone to face challenges in accessing and meaningfully engaging with their medical data.

Previous research consistently points towards the importance of understanding patients' needs, expectations, and perspectives to unfold the full potential of online access (Crameri et al., 2020;

Entzeridou et al., 2018; Fragidis & Chatzoglou, 2018; McGinn et al., 2011). Moreover, best practice seems to depend on the type and level of access (e.g., opt-in/opt-out) (Nøhr et al., 2017) and differ between patient populations in various geographic locations, sociocultural contexts, and stages of online access implementation (Prey et al., 2016). The recentness of introduction of online access in general practice in the Netherlands provides the opportunity to explore patients' needs and expectations in this early stage of implementation to subsequently integrate these in the development and improvement of strategies that support the implementation of online access. To this end, this study aimed to identify needs and expectations of Dutch patients in regard to online access to their medical record in general practice.

Methods

A qualitative study was conducted to reach our study aim. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative (COREQ) Research Guidelines (Tong et al., 2007).

Research design

A series of semi-structured individual interviews were conducted. Individual interviews were chosen as a broader range of information may be generated than through focus groups (Guest et al., 2017). An interview guide was developed based on the concepts described in the introduction and on the researchers' experience in similar fields. The interview guide, patient information letter, informed consent form and demographic questionnaire can be found at the Open Science Framework (https://osf.io/8ezyu/).

Participants and recruitment

Eligible for participation were adults (18+) from the Dutch population who had been in contact with their GP at least once in the six months prior to recruitment. For recruitment, printed flyers were randomly distributed via letterboxes in a mid-sized city in the southern part of the Netherlands, a digital flyer was uploaded on various social media platforms, and one researcher (ESK, not conducting interviews) recruited participants from her network via personal invite. Interested individuals could either contact the main researcher (RT) to ask questions or directly access a digital form with detailed information about the study and request for informed consent. The form also included a five-item background questionnaire about socio-demographic characteristics that earlier research showed to influence use of online access to medical data: age (Lyles et al., 2020), gender identity (Miles et al., 2016), cultural background, highest level of education completed (Emani et al., 2012), and having a chronic disease (Niazkhani et al., 2020). Based on the answers, purposeful sampling was employed to achieve a heterogenic sample. Fifty-one people showed interest in participation by filling in the digital form.

Data collection

As data were collected while contact-limiting COVID-19 measures were in place, all participants preferred to be interviewed via videocall or telephone instead of in person (although this option was provided as well). Interviews were conducted in Dutch. After a first inquiry of participants' experience with online access, they were shown a 40 second videoclip explaining online access to assure understanding of the interview topic. This was deemed necessary as participants were expected to have little experience with online access due to the recent introduction and low user rates (OPEN-Eerstelijn, 2020). Participants were asked questions about 1) their previous experiences with online access to their

GP medical record; 2) whether, under which circumstances, and how they (would) make use of it; 3) expected or experienced advantages and disadvantages, specifically the impact on the GP-patient relationship; and 4) what they perceived as barriers and facilitators for use and consequent needs. Other topics participants mentioned were explored as well. Duration of interviews was between 30 and 55 minutes. After the interview, participants were reimbursed with a 20-euro gift voucher. Audio was recorded with *QuickTime Player* and fieldnotes were taken. Interviews took place between February and May 2021 until data saturation was reached, i.e. three consecutive interviews did not produce new knowledge relevant to the research question (Mason, 2010). The audio records were transcribed verbatim. Transcripts were returned to participants to confirm accuracy and approve further use.

Data analysis

Socio-demographic data from the questionnaire were summarised with Microsoft *Excel*. The coding software *Atlas.ti 9* was used for the analysis of transcripts. Due to its structured yet flexible approach, the steps of template analysis (Brooks et al., 2015), a form of thematic analysis (Braun & Clarke, 2006), were followed: The coders (RT and ESK) (1) familiarised themselves with the data, (2) in an iterative process carried out preliminary coding on a sub-set of the data (25%) with both tentative a priori as well as inductive themes, (3) organised themes into clusters, (4) defined an initial coding template, (5) applied the initial template to 10% of the data, discussed coding and modified the template as necessary, and (6) applied this version of the template to another 10% of the data set based on which inter-coder-agreement was calculated. Krippendorff's alpha (α) was used because of its advantages compared to other common measures (Hayes & Krippendorff, 2007). As α was 0.82, the template could be considered as reliable (Krippendorff, 2004) and was applied to the full dataset by RT.

Ethics approval

The study was approved by the Maastricht University Faculty Research Ethics Committee (approval number: FHML-REC/2020/119). Digital and verbal informed consent was obtained before the start of each interview. Participant data were treated confidentially and the possibility to trace transcripts back to specific participants was removed after participants' check for transcript accuracy.

Results

After interviewing twenty participants, data saturation was reached. Purposeful sampling resulted in a group of 12 women and 8 men. Six participants were aged 18-34, four were aged 35-49, six were aged 50-65, and four were older than 65 years. Twelve participants completed higher or university education. Five participants reported being diagnosed with a chronic disease. Two participants had a cultural background different from Dutch. Four participants had used online access prior to the interview.

Most participants considered online access as "useful" and a "good development". For many, online access matched their feeling of being entitled to access their own data. Some had mixed feelings and were unsure yet whether they would want online access, and a few stated they see no use or prefer to not be more involved in their healthcare. Overall, participants found it important that their individual choice is respected.

During template analysis, needs and expectations in regard to online access were grouped into three overlapping areas: (1) prerequisites for getting online access, (2) using online access, and (3) impact on interaction with healthcare providers.

Prerequisites for getting online access

Prerequisites necessary for participants to get online access pertained to provision of information, technological conditions, and instrumental support.

Most participants had not heard about online access before participating in this study. They stated that if they had known about this possibility, they would have asked their GP about it. Many participants seemed indignant that this option was not communicated to them before and planned to get online access in the future.

> *I didn't know anything at all. I didn't know they were working on that. I heard that from [name daughter]. I thought to myself, oh that's nice. I went right to work on it. But, no, I think most people don't even know about it. (P9, male, 35-49 years)*

Participants saw the GP practice as responsible to inform them about online access. Many wished to be notified either personally or via email. Some imagined it beneficial to see online access advertised in the practice, for example in the form of a poster or videoclip in the waiting room.

> *I think they [GPs] should be proactive. Because there are people who indeed don't know that [the option of online access] and never find out if the doctor doesn't let them know. (P20, male, 65+)*

Most participants identified the degree of complexity for accessing their medical record as substantially influencing their decision and ability to use online access. Many participants feared difficulties related to technology, specifically a high number of complex actions to create an online access account. Most participants said that they would not want to spend more than 10 minutes to make an account.

> *Suppose there is one of these double verifications, so then you have to first type a code from your mobile back into your laptop or whatever, yes, then it already gets complicated very quickly. (P3, male, 18-34 years)*

> *I need to create something that will allow me to get in there, but this creating [of an account], I can't get it done. I don't understand these internet terms there sometimes, so then I stop. (P10, female, 65+)*

Participants that already used online access reported mixed experiences: two participants found making an account easy and intuitive, while two others found it difficult and complicated, and once succeeding also had problems logging back in.

Consequently, participants wished for instrumental support in form of clear instructions on how to create an account. A few participants aged 65+ expected to need help from family members or friends who are more experienced with technology. The majority however found it sufficient but necessary to receive instructions from the GP practice on its website, in an email, pamphlet, or video clip. Most participants were confident that such instructions would enable them to access their medical record.

> *They really don't need to start looking over my shoulder while I'm at the computer trying to create it. But, yes, do provide instruction, on how to create such an account. (P16, female, 50-65 years)*

> *I actually have to have [instructions] on paper: You have to type that in, there. (P10, female, 65+)*

However, a few patients also valued a multi-step registration process as double verification would increase protection of their data. Almost all participants were concerned about the safety and privacy

of their medical or personal data when using online access. Mostly, they were afraid that systems get hacked and strangers will have access to their data. Many participants expressed the wish for support from their GP practice in accessing their medical record safely.

> *The only major drawback is security and privacy. […] I do think that it is more openly accessible if you make it accessible to patients than the way it is organised now. (P17, female, 50-65)*

> *I think that they [GP practice] should support you in choosing a good password, or for example a confirmation code by phone or email, so that there is at least some security. (P8, female, 18-35)*

In contrast, a few participants did not see this as problematic, explaining that they did not perceive their medical record as valuable to anyone else.

> *Look, my medical records, they are not worth the effort. There is not so much going on there fortunately. (P7, male, 65+ years)*

Frequently participants mentioned that they do not want insurance companies or health care providers other than their GP to access their data. A few participants believed that their own access would automatically allow access for healthcare providers other than their GP as well. Many expressed concern that disclosure of medical data to third parties would become normal in the future.

> *If the standard is, in society, that you yourself can see the data, maybe it can also happen at some point that it becomes so normal that data will be further disseminated, so to speak. (P3, male, 18-34 years)*

Beyond support for making an account, participants wanted to have realistic expectations conveyed about which data they can access and which role it can have for their healthcare.

> *Maybe send people a video, for example, […] what is this online environment, or what can it offer you? Well, for example, more insight, that you can prepare well for a conversation. Yes, things like that. And what it cannot offer you, or what it is not. (P8, female, 18-35)*

Using online access

Participants explained how they (intend to) use online access, interact with their medical record, and which immediate benefits and difficulties they expect.

Frequently participants mentioned that they expect online access to reduce the cognitive burden to remember all their health information. They mentioned favourably the possibility of re-accessing information that was given during a consultation and reading about their medical history.

> *How many times have we had it where you've had something, and then you come home, and you actually don't know half of what they [doctors] actually said in there? (P13, male, 35-49)*

Most participants thought that using online access would give them a better overview of their healthcare, especially regarding experienced symptoms, past illness episodes, dates they consulted their GP, and when their next medical check-up has to be scheduled.

> *You really get a better overall picture of, okay, what's going on here now? (P3, male, 18-34 years)*

> *As soon as you go into a kind of longer trajectory, then I think it can be of added value to really keep that overview, then also for yourself, like, okay, where are we at the moment, so to speak,*

what does the GP already know, what are the options for example, and have I suffered from it before. Those kinds of things. (P3, male, 18-34)

Many participants mentioned they want to use online access to detect mistakes in their medical file and valued the opportunity to contribute to rectification. Further, they expected that convincing themselves of the congruence between information given during a consultation and written in their medical record would increase their trust in the GP. Reversely, a few participants also mentioned that earlier experiences of detecting mistakes in their files disrupted their trust in the healthcare provider or caused them distress.

Then of course you can look at it yourself, like: Do I think that's right, or is something missing? (P17, female, 50-65 years)

I did see a number of times that the information in my file was actually incorrect. You can say: yes, that's positive, and then there comes a kind of improvement, that you say to the hospital or GP: I think it's not correct, you have to correct it. But the trust that you then have in the health care institution, that does not increase, of course. (P1, female, 35-49 years)

They further expected online access would increase their understanding of their health issues. Additionally, many mentioned online access would prompt them to research information relevant to their healthcare on the Internet and thereby expand their health knowledge further.

You see the medical terms, quickly look it up, so that you think: ah, yes, now I understand what he [GP] is talking about. (P3, male, 18-34 years)

However, most participants also acknowledged that they would have difficulties to understand and interpret parts of their medical record as they lack medical expertise. Several participants feared that looking for additional explanation on the Internet could lead them to draw the wrong conclusions or find unsettling information.

I think you probably can't read that yourself. (P6, male, 18-34 years)

I would go and look it up, and I wonder if that would be right, because then you could also misinterpret it. (P18, female, 18-35)

Therefore, participants emphasised the need for an adapted, simplified language in their medical record which can be understood without having a medical background.

Of course, they [GPs] do have to write it down so that it's clear to a layperson. (P9 male, 35-49 years)

Moreover, many participants found it important that the GP communicated sensitive information first face-to-face before making it accessible online for the patient. Additionally, several participants were concerned that using online access could cause them emotional distress when reading unexpected or derogatory remarks from their GP which normally would not be intended for the patient to read. For example, to protect herself from negative feelings, a participant who already used online access decided against reading her medical history:

I don't want to just come across things, for example, imagine you went there with a problem, and you're emotionally sharing your problem. Imagine in the file you read something like "she's overreacting", or something. [...] In that case, if I were to read something back, I wouldn't feel good. (P4, female, 50-65 years)

Impact on interaction with healthcare providers

Participants expected their use of online access to impact the interaction with their GP and other healthcare providers.

Participants valued the transparency resulting from online access, leading to increased ability to 'think along' with their GP, discuss more, or be more involved in decisions. They expected that they would feel more equal to their GP in conversations, empowered, and less helpless and vulnerable.

> *It's easier for you to have a say. About your treatment. About your results. […] Before, of course, it was like this: the doctor said A, and the patient also said A, and then the doctor said no, I mean B, and then the patient also said B. Yes, that's not the case, you become more articulate, and you become more aware of, yes, what do I think, and what do I know, and that's just important. (P2, female, 50-65 years)*

Many participants expected that by using online access they would feel better prepared for consultations, enabling them to participate more in the conversation and ask more specific questions. Most participants expected the communication to improve through their increased participation.

> *The mutual understanding [is] greater. […] If you have to go [to the GP], you are much better consulted, much better prepared. You go there more empowered. I think that's a big advantage. (P2, female, 50-65 years)*

> *More and more two-way communication, I think. You can ask more targeted questions. (P16, female, 50-65 years)*

Further, participants expected that online access would improve the transferal of information to specialists they get referred to by their GP. Many had the feeling that the information transfer from the GP to a specialist was frequently incomplete or absent. Online access would enable them as patients to, either verbally or written, share information about their medical situation themselves.

> *Normally you say, well, "I don't have any pills or anything", or "I don't know what it's called". But if you just have it [written] somewhere, then you can say, well, "this is it". Yeah, I think that is actually good. (P1, female, 35-49 years)*

The majority of patients expected fewer telephone conversations with their GP office when having online access, as they would be able to access information, mainly test results, on their own for which they previously required the help of the GP practice.

