Design speaks

Improving patient-centeredness for older people in a digitalizing healthcare context

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PhD thesis, University of Amsterdam, Amsterdam, the Netherlands
ISBN 978-94-6375-249-7

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Cover design by Renske Hortensius, persoonlijkproefschrift.nl
Layout and design by Renske Hortensius, persoonlijkproefschrift.nl
Printed by Ridderprint BV, www.ridderprint.nl

Financial support by the University of Amsterdam for the publication of this thesis is gratefully acknowledged.

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ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. ir. K.I.J. Maex
ten overstaan van een door het College voor Promoties ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit
op vrijdag 22 maart 2019, te 11 uur
door Gaby Anne Wildenbos
geboren te Rotterdam

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**Sometimes ideas, like men, jump up and say ‘hello’.
They introduce themselves, these ideas, with words.**

Log Lady | Twin Peaks, episode 2, 1990

This thesis is dedicated to everyone who helped me to transform ideas into words.

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Preface

To begin with, I will explain my thesis in a generic way. In my thesis you will find information about three things that are probably familiar to most of you. Firstly, digital technologies that many of us use nowadays. Such as apps and the internet on smartphones, tablets and regular computers. Secondly, older people. Your mother or father, or perhaps your grandmother. And thirdly, health. Maintaining healthy. I have combined these aspects in my research. Because my goal is to design digital health technologies for older patients, for example an iPhone app to help patients with taking the right pills at the right time, which interact and communicate with older people naturally and easily.

My research focused on identifying the positive aspects that support the use of digital health technologies by older patients, as well as the barriers that older people may experience on this matter. I think it is important that we get sight on both these positive and negative aspects within the context of our aging populations. Healthcare is faced with big challenges because of people getting older. There will be a lot of older people living with health problems that cannot be fully cured, such as diabetes or heart problems. Costs will rise and there will not be enough staff to take care of all older patients. The promise of digital health technologies is that they can be a solution to those challenges. They can help patients, especially chronically ill patients, and lower costs. To make those promises a reality, we have to get sight on what makes older people with a (chronic) condition embrace the benefits of these technologies as well as what stops older people from using them. We can apply these learnings in designing digital health technologies that are better suited to older people's needs and preferences.

The way I see it, at the moment these digital health technologies are best compared to a wild forest in spring. Full of tall leafy green trees, colorful wildflowers starting to blossom and beautiful mushrooms as hidden gems under the logs. A trail may be there, but it is unclear. There are no good places to take a rest and there is a risk of getting lost. Younger people may want to explore this place, an adventure! And older people may want to enjoy the nature in this forest as well, but it is less easy for them. From the older patients giving their input for my research, I hear that most of them do want to go into that forest, they want to use these technologies. Yet, as their mobility and capacities decrease with age, they have more fear for the consequences of getting lost and thus explore less. They request more guidance and more recognizable places to rest when needed. So my goal is to map the forest, to help making the trail more clear and to create rest places along there. In such a way that older people can also fully enjoy this forest. In such a way that these digital health technologies, become more easy to use and more effective to use for older patients.

Chapter 1

General introduction

This thesis explores the ways in which patient-centeredness for older people can be improved within a digitalizing healthcare context. The first section of this introduction provides background information on the developments of internet usage on computers and mobile smart devices with regard to digitalization in healthcare, and eHealth specifically. It addresses patient portals and mobile health (mHealth) as significant and exponentially evolving eHealth technologies in relation to patient-centeredness. The second section of this introduction provides background information on the aging population and explains why specifically older people are a target group for patient portals and mHealth. The third section describes the challenges regarding eHealth for older patients and addresses the relevancy of this thesis in focusing on those challenges. It explains the need and significance of the studies performed in this thesis within the context of improving patient-centeredness for older people. Then the aims of this thesis are presented, lastly followed by the outline of this thesis. Key terms used in this thesis are explained in Table 1 of this introduction. To indicate that a term can be found in Table 1, the term will be *italicized* when it is first mentioned.

Digitalizing healthcare context in relation to patient-centeredness

In 2017, 84% of households in developed countries had access to the internet [1]. At that time, even 98% of Dutch households had internet access via a broadband connection and 87% of the Dutch population was connected to the internet via mobile (smart) devices, such as smartphones and tablets [2]. From 2012 to 2017, mobile-broadband subscriptions have grown more than 20% annually; up to 4.3 billion globally at the end of 2017 [1]. This proliferation and adoption of internet usage on computers and mobile smart devices have made an impact on society. For instance, information on any given topic is made more accessible. People are further able to shop online, they can participate in politics, journalism or culture and people can form communities to share experiences. The basic functionalities of mobile smart devices, such as high quality imaging, video streaming, location services and internet access, make it possible to do so at any location or time. The possibility to use such internet and mobile smart devices is given a pivotal role in the domain of healthcare as well. These technologies have the potential to improve people's health as well as efficiency and productivity in healthcare and therefore have strengthened the attention to *patient-centeredness*. Patient-centered care aims to tailor care and related decisions to the individual patient's needs and desired health outcomes, in which shared knowledge between the patient and provider is an important aspect [3-4]. In its Health 2020 report, the World Health Organization's regional office for Europe (WHO EU) mentions patient-centeredness as one of their four priority areas for policy action [5]. To do so, the WHO EU advises to make full use of the 21st-century tools and innovations, digital patient records and *eHealth* [5].

The attention for technological changes that can enable new forms of patient-participation and patient-centeredness, is not new. With the internet becoming available to the public in the 1990s, medical and health topics were among the most searched-for subject matters [6]. To provide patients with ownership and control of their own medical data and as a communication and decision support tool, *patient portals* were first introduced in the United States (US) by a few large healthcare organizations [7-8]. In the following years several vendors and healthcare organizations aimed to place the patient at the center of healthcare data exchange and introduced patient portals or personal health record systems [9]. Coinciding with the rise of daily internet usage on computers and the introduction of mobile smart devices around 2007, patient portals became more widespread [7]. From then onwards and stimulated by government programs such as the Meaningful Use program in the US and the eHealth action plan as well as the Acceleration Program Information Exchange Patient and Professional in The Netherlands [10-11], patient portals are increasingly being developed, implemented and evaluated [7]. Within the continuously evolving field of eHealth from the late 1990s up till now, these portals remain one of the main pillars of eHealth. New developments in the field of eHealth have additionally emerged with the popularity of *mHealth*, which is growing at a fast pace. At the start of this PhD research in November 2014, there were approximately 100,000 mHealth apps available for Android and iOS [12]. At the end of 2017, this number had grown to 325,000 mHealth apps and this growth is ongoing with approximately 25% per year [13]. The features of these mHealth services are vast, ranging from video communication between patients and healthcare institutions to (automatically) monitoring biometrics of patients. Therefore, mHealth is assigned the potential to assist patients to more actively engage in the management of their care [14].

In summary, the digitalizing healthcare context is typified by the vast supply of eHealth innovations, with patient portals and mHealth as two main and rapidly expanding domains of such health information technologies. These technologies are seen as meaningful to the delivery of patient-centered care, since they can provide medical data to patients and support information sharing and patient/provider interaction that is specific to individual patients' needs and preferences or needs of groups of patients [15-16]. Thereby, these technologies can likewise facilitate the sharing of knowledge between patients and their provider(s). This thesis especially focusses on patient portals and mHealth in relation to tailoring these services to patients' needs, in specific for the older patient group.

mHealth, patient portals and the aging population

Our populations are aging [16-17]. In 2016, 39% of the total Dutch population consisted of people aged 50+ [18-19]. There were almost 3.1 million people aged 65+; 18% of the total Dutch population [18], of which more than 25% were living alone [20]. In addition, it is expected that in the next 25 years the older population in Japan, Italy and Spain will cover more than 40% of their total populations [17]. In Australia the older population is expected to cover more than 25% by then [17]. In the US the older population is expected to more than double in size in the next 25 to 35 years [21]. Due to these aging populations, our societies face various health and socio-economic challenges [16]. More than 60% of people aged 65+ has one or more chronic conditions [22-23]. Examples of common chronic conditions are diabetes mellitus, heart failure or chronic obstructive pulmonary disease (COPD). To give an indication, diabetes is prevalent in 22% to 33% of older people in the US [24], 16% to 20% of people aged 65+ in Europe and more than 88 million Chinese people aged 60+ have diabetes [25-26]. Chronic conditions generally require long-term treatment consisting of multidisciplinary teams, possibly working at multiple healthcare provider organizations, that all need to communicate with patients as part of patient care along the whole continuum of diagnosis, treatment planning and follow-up care. To manage their disease, chronically ill patients have to attend a variety of consults, that are accompanied by administrative tasks, and undertake health-related measures as part of their treatment plan. A challenge that consequently arises is that patients and their relatives need to adapt their lives to the treatment and management of the patient's disease and medical condition [23]. This can include clinical aspects as well as communication aspects; respectively monitoring symptoms, regulating medication intake and maintaining physical exercise as well as overseeing the planning of appointments and interactions with healthcare providers. An additional challenge related to patients with chronic conditions is their high impact on expenditures within healthcare: 70%-80% of costs are spent on chronic conditions [23]. Combined with the aging populations, this creates the pressure to lower the expenditures within healthcare.

The pivotal role that is attributed to eHealth, including mHealth and patient portals, to place patients at the center of care, tailor care to their individual needs and share their medical data with them, is especially relevant within this aging population context. *Older adult* patients are a main target group for mHealth apps, because of the assistance that these apps can provide to these older patients, especially to chronically ill patients. The apps may for example provide medication assistance by prompting alerts or they can be used to monitor physical activity and vital biometrics of older and chronically ill patients to avoid emergency situations [16, 27]. Patient portals can be specifically beneficial for (older) patients with a chronic condition as well, since the type of features offered via portal can support them in monitoring and managing their health [28]. For example, access to personal health information, such as laboratory test results and appointment information, as well as digital opportunities to request medication refills or communicate with their provider can assist these (older) patients in accomplishing health-related and administrative tasks in the management of their disease [28]. In addition to these benefits for patients, healthcare organizations aim to lower hospitalizations and hospital visits by means of patients' usage of mHealth and patient portals, thereby reducing the financial burden on their healthcare facilities [16].

Taken together, eHealth is ascribed the potential to be a facilitator to patient-centered care for the aging population. The examples of mHealth and patient portals described above show the variety of functionalities offered to older patients via these relatively new technologies. These functionalities are continuously evolving within the fast pace of developing these technologies. From the perspective of patient-centered care, tailored to what patients need and prefer, it is evident to assess the aptness of these technological developments in relation to older patients' needs and preferences. More understanding is needed on the balance between these rapid developments of eHealth and older patients' contexts. Such an understanding can be gained via a *user-centered design* (UCD) approach; an approach that aims to place the patient at the center of the design and development process of eHealth [29]. The research reported in this thesis therefore approached patient-centeredness from the perspective of UCD in gaining more insights on how eHealth fits older patients' needs and contexts.

Challenges of eHealth for older patients and relevancy of this thesis

The adoption of digitalization in society can facilitate the willingness of older people to use eHealth. Nevertheless, even though older patients are showing more interest in eHealth, adoption of eHealth by this target group remains low to this date. As is described in previous research, for technologies to be successfully used by older patients, *usability* and *technology acceptance* by these patients is of critical importance [16, 30-31]. However, within the constantly evolving technical landscape of eHealth and its promising functionalities, a UCD approach is often overseen in the development of these technologies. This challenges the fit of these technologies to older patients' capabilities and needs. This challenge becomes apparent in studies on mHealth, stating that especially older people experience usability problems in its use [26, 32]. What is less clear is the nature of these experienced usability problems by older people and the influence of aging characteristics on the user-experience of mHealth technologies. Current studies regarding patient portals further show that despite portals' long existence, they still fail to be appropriately designed for older patients' actual contexts of use [33-35]. To improve patient-centeredness for older patients by means of mHealth and patient portals, it is thus important to respectively design mHealth interfaces that optimally support the user-experience of older patients as well as to adjust the design and functionalities of patient portals to older patients' user-contexts. This thesis therefore makes a contribution to these matters: it presents knowledge on aging barriers that may influence usability of mHealth interfaces and addresses how to use this knowledge in improving mHealth interface designs for older patients. It further reports on older patients' user-contexts of patient portals. This allows for new insights to emerge on how older patients may want to receive medical information, interact and communicate via mHealth and patient portals with their healthcare providers; insights that can progress our knowledge on what patient-centeredness entails for older patients in a digital setting.

Another key challenge regarding eHealth for older people is rooted within the research methodologies used to examine eHealth on effectiveness. Effectiveness of eHealth is of major importance for older adult patients as they are a key user group. UCD approaches have shown that *Human Factor* aspects may positively or negatively influence health information technologies' effectiveness [29, 36]. So far, little attention has been paid to the appropriateness of research methodologies used to examine these Human Factor aspects for older patients with regards to eHealth. It thus remains unclear if these methodologies are suitable to specifically uncover aging characteristics and needs to older patients' eHealth use and how these influence eHealth's effectiveness for older patients. The relevancy of this thesis on these issues is that it provides recommendations to improve research methods used to develop and evaluate eHealth, specifically from the perspective of UCD for the older patients user group. By improving these methods and making them more adaptive to the aging characteristics of older patients, study outcomes on older patients' needs, capacities and contexts regarding eHealth use will be of greater accurateness, which ultimately improves patient-centeredness for older patients on this matter.