> *Usually if I want to see the blood result, for example, I have to call there first, and then the assistant has to go look it up. And now I can click on it myself. Then I see the result already in there. (P13, male, 35-49 years)*

The majority of participants expected however no change in the number of consultations, as they found it important to consult the GP when experiencing a health problem. Only a few participants expected a decrease in the number of consultations as in case of a recurring health issue, they could compare their current symptoms with those in earlier records and better evaluate the necessity of a consultation or take action on their own. Almost all participants stressed the importance of personal encounters with the GP, especially in times of increased need for care. They stressed that online access could not replace personal contact but should be handled as an additional tool for healthcare.

> *If you really have some problem, you still want to be seen by the GP. I don't think that's going to lead to fewer appointments. (P6, male, 18-34 years)*

Access to your medical records, that has additional value. But that first step is still the personal contact. (P2, female, 50-65 years)

Discussion

This qualitative study explored Dutch adults' needs and expectations regarding online access to general practice medical records. Generated insights were grouped into three overlapping areas: prerequisites for getting online access, using online access, and the impact on interaction with healthcare providers.

Across all three areas, participants identified several obstacles and needs to use online access. First, only a few participants had previous experience with online access to GP medical records and many participants had not even heard about the option yet. This can be explained by the facts that patients' legal entitlement to online access in the Netherlands had been recently implemented (July 2020) and little publicity was given prior to the interviews. This obstacle of low levels of awareness has been found in various countries (Powell, 2017; Van Kasteren et al., 2017). Our study suggests that efforts to raise awareness about online access can already increase intended use, and that patients expect the GP practice to take up an active role in this. However, an umbrella review including research from various countries on health care providers' attitudes towards online access shows they are concerned about anxious, overwhelmed and offended patients, liability, and changes in workload (Antonio et al., 2020). These concerns might create resistance to introduce patients to online access and have to be explored and addressed to implement online access successfully.

Second, participants of this study were concerned that creating an account and using online access would be difficult for them, which is similar to findings from Lyles et al. (2020) that limited digital literacy and confidence of patients are among the most common barriers to online access use among various populations. As 36% of the Dutch population are considered having inadequate or limited functional/cognitive health literacy skills (Rademakers & Heijmans, 2018), this obstacle deserves attention in the implementation process. Improvements of accessibility on portal level or additional trainings for vulnerable groups could address this issue (Forchuk et al., 2015). Positive effects of a support strategy for portal use have already been demonstrated (Ramsey et al., 2018), but additional research is needed on the needs of diverse patient groups, especially those with low digital literacy (Lyles et al., 2020).

Third, almost all participants were worried about the privacy and confidentiality of their data, which is a common concern observed in various populations (Lyles et al., 2020; Powell, 2017). Interestingly, participants of this study seemed willing to accept the perceived risk of security breach as most of them still intended to use online access. Although the worries might thus not decrease user rates, they can possibly interfere with intended effects such as increased patient satisfaction. Some privacy concerns mentioned in our interviews were based on misconceptions, for example that alongside patient access other health care providers automatically have access to the data as well. Misconceptions might be resolvable with educational efforts. Additionally, privacy and security of data should be prioritised in the development of and education about online access.

Fourth, participants wanted to use online access to view and review their medical record and thought that thereby they would gain more knowledge and understanding about their health. However, they were also concerned that the medical language used in their record is incomprehensible for them. Furthermore, not understanding health data could lead to confusion, concerns, and wrong interpretations which might even lead the patient to take unanticipated and potentially harmful actions. Due to this

ambivalence, online access has been described as a double-edged sword (Baun et al., 2020; Lester et al., 2016), which can be either beneficial or harmful, depending on the patient's comprehension of the data. The notion that medical records were initially only developed to be used (and therefore understood) by health care professionals makes it obvious that people without medical background might struggle with comprehending the presented health information (Beard et al., 2012). It is crucial to explore how documentation practices can be changed to serve the needs of both healthcare professionals and patients, and how patients with limited health literacy or insufficient knowledge can be best supported to interpret medical data correctly.

Overall, results of this study suggest that to address the obstacles of low awareness, low digital literacy, security concerns, and complex language in medical records, implementation accompanying strategies are necessary. In line with research priorities listed by Lyles et al. (2020), we propose that future research should address the key role of the GP and staff in promoting and facilitating online access as well as the role of the government in supporting them.

By being able to access and understand their data, participants in this study expected to feel empowered and enabled to contribute more to conversations and decisions regarding their health(care). While these expectations support commonly envisioned effects of online access (Tapuria et al., 2021), systematic reviews conclude that to date, the actual influence on patient empowerment and decision-making remains under-investigated (Ammenwerth et al., 2019; Fraccaro et al., 2018). Research is needed to understand the complex process of how online access might improve health outcomes (Fraccaro et al., 2018). Our study indicates important needs and expectations that can be included in such investigations. Further, to understand how effects of online access relate to patient satisfaction, we recommend including measurement of patients' evaluation of those effects in further investigations of the impact of online access to medical records.

When interpreting the results of this study, certain limitations have to be considered. First, due to the novelty of online access in the Netherlands, participants' imaginability of online access and its potential effects might be limited. To account for this, we showed a brief video, explaining online access, at the beginning of the interview and got the impression and feedback that thereafter understanding was sufficient. Second, it should be noted that sampling bias might have led to participants of this study having a more positive attitude towards online access and imagination of its effects compared to people that did not participate. Overall, we believe that we were able to generate in-depth findings from a diverse group of participants pointing towards priorities for implementation strategies and future research.

Conclusion

This study demonstrated that patients expect benefits from online access such as better overview, personal empowerment, and improved communication with their GP, while they were concerned about technological difficulties, data privacy, and complex medical language in their record. Organisational changes in general practice, for example adjusted documentation practices, and implementation accompanying strategies, such as educational efforts, are needed to support patients to access, understand, and use their medical record and to eventually achieve desired outcomes of increased patient participation and satisfaction.

Chapter 2

3

Relevant determinants of patients' informed decision-making process and use of online access to their medical records

4

The effects of online access to general practice medical records perceived by patients: longitudinal survey study

Abstract

Background: Patient online access to medical records is assumed to facilitate patient empowerment and advance patient-centered health care. However, to date, the actual effects of online access to medical records perceived by patients and other outcomes are insufficiently empirically tested.

Objective: This study aimed to investigate the effects of online access to medical records on patient empowerment, informed decision-making, and the patient-provider relationship perceived by patients.

Methods: A nationwide, 2-wave, longitudinal survey study was conducted among Dutch adults (N=2402). Linear regression analyses were performed. In model 1, the perceived effects of online access to medical records (measured at T1 [first measurement; July 2021]) on 16 outcomes (measured at T2 [second measurement; January 2022]), which were associated with the use of online access to general practice medical records in previous research, were investigated. Model 2 included sociodemographic factors and patient characteristics as confounders.

Results: Users indicated more strongly than nonusers that online access to medical records would increase their participation in health care, improve the relationship with their general practitioner, and support informed decision-making. These results were robust when adjusted for the influence of confounders. Effect sizes were very small, with unstandardized regression coefficients (B) ranging between −0.39 and 0.28. Higher digital and health literacy were associated with higher ratings of almost all effects.

Conclusions: Online access to medical records has the potential to empower patients and foster informed decision-making among patients. The effects in this study were small but might grow over time. Other factors, such as the attitude of general practitioners toward online access to medical records, might moderate these effects. The results indicate that the potential benefits of online access to medical records might be unevenly distributed. We suggest future exploration of the conditions under which online access to medical records can improve health care system functioning and efficiency without increasing health inequality.

Introduction

In an increasing number of countries worldwide, patients are being offered online access to their medical records. The idea behind this is to improve health care system functioning and efficiency by fostering patient empowerment and to advance patient-centered health care (Tapuria et al., 2021). Conceptualizations of these terms often illustrate an ideological shift in the patient-provider relationship from paternalistic to increasingly patient participation-based health care in which communication and respecting the patient's voice are key values (Castro et al., 2016).

Online access to medical records has already become an integral part of many health care systems. In the United States, for example, the "OpenNotes" initiative began over a decade ago (Delbanco et al., 2012) and now facilitates access to the medical records of roughly 41 million patients (Essén et al., 2018). Moreover, in Nordic countries, most patients are already offered online access to their medical records (Hägglund et al., 2019). In the Netherlands, patients became legally entitled to access parts of their general practice medical records electronically in July 2020. Access is mainly facilitated via online patient portals that are directly tethered to the electronic medical records held by the general practice. Patients can currently view medication and allergy lists, medical notes, and diagnostic test results (HealthIT, 2019).

Positive effects from online access to medical records are thought to arise partly due to increased personal health care knowledge (eg, of a health condition or treatment) for patients (Han et al., 2019). This may facilitate informed health care decision-making (Irizarry et al., 2015). Informed decision-making is the process in which a patient comes to a decision that is based on relevant and good quality knowledge, which reflects the patient's values, and that can be subsequently implemented (Bekker et al., 1999; Marteau et al., 2001). Such a decision can prevent the experience of "decisional conflict" for patients, which is the experience of uncertainty or regret about their decision (Knops et al., 2013; O'Connor, 1995), and foster treatment adherence (Sun, 2005).

The results of a previous interview study exploring Dutch patients' expectations regarding online access to their medical records pointed to the possible effects (Thielmann et al., 2023a). Participants imagined that online access to their medical records would give them a better overview about their health care and appointments, and that it would promote trust in and improve communication with their general practitioner (GP) (Thielmann et al., 2023a). They expected increased self-efficacy for actions like accessing test results independently and imagined this to result in fewer telephone calls with the general practice office. Participants indeed anticipated an empowered role in the GP-patient relationship and in health care decision-making (Thielmann et al., 2023a). However, they also imagined distress and anxiety when reading sensitive, incomprehensible, or incorrect information in their medical records (Thielmann et al., 2023a). Patients raised similar concerns in other studies (Baun et al., 2020; Jilka et al., 2015). Connected to this are GPs' worries that patient online access to medical records could increase their workload, as they might have to answer additional questions and resolve misunderstandings (Antonio et al., 2020).

Naturally, monitoring effects is necessary to evaluate the potential impact of online access to medical records as a public health measure. Moreover, exploration of effects is important to accurately inform patients. Patients' interest in using online health information is strongly predicted by their expectations of benefits from it (Mead et al., 2003). Moreover, beliefs about effects were found to be highly relevant for patients to make an informed decision about whether they want to use online access to their medical records (regardless of the outcome of that decision) (Thielmann et al., 2022). Despite efforts to understand the complex process of how online access to medical records might impact patients and health systems, systematic reviews described the evidence to draw conclusions on the actual influence

on patient empowerment and decision-making as insufficient (Ammenwerth et al., 2019; Antonio et al., 2020; Fraccaro et al., 2018). Therefore, this study investigated the effects of patient online access to medical records on patient empowerment, informed decision-making, and the GP-patient relationship perceived by patients.

Methods

Research Design

This study was part of a larger project with a longitudinal cohort design. The project was preregistered in the Open Science Framework (OSF; 3gnx2) (Thielmann et al., 2021). Data were collected via an online survey. For this study, data about participants' use of online access to their medical records from the first measurement (July 2021 [T1]) and perceived effects of online access to their medical records from the second measurement (January 2022 [T2]) were analyzed. Data collected in this study were pseudonymized before analysis, meaning that the researchers could not identify specific persons from the data set (Crutzen et al., 2019). We followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines for observational research to prepare this article (Von Elm et al., 2007). The survey, analysis scripts, output of the analysis including exact *P* values, and nonidentifiable data are available or can be requested at OSF (Thielmann et al., 2021).

Ethics Approval

The project was approved by the Maastricht University Faculty Research Ethics Committee (approval number: FHML-REC/2021/071).

Participants and Procedure

Participants were recruited by the Dutch ISO-certified internet research agency *Flycatcher* (Flycatcher Internet Research, 2022) from among its panel members. We calculated the desired sample size for T1 based on the desired number of participants remaining at the end of the larger project and the expected dropout rate of 30%-35% between measurements. As we could not infer the effect size from earlier research, we assumed a small effect size of Cohen d=0.2, a margin of error (half-width) of 0.1, and a confidence level of 95%. These assumptions were included in the sample size calculation using the "ufs" package (Peters & Crutzen, 2021) in R (R Core Team, 2013). We aimed for a total sample size of 3460 participants for T1 and expected 2336 participants to remain at T2.

Adult patients residing in the Netherlands with at least one contact with a general practice within the past 6 months were eligible for inclusion, as we were interested in recent experiences. The research agency identified these panel members and subsequently invited a sample representative for this group based on age, gender, education, and region within the Netherlands to participate in this study. At T1, within a 1-week time span, the sample received 1 invitation and 2 reminders via email. All participants who completed the survey at T1 were invited again to participate in the T2 measurement via 1 invitation. In accordance with the principle of data minimization (Crutzen et al., 2019), no reminders were sent at T2 as the response following initial invitation was already sufficient to reach the required sample size and we did not want to unnecessarily burden participants. Informed consent was obtained online. Completing each survey took 15 minutes on average. Participants were reimbursed in the form of panel points worth about 2 euros (2.14 US dollars), which could be exchanged for gift vouchers.

Survey items relevant to this study concerned (1) sociodemographic characteristics, (2) the predictor variable (ie, use of online access to medical records at T1), and (3) dependent variables (ie, beliefs about

the effects of online access to medical records at T2). Pretesting of the survey took place with both native and second-language Dutch speakers.

Measurements

Sociodemographic Characteristics

The following sociodemographic characteristics were assessed at T1 as earlier research indicated a potential relationship with the use of online access to medical records: (Lyles et al., 2020), gender identity (Miles et al., 2016), educational level, migration background, region (Emani et al., 2012), digital and health literacy (McAlearney et al., 2021), presence of a chronic illness, health status (Niazkhani et al., 2020), and whether the GP was ever visited due to a psychological complaint (Blease et al., 2021). Sociodemographic variables were used to both describe the characteristics of the study population and investigate the potential confounding impact of these variables in the main analysis owing to possible relationships indicated by earlier research. The highest completed educational level was categorized as low (eg, primary education), intermediate (eg, secondary vocational education), and high (eg, university education) (Statistics Netherlands (CBS), 2022a). A participant was considered a migrant if the participant was born abroad (Statistics Netherlands (CBS), 2022b). Digital literacy, defined by the American Library Association as "the ability to use information and communication technologies to find, evaluate, create, and communicate information, requiring both cognitive and technical skills" (American Library Association, 2022), was assessed with 5 items from the Dutch "Quick scan digital skills" measurement tool. It was developed by the Dutch Centre of Expertise on Health Disparities (2021) to identify patient's digital literacy in general practice. Items asked, for example, "Do you sometimes use an app?" and answer options (scores) were "no" (0), "with help of, for example, family or friends" (2), and "yes" (4). All item scores were summed, divided by 5, and multiplied by 25. Sum scores range from 0 to 100, with a higher score indicating higher digital literacy. The World Health Organization describes health literacy as the skills individuals need to gain access to, understand, and use information in ways that promote their health (Nutbeam & Kickbusch, 1998). To assess health literacy, 6 items were chosen from the HSL-EU-Q47 (Rademakers et al., 2020) that cover all cognitive domains deemed necessary to handle health information within the health care setting (Finbråten et al., 2018). This choice was made to obtain a multifaceted yet concise indication of health literacy. Items were formulated as questions (eg, "How easy would you say it is to find information on treatment of illnesses that concern you?"). Health literacy sum scores were computed by summing the responses "very easy" and "easy" coded as 1, and "difficult" and "very difficult" coded as 0 (Rademakers & Heijmans, 2018). Scores range from 0 to 6, with a higher score indicating higher health literacy.

Predictor Variable: Use of Online Access to Medical Records

Use was defined as having accessed medical records from general practice online at least once at T1. After participants received written and video explanations about what online access constitutes, the survey asked, "Have you ever accessed your GP medical records online?" with answer options "no" and "yes."

Dependent Variables: Beliefs About the Effects of Online Access to Medical Records

At T2, a set of 16 different items was used to assess beliefs about the effects of online access to medical records, resulting in 16 distinct outcome variables. Content of the items was derived from expectations mentioned by patients in a preceding interview study (Thielmann et al., 2023a). Those expectations were operationalized by following instructions on measuring instrumental attitude belief expectations from the *Physical Construct Repository* (PsyCoRe): items all began with "By using online access, ..." followed by the possible effect. Bidimensional 7-point Likert scales were embedded in the statements,

with the left anchor being the lesser/lower/worse assessment and the right anchor being the more/higher/better assessment of a belief (eg, "... I have way less (1) – way more (7) overview about my health care"). Eight items assessed expected practical changes in health care, 5 items assessed the expected impact on affective outcomes and the GP-patient relationship, and 3 items assessed the expected influence on informed health care decision-making. The questions used to assess the outcome variables can be found in Multimedia Appendix 1.

Analysis

Analyses were performed in SPSS 28 (IBM Corp). Descriptive statistics were used to characterize the study population. Chi-square tests were performed to determine whether the proportion of participant characteristics measured with categorical variables was equal, and t tests were performed to determine whether means of characteristics measured with continuous variables were equal between participants who had ever or had never used online access to their medical records. Correlations were explored and categorized as small ($0.10 \leq r < 0.30$), medium ($0.30 \leq r < 0.50$), and large ($r \geq 0.50$) (Cohen, 2013). To investigate the perceived effects of online access to medical records for patients, a (multiple) linear regression analysis was conducted for each effect separately. To evaluate how well the use of online access to medical records could explain an anticipated effect, hierarchical regression was performed with 2 blocks. Model 1 contained only the predictor variable (use of online access to medical records). Model 2 additionally contained potential confounders, that is, sociodemographic variables (categorical variables with k levels were transformed into k−1 variables each with 2 levels). Acknowledging that results following stepwise entry techniques are influenced by random variation in the data and therefore provide a false sense of accuracy (ie, they rarely provide replicable results if the model is retested) (Field, 2013), we used forced entry methods in both models. Unstandardized regression coefficients were reported to interpret the impact of online access to medical records and each confounder on beliefs about effects. To control for multiple testing, we used the Benjamini and Hochberg linear step-up method (Benjamini & Hochberg, 1995). Using Excel (Microsoft Corp), we calculated adjusted significance levels for each effect.

Results

Patient Characteristics

The dropout rate between the study waves was 29.4% (1002/3404), and the characteristics of individuals who dropped out did not differ from those who remained. In total, 2402 participants completed the survey at T2 and were included in the analyses. At T1, 803 (33.4%) participants had made use of online access to their medical records at least once. The mean age of the participants was 52.59 years, and 48.0% (1152/2402) were female. The educational level was categorized as intermediate for 47.0% (1129/2402) and high for 25.5% (613/2402) of the participants. Patient characteristics did not differ between ever users and never users, besides digital literacy ($t_{2,2402}=-4.125$; $P<.001$), chronic disease presence ($\chi^2_{3,2402}=19.42$; $P<.001$), and visiting the GP due to a mental health complaint ($\chi^2_{2,2402}=10.43$; $P=.02$). Table 1 shows the characteristics of the study population.

Table 1. Participant characteristics assessed at T1 (first measurement; July 2021).

Variable	Total (N=2402)	Ever users (n=803)	Never users (n=1599)	*P* value[a]
Age (years), mean (SD)	52.59 (16.39)	52.87 (16.09)	52.46 (16.55)	.56
Gender, n (%)				.88
Female	1152 (48.0)	388 (48.3)	764 (47.8)	
Male	1244 (51.8)	413 (51.4)	831 (52.0)	
Another gender/nonbinary	6 (0.2)	2 (0.2)	4 (0.3)	
Education level, n (%)				.12
Low	660 (27.5)	202 (25.2)	458 (28.6)	
Intermediate	1129 (47.0)	399 (49.7)	730 (45.7)	
High	613 (25.5)	202 (25.2)	411 (25.7)	
Migration background, n (%)	106 (4.4)	35 (4.4)	71 (4.4)	.93
Health literacy (range 0-6), mean (SD) [range 0–6]	5.47 (1.17)	5.47 (1.26)	5.47 (1.12)	.43
Digital literacy (range 0-100), mean (SD) [range 0–100]	92.57 (16.81)	94.56 (14.75)	91.65 (17.68)	<.001
Chronic disease presence, n (%)	977 (40.7)	374 (46.6)	603 (37.7)	<.001
GP[b] visit due to psychological complaint, n (%)	881 (36.7)	330 (41.1)	551 (34.5)	.02

[a]Testing of means was performed with t tests, and testing of frequency distribution was performed with Pearson chi-square tests.

[b]GP: general practitioner

Chapter 4

Linear Regression of the Use of Online Access to Medical Records and Patient Characteristics for Beliefs About the Impact of Online Access to Medical Records

Perceived Effects of Online Access to Medical Records

Results of linear regression analyses of determinants for beliefs about the effects of online access to medical records are shown in Tables 2-5.

Users were more likely to perceive online access to (1) cause practical changes in GP health care, (2) have affective benefits and improve the relationship with their GP, and (3) support informed decision-making. These effects were robust even when sociodemographic factors and patient characteristics were included in model 2. All effect sizes were rather small, with unstandardized regression coefficients (B) ranging between −0.39 and 0.28 (eg, on a 7-point scale, users rated the potential impact of online access on being better able to prepare consultations with the GP 0.1 points higher than nonusers).

First, compared with nonusers, users perceived online access to impact 5 of the 8 effects measured in the domain of *practical changes in their GP health care*. They indicated more strongly that online access would lead to (1) more personal contact with the GP and the practice staff, (2) more consultations, (3) more telephone calls with the GP or the practice assistant, (4) more time investment in health care, and (5) an increased ability to prepare consultations with the GP. There were no differences between users' and nonusers' perceptions of the impact of online access to their medical records on their overview of health care and appointments, and their ability to correct mistakes in the medical record.

Second, across all 5 measured items, users reported that online access would lead to *improvements in affective outcomes and the GP-patient relationship*. Specifically, compared with nonusers, users indicated more strongly that online access would lead to (1) feeling less overwhelmed, (2) feeling less anxious, (3) better communication with the GP, (4) more patient involvement, and (5) more equal-feeling conversations with the GP.

Third, across all 3 items, users indicated more than nonusers that online access would support *informed decision-making*. Users more strongly expressed that online access leads to (1) having more information to make decisions about their health, (2) an increased ability to make decisions about health that align with own values, and (3) an increased ability to make decisions about health in general.

Table 2. Multiple linear regression analyses of determinants for the effects of online access to medical records (overview of health care, overview of appointments, correct mistakes, and feeling overwhelmed; N=2402).

Variable	Overview of health care	Overview of appointments	Correct mistakes	Feeling overwhelmed
Score[a], mean (SD)	5.53 (1.19)	5.45 (1.27)	5.48 (1.27)	3.44 (1.53)
Model 1				
Online access, B[b] (95% CI)	.10 (.00 to .20)	.08 (−.03 to .18)	.05 (−.06 to .16)	−.21[c] (−.34 to −.08)
R^2 (adjusted R^2)	.00 (.00)	.00 (.00)	.00 (.00)	.00 (.00)[c]
Model 2				
Online access, B (95% CI)	.06 (−.04 to .16)	.05 (−.06 to .15)	−.00 (−.11 to .11)	−.16[c] (−.29 to −.04)

Variable	Feeling anxious	Personal contact	Number consultations	Telephone contact
Female vs other, B (95% CI)	–.19 (–1.13 to -1.37)	–.41 (–1.42 to .60)	.05 (–.95 to 1.05)	.08 (–1.13 to 1.28)
Female vs male, B (95% CI)	–.10 (–.19 to .00)	–.06 (–.17 to .04)	–.17[c] (–.27 to –.07)	.03 (–.10 to .15)
Low ES[d] vs medium ES, B (95% CI)	.13[c] (.02 to .25)	.14[c] (.01 to .26)	.13[c] (.01 to .26)	–.36[c] (–.51 to –.21)
Low ES vs high ES, B (95% CI)	.12 (–.02 to .25)	.10 (–.05 to .25)	.09 (–.05 to .24)	–.59[c] (–.76 to –.41)
No vs minimum of one visit to GP[e] due to a mental health complaint, B (95% CI)	.04 (–.06 to .13)	.01 (–.10 to .12)	.12[c] (.02 to .23)	.01 (–.12 to .13)
No vs minimum of one chronic disease, B (95% CI)	–.04 (–.15 to .06)	–.06 (–.17 to .04)	.03 (–.07 to .14)	–.11 (–.24 to .02)
Born in NL[f] vs migrant, B (95% CI)	–.01 (–.24 to .24)	–.05 (–.30 to .20)	–.11 (–.36 to .13)	.15 (–.14 to .45)
Age, B (95% CI)	.00 (.00 to .00)	.00 (–.00 to .01)	.00[c] (.00 to .01)	.00 (–.01 to .00)
Digital literacy, B (95% CI)	.12[c] (.09 to .15)	.09[c] (.06 to .12)	.11[c] (.08 to .14)	–.07[c] (–.11 to –.03)
Health literacy, B (95% CI)	.08[c] (.04 to .12)	.07[c] (.03 to .11)	.07[c] (.03 to .11)	–.14[c] (–.19 to –.09)
R^2 (adjusted R^2)	.05 (.05)[c]	.03 (.02)[c]	.04 (.04)[c]	.05 (.05)[c]

[a]All effects were measured on a scale ranging from 1 to 7.
[b]B: unstandardized coefficient.
[c]Significant value ($P<.05$).
[d]ES: education status.
[e]GP: general practitioner. [f]NL: the Netherlands.

Table 3. Multiple linear regression analyses of determinants for the effects of online access to medical records (feeling anxious, personal contact, number of consultations, and telephone contact; N=2402).

Variable	Feeling anxious	Personal contact	Number consultations	Telephone contact
Score[a], mean (SD)	3.03 (1.46)	3.89 (1.54)	4.03 (1.40)	3.97 (1.43)
Model 1				
Online access, B[b] (95% CI)	–.39[c] (–.51 to –.27)	.28[c] (.15 to .41)	.19[c] (.07 to .30)	.18[c] (.06 to .30)
R^2 (adjusted R^2)	.02 (.02)[c]	.01 (.01)[c]	.00 (.00)[c]	.00 (.00)[c]
Model 2				
Online access, B (95% CI)	–.35[c] (–.47 to –.23)	.31[c] (.18 to .44)	.21[c] (.09 to .33)	.20[c] (.08 to .32)
Female vs other, B (95% CI)	–.21 (–1.35 to .93)	.55 (–.66 to 1.77)	–.03 (–1.14 to 1.08)	.24 (–.91 to 1.38)

Variable				
Female vs male, B (95% CI)	−.02 (−.14 to .09)	.10 (−.03 to .22)	.09 (−.02 to .21)	.11 (−.01 to .22)
Low ES[d] vs medium ES, B (95% CI)	−.19[c] (−.33 to −.05)	−.25[c] (−.40 to −.10)	−.20[c] (−.33 to −.06)	−.12[c] (−.26 to .02)
Low ES vs high ES, B (95% CI)	−.19[c] (−.35 to −.02)	−.50[c] (−.68 to −.32)	−.47[c] (−.64 to −.31)	−.33[c] (−.50 to −.16)
No vs minimum of one visit to GP[e] due to a mental health complaint, B (95% CI)	.11 (−.01 to .23)	−.17[c] (−.30 to −.04)	−.12[c] (−.24 to −.01)	−.16[c] (−.28 to −.04)
No vs minimum of one chronic disease, B (95% CI)	−.07 (−.19 to .05)	−.13 (−.26 to .01)	−.09 (−.21 to .03)	.01 (−.11 to .14)
Born in NL[f] vs migrant, B (95% CI)	.31[c] (.03 to .59)	.54[c] (.25 to .84)	.20 (−.07 to .48)	.18 (−.10 to .46)
Age, B (95% CI)	.00[c] (−.01 to .00)	.00 (.00 to .01)	.00 (.00 to .01)	.00 (.00 to .00)
Digital literacy, B (95% CI)	−.11[c] (−.15 to −.07)	−.02 (−.06 to .02)	−.01 (−.05 to .02)	−.02 (−.06 to .01)
Health literacy, B (95% CI)	−.13[c] (−.18 to −.08)	.08[c] (.03 to .13)	.04 (−.00 to .09)	.06[c] (.01 to .11)
R^2 (adjusted R^2)	.06 (.05)[c]	.04 (.03)[c]	.03 (.02)[c]	.02 (.02)[c]

[a]All effects were measured on a scale ranging from 1 to 7.
[b]B: unstandardized coefficient.
[c]Significant value ($P<.05$).
[d]ES: education status.
[e]GP: general practitioner. [f]NL: the Netherlands.