Aims of this thesis

The overall aim of this thesis is to improve patient-centeredness for older patients within the development and evaluation of eHealth, with a specific focus on mHealth and patient portals. In particular, the aims are to:

1. Synthesize knowledge on older adults' use of mHealth and patient portals to provide a structured overview of barriers and facilitators identified in scientific literature;
   (chapters 2 and 4)

2. Validate identified barriers and facilitators by means of case studies with (chronically ill) older adults to get sight on actual factors influencing mHealth's and patient portals' development and use
   (chapters 3, 5 and 6)

3. To explore user-centered design methods with older adult patients to enhance eHealth's effectiveness for this patient group;
   (chapters 7 and 8)

4. To provide clear recommendations on how to involve older adult patients in eHealth's development and evaluation.
   (chapters 9 and 10)

Outline of this thesis

Part 1: Current mHealth designs for older adult patients

Part 1 starts with **chapter 2**, which provides the results of a synthesis of the literature on aging barriers and complexities of medical conditions that may hamper user-experience of older adult patients with mHealth. We present the framework 'mHealth for older users', MOLD-US, to visualize these barriers and complexities of medical conditions in a centralized and accessible overview. **Chapter 3** reports on two case studies of mHealth apps for older adult patients. These apps were assessed on usability problems that older patients encountered. We applied MOLD-US as a classification framework to analyze these issues and show the value of MOLD-US in identifying intrinsic aging causes to usability problems.

Part 2: Patient portal use by older adults

Part 2 starts with **chapter 4,** describing a synthesis of the literature on the barriers and facilitators to patient portal use by older adults. By using the Unified Theory of Acceptance and Use of Technology (UTAUT) as a classification model for those factors, we thematically clustered the barriers and facilitators and enable a comparison in time of patient portal usage or with other technologies. **Chapter 5** proceeds with a case study exploring patient experiences with a patient portal implemented at the Amsterdam University Medical Center (Amsterdam UMC, location AMC). We report the scope of the older patient user group for various age clusters. We further report on older adult patients' experiences with the portal, one year after its implementation, to evaluate validity of the identified barriers and facilitators in literature to patient portal use by older adult patients. **Chapter 6** evaluates the validity of these barriers and facilitators as well; this cross-sectional study is performed with chronically ill patients of two large Dutch patient associations. Their perspectives on the use of patient portals in general are analyzed, as they are one of the main target groups of patient portals. We have used a conjoint analysis approach, in order to get sight on which functionalities these patients valued as most important for using a patient portal.

Part 3: Patient-centered eHealth research for older adults

Part 3 starts with **chapter 7**, which reports the results of a literature study on the effectiveness of patient-centered eHealth applications regarding patient outcomes. We applied a UCD approach by using the Systems Engineering Initiative for Patient Safety (SEIPS 2.0) model to examine whether (aging) patient user-context factors were taken into account in the studies assessing effectiveness of these applications. In **chapter 8** we specifically reflect on the challenges of assessing contextual factors influencing evaluation research on eHealth and patient portals including older patients. It provides a comprehensive overview of methodological considerations to advance participation of older patients to patient portal research and development in order to improve these patients' health outcomes. **Chapter 9** subsequently proposes several approaches to tackle those challenges, particularly related to user-testing of mHealth, eHealth and medical devices for older patients. This thesis ends with **chapter 10**, the discussion and conclusion. It provides an overview of principle findings of this thesis and discusses these within the perspective of improving patient-centeredness for older people in a digitalizing healthcare context. Practical implications and recommendations for future research are given based upon key learnings of the studies in this thesis.

Table 1: Definitions of key terms used in this thesis, per theme

Term	Definition
Technologies	
eHealth (electronic health)	eHealth is defined by the European Commission as: "the use of ICT in health products, services and processes combined with organizational change in healthcare systems and new skills, in order to improve health of citizens, efficiency and productivity in healthcare delivery, and the economic and social value of health. eHealth covers the interaction between patients and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals" [37]
mHealth (mobile health)	This thesis combines the definitions of mHealth given by the World Health Organization and the National Institutes of Health Consensus Group: "mHealth is an area of electronic health (eHealth) and it is the provision as well as usage of health services and information via mobile and wireless technologies to improve health outcomes, healthcare services and health research" [38-39]. This thesis therein focuses on mHealth for patients.
Patient portal	Patient portals are secure online information systems that provide patients and/or their proxy with access to personal health information [15, 40], such as laboratory test results and appointment information, as well as digital messaging between patients and providers. The foremost type of a patient portal is the tethered patient portal. A tethered patient portal is an application build on an Electronic Health Record (EHR) infrastructure of a specific healthcare organization [41]. The tethered patient portal differs from for example a personal health record, in which the patient can collect health data and he/she decides whether to share that data with providers or family members.
Age	
Elderly	People aged 65+. See further explanation at 'older adults'.
Older adults	The age ranges that have been studied in scientific research on older adult people vary, starting from 50+, 60+ or 65+; there is no fixed consensus on the definition of 'older adults'. As risks for a (severe) decline in visual abilities increase from the age of approximately 50 years and onwards [42], which is of importance i.r.t. technology use, and studies on older adults' technology use start from 50+, this thesis defines the term 'older adults' as people aged 50+. The terms used for other age clusters are: 'seniors' or 'elderly' for people aged 65+, 'middle-aged adults' for people aged 40-50 years and 'younger adults' for people aged 18-40 years.
Seniors	People aged 65+. See further explanation at 'older adults'.

Methodological concepts	
Human Factors	‘Human factors’ (HF) is the scientific discipline that examines the relationship between persons, organizations and the (technological) systems with which they interact by focusing on improving efficiency, creativity, productivity and (user) satisfaction, with the goal of minimizing errors [43-44]. In the HF engineering profession knowledge on human capacities, skills, needs and limitations is used to design products or systems that fit these human abilities and barriers. HF principles and methods are used to uncover hidden needs, assumptions and unexpected interactions, such as usability testing and user-centered design approaches.
Patient-centeredness	Patient-centeredness aims to “deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge” [3], as is described in the concept analysis review by Castro et.al. on patient-centeredness, patient-participation and patient-empowerment. In patient-centered care, the individual patient’s needs and desired health outcomes are of crucial importance in relation to healthcare decisions.
Technology acceptance	Technology acceptance of users is multidisciplinary; psychological factors such as a user’s attitude and beliefs towards technology, as well as user characteristics, such as age, influence if a user will accept and use a technology [45]. Technology acceptance (accepting to use a technology and willingness to use a technology) differs from technology adoption, where a user actively engages with the technology over a longer period of time.
Usability	Usability is explained by Nielsen, an authority within the field of usability, as: “a quality attribute that assesses how easy user interfaces are to use. The word “usability” also refers to methods for improving ease-of-use during the design process. Usability is defined by 5 quality components: *Learnability*: How easy is it for users to accomplish basic tasks the first time they encounter the design? *Efficiency:* Once users have learned the design, how quickly can they perform tasks? *Memorability:* When users return to the design after a period of not using it, how easily can they reestablish proficiency? *Errors:* How many errors do users make, how severe are these errors, and how easily can they recover from the errors? *Satisfaction*: How pleasant is it to use the design?” [46].
User-centered design (UCD)	User-centered design (UCD) focusses on the user as the heart of the design approach, instead of placing the technology or the idea at the center of the design process [29, 47]. Design does not focus purely on aesthetics; it is a process in which the user’s interaction with the environment or system are made more natural and complete [47]. A UCD process focusses on users throughout the planning, design, development and evaluation of a product or system. According to the ISO 9241-210:2010 standards, the UCD process consists of four main activities: to understand and specify the context of use, to specify the user requirements, to produce design solutions and to evaluate design against requirements [48]. These activities form the basis for designing usable systems that increase the chances of successful system implementation and adoption [49].

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Part 1

Current mHealth designs for older adult patients

Chapter 2

Aging barriers influencing mobile health usability for older adults: a literature based framework (MOLD-US)

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International Journal of Medical Informatics. 2018, Jun;114:66-75
doi: 10.1016/j.ijmedinf.2018.03.012.

Abstract

Background: With the growing population of older adults as a potential user group of mHealth, the need increases for mHealth interventions to address specific aging characteristics of older adults. The existence of aging barriers to computer use is widely acknowledged. Yet, usability studies show that mHealth still fails to be appropriately designed for older adults and their expectations. To enhance designs of mHealth aimed at older adult populations, it is essential to gain insight into aging barriers that impact the usability of mHealth as experienced by these adults.

Objectives: This study aims to synthesize literature on aging barriers to digital (health) computer use, and explain, map and visualize these barriers in relation to the usability of mHealth by means of a framework.

Methods: We performed a scoping review to synthesize and summarize reported physical and functional age barriers in relation to digital (mobile) health applications use. Aging barriers reported in the literature were mapped onto usability aspects categorized by Nielsen to explain their influence on user experience of mHealth. A framework (MOLD-US) was developed summarizing the evidence on the influence of aging barriers on mHealth use experienced by older adults.

Results: Four key categories of aging barriers influencing usability of mHealth were identified: cognition, motivation, physical ability and perception. Effective and satisfactory use of mHealth by older adults is complicated by cognition and motivation barriers. Physical ability and perceptual barriers further increase the risk of user errors and fail to notice important interaction tasks. Complexities of medical conditions, such as diminished eye sight related to diabetes or deteriorated motor skills as a result of rheumatism, can cause errors in user interaction.

Conclusions: This research provides a novel framework for the exploration of aging barriers and their causes influencing mHealth usability in older adults. This framework allows for further systematic empirical testing and analysis of mHealth usability issues, as it enables results to be classified and interpreted based on impediments intrinsic to usability issues experienced by older adults. Importantly, the paper identifies a key need for future research on motivational barriers impeding mhealth use of older adults. More insights are needed in particular to disaggregating normal age related functional changes from specific medical conditions that influence experienced usefulness of mHealth by these adults.

Keywords: mHealth, eHealth, elderly, aging barriers, human factor design, user experience

1. Introduction

The extensive functionalities of current smartphones, tablets and other devices allow the development of mobile health applications (mHealth) to thrive; it is estimated there are 259,000 mHealth apps in the major app stores from 2016 onwards [1-3]. This boost in innovation finds its foundation in the potential of mHealth to assist patients in self-management of diseases and independent living [4-5]. For the older adult patient population, this advancement is especially important as risks for functional decline and loss of independence increase with normal aging and accumulation of chronic diseases, approximately from the age of 50 and onwards [6]. MHealth apps may provide medication assistance by prompting alerts, provide self-care advice to patients, facilitate self-monitoring of various biometrics or educate patients on disease outcomes [1, 7]. These mHealth advances align well with the upcoming interest of older adults to integrate technologies into their own health care [1-2].

Despite the interest and intention of older adults to use mHealth, studies report that actual usage and adoption of mHealth amongst this patient population is low and inconsistent [4, 8-9]. When mHealth is aimed at older users, it is important to understand specific facilitators and barriers potentially impacting acceptance of mHealth by this population. Prominent technology acceptance models such as the Unified Theory of Acceptance and Use of Technology (UTAUT) and the Senior Technology Acceptance Model (STAM) provide a theoretical basis for this [4, 10]. These models define usability and usefulness as important constructs impacting user acceptance, as well as age as a moderator of these constructs. Yet these models fall short in defining which age-related barriers and facilitators influence usability and usefulness of technology, and how. Furthermore, several studies on older adult acceptance of mHealth emphasize the importance of user-centered interface design and clear user instructions [2, 5, 11]. However, these studies do not disaggregate the specific aging characteristics and barriers faced by older adults related to the encountered usability issues that influence their acceptance of mHealth. A more detailed understanding of how aging characteristics of older adults affect mHealth usability and usefulness is thus valuable to facilitate mHealth adoption - as well as to ensure safe and effective use of mHealth by this population [9].

For almost two decades it is known that older adults interact differently with information technology compared to younger people [12-13]. In 2000, design guidelines to enhance website interfaces and desktop computer usability attuned to older adults' cognitive abilities were published [14]. Smith et.al. have likewise reported motor control barriers in relation to older adults' performance of computer mouse tasks [15]. At the same time, literature on this topic remains fragmented across different domains, and mostly focusses on older technologies (such as computer desktops) that preceded the introduction of smartphones, tablets and other modern devices.

Design issues related to user data entry and screen size of these earlier technologies cannot automatically be applied to mobile devices. Although aging barriers experienced by older adults may remain the same, the effect of these aging barriers differs for the use of modern devices compared to preceding technology use. Research on touch screens for example, shows a reduction of cognitive and physical workload of older adult users because the interface on the display can be directly controlled with one's fingers [9]. The direct input on the interface of large touch screen devices, such as an iPad, make the software installed on those devices easy to use for older adults [16]. Certain design aspects of mobile devices may have the opposite effect and hamper, instead of support, older adult usage. To recognize icons and interpret their functionality as buttons within the interface of apps is problematic for older users since they may be more familiar with website interfaces having different and larger buttons. Therefore, they might fail to locate relevant information that is only visible after clicking an icon [17].

Age is not only associated with normal physical decline that poses a barrier to effective mobile device use, it is also associated with the development of multiple chronical diseases and related impairments [18]. Developers of apps for diabetes patients for instance, should be aware that diabetes is most prevalent in people aged 65 years old and above and more prevalent in low literate people than in high literate people [19]. Furthermore, one of the complications of diabetes is a diminished eye sight [20]. Designers should thus be aware of these kinds of complexities of user populations and take these into account in developing mHealth apps. At present, these disabilities and complexities of older adults (with chronic conditions) are often overlooked. This results in mHealth apps that consist of many hard to understand features, thereby decreasing their usability for the older adult target group [7-8] and are more susceptible to induce user errors and thus to comprise patient safety [21].