Table 4. Multiple linear regression analyses of determinants for the effects of online access to medical records (time investment, involvement in health care, equal conversations, and prepare consultations; N=2402).

Variable	Time investment	Involvement in Healthcare	Equal conversations	Prepare consultations
Score[a], mean (SD)	4.66 (1.23)	5.28 (1.24)	4.74 (1.17)	5.21 (1.15)
Model 1				
Online access, B[b] (95% CI)	.13[c] (.02 to .23)	.20[c] (.09 to .30)	.18[c] (.08 to .28)	.12[c] (.02 to .22)
R^2 (adjusted R^2)	.00 (.00)[c]	.01 (.01)[c]	0.01 (.00)[c]	.00 (.00)[c]
Model 2				
Online access, B (95% CI)	.11[c] (.01 to .22)	.16[c] (.06 to .27)	.16[c] (.06 to .26)	.10[c] (.00 to .20)
Female vs other, B (95% CI)	.34 (−.65 to 1.32)	.36 (−.62 to 1.34)	.45 (−.48 to 1.38)	.81 (−.10 to 1.73)

Female vs male, B (95% CI)	−.05 (−.15 to .05)	−.13[c] (−.23 to −.03)	.00 (−.09 to .10)	−.04 (−.14 to .05)
Low ES[d] vs medium ES, B (95% CI)	−.01 (−.13 to .12)	.04 (−.08 to .16)	.00 (−.12 to .11)	.08 (−.04 to .19)
Low ES vs high ES, B (95% CI)	−.11 (−.25 to .04)	−.01 (−.15 to .13)	.08 (−.05 to .22)	.10 (−.03 to .23)
No vs minimum of one visit to GP[e] due to a mental health complaint, B (95% CI)	−.13[c] (−.23 to −.02)	−.08 (−.19 to .02)	−.07 (−.17 to .03)	−.05 (−.15 to .05)
No vs minimum of one chronic disease, B (95% CI)	.05 (−.05 to .16)	.00 (−.11 to .10)	.03 (−.07 to .13)	.01 (−.08 to .11)
Born in NL[f] vs migrant, B (95% CI)	.20 (−.04 to .44)	.07 (−.17 to .31)	.11 (−.11 to .34)	.11 (−.11 to .34)
Age, B (95% CI)	.00 (.00 to .00)	.00 (.00 to .01)	.00[c] (.00 to .01)	.00[c] (.00 to .01)
Digital literacy, B (95% CI)	.05[c] (.02 to .08)	.12[c] (.08 to .15)	.06[c] (.03 to .09)	.06[c] (.03 to .09)
Health literacy, B (95% CI)	.06[c] (.02 to .11)	.06[c] (.01 to .10)	.04[c] (.00 to .09)	.02 (−.02 to .06)
R^2 (adjusted R^2)	.02 (.01)[c]	.04 (.03)[c]	.02 (.02)[c]	.02 (.01)[c]

[a]All effects were measured on a scale ranging from 1 to 7.
[b]B: unstandardized coefficient.
[c]Significant value ($P<.05$).
[d]ES: education status.
[e]GP: general practitioner.
[f]NL: the Netherlands.

Table 5. Multiple linear regression analyses of determinants for the effects of online access to medical records (better communication, informed decision-making [IDM] information, IDM values, and IDM making decisions; N=2402).

Variable	Better communication	IDM[a] information	IDM values	IDM making decisions
Score[b], mean (SD)	5.00 (1.21)	5.17 (1.17)	5.22 (1.16)	5.22 (1.17)
Model 1				
Online access, B[c] (95% CI)	.24[d] (.14 to .34)	.13[d] (.03 to .22)	.16[d] (.06 to .26)	.19[d] (.09 to .29)
R^2 (adjusted R^2)	.01 (.01)[d]	.00 (.00)[d]	.00 (.00)[d]	.01 (.01)[d]
Model 2				
Online access, B (95% CI)	.22[d] (.12 to .33)	.11[d] (.01 to .21)	.14[d] (.04 to .24)	.16[d] (.06 to .26)
Female vs other, B (95% CI)	.21 (−.75 to 1.17)	−.00 (−.93 to .93)	−.24 (−1.16 to .69)	.28 (−.65 to 1.22)

Female vs male, B (95% CI)	.03 (-.07 to .13)	-.04 (-.14 to .05)	-.06 (-.16 to .03)	-.04 (-.13 to .06)
Low ES[e] vs medium ES, B (95% CI)	.05 (-.07 to .17)	.09 (-.02 to .21)	-.03 (-.15 to .08)	-.01 (-.12 to .11)
Low ES vs high ES, B (95% CI)	.02 (-.12 to .16)	.04 (-.10 to .18)	-.07 (-.21 to .06)	-.05 (-.18 to .09)
No vs minimum of one visit to GP[f] due to a mental health complaint, B (95% CI)	-.02 (-.12 to .08)	-.05 (-.15 to .05)	-.04 (-.13 to .06)	-.05 (-.15 to .05)
No vs minimum of one chronic disease, B (95% CI)	-.07 (-.18 to .03)	-.02 (-.12 to .08)	.00 (-.10 to .10)	.02 (-.08 to .12)
Born in NL[g] vs migrant, B (95% CI)	.10 (-.13 to .34)	.20 (-.03 to .43)	.13 (-.09 to .36)	.20 (-.02 to .43)
Age, B (95% CI)	.00[d] (.00 to .01)	.00 (.00 to .00)	.00[d] (.00 to .01)	.00[d] (.00 to .01)
Digital literacy, B (95% CI)	.07[d] (.04 to .10)	.07[d] (.04 to .10)	.08[d] (.05 to .11)	.08[d] (.05 to .11)
Health literacy, B (95% CI)	.04 (.00 to .08)	.05[d] (.01 to .09)	.03 (-.01 to .07)	.03 (-.01 to .07)
R^2 (adjusted R^2)	.02 (.02)[d]	.02 (.01)[d]	.02 (.02)[d]	.02 (.02)[d]

[a]IDM: informed decision-making.
[b]All effects were measured on a scale ranging from 1 to 7.
[c]B: unstandardized coefficient.
[d]Significant value (*P*<.05).
[e]ES: education status.
[f]GP: general practitioner.
[g]NL: the Netherlands.

Confounders

Across most effects, differences in ratings were associated with digital and health literacy. Participants with higher digital literacy as well as those with higher health literacy indicated more strongly that online access would cause *practical changes in their GP health care*, specifically a better overview of health care and appointments, an increased ability to correct mistakes in the medical record, and more time investment in health care. Additionally, the belief that online access leads to more personal contact with the GP or the practice staff, and more telephone calls with the GP or the practice assistant was stronger for participants with higher health literacy. Participants with higher digital literacy more strongly believed that online access to medical records would increase their ability to prepare consultations with the GP.

Participants with higher digital literacy as well as those with higher health literacy also rated most *improvements in affective outcomes and the GP-patient relationship* more strongly (ie, feeling less overwhelmed, feeling less anxious, more patient involvement, and more equal-feeling conversations with the GP). Further, participants with higher digital literacy more strongly perceived the effect of better communication with the GP from online access to medical records.

Lastly, the effect on *informed decision-making* was perceived more strongly by both participants with higher digital literacy and those with higher health literacy, specifically the effect of having more

information to make decisions about their health. Perceptions that online access to medical records can increase the ability to make decisions about health that align with own values and can increase the ability to make decisions about health in general were higher for participants with higher digital literacy.

Discussion

This study showed robust effects of the use of online access to medical records on patient empowerment, the GP-patient relationship, and informed decision-making, even when taking sociodemographic factors and patient characteristics into account. The results align with commonly envisioned effects of online access (Tapuria et al., 2021). By supporting informed decision-making, online access to medical records might help to prevent decisional conflict for patients (Knops et al., 2013; O'Connor, 1995) and thereby foster treatment adherence (Sun, 2005). Online access might have the potential to increase patient satisfaction, as patient empowerment and involvement have been linked to patient outcomes, such as patient satisfaction, previously (Shay & Lafata, 2014). However, effect sizes in our study were small. There are several possible explanations and implications.

First, the impact of online access to medical records on patient empowerment, the GP-patient relationship, and informed decision-making might not be that large. This might be in line with the observation of several reviews that research to date fails to provide strong evidence that online access to medical records improves the patient-provider relationship and empowers patients (Ammenwerth et al., 2019; Antonio et al., 2020).

Second, a time period of 6 months between the measurement of online access use and effects might have been too short for the effects to unfold completely. The rates of provision and use of online access have only recently been rising noticeably since the introduction of the statuary right for patient access in 2020. According to the inclusion criteria, all participants in this study had contact with their GP at least once in the 6 months prior to the study. However, it might still be that participants did not make use of GP health care or online access to medical records enough to experience noticeable effects in their health care process yet. The small effects after 6 months could indicate a trend that might continue in the future. This implies that to monitor how effects develop, repeated measurements over a longer time period are warranted.

Third, there might be other factors moderating the effects. An umbrella review on the current state of evidence regarding patient portals suggests that differences in local organizational contexts, such as the attitude of health care providers, might be a reason for incongruent effect findings (Antonio et al., 2020). Similarly, provider encouragement for use was found to be crucial for long-term (Phelps et al., 2014) and meaningful (Powell, 2017) use. Especially in this early phase of online access implementation, the strength of effects for patients might considerably depend on the attitudes of GPs and practice staff toward online access. Contrary to patients' expectations of fewer telephone calls (Thielmann et al., 2023a), GPs' worries about (Antonio et al., 2020) and experiences of (Keuper et al., 2021) increases in workload are supported by our finding that compared with nonusers, users indicated more strongly that online access to medical records would lead to more personal contact, consultations, and telephone contact with the GP or practice assistant. For online access to improve health care system functioning and efficiency, provider perspectives, and especially potential concerns about increases in workload, have to be explored and addressed. We would like to inform policy makers that to unlock the potential of patient online access to medical records, the implementation should be accompanied, or better still preceded, by an investigation of the optimal conditions and corresponding strategies that facilitate a positive impact for patients.

Chapter 4

Digital literacy and health literacy were associated with differences in ratings across almost all effects (eg, participants with higher digital or health literacy scores rated the potential impact of online access to medical records on having a better overview of their health care more strongly than participants with lower scores). Thus, the benefits of online access to medical records might be unevenly distributed. Generally, patients with lower health literacy rate their health as worse (Heijmans et al., 2018). Our results suggest that while health care demand is the highest among this group, they are less likely to benefit from online access. As members of an internet research panel, participants in our study presumably had above-average digital skills, as reflected in the high score on digital literacy (Table 1). However, at the same time, this high score might be representative of the Dutch population, where almost 80% were classified as having basic or high digital skills in 2019 (Eurostat, 2021). Introduction of new digital health care tools should not lead to a relative disadvantage for groups that are already more vulnerable. Possibly, additional training for vulnerable groups or improvements of accessibility at the portal level could address this issue (Forchuk et al., 2015), but additional research is needed on the needs of patient groups with low digital and health literacy (Lyles et al., 2020). As long as disparities in the benefits of online access to medical records (and other digital health care tools) persist, nondigital options should remain available for all actions in the health care management of patients.

While it is important to take advantage of the knowledge gained from researchers worldwide, international perspectives highlight the influence of social and cultural factors on patients' use of online access to medical records and the potential effects of this access (Prey et al., 2016). Those appear to differ across patient populations in different geographical areas, sociocultural contexts, and stages of online access implementation (Prey et al., 2016). Consequently, we concluded that the generalizability of our results and the applicability of implications are particularly relevant and likely limited to countries that have sociocultural contexts and technical infrastructure similar to the Netherlands.

A strength of the study is that in addition to building on insights from previous research conducted in different contexts and countries, the inclusion of variables measuring effects was informed by preceding local qualitative research. Thereby, we were able to include insights into the possible effects of online access to medical records from the Dutch perspective. Another strength is that the large sample size enabled detection of even small effects, which might have remained undetected in a smaller sample. Thereby, we might have discovered trends and laid the foundation for future effect monitoring.

It should be noted that we measured effects by comparing users' and nonusers' beliefs about the impact of online access to medical records on specific outcome measures. Thus, for both groups, participants had to attribute possible changes in outcome measures themselves to the use of online access. For nonusers, this might have been more challenging, but because our goal was specifically to examine patient perceptions, we believe the measurement is appropriate for our research.

As the gender (identity) group "nonbinary/another gender" had only 6 participants, we cannot draw conclusions from the regression coefficients for this gender category. The wide confidence intervals reflect this inaccuracy of estimates. However, precisely because of the very small proportion of this group in the total sample, this most likely has no influence on the rest of the results.

The findings of this study can inform impact evaluations as well as strategies that provide patients with information about possible effects that they can consider in their decisions about whether to use online access to their medical records.

Online access to medical records has the potential to empower patients, increase patient participation in health care, and foster informed decision-making. The effects in this study were small but might grow over time. Thus, monitoring the development of effects is advised. Differences in ratings across almost

all effects that were associated with digital and health literacy indicated that the potential benefits of online access might be unevenly distributed. Future research should explore the needs of vulnerable patient groups, the conditions under which online access to medical records might have positive effects for patients, and the impact of online access to medical records on providers' workload. This knowledge will help to prevent disparity in effect distribution and possibly facilitate the improvement of health care system functioning and efficiency. Additionally, the results from this study can inform impact evaluation and support individual patients in their decisions about whether to use online access to their medical records.

Multimedia Appendix 1: Survey items assessing beliefs about online access

The following questions are about possible consequences of accessing your GP medical records online.

Do you not use online access? If so, when answering, think about the consequences you would expect if you used it.

Do you use online access? If so, when answering, think about experiences you have had.

By having online access...

1. … I have [much less/ much more] overview of my health care.
2. ... I have [much less/ much more] overview of my appointments.
3. ... I am [much less/ much more] able to ensure that mistakes in my medical record are corrected.
4. ... I feel [much less/ much more] overwhelmed.
5. ... I feel [much less/ much more] anxious.
6. ... I have [much less/ much more] personal contact with the GP and practice staff.
7. … I have [much fewer/ much more] consultations with the GP or practice assistant.
8. ... I have [much less/ much more] telephone contact with the GP or practice assistant.
9. ... I invest [much less/ much more] time in my health care.
10. ... I feel [much less/ much more] involved in my own health care.
11. … conversations with my GP feel [much more unequal/much more equal].
12. … I can prepare my consultations with the GP [much worse/much better].
13. … communication with my GP becomes [much worse/much better].
14. ... I have [much less/much more] information for making decisions about my health.
15. ... I am [much less/much more] able to make decisions about my health that suit me and what I think is important.
16. ... I am [much less/much more] able to make decisions about my health.

[All answer scales range from 1 to 7.]

Chapter 4

5

Patient online access to medical records in general practice: perceived effects after one year follow-up

6

General discussion

The main goal of the studies presented in this dissertation was to explore the patient perspective on online access to their own general practice medical records. The research was conducted alongside the nationwide policy implementation of patient online access to medical records. First, patients' needs and expectations were identified (Chapter 2). Second, the relevance of the determinants for patients' (decision regarding the) use of online access was explored (Chapter 3). Third, the effects patients perceive from online access on practical changes in healthcare, the GP-patient relationship, and informed decision-making after six months were investigated (Chapter 4). And fourth, the development of effects, i.e., within-person changes in effect measures after a one-year follow-up was investigated (Chapter 5). This chapter includes a brief overview of the findings from the preceding chapters, a discussion of their implications in a broader context, a reflection on and discussion of several overarching aspects of this project, and a reflection on the generalizability of the results found.

Main findings and implications

Patient expectations and needs regarding online access

Chapter 2 demonstrates that patients expected benefits from online access, such as a better overview of their healthcare, personal empowerment, and improved communication with their general practitioner (GP). At the same time, patients were concerned about technological difficulties, data privacy, and complex medical language in their record. Chapter 3 shows that secured data privacy and feeling sufficiently instructed were most relevant in explaining patients' use of online access. This implies that it is essential to prioritize data privacy and security measures to instil confidence in patients. Moreover, patients additionally require information about potential effects in order to be able to make an informed decision about use. Clear instructions and explanations about online access and information about its potential effects should be provided to enhance patient understanding and facilitate informed decision-making about use. However, the total variance explained by these determinants was low, which underlines the importance of exploring individual patient preferences and and minimizing the effort required to use online access.

Perceived effects of online access

Chapter 4 indicates that online access has the potential to empower patients, increase patient participation in healthcare, and foster patient informed decision-making. The effects reported were small. Results indicate that benefits of online access might be unevenly distributed, i.e., that patients with lower health or digital literacy benefit less from online access. Furthermore, the study presented in Chapter 5 reports that there was no evidence of positive effects from online access on practical changes in healthcare, the GP-patient relationship, and informed decision-making after a one-year follow-up. The most apparent implication of these findings is that the potential impact of online access on patient empowerment, the GP-patient relationship, and informed decision-making might not be as substantial as initially assumed. The findings possibly imply the need for improvement of the current system of online access in the Netherlands, for example in terms of accessibly and comprehensibility of information in the medical record, as suggested by participants of the interview study presented in Chapter 2. This could be particularly crucial for individuals with lower digital or health literacy. Additionally, for online access to facilitate informed decision-making, consultation and treatment procedures might require a stronger focus on individual patient preferences. This could, for example, be facilitated through integrating value clarification exercises that support patients in understanding personal values and preferences, weighing the pros and cons of alternative courses of action, and clarifying decisional preferences (Rimer et al., 2004). Subsequently, patients need to be able to have the

degree of control over their healthcare choices they want. Future research needs to shed more light on conditions under which online access can have positive effects for patients and specifically focus on the needs of vulnerable patient groups to prevent disparity in effect distribution.

Impact of online access to mitigate pressures on healthcare appears limited

The increasing emphasis on patient empowerment and patient-centered healthcare is both driven by an idealistic paradigm shift in recent years and the mounting pressures on the healthcare system. The healthcare sector is facing a growing shortage of personnel and rising costs, posing a significant threat to the continuity of care as it is currently known. Digital care, including online access, is believed to play a central role in resolving current and future challenges.

While the research presented in this dissertation has provided valuable insights from the patient perspective, it is important to recognize that there are inherent limitations to our ability to draw conclusions regarding the implications on workforce shortages and other challenges in general practice. Due to our focus on patient perceptions, our conclusions regarding healthcare efficiency outcomes such as effects on general practice staff workload are drawn indirectly. However, findings in this dissertation do not support the notion that patient online access to medical records substantially alleviates the increasing pressures on healthcare. Contrary to initial expectations that online access might enhance care efficiency by, for example, saving time, participants in the research presented in chapters 4 and 5 reported a slight increase in the number of phone calls and consultations with GPs or practice assistants. Similarly, Dutch GPs have reported both an increased number of patient contacts through e-consultations and a higher administrative burden associated with online access (Keuper et al., 2023).

There is little evidence in the scientific literature regarding the (cost) effectiveness of online access and other digital GP care. However, research that I was involved in on the effectiveness of four digital healthcare applications (e-consultation, video consultation, telemonitoring, and digital self-triage) in general practice in the Netherlands reached similar conclusions (Van der Burg et al., 2023). No evidence was found that these forms of digital GP care were helpful in reducing staff shortages in general practice (Van der Burg et al., 2023). Despite these findings, it remains important to continue the development and implementation of digital care applications in GP care and to let research results guide ongoing improvements. Efforts should be made to structurally evaluate, improve and integrate digital care applications into work and care processes as well as allocate financial resources to support their implementation.

Countering the inherent risk of further disadvantaging already vulnerable groups

It is likely that patients with limited digital skills may face additional challenges in utilizing online access (e.g., Lyles et al., 2020; Yamin et al., 2011). The study in Chapter 3 did not find that differences in digital skills could explain large differences in use, however, it should be considered that the results presented in Chapters 3-5 are obtained from participants that are members of an internet research panel and might therefore possess above-average digital skills in comparison to non-members. Thereby, individuals with insufficient digital skills or limited willingness to register with an internet research panel were automatically excluded. This can be seen as a limitation of the studies and a lesson that efforts should be made to collect data through alternative offline means such as paper-based questionnaires to ensure representation of this groups in research. However, using online access inherently requires a certain level of digital skills. It can therefore be argued that this specific barrier faced by individuals with below-average digital skills is already obvious and does not require additional proof. However, this does not diminish the importance of exploring how to address this problem in research in general.

Chapter 6

The introduction of new digital healthcare tools like online access carries the inherent risk of potentially disadvantaging patients with lower health literacy and digital skills. These groups are already more vulnerable as they often have poorer health status and an increased need for care (Heijmans et al., 2018). It is important to recognize the responsibility associated with introducing digital care tools and to take proactive measures to counteract this issue. By ensuring that these tools are designed with inclusivity in mind and providing adequate support and resources, we can minimize the risk of further disadvantaging these patients and promote equitable access to healthcare for all individuals.

The risk is reflected in our finding that patients with lower health or digital literacy benefit comparatively less from online access. If online access to medical records becomes the default and a normal part of the healthcare process for the majority of patients but remains inaccessible for those who are most in need of care, it will inevitably contribute to the increasing of health inequalities and worsening of health disparities. Several complementary strategies may be required to counteract this issue, which can be grouped into three levels based on their focus: First, at the portal level, improvements can be made to minimize the digital skills required for accessing and navigating the online environment. It is often emphasized in other studies that across different patient portals, there is a need for better functionality, simplified login processes, and improved navigation (Lyles et al., 2020). Second, at the level of general practices, it is essential to ensure that non-digital options for all aspects of patients' healthcare management not only remain available but continue to be offered as equal alternatives. Consistent with the Dutch College of General Practitioners (NHG) vision of digital care complementing non-digital care (Nederlands Huisartsen Genootschap, 2023), online access should be seen as a supplement rather than a substitute to non-digital options of accessing information. The value of online access and other digital care tools for both caregivers and patients relies on individual decisions regarding the use. By maintaining a range of accessible options that accommodate patients' preferences and varying levels of digital skills, we can facilitate comprehensive and inclusive healthcare services for all. General practitioners may be required to pay even closer attention to the digital skills of individual patients. To assist with this, the Dutch Centre of Expertise on Health Disparities (Pharos) developed a freely available "Quickscan for digital skills" (Pharos, 2021). This tool helps healthcare providers together with patients to gain insight into the patients' digital skills by answering some questions together, for example: "Do you have a computer, phone, or tablet with Internet?" and "Do you ever search for information (about health and diseases) on the Internet?". Defining and identifying specific patient groups often increases the risk of stigma. Therefore, it is important that health workers in general practice use this tool *together* with individual patients to determine the role that digital tools can play in each patient's healthcare process. The tool may also help to identify the potential support patients need. For example, support in the form of providing patients with initial login assistance has been associated with higher rates of long-term usage (Phelps et al., 2014). However, more and ongoing research is necessary to identify the most effective support strategies for patient groups with low digital literacy. Responsibility for addressing this issue extends beyond healthcare organizations. In the public domain, government bodies and policymakers along with community groups could provide digital literacy training or collaborate with technology companies to develop user-friendly tools accessible for patients with diverse levels of digital literacy. And third, on the patient level, efforts can be focused on empowering patients to actively ask questions and on stimulating them to make informed decision regarding accessing their medical records that are in line with their digital skills and consider alternative options. Chapter 3 highlights the most relevant facilitators for patients to make an informed decision about use, i.e., sufficient instruction, ensured data privacy, and information about potential effects. However, it is important to note that in this particular study, participants were only prompted to consider the alternatives of either using online access or not using it, without considering alternative offline

options. As mentioned above, it is crucial to ensure that patients have the choice to access their data offline, and this option should also be included in future investigations of their decision-making process. Patients can be encouraged in taking certain steps to gain relevant insights in order to make informed decisions about whether online access is suitable for them. The *Patient First Program*, in collaboration with the consumer health advice book *Smart Health Choices* (Irwig, 2008), developed three simple and generic questions: "What are my options?", "What are the benefits and harms?", and "How likely are these?" (In Dutch known as *3 goede vragen*). Patients can ask their general practitioners these key questions during consultations to gain relevant insights and make informed decisions. When patients asked these questions in a cross-over trial conducted in Australian general practices, they received higher quality information about therapeutic options and their benefits and harms without increasing the consultation length (Shepherd et al., 2011). Similarly, patients could be encouraged to ask these questions about their options to access their medical record. Promoting patient question-asking is a potentially simple, cost-effective, and sustainable approach (Shepherd et al., 2011).

The hope remained that the utilization of online access by patients with adequate digital skills could potentially free up consultation time, allowing healthcare providers to focus more on patients who are not proficient in digital technology or choose not to use online access. However, our studies and the existing literature have not provided supporting evidence for this. Instead, increases in workload and number of consultations associated with online access were reported (Keuper et al., 2023). In the context of Social Return on Investment (SROI) analyses conducted on implementation of online access in the Netherlands, it was estimated that healthcare providers' time spent on explaining and instructing patients in their first-time use of online access accounts for half of what SROI describes as the incidental costs of online access (Gupta Strategics, 2022). These costs are considered one-time expenses associated with preparing for the initial adoption of online access, which the SROI assumes to occur primarily in the first year after implementation. After this initial phase, it is expected that providers' time investment will substantially decrease in subsequent years, but this assumption has yet to be proven.

Synthesizing broader project insights

Advantages of interdisciplinary collaboration

As mentioned in the general introduction, the research presented in this dissertation was funded through the OPEN program, which aimed to assist general practices in implementing patient online access to medical records. With what OPEN describes as only a "small portion" of the budget (i.e., 1% of €70 million) it was possible to commission extensive research to evaluate the impact of online access and the OPEN program. What sets this evaluation apart is that the research was divided into three complementary working packages, each examining online access from a different perspective. The first working package, conducted by the Scientific Institute for Quality of Healthcare (IQ Healthcare), delved into the impact of health data sharing on various healthcare users and providers through an in-depth study in general practices. The second working package, led by the Netherlands Institute for Health Services Research (NIVEL), explored the perspective of general practitioners and the potential effects within general practices. Lastly, the research of Maastricht University presented in this dissertation focused on the perspective of patients and the potential impact of online access to medical records on their care process. The following section describes and exemplifies the advantages of this collaborative approach.

Throughout the planning, execution, and interpretation phases of the research, meetings were held every six weeks among researchers to discuss progress and results. Once a year, the researchers met with the

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project leadership, primary care physicians, members of healthcare organisations, and other experts in the field to talk about recent research findings and pre-discuss future steps. Twice a year, together with communication and design specialists from OPEN, the researchers from all working packages collaboratively developed and published an infographic summarizing and comparing the recent research findings from the working packages. The collaboration facilitated infographics with comprehensive yet detailed results. Furthermore, the findings from all the working packages were utilized in a social return on investment (SROI) analysis conducted by an independent consulting firm specializing in the Dutch and international healthcare sector. It remained difficult to combine research results from different disciplines and convert various outcome measures into monetary units for a unified and understandable calculation. However, I believe that adopting this approach that considers data from all parties affected by a public health initiative optimizes the accuracy of evaluation of overall impact and return on investment.