This fragmentation of knowledge on aging barriers across various medical domains combined with knowledge gaps regarding mHealth design in the context of older (chronically ill) adults, pose a key barrier to improving (safe) use and adoption of mHealth by these user groups. This paper aims to synthesize and centralize knowledge on aging barriers in mHealth by relating complexities of medical conditions to their influence on mHealth user experience. We conduct a structured scoping review to synthesize and explain aging barriers to usability of mHealth by older adults. To map and visualize the review results we suggest a framework of these barriers and complexities associated with chronic diseases, and their potential impact on specific usability aspects of mHealth. The framework aims to support designers of mHealth and to improve analysis of usability evaluation studies.

2. Methods

We performed a scoping review as such a review provides a rigorous and transparent method for structured mapping of a certain research domain [22]. This is important because existing literature on aging barriers influencing mHealth usability is fragmented across technologies, health concerns and age groups, and lacks a comprehensive and up-to-date synthesis for older adults. We first identified and examined key literature on aging barriers that may hamper hardware and software use by older adults by prominent authors in this field. Based upon this key literature and the snowballing method, we identified (common) medical conditions related to specific aging barriers. We then performed a literature search to assess if the aging barriers were addressed in articles on older adults' user experience of healthcare systems, including mHealth usage. We searched four databases - PUBMED, EMBASE, ScienceDirect and WebofScience - for relevant publications using the following search terms related to aging barriers and digital user experience: *aging*, *elderly*, *older adults*, *usability*, *experience*, *adoption*, *barrier*, *barriers*, *eHealth*, *mHealth*, *mobile health* and *computer (use)*. We reviewed the identified articles based upon their relevancy to usability and usefulness of consumer healthcare hardware and software. Studies were included in which: 1) study participants => 50 years; and 2) aging barriers were mentioned related to interface design/usability of computers, eHealth or mHealth. Studies were excluded if they reported on 1) participants < 50 years old or if mean age was below 50 years old; and 2) adoption/acceptance of eHealth/mHealth by older adults without mentioning usability issues. Author GAW screened for title and abstract. Full text reviews were independently performed by authors GAW and LDP, any disagreements on inclusion of articles were discussed until agreement was reached.

We performed a thematic analysis to capture and synthesize the data from the included studies. To map reported user experiences of older adults to aging barriers categories, we used the five usability aspects that influence user experience, as defined by Nielsen: learnability; efficiency; memorability; errors; satisfaction [23]. Finally, we developed a framework to visualize the aging barriers, and medical conditions related to those barriers, and their possible influence on usability aspects of mHealth.

3. Results

3.1 Aging barriers for mHealth user experience

Four aging barrier categories were identified in key literature of Holzinger, Rogers & Fisk, Cjaza as well as the W3C [24-27], which we use to organize our findings: (1) cognition; (2) physical abilities; (3) perception; (4) motivation. Supplementary file A shows the 23 included studies of the scoping review. Information regarding prevalence of age related barriers is mostly described in literature for the elderly age cluster (65+ years old); therefore we provide prevalence numbers for this target group only. Tables 1-4 list the diminishing age dependent abilities and their impact level on usability per aging barrier, and include relevant (common) medical conditions related to each specific barrier. These medical conditions involve diminished cognitive, physical, perceptual or motivational capacities as a complexity of a medical condition.

3.1.1 Barrier 1: Cognition

Cognitive aging barriers are related to a reduced capacity of working, prospective, semantic and procedural memory as well as attention [28-34], which may all negatively influence software use. Moderate to severe impairments affects 15% of men aged 65+ and memory impairment affects 11% of women aged 65+ [35]. The impact of age is that older people can process fewer discrete information bits in a given time, and recall also decays faster [28]. For example, recall of future based time-based tasks (such as taking a pill after 4 hours) becomes more difficult [28, 36]. In addition, older people need more time to learn new skills [24, 25, 28]. Mentally transforming spatial information becomes more difficult with age and influences computer task performance negatively [28, 36-37]. In addition, a decline in numeracy and representational fluency hampers older adults in understanding content specific to eHealth and mHealth interventions, such as tables and charts on biometrics [33, 38-39]. Cognitively impaired older adults showed a significantly smaller percentage of task success than unimpaired older adults in a usability study of an electronic medication delivery unit, because of confusing terminology used [40].

Table 1: *Cognitive barriers*

Impact level	Diminishing age dependent abilities	(Possible) cognitive diminishment as complexity of medical condition
Errors	Working memory [24-26, 28-34, 37-38, 42] Spatial cognition [28, 37] Dynamic/selective attention [24-25, 28, 30, 37] Phonemic/semantic fluency [28, 33] Reasoning [31] Numeracy and representational fluency [33, 38-39]	Diabetes [43] Stroke [43] (more likely to develop dementia): Multiple sclerosis [43] Motor neurone disease [44] Parkinson's disease [44] Huntington's disease [44]

3.1.2 Barrier 2: Physical ability

Physical impairments due to aging are difficult to quantify universally, yet a common age-related illness (though not exclusively) mentioned in literature that may influence software use negatively is rheumatoid arthritis [24, 31]. For example, diminished motor skills make it more difficult to click on small buttons in website interfaces and rheumatoid arthritis can make holding a device in one hand uncomfortable [29, 31]. Functional limitations such as arthritis and other rheumatic conditions are reported to affect 60% of the American population aged 65+ [35], while Arthritis Care in the United Kingdom (UK) report that 20% of all adults in the UK are affected [44]. Other age related physical changes are slower movement and reflexes, stiffer muscles and joints, tremor (in hands) and a diminished balance [28, 36, 41]. According to the Centers for Disease Control and Prevention, more than 75% of the American population aged 65+ has a difficulty in physical functioning [45]. Regarding computer use these impairments might influence learning time, speed of performance, error rate, retention of time and subjective satisfaction [24-25, 41].

Table 2: *Physical ability barriers*

Impact level	Diminishing age dependent abilities	(Possible) physical diminishment as complexity of medical condition
Errors Efficiency	Speed of performance [24, 31] Flexibility of joints [24, 31, 41] Hand-eye coordination [31, 41] Retention in hand movement [29, 31] Grip strength [28, 31, 41]	Rheumatoid arthritis [24] Parkinson's disease [44] Diabetes [43]

3.1.3 Barrier 3: Perception (vision and audition)

It is estimated that 21% of the American population aged 65+ has a visual impairment, such as macular degeneration and bifocal glasses, which makes viewing a digital screen difficult [35, 46]. The Royal National Institute for the Blind (RNIB) estimates that eyesight decline in the older population in the UK, for who this decline in sight significantly affects their daily life, is 15.8% aged 65 to 74 years, 18.7% for ages 75 – 84 years and 45.8% for ages 85+ years [44]. Visual abilities that decrease with age are the ability to resolve detail, the ability to focus on close objects, the ability to discriminate between colors (violet, blues and greens), the ability to detect contrast, the ability to adapt to darker conditions and susceptibility to glare (vision is impaired by direct and reflected light) [24-25, 28, 31, 33-34, 36, 39]. Older people also require more light to see sharply, and have reduced motion estimation and peripheral vision (tunnel vision) [24, 28, 31].

With aging, hearing ability will decline over time [47]. The Royal National Institute for Deaf People (RNID) estimates for the UK that at around the age of 50 the proportion of deaf people begins to increase sharply and 55% of people over 60 are deaf or hard of hearing [44]. While audio is seldom fundamental to interaction with a software product, there are some implications, for example for video content and alerts [48]. In addition, older adults with moderate to great hearing difficulties showed lower computer desktop and internet use than those with no hearing difficulties [47].

Table 3: *Perception barriers*

Impact level	Diminishing age dependent abilities	(Possible) perception diminishment as complexity of medical condition
Errors Efficiency	Vision: Visual acuity/ accommodation [24, 26, 28-34, 41-42] Color vision [24, 26, 28-31, 39, 41, 51] Contrast detection [24, 26, 28-31, 34] Dark adaptation [24, 28] Glare [24, 31] Audition: Auditory acuity [24-25, 28, 30-31, 41-42] Touch sensation [28, 31]	Vision: Cataracts [44] Age-related macular degeneration [44] Refractive error [44] Glaucoma [44] Myopic eye disease [44] Diabetes (retinopathy) [33, 43-44] Audition: Presbycusis [49], High blood pressure [49], Diabetes [49], Depression [50]

3.1.4 Barrier 4: Motivation

Studies on the acceptance of technology by older people report on motivational issues as a barrier; this accounts for older adults as well as elderly [24-25, 27, 42]. A systematic review by Hawley-Hague et. al. shows that usability and feedback are, amongst others, important in supporting attitudes and perception of technology [51]. Several studies reported that older adults are less likely to use a technology if the benefits of the technology do not manifest themselves easily and quickly during the actual use of the technology [24-25, 30, 32-33, 39, 51-52]. For example, in a usability study on an app for heart failure patients, participants were positive about the benefits of the app, yet they found entering data in the app cumbersome [39]. The benefits were not being obvious to the older adults during the actual use, resulting in frustration and the desire to stop using the app [39].

Table 4: *Motivational barriers*

Impact level	Diminishing age dependent abilities	(Possible) motivational issues as complexity of medical condition
Errors Efficiency Learnability Memorability Satisfaction	Trust in own ability [24, 30-31, 33, 35-36, 42] Efficiency in seeing benefits [24-25, 30, 32-33, 39, 51-52] Computer literacy [24, 31, 35-36, 41] Self confidence in using wearables [53] Shift in responsibilities from provider to patient not preferred [29-30] Integration of functions during daily activities [30-32]	Concentration issues [24] Learning disabilities [24]

3.2 mHealth for older users: the MOLD-US framework

The MOLD-US framework (Figure 1) provides a visual overview of the possible impact of each aging barrier category, related diminishing age dependent abilities and medical conditions to the usability of mHealth in older adults. It consists of three dimensions:

- Four aging process barriers categories: cognition, motivation, physical ability and perception. These are presented by pie chart pieces within the diagram.
- Medical conditions that involve a deterioration in capacities related to the barrier as a complexity of the condition. These are presented in a lighter color as an extension of the pie chart pieces.
- Five structural levels of mHealth user experience, based upon the usability aspects defined by Nielsen: (1) errors; (2) efficiency; (3) learnability; (4) memorability; (5) satisfaction [23]. These are represented by the triangular shapes at the outer edges of the diagram.

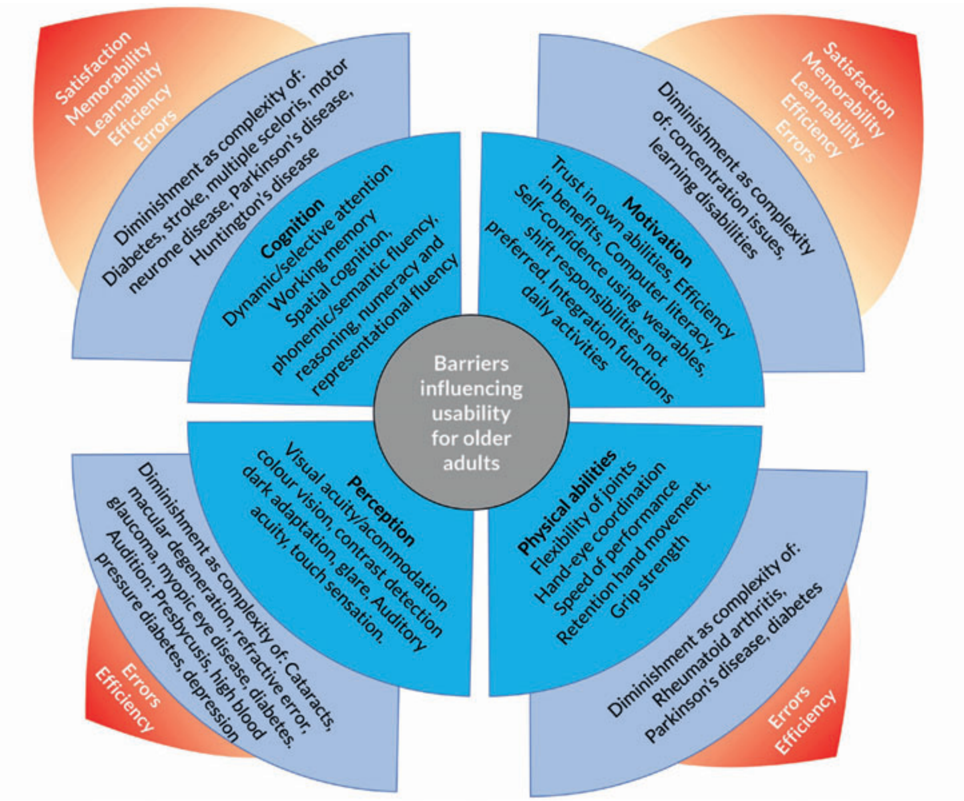

***Figure 1:** MOLD-US framework, barriers of older adults influencing usability of mHealth*

The MOLD-US framework is unique, because it integrates acknowledged aging barriers impeding digital user experience, aging barriers identified in empirical studies on digital (mobile) health applications usability and complexities of medical conditions possibly influencing mHealth usability. The strength of the MOLD-US framework is that it enables (future) usability testing results of mHealth aimed at older adults to be classified and interpreted based on impediments intrinsic to encountered issues. It thus allows for improved analysis of results in systematic usability evaluations of mHealth aimed at older adults. Finally, MOLD-US informs more robust design of mHealth tools by providing insights that allow better attunement of technology design to the impairments of older adults.