Evaluating the impact of online access from multiple perspectives and comparing results across different working packages allowed a broader understanding of its effects. For example, while the interview study (Chapter 2) and others (Powell, 2017) indicated that patients generally value online access to their medical data, desire information about the option from their GP, and are more likely to use it when encouraged by them, it was observed that many patients remain unaware of the possibility of online access. So, although patients have statuary right to access their medical record, this is no guarantee that they will be aware of this option, let alone actually use it. Recommendations following this finding might normally be limited to the advice that GPs should be more proactive in promoting online access. However, insights from the simultaneously conducted research on the provider perspective within NIVELs working package shed light on the challenges faced by GPs, which might create resistance towards actively promoting online access: A majority (302/474, 63.7%) of general practice staff reported an increase in administrative tasks related to online access provision, primarily due to patient inquiries and questions related to Information Technology (IT) (Keuper et al., 2023). By considering the findings from both working packages and thereby looking at the problem from several perspectives, it became evident that understanding how online access can benefit both patients *and* general practice staff is crucial, and that these benefits may be contingent to some extent. Interestingly, Keuper et al. (2023) also demonstrated that practices which adopted online access earlier reported more positive experiences with it. It is possible that the findings suggest a positive shift in physicians' attitude over time due to positive experiences, but their study could not entirely rule out the presence of selection bias. It might be that early adopters already had pre-existing positive attitudes towards digital innovations, including patient online access. The two possible explanations are not mutually exclusive, and both supported by propositions of Rogers' Diffusion of Innovations Theory (Rogers, 2010). This sociological theory seeks to explain how, why, and at what rate new ideas, innovations, or technologies spread through a social system. According to the theory, individuals and groups will respond to a digital transition with varying degrees of resistance or satisfaction. The theory identifies five adopter categories based on their attitudes toward innovation adoption: Innovators and Early Adopters are typically quick to embrace new technologies; the Early Majority follows them, but considers the experiences of those who have already adopted the innovation before making their decisions; and the Late Majority and Laggards are more cautious in their approach to change and require more time to observe the outcomes and benefits of the innovation before embracing it. Further, the theory recognizes that time and experience play crucial roles in shaping individuals' attitudes and perceptions of digital transitions. Resistance may stem from various factors, such as fear of the unknown or uncertainty about the benefits of the new technology. Satisfaction arises when individuals perceive the innovation as user-friendly and advantageous to their lives or work. Following the theory, to accelerate formation of positive attitudes towards online access

in practices more resistant to this change, it might be useful to stimulate interaction between adopter groups. Practices that adopted online access earlier (Innovators and Early Adopters) might highlight benefits and solutions to challenges that arose in the communication with practices more resistant to embrace online access (Late Majority and Laggards). Using the Diffusion of Innovation Theory as a framework to understand adoption dynamics and adopter characteristics of both care providers and patients might help organizations and policymakers in designing strategies to promote higher levels of satisfaction during the adoption of online access and support the implementation.

To fully comprehend the temporal dimension of patients' and GPs' experiences with online access, periodic monitoring is necessary. It would be valuable to determine if there is an acclimatization or adjustment phase after which GPs' experiences, attitudes, and subsequent communication towards and encouragement of patients regarding online access change naturally. Additionally, exploring whether GPs require additional support in the implementation of online access seems essential. The results of such investigations can inform recommendations for necessary measures that serve both patients and GPs.

To summarize, the interdisciplinary collaboration with other working packages and various stakeholders offered several advantages. First, it facilitated a deeper understanding of relevant factors, potential barriers, and interconnections surrounding online access. It allowed us to uncover aspects that may have otherwise gone unnoticed. Second, the comprehensive perspective led to the proposition of inclusive solutions that aim to address the needs and concerns of all affected parties. Such solutions may more likely be relevant and practical and contribute to sustainable outcomes. Third, the active involvement of affected parties and relevant stakeholders in the research process (e.g., care providers, patients, GP organisations, authorities) might have created a sense of ownership and responsibility. As a result, the stakeholders might be more likely to support the implementation of proposed solutions and ensure the research findings have a lasting impact. For future projects, I recommend more active involvement of IT providers and policy decision-makers to encourage their support and participation more strongly in the implementation of solutions.

The importance of systematic planning in health promotion

Health promotion interventions consist of planned programs or efforts aimed at improving or maintaining the health and well-being of individuals or communities. As patient online access was implemented with the overall aim of improving quality of care, it can be considered a health promotion intervention. The development, implementation, and evaluation of health promotion interventions can be systematically guided by the Intervention Mapping approach (Eldredge et al., 2016). This approach provides a stepwise iterative process for development, implementation, and evaluation of interventions, ensuring that they are theory-based, evidence-informed, and tailored to the specific needs of the priority population. Logic planning models such as the PRECEDE-PROCEED (Green et al., 2022) are often used to conceptualize various phases in development, implementation, and evaluation (Gielen et al., 2008). The PRECEDE phases involve assessing needs, priorities, and contributing factors, while the PROCEED phases focus on intervention design, implementation, and evaluation. The research projects described in Chapters 2 and 3 of this dissertation are part of the PRECEDE phases, i.e., needs assessment and analysis of priorities and contributing factors, while the content of Chapters 4 and 5 can be placed in the PROCEED phases, i.e., evaluation of intervention effects.

The process of Intervention Mapping is both iterative and sequential. Steps are repeated and refined based on feedback, which reflects the iterative nature of the approach. At the same time, there is a specific sequential order to the steps, emphasizing the importance of following a logical progression in planning and research. Ideally, in an optimal scenario, planning and research would always adhere to

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this sequential order, ensuring that interventions are a logical and well-informed response to identified problems. However, in reality, intervention planners and collaborators often receive the order to tackle a pre-defined problem by developing an intervention which is already at least roughly specified in terms of structure and scope. Nonetheless, the use of Intervention Mapping in a more flexible manner remains valuable also then, as it helps planers to develop the most effective intervention within the given constraints. In fact, flexibility is generally an important feature of the approach, allowing planners to use the framework as a guiding tool rather than a rigid plan. Similarly, the latest version of the PRECEDE-PROCEED model acknowledges the option to skip phases when appropriate evidence already exists (Green et al., 2022). However, skipping phases without sufficient evidence may lead to interventions that fail to achieve the desired outcomes and jeopardize program effectiveness.

Possibly, the findings presented in this dissertation serve as an example of this phenomenon. Since the research was conducted after the implementation of online access, it could not inform the development of the health promotion intervention itself nor its implementation supporting strategies. The effect evaluation results in Chapters 4 and 5 did not provide strong evidence of positive effects of online access for patients, leading to the conclusion that there might be potential areas for improvement in the current system. Consequently, enhancing the accessibility and comprehensibility of information for patients, as well as adjusting consultation procedures, was recommended. These specific recommendations were informed by the research on patient needs presented in Chapters 2 and 3. Although conducting an assessment of needs, facilitators, and barriers regarding patients' use of online access was valuable as it contributed to expanding the research in the field, its practical impact could have been significantly higher if the research had been conducted during the appropriate phase, namely, the needs assessment phase. Conducting the research earlier in time would have made it possible to better inform the development and implementation of the intervention, more immediately leading to potentially more positive outcomes for patients. Placing our project within the Intervention Mapping approach allows identifying and explaining these limitations related to the project's time structure and overall research process. Based on this reflection, it is recommended that decision-makers involved in public health promotion interventions consider the sequential order of Intervention Mapping and ensure that needs assessments and integration of results precede implementation of a health promotion intervention.

Intersection and integration of informed decision-making and health promotion

Research and strategies with the primary focus on promoting health vs. supporting informed decision making are usually discussed in two separate fields (i.e., focusing on behaviour change with a desired outcome in mind vs. informed decision making regarding possible behavioural choices). However, there has been a call for integration of the two fields to create synergistic effects (Gültzow et al., 2021).

The current disconnect between the two fields is reflected in the fact that theories in the fields of health promotion and informed decision-making often tend to focus on their specific domains. Behaviour (change) theories, such as the Theory of Planned Behaviour (Fishbein & Ajzen, 2011), primarily address the process of behaviour change, aiming to understand factors that influence individuals' decision to adopt one specific behaviour. In the Conflict Model of Decision Making (Janis & Mann, 1977), as an example from the other field, decision-making is characterized as a process in which individuals must consider the inherent advantages and disadvantages of a set of alternatives before choosing one option. While behaviour (change) theories provide insights for understanding how to influence behavioural outcomes, decision-making theories focus on shaping the decision-making process itself. The importance of informed decision-making within healthcare, i.e., a patient coming to a decision which is based on good and relevant information, in line with their values and preferences, and behaviourally executed (Bekker et al., 1999; Marteau et al., 2001), is closely tied to the concept of decisional conflict,

which individuals are more likely to experience when making less informed decisions. When decisional conflict is present, individuals may experience regret regarding their choice (Knops et al., 2013; O'Connor, 1995) and may even discontinue the initial chosen option (Sun, 2005).

The studies presented in this dissertation demonstrate the intersection of informed decision-making and health promotion in multiple ways. First, the needs assessments conducted in Chapters 2 and 3 among other things aimed to explore how patients can be supported in making informed decisions regarding the use of online access to their medical records. Online access is seen as a means of empowering patients, enabling them to be active participants in their healthcare decisions, and potentially leading to better health outcomes. Second, the effect evaluations in Chapters 4 and 5 examined the extent to which the use of online access facilitated informed decision-making among patients, particularly in the context of choosing between treatment options. Informed decision-making has the potential to enhance treatment adherence and ultimately contribute to better health outcomes.

The concept of promoting informed decisions as a means to foster continued engagement in a chosen option offers a potential avenue for integrating the fields of informed decision-making and health promotion theoretically and can be exemplified with the topic of this dissertation. This notion aligns with the principles of the Self-Determination Theory (SDT) (Deci & Ryan, 2012), which explains how different qualities of motivation are formed by the fulfilment of various psychological needs, including the need for autonomy. When these needs are adequately satisfied, individuals are more likely to experience autonomous forms of motivation for a specific behaviour. In contrast to more controlled forms of motivation, these forms of motivation are characterized by factors like personal enjoyment and alignment with important values, and results in greater likelihood of sustained execution of the behaviour (Calvo et al., 2010; Edmunds et al., 2008). In the context of healthcare decision-making (e.g., deciding between two treatment options), the provision of online access to medical records might potentially serve as a tool to support the fulfilment of patients' need for autonomy, thereby improving the quality of their motivation to engage in the necessary actions associated with their chosen option. This, in turn, supports the maintenance of desired behaviours and the continued pursuit of the selected course of action.

The natural convergence of these fields evident in this project highlights the need to continuously bridge the gap between them and develop comprehensive approaches that combine the principles of informed decision-making with health promotion strategies in research, practical application, and theoretical interpretation. The integration of these disciplines within this dissertation exemplifies the intersection of the fields and might help to enhance the understanding and implementation of interventions that support individuals in making informed choices while promoting their overall health and well-being.

Generalizability

Differentiating online access from other forms of digital care is difficult

Our research specifically aimed to investigate perceptions related to online access, focusing exclusively on this aspect rather than a broader range of digital care tools that include more active digital communication features. Examples of such more active tools are remote e-consultation (digital written contact about a medical question between a patient and a healthcare provider (here: the GP)) and video consultation (digital consultation via a direct "live" video link about a medical question, with the aim of replacing a physical consultation). The focused approach allowed conduction of a more detailed and comprehensive analysis which provided a clear understanding of patients' specific needs and perceptions regarding online access. As a result, throughout all stages of research (planning, conducting,

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and reporting), it was important to define the term "online access" and differentiate it from other applications of digital care. Previous research and our own experience have shown that it is challenging for patients, GPs, and researchers to make this distinction. To address this, participants were provided with clear explanations about this distinction in the beginning of interviews (Chapter 2) and the online survey (Chapter 3-5). Likewise, when considering the scope of implications in this dissertation, it is important to note that the research solely examined the perceptions and implications of online access as a digital GP care application. The studies did not investigate the outcomes of active GP-patient communication tools or other services that Dutch patients may already be familiar with, such as online appointment scheduling or online medication requesting. Future research projects may explore these digital applications to further expand the knowledge in this area.

Influence of COVID-19 pandemic on results

As data were collected during the COVID-19 pandemic, results have likely been influenced by the unique circumstances surrounding the global health crisis. The COVID-19 pandemic has greatly increased and advanced the use of digital healthcare in general. With limited possibility for patients to visit their general practitioner face to face due to contact-restricting measures, digital alternatives were sought to ensure continued access to high-quality care (Meurs et al., 2020). It was not possible to investigate this potential effect in the current project, as all data collection took place after the start of the pandemic. However, it is important to consider the potential influence of the pandemic on patients' needs, expectations, and experiences concerning online access to their medical record. The pandemic likely played a role in increasing public awareness and knowledge about digital healthcare tools, which might have led to heightened expectations and interest in using online access to medical records. Additionally, the necessity to minimize physical contact during the pandemic may have motivated previously hesitant patients to use online access as a way to reduce visits to the general practice. Lastly, the increased use of digital healthcare tools during the pandemic may have contributed to patients' growing comfort and familiarity with such technologies, potentially extending to their experiences with online access to their medical records.

Representativeness

Earlier research consistently found associations between the use of and benefits from online access to medical records and several socio-demographic and personal characteristics, i.e., age, gender identity, educational level, migration background, digital and health literacy, presence of a chronic illness, health status, and previous visits to the GP for psychological complaints. Patient characteristics were assessed and considered in the studies presented in this dissertation (i.e., by employing purposeful sampling techniques) to facilitate inclusion of heterogeneous samples. Overall, this enabled recruitment of a heterogenic sample for the interview study in Chapter 2. By comparing the characteristics of the cohort participants with the data from the "Golden Standard", which represents the current demographic and social status of the Dutch population (MOA (Center for Marketing Insights Research & Analytics) in collaboration with Statistics Netherlands, 2021), the cohort participants (Chapters 3-5) can be considered representative of the Dutch population. However, this is true except for the representativeness of gender when non-binary gender identities are considered (which is not the case in the Golden Standard).