4. Discussion

In this research a synthesis of the literature was performed in order to map, centralize and explain aging barriers in relation to usability of mHealth; and visualize this by means of a framework, MOLD-US. Age related physical function and perception limitations, for example arthritis and other rheumatic conditions as well as hearing or vision loss, may limit usefulness and usability of mHealth as experienced by older adults. While interacting with mHealth these aging barriers can lead to difficulties, such as holding a smart device in one hand, attempting to click buttons which are close together (as is often the case in smartphone interfaces), making certain gestures (such as pinches and swiping) or visually distinguishing between similarly shaped software icons used on screens. This hampers efficient use of mHealth and increases the risk of user errors and failure to notice important user interaction tasks, resulting in either hazardous use or non-adoption of mHealth by older adults. Prominent cognitive barriers such as a decline in working memory may further impede older adult patients in fully benefiting from mHealth apps. If an interface is cluttered and complex, older adults experience difficulties in navigating through the application and in interpreting the subsequent system feedback. MHealth apps may therefore be difficult to understand and learn, inefficient to use, induce user errors, and frustrate the older adult user. Motivational barriers, such as trust in one's own ability to use mHealth, likewise may limit effective and satisfying use of mHealth. For example, older adults tend to be afraid to experiment with a mobile device and an app's navigation, because they fear they might 'break something'. Many older adults further suffer from complexities of medical conditions, such as eye sight problems related to diabetes or a decline in cognitive skills due to a stroke. When developing mHealth - especially if the mHealth intervention is targeted at a specific patient population such as diabetic patients or heart failure patients -it is thus important to be aware of these complexities, since they further affect the cognitive, physical, perception and motivation abilities of older adults negatively, thereby hampering their use of mHealth.

4.1 Inclusive design accommodating aging barriers

The aim of designers, programmers and developers should be to create mHealth interventions that accommodate aging barriers [28] and possible multimorbidity issues [7]. A design effort that minimizes demands on as many users as possible is known as inclusive design; a design that is flexible enough to be usable by people with no limitations as well as by people with functional limitations related to disabilities or old age [31]. The MOLD-US framework can be of value to mHealth designers in inclusive design efforts. The visual overview of MOLD-US enables a quick assessment of aging barriers and medical conditions that involve deterioration in capacities related to these barriers to take into account while designing an mHealth app for older adults.

4.2 Possible correlation between aging barriers

The results from this scoping review show that older adults can be unmotivated to use an mHealth tool if the benefits of app usage cannot be quickly determined by them in the first phases of use [30, 39, 52]. However, what is not yet clear from the current literature is whether the cognitive, physical and perception barriers are correlated to the demotivation of older adults to use mHealth. We hypothesize that it may be more difficult for older adults to determine the benefits of mHealth due to the variety of utilities of mHealth - which require more cognitive, physical and perception skills compared to traditional computer-based digital health interventions for patients. Digital health interventions preceding mHealth apps mostly focused on providing medical information to patients via websites and pioneering with patient portals use. MHealth apps have vastly more options for use: gathering patient data via sensors, using decision-making algorithms to assist patients in health monitoring and presenting real-time medical data visually. Older adults need to perform many interaction tasks related to this variety of utilities of mHealth, such as interpreting numeracy and graphical data, activating the application to perform measurements or manual input of blood pressure levels; many of which are difficult for them due to normal physical and functional decline.

To gain insight into whether aging barriers correlate in influencing usability of mHealth experienced by older adults, priorities for future research are to examine possible associations between the four aging barriers and encountered usability issues in user testing. Study designs and methodologies used in usability evaluations of mHealth should therefore accommodate the assessment of how aging barriers of older adults relate to usability issues. The MOLD-US framework provides a reference model for this type of research. Firstly, the overview of older adults' (medical conditions related to) degradation of sensory, physical and cognitive abilities can assist researchers in setting inclusion criteria of study participants, assuring representativeness of the overall user population, and selecting specific usability metrics relevant to user-based usability testing by the user population. Secondly, since the framework addresses the impediments intrinsic to usability issues of mHealth that may be encountered by older user populations, it can be used as a classification tool to interpret usability testing results. MOLD-US adds value to current classification tools, such as the Usability Problem Taxonomy (UPT) and User Action Framework (UAF) [55-56], because it is unique in integrating aging barriers and categories of usability aspects that influence user experience. By using MOLD-US in assessing which age barriers are intrinsic to experienced usability issues of mHealth by older adults, multiple snapshots of aging barriers influencing usability can be taken over time and compared to gain insights in the evolution of the framework.

4.3 Limitations

A drawback of the scoping review methodology is that we might have missed relevant publications. However, key literature on older adults' barriers was detected in our review approach. Though the scoping review is also limited in the exclusion of grey literature and studies published in a non-English language, the proposed MOLD-US framework provides a first basis that can evolve by means of including more and future research on aging barriers related to mHealth usability. True to the scoping review method, we did not asses the quality of the included studies by means of a formal measurement tool. Hence, this review might include a greater range of study designs and methodologies than a systematic review. Yet, this scoping review aimed to synthesize the reported evidence on aging barriers related to digital user experience in order to provide new directions of future research based on the variety of studies on this topic.

5. Conclusion

The potential of mobile health to facilitate patients' self-management of diseases is high, yet use of mHealth by older adult patients aged 50 years and above is prone to Human Factor design problems related to aging barriers. This study identified four aging barriers, cognition, physical ability, perception and motivation, which may be reinforced by certain medical conditions of patients. This research will serve as a base for future studies as it enables new systematic analysis of mHealth usability issues encountered by older user populations by means of the MOLD-US framework. The framework can be used to classify and interpret results based on older adults' impediments intrinsic to usability issues. MOLD-US also contributes to creating awareness on aging barriers and disease complexities of older adults amongst stakeholders involved in mHealth development. Further studies could investigate whether the cognitive, physical and perception barriers are correlated to the demotivation of older adults to use mHealth, and thereby evolve the framework.

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Supplementary file A

The table shows the included studies informing on aging barriers related to usability of digital health technologies. Studies informing on the prevalence of physical and functional decline of older adults, as well as on which medical conditions involve such a decline as a complexity of the disease, are not included.

Supplementary file B

The prototype of the framework 'mHealth for Older Users' as presented at a 2015 conference on 'Digital Healthcare Empowering Europeans', organized by European Federation for Medical Informatics, shown in appendix 1 [17].

Supplementary file A – Table 1

Author, year, ref.nr.	Type of article/ Study design	Technology / Innovation	Age participants (years)	Type of barrier and age dependent ability mentioned			
				Cognitive	Perception	Physical	Motivational
Athilingam, 2016 [53]	Case study (usability)	Mobile application	Mean age: 58				Self confidence in using wearables
Bolle, 2016 [29]	Case study (usability)	Website (internet skills)	Mean age: 73	Working memory	Visual acuity/ accommodation Color vision Contrast detection	Retention in hand movement	Shift in responsibilities from provider to patient not preferred
Cjaza, 2013 [27]	Case study (usability)	Website (internet skills)	Mean age: 70	Cognitive abilities			Computer literacy
Farage, 2012 [28]	Literature review	Computer (use)	65+	Dynamic / selective attention Working memory Phonemic/ semantic fluency Spatial cognition Reasoning	Visual acuity/ accommodation Color vision Contrast detection Dark adaptation Auditory acuity Touch sensation	Grip strength	
Fisher, 2014 [36]	Literature review	Health Information Technology	Older adults (age not specified)	Cognitive issues Memory issues	Vision loss Hearing loss	Physical issues	Trust in own abilities Computer literacy
Foster, 2014 [41]	Literature review	Telemedicine applications	65+	Working memory	Visual acuity/ accommodation Color vision	Flexibility of joints Hand-eye coordination Grip strength	Computer literacy

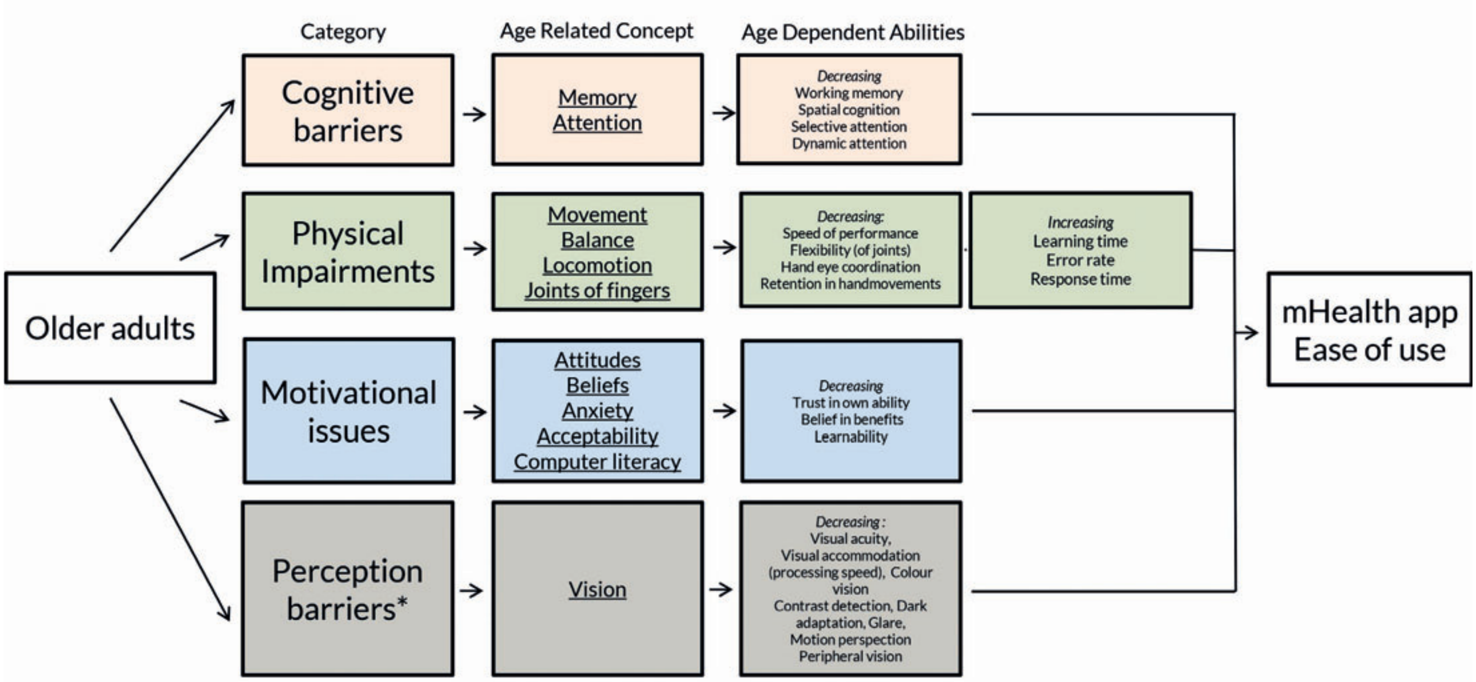
Author, year, ref.nr.	Type of article/ Study design	Technology / Innovation	Age participants (years)	Type of barrier and age dependent ability mentioned			
Grindrod, 2014 [30]	Case study (usability)	Mobile application (medication management)	Mean age: 67	Dynamic / selective attention Working memory	Visual acuity/ accommodation Color vision Contrast detection Auditory acuity		Trust in own abilities Efficiency in seeing benefits Integration of functionalities during daily activities Shift in responsibilities from provider to patient not preferred
Harte, 2014 [31]	Descriptive	Connected health devices	60+	Working memory Phonemic/ semantic fluency Reasoning	Visual acuity/ accommodation Color vision Contrast detection Glare Auditory acuity Touch sensation	Flexibility of joints Hand-eye coordination Speed of performance Retention in hand movement Grip strength	Trust in own abilities Computer literacy Integration of functionalities during daily activities
Hawley-Hague, 2014 [51]	Literature review (systematic)	Fall detection, prevention and monitoring technology	50+		Color vision		Efficiency in seeing benefits Self confidence in using wearables
Hendrix, 2000 [42]	Literature review	Computer (use)	65+	Working memory	Visual acuity / accommodation Hearing loss	Mobility impairments	Trust in own abilities
Henshaw, 2012 [47]	Descriptive	Computer (use), website(internet skills)	Mean: 62		Auditory acuity		

Author, year, ref.nr.	Type of article/ Study design	Technology / Innovation	Age participants (years)	Type of barrier and age dependent ability mentioned			
Holzinger, 2007 [24]	Descriptive	Computer (use)	Elderly (age not specified)	Dynamic/ selective attention Working memory	Visual acuity/ accommodation Color vision Contrast detection Dark adaptation Glare Auditory acuity	Flexibility of joints Speed of performance	Trust in own abilities Computer literacy Efficiency in seeing benefits
Isakoviç, 2015 [33]	Case study (usability(	Mobile application (diabetes)	Mean age: 64	Working memory Phonemic/ semantic fluency Numeracy and representational fluency	Visual acuity/ accommodation Color vision		Trust in own abilities Efficiency in seeing benefits
Kaufman, 2003 [38]	Case study (usability)	Telemedicine application (diabetes)	Mean age: 70 (NYC) 74 (upst.)	Working memory Numeracy and representational fluency			
Ligon, 2014 [40]	Case study (usability)	Electronic medication delivery unit	Mean age: 87	Cognitive impairment			
Lober 2016 [35]	Descriptive	Personal Health Record	Mean age: 69	Cognitive impairment	Visual impairment	Physical impairment	Trust in own abilities Computer literacy
Matthew-Maich, 2016 [32]	Literature review	Mobile applications and technologies		Working memory	Visual acuity/ accommodation		Efficiency in seeing benefits Integration of functionalities during daily activities

2

Author, year, ref.nr.	Type of article/ Study design	Technology / Innovation	Age participants (years)	Type of barrier and age dependent ability mentioned			
Morey, 2017 [39]	Case study (usability)	Mobile applications	Mean age: 72	Working memory Numeracy and representational fluency	Color vision		Efficiency in seeing benefits
Or, 2012 [34]	Case study	Computer based self- management system	Mean age: 72	Working memory Numeracy and representational fluency	Visual acuity/ accommodation Color vision Contrast detection		
Pak, 2008 [37]	Clinical trial	Interactive Voice Respond System	Mean age: 71	Dynamic / selective attention Working memory Spatial cognition			
Rogers, 2010 [25]	Descriptive	Technology (general)	Older adults (age not specified)	Dynamic / selective attention Working memory	Visual impairments Hearing impairments		Efficiency in seeing benefits
Timmerman, 2016 [52]	Case study (usability)	Telemedicine application	Mean age: 62				Efficiency in seeing benefits
W3C, 2008 [44]	Descriptive	Technology (general)	Older adults (age not specified)	Working memory	Visual acuity/ accommodation Color vision Contrast detection	Motor skill diminishment	

Supplementary file B



Chapter 3

Mobile health for older adult patients: using an aging barriers framework to classify usability problems

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International Journal of Medical Informatics
Submitted

Abstract

Background: With populations aging, digital health tools and mobile health applications (mHealth) are becoming more common to assist older people in independent living and self-management of (chronic) illnesses. These mHealth services can be beneficial to older patients, provided that they are adjusted to their needs and characteristics, as the current mHealth landscape lacks user-friendly services for this target group. Understanding of intrinsic aging barriers, which cause and impact usability problems older patients encounter, is needed to achieve this.