In this context, I would like to draw attention to an unfortunately still frequent shortcoming regarding gender inclusiveness and diversity of study samples. In the cohort (Chapters 3-5), the representation of non-binary participants was only 0.3%, which is likely not reflective of their actual proportion in the population. The precise proportion of individuals in the Netherlands identifying as non-binary is not well-established due to limited research on this topic, but estimates range between 2.8% and 6% (Van

Kleef et al., 2023). This difference can be attributed to a limitation in the registration process of the research agency panel, where members are only given the option to choose between the two binary gender options. The inclusion of non-binary options in the survey was an additional measure taken by the research team. However, these options were only presented to people that were already members of the panel. It is possible that the presentation of two binary gender options during the registration process hindered the participation of non-binary individuals in the research panel, as they are unable to register under their self-identified gender. This has two major drawbacks. First, this automatically leads to the of exclusion of non-binary participants from this research. Researchers have a responsibility to ensure that their studies respect the dignity of their priority population and participants, including those with diverse gender identities. And second, reducing gender to a binary construct may limit our understanding of the way in which gender identity may impact use of online access. Gender identity might be related to online access as previous research has repeatedly associated the female gender with the use of online access (Miles et al., 2016) and other eHealth services (Escoffery, 2018; Owens, 2008). Unfortunately, all these studies measured gender solely through binary response options, potentially excluding non-binary participants and impeding the exploration of this characteristic in relation to online access. Although non-binary options were added in the survey as an additional measure, the limitation accounts for the studies in this dissertation as the proportion of non-binary participants was too small for statistical exploration. For instance, in the first measurement within the cohort, the cross-sectional study on relevant determinants of patients' informed decision-making process and use of online access (Chapter 3), the gender (identity) group "nonbinary/another gender" consisted of only 10 participants. However, with an inclusive approach to gender measurement already during the panel registration process, the study population of 3403 participants would have counted between 95 and 204 non-binary participants according to above-mentioned estimations of Van Kleef et al. (2023). This would have reduced the statistical issue, facilitated inclusive exploration of the role of gender identity in regard to online access, and increased the degree to which the research accurately reflects the diverse gender makeup of the studied population. I strongly advocate for research panels and affiliated institutions to incorporate non-binary gender answer options as a matter of inclusion and ensuring that the diversity of the general population is accurately represented.

External validity

International perspectives have highlighted the influence of social and cultural factors on patients' adoption of online access to medical records and their experiences with it, which appear to differ across patient populations in various geographical areas and sociocultural contexts (Prey et al., 2016). For example, research has demonstrated variations in citizens' understanding and concerns regarding data protection and security between Germany and countries like the UK (Pleger et al., 2021) and the USA (Ilhan & Fietkiewicz, 2021). Even neighbouring countries in close geographical proximity, such as the Netherlands and Germany, show differences in their levels of uncertainty avoidance, with Germany ranking higher. This divergence has been associated with the varying importance placed on privacy risks when making decisions related to disclosing personal information (Trepte et al., 2017). Therefore, while it is valuable to consider and build upon research findings from scholars worldwide, the generalizability of findings presented in this dissertation and the relevance of their implications may be most applicable to countries with similar sociocultural contexts and technical infrastructure as the Netherlands. Nevertheless, it remains crucial to acknowledge differences among even patient populations presumed to be similar and to account for their distinct research needs, expectations, and perceived effects.

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General conclusion

The studies in this dissertation offered insights into the patient perspective on online access to medical records in general practice. Patients anticipated benefits such as better healthcare overview, empowerment, and improved GP communication, but also expressed concerns about technological challenges, data privacy, and complex medical language in their records (Chapter 2). To promote adoption of and informed decision-making about online access, efforts should prioritize secured data privacy, easy access, sufficient instruction, communication of potential effects, and understanding individual patient preferences and skills (Chapter 3). While online access shows the potential to empower patients and foster patient informed decision-making (Chapter 4), the actual effects may not be as substantial as initially assumed (Chapter 5). There is room for improvement in the current system of online access in the Netherlands in terms of information accessibility and comprehensibility in medical records. Measures to prevent further disadvantages for vulnerable groups include improving portals, offering equal non-digital options, and empowering and educating patients with lower digital skills.

A major strength of the research in this dissertation was the interdisciplinary collaboration, which enabled a deeper understanding, formulation of more inclusive conclusions and implications, and potential stakeholder participation in proposed measures. A learning point is that conducting the research earlier would have better informed the development and implementation of online access, leading to potentially more positive outcomes for patients. The studies in this dissertation highlight the natural intersection of health promotion and informed decision-making, indicating the importance of integrating these fields in theory and practice.

The results and implications of this dissertation may inform strategies to support the implementation and evaluation of patient online access to medical records in countries with similar sociocultural contexts and technical infrastructure as the Netherlands.

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Impact paragraph

Innovative solutions are required to address the growing pressure on healthcare systems. In line with the paradigm shift towards patient empowerment and patient-centred care, digital care innovations emerge such as patient online access to medical records. This dissertation provides valuable insights into needs, expectations, and perceived effects of patients regarding online access with the aim to evaluate and enhance the potential of online access in improving the quality of care provided to patients.

In this paragraph, the societal impact of the main findings and conclusions of this dissertation will be outlined. This is followed by a description of practical implications for relevant stakeholders. Next, the efforts presently made and yet to be undertaken to disseminate the findings to stakeholders will be outlined. Finally, the scientific impact of the research is summarized.

Societal impact

The research presented in this dissertation primarily benefits citizens, as the studies aimed to enhance the quality of care provided to patients. While the advantages of online access for healthcare systems at large may not be as significant as initially assumed, this dissertation nevertheless offers valuable recommendations to enhance its potential benefits for individual patients and mitigate potential downsides. Online access to medical records has been described as a double-edged sword which can have both positive and negative impact. This dissertation emphasizes the importance of (re-)designing the system of online access to meet patients' needs and integrate their perspectives.

The key recommendations include providing clear instructions and explanations about online access to patients, prioritizing data privacy and security in development and communication, informing patients about potential effects, and exploring individual patient preferences and skills to support their informed decision-making process regarding the use of online access. If these recommendations are translated into implementation supporting strategies, the findings of this dissertation can thus help patients in making informed decisions about adopting online access. This will increase the likelihood that patients choose an access option for their medical records that aligns with their unique needs, preferences, and abilities, optimally supporting them in their healthcare process. This may also include choosing not to access their medical records at all if this is a patient's preference. Furthermore, better accessibility and comprehensibility of information in medical records is highlighted in this dissertation as an important area for improvement. Offering non-digital options alongside online access is advised to prevent a relative disadvantage for patients with lower digital and health literacy. Implementation of proposed improvements might increase the likelihood that online access will foster patient participation, enhance the patient-provider relationship, and facilitate informed decision-making, regarding for example treatment options. As a result, the research presented in this dissertation may lead to more efficient consultations and healthcare delivery and has the potential to alleviate or at least mitigate the current increase in administrative burden experienced by healthcare workers in general practice due to online access. Ultimately, these improvements enhance the potential of online access for improving the quality of care and can thereby benefit healthcare systems and thus society as a whole.

Practical implications

In addition to patients, the results of this research bear relevance and practical implications for various other stakeholders. Addressing the implications in this dissertation is a comprehensive and coordinated effort involving healthcare workers in general practice, healthcare organisations, IT companies,

government entities, patient advocacy groups, educational institutions, and intervention planners. Collaboration among all stakeholders might build additional trust and confidence of patients in online access to medical records and facilitate the implementation of proposed improvement measures.

Healthcare workers in general practice are expected to play a crucial role in informing patients about the option of online access, educating them about its potential effects, and addressing data privacy concerns. For patients requiring additional support, healthcare workers may assist in creating accounts or directing them to available resources. However, the responsibility for educating and instructing patients regarding online access should be shared among various stakeholders. Governmental institutions and patient organizations can contribute through educational efforts using, for example, mass media communication channels. IT companies must prioritize data security and privacy in the development of online access platforms, while governments should establish regulations and guidelines related to patient data privacy. Some privacy concerns identified in the interview study (Chapter 2) were based on misconceptions. For example, there was a belief that alongside patients, other healthcare providers than the GP would automatically have access to the data as well. Besides healthcare workers in general practice, healthcare institutions and patient advocacy organizations play an important role in providing accurate information about the privacy safeguards in place for online access, so that misconceptions can be avoided in future.

For organizations and institutions responsible for commissioning and financing IT-related portal improvements, the results emphasize the importance of improving online portals to facilitate easier accessibility of medical records for patients. Further, it will be necessary to design strategies appropriate to modify documentation practices in medical records in order to increase comprehensibility of information for patients. The findings in this dissertation could encourage curriculum developers to integrate the development and promotion of optimal documentation practices that serve both patients and providers in the education of health workers. Additionally, physician education may need more emphasis on effective integration of online access and consultation procedures to support patients in informed decision-making. One possible approach could be physicians employing value clarification exercises with patients. Such exercises aid patients in understanding their personal values and preferences, weighing the pros and cons of different options, clarifying decisional preferences, and ultimately enabling them to have greater control over their healthcare choices. Physician education can equip healthcare professionals with the skills to employ those exercises and support patients in using online access as a tool to make better informed decisions, resulting in potential benefits for both patients and the healthcare system. However, considering general practitioners' concerns and experiences of the implementation of online access increasing their workload, future research has to explore how this can be accomplished without imposing additional burden on them. One potential avenue for addressing this issue could be through the use of online decision aids. These interactive tools, available on the internet, are specifically designed to support individuals in making informed decisions on various health-related aspects of their lives.

The results of this dissertation can inform intervention developers entrusted with the task of designing strategies to support the implementation of online access. They are equipped with the skills to address the most relevant needs identified in this research by selecting appropriate and effective methods and identifying and involving specific stakeholders to carry out measures. By strategically addressing the patient needs uncovered in this dissertation, intervention developers can help to bridge the gap between high patient interest and low user rates and provide support for patients in deciding whether to use online access. Ultimately, this approach can enhance the potential benefits of online access for individual patients and contribute positively to the broader healthcare system.

Involving and informing stakeholders

Efforts were made to involve stakeholders in the research process and inform them about the findings, so they may apply the knowledge gained in the future.

Conclusions and implications from this dissertation highlight the importance of exploring and addressing the perspective of the specific priority population as an important step in the design of public health interventions. The reflection on the project structure in the general discussion of this dissertation underscores the importance of following a sequential order of steps during the design and implementation of such interventions to enhance their effectiveness and efficiency. The limitations resulting from the project's time structure emphasize the importance of exploring perceptions and needs of the involved groups *before* implementing an intervention. This recommendation is particularly relevant to policy research, wherein the national implementation of a policy is frequently beyond the scope of the research project. We communicated those lessons learned to the funders through the project lead in evaluation meetings. We thereby hope to inspire funders and decision-makers involved in current and future public health promotion interventions to prioritize the sequential order of Intervention Mapping, ensuring that needs assessments and the integration of results take place prior to the implementation of a health promotion intervention. By adopting this approach, decision-makers can increase the likelihood of intervention success and make a more significant impact on public health.

Results from this project informed an impact evaluation of online access by being utilized in a social return on investment (SROI) analysis. We provided information on potential costs for patients and healthcare workers, for example the time patients spend on creating an account in the online portal or consulting the general practice with questions. Additionally, we shared information on potential benefits, such as patients' perception of online access reducing the number of consultations or telephone calls with the general practice. SROI analyses help to determine the social value generated by a particular intervention or project in relation to the resources invested. By contributing to this analysis, the research in this dissertation helped to facilitate that resources are effectively utilized for interventions which are impactful and that policies are designed to address societal challenges.

The results of the research presented in this dissertation were furthermore communicated using infographics, which were published biannually on a dedicated program website (open-eerstelijn.nl). Developed collaboratively with researchers from all working packages as well as communication and design specialists, these infographics summarized and compared recent overarching research findings. In the infographics, the findings were presented in a clear and concise manner combining text, numbers, and illustrations. We aimed to thereby make the information easily accessible, understandable, and sharable for a wider audience beyond the science community, e.g., healthcare professionals and patients themselves. As indicated by the results presented in Chapter 3, communicating the potential effects of online access can support the public's ability to make informed decisions regarding their own use of online access. In addition to sharing specific study results, by presenting scientific information in an easily understandable format we aimed to foster a better understanding of the scientific process and methodologies we employed.

Together with a working group, a teaching session was developed and conducted to disseminate the findings among prospective general practitioners and encourage discussions. I used the ADDIE model (Molenda, 2015) as a framework to guide the development process. The model facilitates educational development by providing a structured approach that involves sequential and iterative steps: analysis, design, development, implementation, and evaluation. This systematic framework ensures a

comprehensive and effective development process for educational materials. In preparation for the session, we included specific questions related to digital care tools in an annual survey that assesses the quality of GP education as perceived by resident physicians (AIOS). This approach allowed us to gain a deeper understanding of their educational requirements concerning digital care tools and enabled us to tailor the session's focus accordingly. Approximately half of the respondents indicated that their current education did not adequately address the opportunities and targeted use of patient online access to medical records and digital consultation techniques. Consequently, the findings of the studies presented in this dissertation informed the development of an interactive teaching session. Titled "De Digitale Huisarts" (in English: The Digital General Practitioner), the primary objective of the session was two-fold: First, it aimed to provide resident physicians with knowledge about the existence, application, benefits, and challenges associated with online access and digital communication options in general practice. Second, it aimed to cultivate enthusiasm among participants and encourage them to embrace and explore the potential of these emerging digital care tools. The lesson was initially introduced as part of the annual summer course for Dutch resident physicians in August 2022, with simultaneous sessions held in Eindhoven and Maastricht. Active participation and lively discussions as well as positive evaluation results of the overall course let us perceive that it was well received. Moving forward, the intention of the working group is to integrate the lesson as a permanent component of the course. Regular updates will be made to ensure that it remains up to date with the evolving landscape of and research about digital care developments and continues to provide relevant and valuable insights to participants.