Objectives: This study set out to assess usability problems older patients encounter in two mHealth apps and aims to show the value of MOLD-US, a recent aging barriers framework, as a classification tool to identify the intrinsic cause of these problems.

Method: A case-study design, with in-depth analysis of usability issues older adult patients experience. Data on usability issues were collected using the Think Aloud Protocol for two mHealth apps. The MOLD-US framework and Nielsen's severity rating were used to classify identified issues and their potential impact.

Results: In total 28 high severe usability issues of the mHealth apps were identified. Core natures of most issues were related to motivational and cognitive barriers of older adults. Participants had difficulties in understanding the navigation structure of the apps. Important text, buttons and icon elements were overseen.

Conclusion: Current knowledge on creating interfaces for older target groups is not well applied within the assessed mHealth designs. Specifically, design guidelines should address older adults' diminishing cognition skills, physical ability and motivational barriers. By classifying usability problems with MOLD-US, insights on these barriers can be enhanced to adequately address these issues in new designs. In addition, we propose that future research focuses on investigating suitable usability evaluation methods adapted to older patients' characteristics to ultimately be able to gain unbiased sight on usability issues older patients may experience while interacting with technology.

Keywords: Usability, Elderly, Think Aloud Protocol, Computer Literacy, eHealth

1. Introduction

With populations aging, digital health tools and mobile health applications (mHealth) are becoming more common to assist older people in independent living and self-management of (chronic) illnesses. These mHealth services can be beneficial to older patients in supporting their health as well as to the healthcare system in controlling healthcare costs, provided that they are accepted and used by their target group. Evidence suggests that one of the most important factors for acceptance of technology by older people is 'usability', the ease of use of the user interface [1]. Yet, according to the European Union (EU) commission's 2012-2020 eHealth Action Plan [2], there is a lack of user-friendly tools and services within the current mHealth landscape and especially older people experience usability problems in mHealth use [3-4].

This is of particular concern within the context of a growing population of older adults, aged 50+, and specifically for the subset of seniors within this target group, aged 65+. Digital tools for (senior) older adults may for example provide medication assistance by prompting alerts, self-care advice for diabetes patients, assist heart failure patients in monitoring their blood pressure, promote hospital appointment attendance as well as identify and alleviate fall risk factors [5-8]. To gain health support benefits from these tools, older adults need to interact with a vast set of functionalities, a smart device or even a combination of various connected devices. A key issue is thus the complexity of mHealth tools compared to eHealth tools such as a health website, which are more informative of nature. Hence, there is a need to attune the interface design of interactive mHealth services to older patients' needs and characteristics.

Insights into the cause and impact of usability problems these older patients encounter is essential to guide these (re)design efforts. The International Organization for Standardization (ISO) standard and Food and Drug Administration (FDA) regulations state that usability testing with end-users is the norm [9-10]. End-user usability testing sheds light on how a technology communicates specifically with its intended users and identifies which aspects of the user interface are not interacting with the target group as anticipated. The identified flaws in such tests with older adults, including their severity and effects, may be influenced by age related functional decline and disease complexities, occurring from the age of approximately 50 years and onwards, of the older patient target group. By means of a scoping review, we previously investigated aging characteristics of older adults possibly influencing mHealth usability [11]. We identified cognitive, motivational, physical ability and perception barriers and complexities of medical conditions related to these barriers, visualized in the MOLD-US framework, that may impact mHealth usability experienced by older adults [11]. In current usability tests with older adults, aging characteristics and disease complexities are no specific aspect of data analysis, due to a lack of aging barriers frameworks in relation to mHealth usability; MOLD-US provides the first mHealth aging barriers framework on this matter.

It is necessary to consider these aging characteristics and disease complexities in assessing usability issues of mHealth for older patients, since they provide understanding of the intrinsic cause and impact of usability problems older patients encounter. This study performed usability evaluations of two mHealth apps, both targeted at older people. By analyzing and classifying the usability test results by means of MOLD-US, we aim to demonstrate its value in the data analysis of these mHealth studies. It further reveals which intrinsic causes underly older patients' usability problems encountered while using mHealth.

2. Methods

2.1 Case study apps and their designs

A case-study approach was chosen to provide detailed illustrations of various interaction issues older adults can encounter in using mHealth. We investigated these interaction issues in two different case studies; an app for older adults facilitating their hospital appointment attendance (App 1) and a self-monitoring app for chronically ill older patients (App 2). Supplementary file A describes both apps and Supplementary file B presents a flow chart of the study designs attuned to both apps. Figures 1 and 2 show screenshots of respectively App 1 and App 2; these were the main screens that were assessed on usability.

2.2 Identification of usability issues

The most prominent *user-based* method, the Think Aloud (TA), was used to gain sight on the usability issues [12-13]. The TA was executed conform the three stages of Nielsen [14]. The tasks, in Table 1, included sets of cognitive tasks and navigation and information search tasks. These tasks were designed by first (GAW) and fourth (LDP) authors, both usability experts and experienced in designing and performing Think Aloud studies with seniors. GAW and LDP identified the main and health-related functionalities of the apps. Subsequently they developed tasks based on these functionalities that were typical for how people might actually use the apps.

2.3 Population and TA sessions

Primary inclusion criteria of all TA participants were: (1) age 50 or above (2) the ability to read and speak Dutch language adequately. Additional inclusion criteria for App 2 were: (3) Heart Failure patient or (4) Chronic Obstructive Pulmonary Disease (COPD) patient. Participants for the TA of App 1 were recruited within the network of the usability evaluators and by contacting and visiting elderly homes of senior older adults. Participants for App 2

Figure 1. *Screenshots of main screens of App 1*

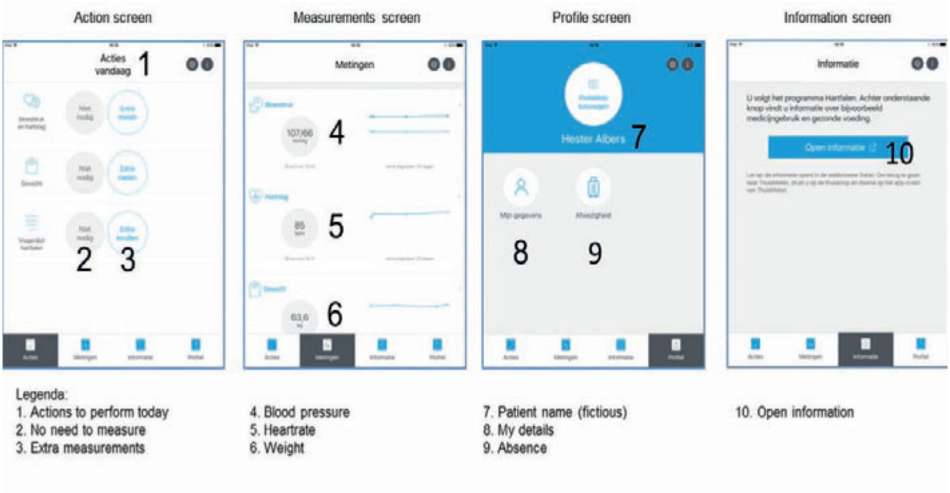

Figure 2. *Screenshots of main screens of App 2*

were recruited during the installation of the app at the patient's home. The TA sessions, performed by junior usability experts were videotaped. These evaluators received two weeks of intensive training on performing usability evaluations, instructed by authors GAW and LDP. The participants received instructions on the tasks to perform and first performed a simple practice task, not related to the apps, to get acquainted with the TA method. To assure accurateness of results, authors GAW and LDP validated the results of the evaluations performed by the junior experts by verifying the issue and its severity level.

2.4 Data analysis

Data for the performance measures was extracted from the videos and field notes. Practice task data was excluded from the data analysis. The encountered usability issues were clustered amongst the predefined tasks. Then, issues were prioritized by means of a severity rating from 0 to 4 according to Nielsen's classification of severity [15]. Of the issues with severity rating 3 or 4, authors GAW and LDP independently classified issues by means of the aging barrier aspects of the MOLD-US framework and compared results afterwards. Usability issues were classified by determining where in the app the issue occurred and at which phase of the task, i.e. before even performing the task, during the interaction or in interpreting information after interaction, in combination with older adults' verbal description of the issue they encountered. When any disagreement about the classification occurred, this was noted to measure disagreement frequency. Authors then discussed the usability issue and the classification until 100% agreement was reached.

Table 1: *Tasks of the Think Aloud evaluations of App 1 and App 2*

	App 1	App 2
Task 1	Register at the app	Open the app
Task 2	Change postal code of home address after registering	Measure blood pressure levels and send to healthcare professional
Task 3	Find out how to change a scheduled appointment to another date	Measure weight and send to healthcare professional
Task 4	When requested in hospital guidance, find out what to do when the guide is not there	Complete and send health questionnaire
Task 5	Find out if you can use the app if you are visiting the hospital with a family member	Show how many points you had on the previous questionnaire
Task 6	--	Find out how many minutes you should exercise per day
Task 7	--	Register that you will be absent from 10 - 12 October
Task 8	--	Check whether you have messages or missed measurements
Task 9	--	Find out if you can change your measurements' day as a patient

3. Results

Table 2 shows participants' demographics. Table 3 shows the TA performance measures. Table 4 shows the identified usability issues with severity 3 and 4 (n=28). These issues were classified by means of the MOLD-US framework (kappa=0.74); most occurring aging barriers were motivational (n=14) and cognitive (n=7).

Table 2: *Demographics of the participants of the TA.*

		App 1	App 2	
			Heart Failure	COPD
Gender	Male	5	3	4
	Female	8	2	1
Age (mean)		--	66y	67y
Age cluster	50-64y	9	--	--
	65-80y	2	--	--
	80+y	2	--	--
Experience in using smartphone / tablet	Unexperienced	8	3	1
	Reasonably experienced	0	1	3
	Experienced	5	1	0
	Very experienced	0	0	1
Use of visual aid	Yes (reading glasses, contact lens, etc.)	--	4	5
	No	--	1	0
State of hearing	Good	--	4	3
	Reasonable	--	0	1
	Bad (usage of hearing device)	--	1	1
6CIT score (mean)		--	2.8	1.2

3.1 Usability issues related to motivational and cognitive barriers

Half of the identified high severity issues were categorized as motivational barriers with highest frequencies of low computer literacy and low trust in a patient's own ability to use the app. Patients for example did not know how to return to the app (1 and 2) when they had visited a website/browser.

Cognitive barriers were the second largest category of intrinsic aging barriers negatively influencing usability of the apps. Twenty percent and 31% of the issues of App 1 and App 2 were categorized as cognitive issues respectively. Users found the navigation hierarchy of both apps unclear and did not know how to return to previously shown information in the app, which was categorized as a decline in 'working memory' as intrinsic barrier to this issue. For App 2, users experienced issues in deciding where to find information and how to perform interactions if these were not part of the app's main functionalities. Although participants had a good score on the six item cognitive impairment test (6CIT), they still experienced issues related to a cognitive overload.

Table 3: *Completion rate per task and average time on task per age cluster of the TA*

	App 1					App 2		
Task		**Completion rate Age 50-64y**	**AVG time on task Age 50-64y**	**Completion rate Age 65+**	**AVG time on task Age 65+**		**Comple-tion rate**	**AVG time on task**
1	Register	78%	4:45	n.a.	n.a.	Open app	100%	0:29
2	Change postal code	33%	5:52	25%	2:22	Measure and send blood pressure	80%	6:39
3	Reschedule appointment	100%	2:01	75%	26	Measure and send weight	100%	2:46
4	Guide not there	78%	3:08	50%	1:26	Complete and send questionnaire	90%	2:01
5	Use app to request guide if family member present	78%	4:09	0%	n.a.	Show score points previous questionnaire	60%	1:26
6	--	--	--	--	--	Find info on exercise per day	80%	2:22
7	--	--	--	--	--	Register absence	50%	4:52
8	--	--	--	--	--	Check missed measurements	30%	3:25
9	--	--	--	--	--	Change measure-ments' day	66,6%	3:03

Table 4. Encountered usability issues (severity 3 or 4) of App 1 and App 2 - categorized by MOLD-US

MOLD-US category	MOLD-US sub cat.	Usability issue *(task)*	Sev.	Usability issue *(task)*	Sev.	Related to	Impact
	Cause	**App 1**		**App 2**			
Motivation	Trust in own ability	Users do not know where to change their postal code and do not expect that this can be done under profile details. *(Change postal code)*	3	Blood pressure is automatically sent via Bluetooth from the blood pressure monitor to the app. If the bluetooth connection fails (i.e. Bluetooth button is switched off),no feedback message is given in the app to the user. *(Measure and send blood pressure)*	3	Novice mHealth / medical device users	*App 1:* Possibility for incorrect address details, problem for taxi service. *App 2.* If user repeatedly fails to get measurements on the app, user gives up. Healthcare provider will call to ask what went wrong, that makes user nervous.
		Users do not understand app's functionalities due to a lack of instructions on goal and use of the app. *(Use app with family member)*	4			Complexity of functionalities/ navigation - not attuned to older mHealth older users	Insecurity, leading to non-exploration and rejection.
		In interaction with the apps functionalities users mention the need for usage support. *(Overall issue)*	3			Complexity of functionalities/ navigation - not attuned to older mHealth older users	Insecurity, leading to non-exploration and rejection.

MOLD-US category	MOLD-US sub cat.	Usability issue *(task)*	Sev.	Usability issue *(task)*		Related to	Impact
	Cause	**App 1**		**App 2**	**Sev.**		
	Computer literacy	'Submit' button for completing registration is not understood by user. *(Register at app)*	3	User does not understand the feedback from the blood pressure monitor (blinking lights) in relation to the text feedback in the app on performed measurements. *(Measure and send blood pressure)*	3	Novice mHealth / medical device users	*App 1:* Uncompleted registration. *App 2:* It is unclear to user if measurements are performed correctly. User tries to perform measurements again, until feedback in the app says blood pressure measurements are received.
		User does not know how to go back from 'help' function. *(Change postal code)*	4	User does not know how to recover from mistake (so uses home button of iPad). *(Show score points previous questionnaire)*	3	Complexity of functionalities/ navigation - not attuned to older mHealth older users	Insecurity, leading to non-exploration and rejection.
		User reached website and does not know how return to app. *(Change postal code)*	3	User reached web browser and does not know how return to app. *(Register absence)*	3	Novice mHealth / medical device users	App 1 & App 2: User does not return to using the app.
		Profile icon not understood by user. *(Change postal code)*	4			Novice mHealth / medical device users	Functionalities at profile not used, possibility for incorrect address details, problem for taxi service.

MOLD-US category	MOLD-US sub cat.	Usability issue *(task)*	Sev.	Usability issue *(task)*	Sev.	Related to	Impact
	Cause	**App 1**		**App 2**	**Sev.**		
		Users mention the need for support on general mHealth use when unacquainted with mHealth technology. *(Overall issue)*	3			Novice mHealth / medical device users	Insecurity, leading to non-exploration and rejection.
		Users do not recognize the function of buttons due to unclear button design in the app. *(Overall issue)*	4			Novice mHealth / medical device users	Users do not click on buttons, information and actions one level after relevant buttons are not reached and thus not used.
	Efficiency in seeing benefits	Users mention the need for explaining the apps functionalities in the app. *(Overall issue)*	4			Content not attuned to end-user	Insecurity, leading to non-exploration and rejection.

3

MOLD-US category	MOLD-US sub cat.	Usability issue *(task)*	Sev.	Usability issue *(task)*		Related to	Impact
	Cause	**App 1**		**App 2**	**Sev.**		
Cognition	Working memory	Unclear hierarchy in app, unknown to user how to return to the previous screen (android specific, no back function on screen, only physical unmarked button on phone). *(Reschedule appointment)*	3	Unknown to user which button to click to view previous measurement. *(Show score points previous questionnaire)*	3	Complexity of functionalities/ navigation - not attuned to older mHealth older users.	Insecurity, leading to non-exploration and rejection.
	Dynamic/ selective attention	Information overload in FAQ, questions not ordered, user unable to find answer quickly. *(Reschedule appointment)*	3			Content not attuned to end-user	Relevant information in the app cannot be found by user. Users has to find another solution to obtain information.
	Semantic fluency	English term 'hospitality host' not understood by user *(Hospital guidance)*	3			Content not attuned to end-user	Insecurity, leading to non-exploration and rejection.

MOLD-US category	MOLD-US sub cat.	Usability issue *(task)*	Sev.	Usability issue *(task)*	Sev.	Related to	Impact
	Cause	**App 1**		**App 2**	**Sev.**		
	Reasoning			User does not know where to go to receive information about healthy behavior. *(Find info on exercise per day)*	3	Complexity of functionalities/ navigation - not attuned to older mHealth older users	Relevant information in the app cannot be found by user. User has to find another solution to obtain information.
				User does not know which actions to take to register absence and send this to healthcare professional. *(Register absence)*	3	Complexity of functionalities/ navigation - not attuned to older mHealth older users	Not registering absence due to missing data. User subsequently contacts health provider by phone.
				Start date and end date should be registered before clicking ‹add absence›. *(Register absence)*	3	Complexity of functionalities/ navigation - not attuned to older mHealth older users	Not registering absence due to missing data. User subsequently contacts health provider by phone.

MOLD-US category	MOLD-US sub cat.	Usability issue *(task)*	Sev.	Usability issue *(task)*		Related to	Impact
	Cause	App 1		App 2	Sev.		
Perception	Visual acuity	Profile icon is overseen by user due to its small size	3	Button 'back to measurements' is too small and overseen by user when information screen is opened. *(Show score points previous questionnaire)*	3	UI Design not attuned to end-user	App 1: Functionalities at profile not used, possibility for incorrect address details, problem for taxi service. App 2: Insecurity, leading to non-exploration and rejection.
				Message 'data not received' is too small and overseen by user. (Task: Measure and send blood pressure)	4	UI Design not attuned to end-user	If user repeatedly fails to get measurements on the app, user gives up. Healthcare provider will call to ask what went wrong, which makes user nervous.
		User cannot read text in app (too small) *(Overall issue)*	3	Text of frequently asked questions are too small to read for user. *(Change day of measurement)*	3	UI Design not attuned to end-user	Relevant information in the app cannot be found by user. User has to find another solution to obtain information.
Physical abilities	Hand-eye coordination			Scroll bar *absence* is difficult to use for user. *(Register absence)*	3	UI Design not attuned to end-user	Not registering absence. User subsequently contacts health provider by phone.
				Dates are too small for user to click on in webapp for filling in absence. *(Register absence)*	3	UI Design not attuned to end-user	Not registering absence. User subsequently contacts health provider by phone.

3.2 Usability issues related to perception and physical ability barriers

In both apps, patients experienced issues that were categorized at perception level as an intrinsic aging barrier. Users for example oversaw important icons or feedback messages and had difficulties with reading the small font texts in both apps. Of the participants 90% used a visual aid such as glasses during the testing of App 2, but nonetheless experienced usability issues related to perception barriers. Patients only experienced issues categorized at physical ability barriers with App 2; users had difficulties with selecting the scroll bar and clicking at small interaction features.

4. Discussion

In two case studies in which Think Aloud usability evaluations were performed with older adults, we respectively revealed 15 and 13 high severe usability issues of mHealth App 1 and App 2. We applied the MOLD-US framework to classify the usability issues revealed in these case studies based on impediments intrinsic to these issues. Classification via MOLD-US revealed that motivational and cognitive barriers of the older adult users provoked most usability issues in the case studies' apps. Perception and physical abilities of these adults further impeded usability in the studied apps. The case studies showed that MOLD-US allows for improved analysis of results in systematic usability evaluations of mHealth aimed at older adults.

4.1 Perception, cognition and physical ability barriers in relation to design

These findings have important implications for developing mHealth for an aging population. Prior studies noting the importance of specific user interface designs for older people state that use of small targets and characters should be avoided [16]. Likewise the importance of using a proper visual display with objects, such as buttons, that older adults can distinguish from other visual display features is emphasized [16]. The results of this study further support the notion that user-interface design elements such as font size and buttons should be adjusted to the older adult user population. This study additionally points out that existing knowledge on usability heuristics focused on older adults usage of mHealth tools is not yet applied in these services. Regarding cognitive barriers, recent design guidelines for mobile interfaces acknowledge the relevancy of cognitive skills in interacting with mobile services and state that cognitive load should be minimized, i.e. by a clear navigational structure and aligning an interface with expectations of older adults [16-18]. Our results further confirm the association between degenerating cognitive skills due to aging and occurring usability issues due to a complexity in functionalities and navigation of the apps.

The analysis of usability issues in our case studies by means of MOLD-US provides us with understanding of these prominent barriers hampering older adults' usage of the apps. However, MOLD-US in its present form does not provide recommendations on (re)designing apps for older patients based on usability issues encountered. For example, while physical and perceptual problems may be relatively easy to be corrected with existing knowledge on how to design for older adults [16], the functional and conceptual issues are more difficult to tackle. A possible explanation for this might be that many young and middle-aged designers may not be aware of what degenerating cognitive skills of older adults entail, especially not of the seniors. Hence, designers create (unintentionally issue prone) mHealth functionalities and interfaces based on their own assumptions of what older adults can comprehend, as in our case studies. Within this context, Tang et.al. [19], showed that senior mobile phone users, even after more than one year experience, still had misconceptions of basic operations and functions. These older users still faced complex problems in terms of understanding how mobile services are structured. Design of mHealth apps could therefore further profit from looking at mental models that older adults have of how something should work, based on their experiences in the real world. Older adults tend to rely on their "rules of thumb" strategies to make decisions and in doing so perform worse on integrating and extracting (new) information [20]. Their rules of thumb might apply to known functions of a smartphone, tablet or an app. Yet, when an app's functionalities are dependent on and/or integrated with unfamiliar device functions and interactions to older adults, they might flounder in its use. Considering the complex hierarchy of a smartphone's or tablet's menu, older adults might permanently experience difficulties in making decisions to navigate through the device's functions, since it places a high demand on remembering a sequence of actions. In the design of our case study apps the functional hierarchical menus and their integration with other device functions, such as internet browsing, alienated the older adult users who were not familiar with these concepts. This hierarchy of these apps could possibly be improved by aligning it with chronological and natural use of the app. Colored information visuals, in our case for example explaining the navigational path and consequences of a decision, could be used as a decision aid tool since these type of visuals have a positive effect on the accuracy of the decisions made by older adults in eHealth tools [20]. We aim to perform more case-studies on usability of mHealth apps as experienced by older patients to expand MOLD-US with these types of recommendations.

4.2 Motivational barriers of older adults in relation to usability and acceptance

Although motivational barriers are acknowledged in acceptance research [8, 21-23], they are barely addressed in mobile interface design guidelines and usability research. It is believed that these barriers will diminish over time as middle-aged adults will age and become older adults acquainted with mobile technology [23]. Even though older adults are starting to display interest in using smartphones and tablets for obtaining health information [24], more than 75% indicates they would need help to walk them through the process of learning how to use a new device such as a smartphone or tablet [25]. Based on these insights, we advise to put more emphasis on addressing motivational barriers of older adults within user interface design and guidelines. For example, the Health Information Management and Systems Society guidelines for mHealth state that if a user (intends to) make a mistake, the application helps to avoid it or provides a method to recover from errors gracefully (the system is "forgiving") [18]. In line with Zhang et. al. [26], we propose using feedback messages in interfaces and argue that these messages should not only inform users on (the result of) their actions, but should also offer the user options to recover from wrong actions and return to previously retrieved information or actions. Further, a clear (video) instruction on how to use an app should be given when older users register for an app, including an aid to return to this instruction during any point in an app's usage. We additionally advise to involve older populations as co-creators in the requirements analysis and design phases when developing mHealth. Tapping their knowledge and taking the perspectives of these user groups into account is crucial to create app designs that are easy for them to use.

4.3 Usability testing with older adults

MOLD-US can be of value in improving current approaches to usability engineering. Prominent frameworks used for usability data analysis, such as the User-Action Framework and the Usability Problem Taxonomy [27-28], as well as engineering approaches for evaluation in the design of healthcare information systems, such as explained by Kushniruk [29], may not anticipate the limitations posed by aging barriers in relation to usability evaluations with older adults. Such limitations are nevertheless of importance to take into account, since they may influence study outcomes; MOLD-US can provide an overview of aging barriers that may hamper usability testing. For example, we found that physical as well as cognitive aging barriers and/or medical conditions can cause difficulties with verbally disclosing problems in the interaction with the apps; a high level of trust is needed to have older adults explain such problems to the evaluators, as well as a high level of specific knowledge by the evaluator on the aging characteristics and medical conditions of participants [30]. Secondly, we experienced that the TA method relies heavily on the cognitive capacities of participants, such as communication, attention and speed of comprehension, whereas it is exactly these cognitive capacities that decline with aging. These cognitive skills, especially attention, are deeply solicited by the TA method, hindering people with cognitive limitations like older patients in retaining sufficient attention for using the app under evaluation. An implication of this is the possibility that usability evaluation approaches may need adjustments to prevent reporter bias and become better suited for testing mHealth services with the older adult and chronically ill patient populations. Experts within the field of usability testing are encouraged to undertake future research to improve user-based testing with older adults in dealing with aging barriers that influence usability test results of mHealth applications.

5. Conclusion

The findings of this study showed that use of the MOLD-US framework can reveal usability issues encountered by older adults in using mobile health due to aging barriers that are alike in origin and impact, across different apps or devices used. We conclude that existing knowledge from user interface guidelines on perception, cognitive and physical ability barriers of older adults are currently not applied to the fullest in mobile health interfaces. In addition, motivational barriers of older adults should get more attention in usability research in the field of mobile health. An issue raised by this study is if current end-users usability evaluations, when performed with older participants, and specifically older *patients*, might bias the evaluation results. Especially the Think Aloud method monopolizes attention resources of the older participants, hindering them to fully focus on evaluating the studied technology. Additionally, usability issues provoked by physical ability barriers are not easily identified by the Think Aloud method. To tackle these issues, research into suitable usability evaluation methods adapted to older patients' characteristics is needed. Such methods could ultimately provide unbiased sight on usability issues older patients may experience while interacting with technology.