Scientific impact

The recent implementation of online access in general practice across the Netherlands in 2020 has offered the unique opportunity to examine patients' needs, expectations, and experiences during the initial stages of this nation-wide policy rollout. Through this research, substantial contributions have been made to the understanding of patient perspectives regarding online access.

The articles included in this dissertation published to date have been published in peer-reviewed journals, are available as open access, and made a valuable contribution to the existing body of research in this field. Findings were presented at conferences of the Dutch College of General Practitioners (in Dutch: Nederlands Huisartsen Genootschap), the International Conference on Communication in Healthcare (ICCH), and the European Health Psychology Society (EHPS).

The findings have not only addressed existing gaps in the scientific literature but have also led to the formulation of recommendations for future research. Key recommendations for future research in this dissertation are: (1) Investigate how documentation practices in medical records can be changed to serve the needs of both healthcare professionals and patients; (2) Explore how especially patients with limited digital or health literacy can be best supported in accessing and interpreting medical data; (3) Address the role as well as concerns of GP and other health workers in general practice in promoting and facilitating patient online access as well as the role of the government in supporting them; (4) Monitor development of effects with repeated measurements over a longer time period, ideally including the reasons and frequency of patients' online access usage to contextualize findings; and (5) Explore key conditions in healthcare procedures and patient-provider communication dynamics that create an enabling environment for online access to effectively contribute to patient empowerment.

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Summary

Patient empowerment and patient-centeredness are increasingly recognized as key elements for improving healthcare quality. This shift is driven by both idealistic aspirations and the need to address growing challenges in the healthcare sector. The rising demand and costs for care coupled with increasing shortages of personnel require innovative solutions to deliver complex care with limited resources. Digital care is believed to play a central role in addressing current and future challenges by empowering patients and promoting their active engagement in their care process. One promising digital care innovation to empower patients to be more involved in their own care is patient online access to medical records. In recent years, there has been a growing trend towards implementing patient online access in healthcare systems worldwide. Since July 2020, patients in the Netherlands have been legally entitled to electronically access their medical record in general practice. However, experiences from pioneering countries have shown that user rates often remain low despite high patient interest. There are various challenges associated with the adoption and implementation of online access that must be understood and addressed to maximize its potential benefits. Results of research on potential benefits from online access are inconclusive. This dissertation presents a series of studies that explore patient needs, expectations, and perceived effects to evaluate and enhance the potential value of patient online access on patients and healthcare systems.

Chapter 1 provides a general introduction to the research presented in this dissertation. It includes a description of the context in which the studies were conducted, explains the purpose behind the research, and introduces the research objectives of the studies. This chapter explains the concept of informed decision-making and highlights its importance for patients in their healthcare process. The value of exploring patient perspectives regarding online access to medical records in general practice is emphasized.

Chapter 2 reports the results of an interview study that explored the needs and expectations of patients concerning online access to their medical records in general practice. Participants anticipated benefits like improved overview of their healthcare, empowerment, and better communication with their general practitioner. However, they also identified concerns regarding technological difficulties, data privacy, and complex medical language in their records. The findings furthermore highlight the importance of organizational changes in general practice and the role of healthcare providers in promoting and facilitating online access to address patient needs and achieve desired outcomes of patient involvement and satisfaction.

Chapter 3 describes the results of a nationwide cross-sectional online survey study. The study examined the relevance of psychological determinants identified in Chapter 2 for patients' use of online access to medical records and informed decision-making regarding use. Informed decision-making was assessed by measuring decisional conflict. The results revealed that secured data privacy and feeling sufficiently instructed were most relevant in explaining use. Additionally, beliefs about the effects of online access on patient participation and the patient-provider relationship were most relevant for (mitigating) decisional conflict regarding use. The findings emphasize the need to prioritize data privacy, sufficient instruction, and communication of potential effects in efforts to support patients' adoption of and informed decision-making about online access. The overall explained variance was low, which underlines the importance of exploring individual preferences and skills together with patients who are considering making use of access.

Chapter 4 reports the results of a nationwide two-wave longitudinal online survey study that investigated the perceived effects of online access to medical records among patients on patient

empowerment, informed decision-making, and the patient-provider relationship. Online access users perceived positive effects on their participation in health care, on the relationship with their general practitioner, and on informed decision-making. However, the effect sizes were small. Perceptions of the effects were less positive among patients with lower digital and health literacy, which highlights the importance of providing non-digital access options to the medical record. The results suggest that online access has the potential to empower patients and facilitate informed decision-making, but further and ongoing exploration is needed to fully understand its impact. It appears especially important to explore the conditions under which online access to medical records can improve health care system functioning and its efficiency without increasing health inequality.

Chapter 5 reports the results of a study that examined the changes in perceived effects of online access to medical records among patients after one year. A nationwide online survey assessed within-person belief changes across three user groups: patients who 1) used online access before the study, 2) started use during the study, and 3) did not use it at all. The findings showed that beliefs around online access facilitating patient empowerment and participation declined slightly among those who started using online access during the study. The results indicate that the benefits of online access for patients might not be as substantial as anticipated. Revelation of benefits might depend on improvements in the current system of online access provision, particularly in terms of enhancing the accessibility and comprehensibility of information in medical records for patients. Consultation practices that actively enable patient participation may further enhance the potential benefits of online access for patients.

Chapter 6 integrates the main findings and implications of the studies described in this dissertation and discusses them in a boarder context. The chapter reflects on the potential impact of online access to mitigate pressures on health care. It further provides suggestions for measures that prevent online access to put vulnerable groups at a disadvantage. It additionally includes a reflection on and synthesis of several overarching aspects of the project. Therein, it describes the advantages of interdisciplinary collaboration, highlights importance of systematic planning in health promotion, and shows the convergence of the two fields health promotion and informed decision-making in this dissertation. The chapter ends with a reflection on the generalizability of the results found.

Curriculum Vitae

Rosa Ricarda Leni Charlotte Thielmann was born on 2 June 1994, in Stuttgart, Germany. In 2013, she graduated from Amos-Comenius-Gymnasium in Bonn, Germany. She then completed a Bachelor of Science in Nutrition and Food Sciences at the University of Bonn in 2017 and a Master of Science in Health Education and Promotion (cum laude) at Maastricht University in 2019. From 2020 to 2023, Rosa worked as a PhD candidate at the Department of Health Promotion at Maastricht University on the project described in this dissertation. She was involved in various educational tasks throughout her PhD and obtained her University Teaching Qualification in 2022.

Dankwoord

Rik. Er zijn veel dingen waar ik je dankbaar voor ben, maar eerst en vooral ben ik dankbaar dat je drie jaar geleden vertrouwen in me had en sindsdien elke dag. Dat heeft me geleerd om dat ook te hebben. Je bent de beste supervisor op aarde – dit statement is evidence based en meningen zijn unaniem, ik heb er met veel mensen over gesproken. Bedankt voor alles. Santé!

Ciska. Jouw expertise was onmisbaar voor het project en jouw feedback bracht onze gezamenlijke artikelen naar een hoger niveau. Ik wil je bedanken voor alle tijd die je in het project en mij hebt geïnvesteerd en voor je inlevingsvermogen in mij.

Jochen. Ik heb veel geprofiteerd van je praktische en theoretische inzichten en scherpzinnige observaties, maar ook van je ontspannen, vriendelijke en humoristische persoonlijkheid en communicatie. Bedankt voor je waardevolle steun.

Thomi. Du hast von Anfang an - sogar noch vor dem Anfang - alle meine Fragen mit viel Geduld beantwortet. Es tat mir gut zu wissen, dass du für mich da bist. Dein Enthusiasmus ist ansteckend und dein Erfolg motivierend. Danke für leckere Pizzaabende, ehrliche Gespräche, und unsere Freundschaft.

Gido. Hoe geweldig het was om de reis van junior onderzoeker zijn met jou te beginnen! Homeofficen bij jou waren toen mijn wekelijkse hoogtepunten. Afgezien van de extra motivatie en concentratie die het me gaf, was er tussendoor tijd voor een koffiepauze met croissants, koekjes... en een flinke portie confronterende zelfreflectie. Bedankt voor de vele goede gesprekken van de afgelopen jaren.

Francine. Je hebt de unieke gave om studenten en collega's op hun gemak te stellen en een veilige omgeving te creëren waarin ze hun vaardigheden optimaal kunnen ontwikkelen. Bedankt dat je dat bij mij deed, en me altijd serieus nam en waardeerde.

Sarah S. Aan mijn voortdurende bewondering voor jou werd een vriendschap met jou toegevoegd. Met je praten en luisteren naar je ideeën, ervaringen en opvattingen gaf me kracht en nieuwe impulsen om na te denken.

Latifa. Je had altijd een open oor en een knuffel voor me als ik die nodig had. Bedankt voor je empathie, je openheid en je vertrouwen.

Jessica & Sanne. Jullie hebben me veel kansen gegeven om me binnen onderwijs te ontwikkelen en uit mijn comfortzone te stappen. Bedankt voor jullie vertrouwen in mijn vaardigheden en voor jullie toegankelijkheid.

Esther. Ik heb erg genoten van al onze belafspraken, gesprekken, en samenwerking. Bedankt voor je warme en vriendelijke uitstraling, die me altijd beter liet voelen.

Daša. You were so welcoming to me from the first moment I met you and ever since. Thank you for all the helpful conversations and a ton of good advice.

Lieve, Lisa, & Gido. Heel veel dank voor jullie inzet als TMO-board. Naast veel organisatorisch werk hebben jullie er enorm aan bijgedragen dat ik me welkom voelde op de afdeling.

Patricia, Kim, Daisy, Leon. Heel veel dank voor jullie 100 antwoorden op mijn 100 vragen en jullie praktische hulp de afgelopen jaren.

Jelle & Sevde. Ik ben blij dat ik jullie mocht leren kennen en met jullie samen mocht werken. Mijn hoogtepunt van onze samenwerking was je ontmoeten op de NHG-dag. Ik ben ongelooflijk blij voor jullie dat jullie allebei onlangs ouders zijn geworden. Ik wens jullie en jullie families geluk voor de toekomst!

Bart. Ik had me geen betere projectmanager voor het programma kunnen wensen. Bedankt dat je de tijd hebt genomen om je waardering voor ons onderzoekers duidelijk te maken, zowel persoonlijk als online. Je vriendelijke manier zorgde ervoor dat de overleggen altijd plezierig waren en dat mijn zenuwen elke keer minder werden. De sfeer was... open. ☺

Carolin. Es ist denke ich offensichtlich, dass du ein Vorbild für mich bist. Ich denke gerne an unsere vielen Spaziergänge zurück und empfinde jedes Gespräch mit dir als inspirierend. Danke für unsere Freundschaft.

Marijn H. Ik ben zo blij dat we vrienden zijn geworden in de Master. Je had vertrouwen in mij en mijn toekomst, zelfs in tijden dat het moeilijk voor me was. Ik ben heel dankbaar voor al je steun en hulp.

Sarah W. You are such a creative person and I admire your determination. Thank you for many lekker brunch and coffee dates and honest conversations.

Filippo. Deine innere Gelassenheit strahlt auf Menschen um dich herum aus und ist bewundernswert. Thank you for keeping me sane during early corona - or actually, even making me saner through many therapeutic hike & talk meetings.

Seff. Bedankt voor de tijd samen in Maastricht. Je gaf me het gevoel gezien, begrepen en geaccepteerd te zijn.

Anna. Vor etwa 10 Jahren sind wir Mitbewohnerinnen geworden und du hast mein Leben unfassbar bereichert. Du bist eine der beeindruckendsten Personen, die ich kenne und ich bin so froh, dass wir Freundinnen sind.

Charlotte & Yannic. Mit euch zu (re)connecten zählt zu meinen Highlights der letzten Jahre. Danke für eure offenen Arme und Herzen.

Maria. Ich habe wirklich Glück gehabt, dass Mathis und du mich in eure Crew aufgenommen habt. Danke, dass du den Sommer so wunderbar für mich gemacht hast. Ich bin gespannt, wo die Zukunft dich hinführt!

Lea & JF. You regularly remind me to enjoy the little things in life and to be brave. To move places, change jobs, drop towels, get married, play Würmchen in bars (all equally brave). Thank you for many great adventures!

Patricia. Mit dir zusammen zu wohnen war ein Geschenk für das ich sehr dankbar bin. Du warst eine Zeit lang literally mein zuhause und emotionally bist du das noch immer. Danke für stundenlange Telefonate, gute Ratschläge, relating & reality TV evaluations, und jeden gottverdammten Aperol auf diesem Planeten.

Florian & Antonia. Ihr seid Familie. Danke, dass ihr immer da seid. <3

Mathis. Vom ersten Treffen im Büro an waren wir unzertrennlich und unsere Freundschaft hat mich durch einige herausfordernde Phasen begleitet. Obwohl du es sicher nicht immer leicht mit mir hattest, warst und bist du immer da. Du hast das Herz am rechten Fleck - danke, dass ich einen Platz darin haben darf.

Daniëlle. Waar zou ik zijn zonder jou. Je bent gewoon een heldin en iedereen die je liefhebt en wies leven je managet mag blij zijn dat ze zo een geweldige vriendin hebben. Dankjewel.

Marc. Danke für deine kontinuierliche Ermutigung, Wertschätzung und deinen festen Glauben in mich und meine Fähigkeiten.

Mama und Papa. Für euer Interesse an mir und meinen Gedanken und eure unerschöpfliche Unterstützung danke ich euch von Herzen.

Nori. Okay, getting a PhD is cool, but you are by far my biggest flex in life. Thank you for being my best friend for 23 years. 我愛你