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Supplementary file A

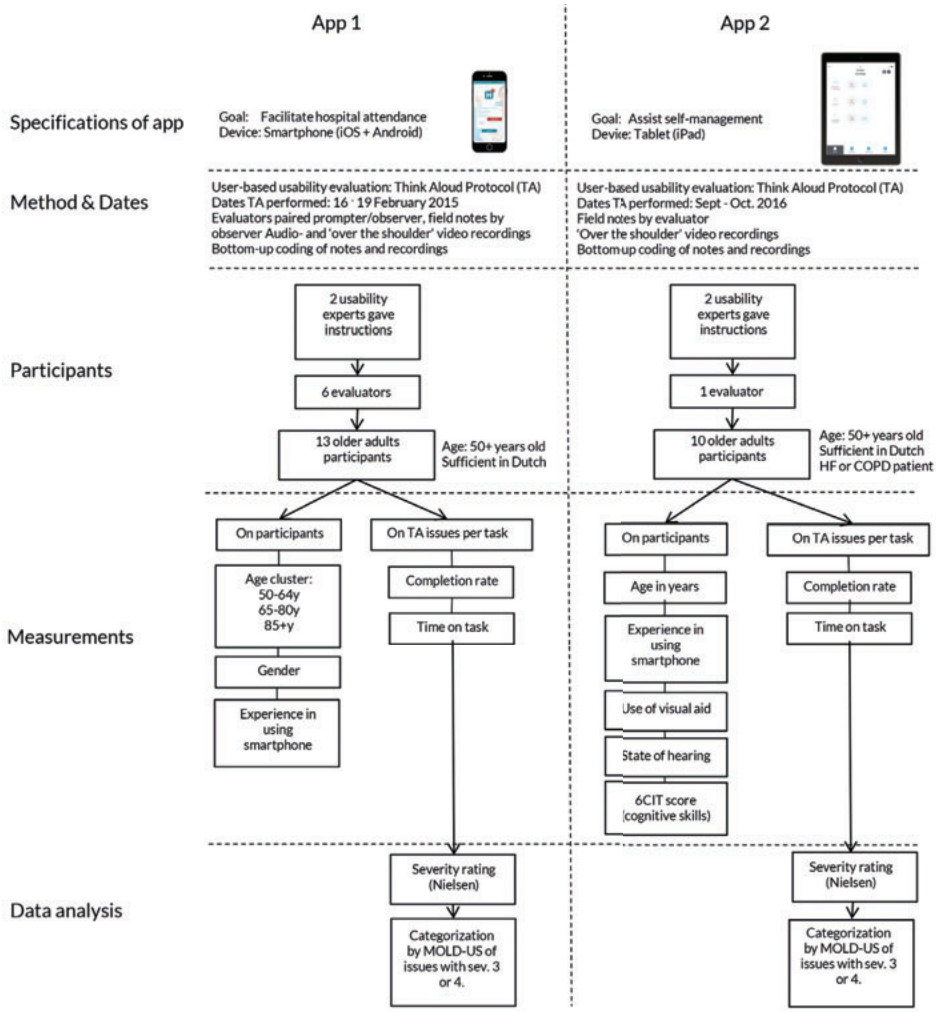
Description App 1

App 1 was developed by the Academic Medical Center (AMC) in Amsterdam, The Netherlands, and aimed to support older adult patients in their visits to the clinic. App 1 assisted older adults in navigating to and in the hospital, thereby aspiring to lower their stress levels and to increase hospital attendance. The patient was required to download the app prior to the appointment at the clinic. During the implementation of the app, its (potential) users could seek advice on how to use the app via a telephone helpline and via a website. The website included instructions on how to download the app as well. The app operated on iOS and android as a native app for smartphone usage. Design decisions made by the developers of the app were based on iOS guidelines, their experience and on what they thought would suit the target group.

Description App 2

App 2 was a home telemonitoring application developed by a Dutch health innovation company, and aimed to help heart failure (HF) and Chronic Obstructive Pulmonary Disease (COPD) patients in monitoring their health and communicating with their healthcare professionals. As a main functionality, patients could perform blood pressure and weight measurements, at a pre-arranged schedule, and sent it to their healthcare professional. In using App 2 patients had to use a connected weight scale and blood pressure monitor. App 2 was installed at the home of patients, with the help of a technician of the Dutch company that built the app. Patients received an instruction by the technician on how to use App 2 after the installation. Patients experiencing problems with the use of the App 2 could call the service desk of the Dutch company that build the app. App 2 operated on iOS as native app for an iPad. A web browser app of App 2 was also available. Design decisions made by the developers of the app were based on iOS guidelines, their experience and on what they thought would suit the target group.

Supplementary file B



Flowchart of the study design

Part 2

Patient portal use by older adults

Chapter 4

Facilitators and barriers of electronic health record patient portal adoption by older adults: a literature study

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Studies in Health Technology and Informatics. 2017;235:308-312
PMID: 28423804

Abstract

Patient portal usage by older adults, patients aged 50 years old and above, is intended to improve their access and quality of care. Acceptance of patient portals by this target group is low. This paper discusses the results of a literature review to determine the facilitators and barriers that drive or inhibit older patients to adopt patient portals. Articles were included when they described an acceptance, adoption or usability evaluation study of a patient portal. From a total of 245 potentially relevant articles, 8 articles were finally included. We used the Unified Theory of Acceptance and Use of Technology (UTAUT) as a classification model to analyze factors influencing older adults' acceptance of patient portals. Main facilitators for acceptance were 'performance expectancy' and 'voluntariness of use' related to a higher level of education and experienced health. Main barriers were limited health literacy and motivation related to involuntariness to use a patient portal. Poor facilitation conditions (limited technology access and no prior knowledge on existence of a patient portal) hampered access to a portal. More thorough insight into the latter is needed to improve the reach and effectiveness of patient portals among older patients.

Keywords. Patient portal, older adults, elderly, acceptance, adoption, UTAUT

1. Introduction

The deployment and usage of electronic health record (EHR) patient portals is promoted by governments and healthcare delivery systems worldwide [1-2]. The use of patient portals is intended to improve access and quality of care and may result in improved health outcomes, especially for chronically ill patients [3-4]. The proliferation of patient portals is also associated with reducing healthcare costs; health care expenditures among elderly Americans are for 95% related to chronic diseases [5]. Effective use of patient portals by older adults, patients aged 50 years old and above, is expected to lower such expenditures. Despite the associations of patient portal use with these favorable outcomes, voluntary uptake and use of patient portals by this target group have been low [6-7]. Older adults' *enrollment* to patient portals is expected to rise, since the elderly population is one of the fastest growing user segment of internet [7]. However, their *adoption* of patient portals will only be successful if the perspective of older adult patients is kept at the forefront [8]. Besides a patient's age, aspects as health literacy level and socioeconomic status influence patient portal acceptance [9]. Adoption of patient portals of older adults is further jeopardized by biological, psychological and social aging processes; it is thus relevant to examine which factors contribute to or impede the adoption of patient portals by this target group [10]. This is particularly relevant for chronically ill older adult patients, since it is foreseen that portals will increasingly fulfill a role in patients' self-management of their disease and care [11]. If patient portals indeed become a key tool for self-management and adoption rates of patient portals by older adults remain low, chronically ill older adult patients might be withheld from patient portal usage benefits and they might encounter difficulties due to a lack of non-patient portal services, such as a dedicated nurse practitioner to answer questions by telephone. It is thus needed to evaluate older adults' experiences and preferences for using a patient portal. The goal of this literature review is to determine the facilitators and barriers that drive older adult patients to adopt EHR patient portals by using the Unified Theory of Acceptance and Use of Technology (UTAUT), a prominent technology acceptance framework [11-12], as a classification model for those factors.

2. Methods

The database PUBMED was searched on the 7th of October 2016 for studies reporting on possible factors influencing the usage of patient portals. We used the following search strategy: "patients"[MeSH] OR "patients"[All Fields] OR "patient"[All Fields]) AND ("Electronic Health Records"[MeSH] OR "Telemedicine"[MeSH]) AND (factors[All Fields] OR barriers [All Fields] OR reasons [All Fields]) AND acceptance[All Fields]). We performed three additional searches including 'patient portal', 'barriers' and 'acceptance' in all fields. We limited all searches to articles in English published between January 2010 and July 2016. Studies were included if the abstract described an acceptance, adoption or usability evaluation study of a patient portal (1) with patients over 50 years old (2) in a hospital or primary care setting (3). We excluded articles reporting on a general status update of patient portals, with physicians as study population, reporting solely on one functionality of a patient portal, assisted living technologies, or a disease specific eHealth or mHealth tool.

The methodological quality of each article was evaluated by means of the Mixed Methods Appraisal Tool (MMAT), used for systematic mixed studies reviews, resulting in a standardized quality score across diverse type of study designs, study populations and sampling [13]. Per study, the first and second author independently identified facilitators and barriers and mapped these onto UTAUT concepts. If needed, a new concept in the UTAUT was introduced.

3. Results

3.1. General characteristics of included studies

The searches resulted in 245 potentially relevant articles. Deduplication and abstract screening resulted in the rejection of 213 articles. Full text versions were not available for 2 articles and 22 articles were excluded after reading the full text version. This resulted in the inclusion of 8 articles for further analysis. The interrater reliability score was κ=0,65. Five studies followed a qualitative design, with one using the UTAUT framework to formulate questions for the interviews and questionnaire [15].

3.2. Facilitators and barriers of older adults' patient portal usage

Table 1 and 2 respectively show the reported facilitators and barriers related to UTAUT concepts. Concerning facilitators, non-occurring UTAUT concepts were: effort expectancy, gender and age. We introduced one UTAUT sub-concept for performance expectancy and five sub-concepts for voluntariness of use. Concerning barriers, non-occurring UTAUT concepts were: performance expectancy and gender. We introduced two UTAUT sub-concepts for facilitating conditions and three sub-concepts for voluntariness of use.

Table 1. *UTAUT categories related to facilitators of older adults' patient portal usage*

UTAUT ***Extended UTAUT***	**Reported facilitators**	**Age cluster**	**[Ref #]** ***Quality %***
Performance expectancy	Options for digital archiving and analysis of one's own medical data	55-75+	[14], *33*
	Beneficial aspects of patient portal: self-health monitoring by patient	Mean 56 Mean 51	[15], *40* [16], *40*
	Reread medical information at home	Mean 64	[3], *13*
Performance expectancy: benefits patient/provider relationship	Patient participation: patient portal facilitates influence of patient on their disease management and treatment	Mean 64	[3], *13*
	Option for sending secure messages to healthcare team via patient portal	65-79, Mean 56	[17], *13* [15], *40*
	Patient portal is neutral medium for delivering difficult news or 'difficult to hear' advice	55-75+	[14], *33*
Social influence	Availability of other person to help with usage	Mean 64	[3], *13*
	Physician or someone else thought use of patient portal would be useful for patient	Mean 64	[3], *13*
Facilitating conditions	Use via mobile device (smartphone, tablet)	65-79	[17], *13*
	Comfortable in using the internet	45-64, 65+	[18], *40*
Experience	Regular use of internet	Mean 64	[3], *13*
Voluntariness of use (VoU)	Ambition to learn how to use patient portal	50-100	[19], *40*
VoU: level of education	Higher level of education related to higher probability of using of patient portal	65-79 55-75+ Mean 55	[17], *13* [14], *33* [20], *13*
VoU: health interest & status	Better health conditions related to higher use of patient portal	65-79	[17], *13*
	Patients regularly searching health information on internet more likely to use patient portal	Mean 64	[3], *13*
VoU: dissatisfied current care communication	Dissatisfaction concerning current care communication	Mean 64	[3], *13*
VoU: Satisfied current care communication	Positive experiences healthcare clinic (careful listening, easy information explanation)	45-64, 65+	[18], 40
VoU: Cultural background	Cultural background might influence of use: Caucasians more positive attitude toward use and less connectivity problems than black patients	Mean 51	[16], *40*

__Table 2.__ UTAUT categories related to barriers of older adults' patient portal usage

UTAUT ***Extended UTAUT***	**Reported barriers**	**Age cluster**	**[Ref #]** ***Quality%***
Effort expectancy	Use of patient portal would be too complicated for patient according to patient	Mean 51	[16], *40*
Social influence	Older adults not able to use internet by themselves, only browse internet with help of others	65-79	[17], *13*
Facilitating conditions (FC)	Limited technology and/or internet access	55-75+ Mean 51 50-100	[14], *33* [16], *40* [19], *40*
FC: implementation issues	Limited to no prior knowledge on existence of patient portal	Mean 64 Mean 51 50-100,	[3], *13* [16], *40* [19], *40*
FC: concerns	Concerns about privacy or security issues of medical data in patient portal	Mean 56 Mean 51	[15], *40* [16], *40*
Age	70 years old and above limited to no to use of patient portal	mean 64 55-75+ 65-79	[3], *13* [14], *33* [17], *13*
Experience	Lack of or limited technology experience and proficiency	55-75+ mean 56	[14], *33* [15], *40*
VoU: Health literacy	Limited health literacy	Mean 55	[20], *13*
VoU: satisfied with current care communication	Satisfied with the status quo	50-100	[19], *40*
	Wish to preserve in-person aspects of existing patient-provider relationships (i.r.t. limited health literacy)	Mean 56 Mean 51	[15], *40* [16], *40*
	Prefer to leave disease management to physician	Mean 64	[3], *13*
VoU: motivation	Lack of motivation to use patient portal	Mean 51	[16], *40*

4. Discussion

This literature review gives insight into the facilitators and barriers on patient portal acceptance by older adult patients, analyzed and clustered by means of the UTAUT. If needed, we introduced new UTAUT sub-concepts. In the 8 studies, 18 facilitators predominantly concerned the UTAUT (extended sub) concepts 'performance expectancy: 'benefits patient/provider relationship', 'voluntariness of use: level of 'education', 'health interest & status', '(dis)satisfied with current care communication' and 'cultural background'. Twelve barriers predominantly concerned the UTAUT (extended sub) concepts 'facilitating conditions: implementation issues' & 'concerns' and 'voluntariness of use: 'health literacy', 'satisfied with current care communication' and 'motivation'.

We introduced 11 sub-concepts to the UTAUT, 6 related to facilitators and 5 to barriers. The UTAUT provides a theoretical framework for analyzing users' acceptance of health technology, but needs to be supplemented with concepts reflecting barriers and facilitators of older patients influencing their acceptance of patient portals. Another review suggests three additional constructs to the UTAUT for analyzing older users' home telehealth services acceptance: 'Doctor's Opinion', 'Computer Anxiety' and 'Perceived Security' [10]. These constructs correlate with the sub-concepts we introduced for 'performance expectancy' reflecting the (changing) patient/provider relationship by introduction of a patient portal and 'voluntariness to use' reflecting motivational reasons to use or not use a patient portal – such as (dis)satisfaction with current care communication, health literacy level and level of education. Yet, we found additional barriers related to access of digital health services for older adults, such as limited technology and internet access and privacy concerns on the medical data in the portal. Though most trend studies report that internet access issues of older adults will vanish over time, relying on everyday technology or generic internet use rates of seniors to estimate digital health use may be misleading [21]. Seniors have used digital health tools at low rates with only modest increases from 2011 to 2014; these tools are not reaching most seniors and their underuse is associated with socioeconomic disparities, raising concerns about their ability to improve quality, cost, and safety of seniors' health care [21]. With the role of patient portals concerning patients' self-management growing, it is important to gain more sight on the conditions that hamper or facilitate the reach and acceptance of these portals by older patients.

5. Conclusion

Patient portal use is promoted by health care delivery systems but acceptance rates of older patients are low. Older patients' expectancy of performance of a portal and higher education levels facilitate acceptance. Whereas a lower health literacy level and being satisfied with the status quo relate to involuntariness to use a patient portal. Poor facilitation conditions, such as limited technology and internet access, hamper older adults' access to a patient portal. Future research should focus on conditions for engaging older patient populations in patient portal usage within the broader context of patient profiles, the patient/provider relationship, decision making, provision and self-management of care.

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Chapter 5

Older adults using a patient portal: registration and experiences, one year after implementation

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Digital Health. 2018, Sep 2;4
DOI: 10.1177/2055207618797883

Abstract

Background and Objectives: The interest of older adults in using patient portals is rising, yet subject to functional and usability barriers. This study aims to gain insight into registration rates and experiences of older adult patients using a patient portal, one year after implementation in an academic hospital.

Methods: Registration rates for one year were collected via automated data extraction. Older adult patients' experiences were collected through a survey, available via the portal in the last three months of the year.

Results: Older adults were a large user group of the patient portal, and appreciated its functionalities. In one year, 10,679 older adult patients (aged 56+) registered, which constituted 47% of total portal registrations in one year's time. The 131 older adult survey respondents had a mean age of 64.5 years and 40% indicated that they like to review their medical information and appointments via the portal. Yet, older adults experienced user interaction issues and had higher expectations of content within the portal and patient/provider communication through the portal. Of the survey respondents, 22% experienced usability issues at login and in viewing test results, 15% commented on late or no response by providers on patients' sent messages and 24% expected the portal to provide medical history information.

Implications: Patient portal designs should be optimized to usability needs of older adults. Portals preferably include medical history information, physicians' notes and require prompt responses of providers.

Keywords: patient portal; technology acceptance; usability; user interaction; patient provider communication; elderly

1. Introduction

Over the past few decades, there has been a significant proliferation in the implementation and use of electronic health records (EHRs) creating vast opportunities for improvement in the efficiency and quality of patient care as well as reduction in healthcare costs [1]. Driven by a multitude of social and economic factors, most notably financially-overstretched healthcare systems and patients' wishes for a more active role in the management of their disease, patient portals are increasingly being seen as powerful tools for health promotion. A patient portal is often tethered to the EHR of the hospital and most portals offer the same set of basic functions to patients, such as a secure means to schedule appointments, view laboratory results, request medication prescriptions and send secure messages to a healthcare team [2-4]. Older adults, aged 50 years and above, typically need healthcare services related to multi and comorbidity problems and for this reason can benefit in particular from the use of a portal. Access to their medical record content and interaction with their providers via a portal can support them specifically in maintaining wellness and independence during the management of their medical condition(s) [5].

Despite the potential benefits of patient portals, previous research has identified several factors as barriers that thus far hampered their use, including privacy concerns [6-8], unresponsiveness to messages sent to physicians [8], a mismatch between patients' expectations and the actual functionalities of a portal [6] as well as health literacy and usability problems [9]. Further, examples of specific barriers mentioned by older adults are that they have limited access to technology or internet, are not aware that their hospital offers a portal and they are satisfied with the current, face-to-face, care communication [2, 9-12]. These reported barriers suggest that older adult patients use portals less often compared to middle aged or younger adults. However, a number of studies have indicated that there is a rise in older adults' interest in using portals to manage personal health information [5, 9]. A recent systematic review by Sakaguchi-Tang et. al. indicates that older adults perceive portals as useful and have an intention to use these portals [13]. A 2016 study by Walker et. al. likewise reported the growing interest of older people (aged 75+) and their families in online resources such as medication lists, provider rosters, clinicians' encounter notes and guides to community resources [9].

Yet, most studies in the review by Sakaguchi-Tang et. al. focused on older adults' intention to use portals, instead of actual activation rates and use of portals by older adults. Four of the included studies evaluated the older patients' use experience, and only one study reported on actual activation rates of portals among the older adult patient population [13]. Our study contributes to these previous studies on older adults and patient portals by examining actual registration rates of older adult patients one year after a portal's implementation in a large academic hospital in The Netherlands. It further explores positive or negative experiences of this portal's use amongst older adult patients with an activated account. A deeper understanding of older adults' portal usage could be helpful to physicians and other care givers in using portals while providing care for older adults. These insights could likewise enable policy makers to adjust portals to better suit the needs of older adults. Therefore, this study aims to expand the knowledge on 1) enrollment to patient portals amongst the older adult patient population and on 2) experienced factors that contribute to or inhibit portal use by older adults.

2. Design and Methods

2.1 Context: Patient portal 'Mijn Dossier'

As part of the implementation of a new EHR system, the Academic Medical Center (AMC) in Amsterdam launched a tethered patient portal, named 'Mijn Dossier' (MyChart) on the 25th of October 2015. The portal provided the following main functionalities to patients at the time of implementation: 1) patient/provider communication through secure messaging; 2) viewing of medical correspondence; 3) viewing and editing of medical conditions, over the counter medication and allergies list; 4) requesting medication prescriptions; 5) viewing test results, which were automatically shown in the portal 7 days after being recorded in the EHR; pathology, radiology and sexual transmitted diseases test results were automatically shown in the portal 21 days after being recorded in the EHR; 6) viewing and cancelling appointments, or requesting a new appointment. From the date of launch and onwards, information on these 6 aspects, if registered in the EHR, was visible in MyChart; information prior to that date, such as a patient's historical medical record, was not visible. Patients were informed on MyChart by means of flyers distributed amongst the outpatient clinics and a 'MyChart page' at the website of the hospital, including a short video on MyChart and a 'questions and answers' section. At the first two weeks of the implementation, MyChart was promoted by the implementation team at the entrance of the outpatient clinics. Patients received a letter with an activation code within the hospital to register to MyChart, which was provided by hospital staff (administration or physicians). Once the activation code was given, the patient could activate his/her account at home. After activation, patients could login by means of a two-factor-authentication method, using a username and password as well as a login code that was sent via a mobile text message. A continuous web support team for patients was available to answer questions from patients regarding the use of the portal. Researcher GW coordinated the implementation and web support activities.

2.2 Data collection

2.2.1 Older adults' patient portal registration rates

Registrations rates were collected from the EHR database. The vendor of the EHR system provided a report on the MyChart 'status type' of patients who had had a hospital visit between the 25th of October 2015 and the 25th of October 2016. Descriptions of status types are explained in Table 1. Due to the report settings of the EHR vendor, the age clusters in the report ranged from 56 to 105 years, with increments of 10 years. For this reason the age range of the registration rates differs from the survey respondents' age range (50+).

***Table 1:** Status types of MyChart, including description*

Status type	Description
Active	Patient has activated his/her MyChart account
Expired	Patient received activation code, but has not activated his/her MyChart account (code has expired)
Declined	Patient has indicated he/she does not want to use MyChart

2.2.2 Survey on older adults' patient portal experiences

The MyChart web support team created an online survey in Dutch with open-ended questions (Supplementary file A). Patients could provide compliments and/or suggestions on main functionalities of MyChart, including the registration and login process, the messaging feature and viewing/editing of medical information. The survey served to gain insight in how MyChart's functionalities could be improved. The management team of MyChart in the AMC set the survey's requirements: it had to be non-obtrusive regarding a patient's regular MyChart use, thus short in length and not excessively present or marketed while a patient used MyChart. A patient communication advisor and two eHealth specialists of the AMC pre-tested and approved the survey. Consent by patients for scientific research was included in the terms and conditions of MyChart and this study was approved by the Medical Ethical Committee of the AMC.

From the beginning of October 2016 until the end of December 2016, the survey was accessible via a message on the homepage of MyChart after a patient had logged in. Patients could only answer the questions if they had had experiences with (basic) functionalities and could choose to complete the survey anonymously or with their patient ID. Blank returned surveys and anonymous survey data not providing demographics were excluded. We included data from patients with a patient ID to obtain data on gender and age of the patients. Data from patients aged 50 years old and above was anonymized for identity and used for data analysis.

2.3 Data analysis

A coding frame was inductively constructed from the data [14]. Researcher KM carried out an initial reading of the data and identified specific text segments related to the research objectives. He labeled the text segments to create themes that constituted the preliminary findings and performed an initial coding of the data with those themes. Researcher GW was given the evaluation objectives, the coding themes and the raw data. GW performed an independent parallel session of coding of the raw data. KM and GW conferred to compare, discuss, refine and reduce overlap and redundancy among the themes to develop a more robust coding frame. GW and KM then performed a second round of coding the data. When any disagreement about the coding occurred, researcher LP was involved to discuss the coding to ensure data integrity. The process continued until 100% agreement was reached. In subsequent analysis, it was examined whether both positive and negative aspects regarding MyChart use were reported in individual responses.

3. Results

3.1 Registration rates of older adults

Figure 1 and Supplementary file B show the registration rates of MyChart of older adult patients per age cluster; in total 10,679 older adults activated their MyChart account in one year's time, this is 47% of all 22,724 patients who activated patient portal account and 20% of all 53,215 older adults who had a visit in the hospital between the 25th of October 2015 and the 25th of October 2016. In the age clusters 56-65 years and 66-75 years, the activated accounts (9,347) outnumber the number of patients who declined to create an account (4,813). However, in the categories above 76 years of age, the number of patients who have declined to create an account (1,858) moderately outnumber the activated accounts (1,332)

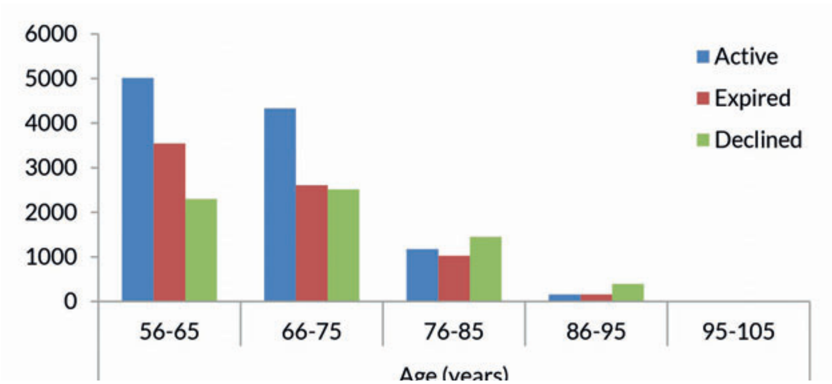

Figure 1: *Registration rates MD of patient aged 56 years and above (25th of Oct 2015 - 25th of Oct 2016)*

3.2 Survey demographics

Between October 2016 and December 2016, 406 MyChart users responded to the survey (response rate is approximately 15%), of which 203 responded with a patient ID. Forty returned surveys were excluded due to either being blank on all questions or containing special request texts such as questions directed to the treatment team. Of the remaining 163 responses, 32 were excluded as they were replies from patients younger than 50 years old. The remaining 131 responses were used for data analysis. Demographics of these respondents are shown in Table 2.

Table 2: *Demographics of older adult AMC survey respondents (n=131)*

Age (years)	
Mean (±SD)	64.5 (±8.4)
Min-Max	50 - 90
Female (n)	50
Male (n)	81

3.3 Older adult patient experiences

Six themes were identified: 1) usefulness of the portal (positive / negative); 2) usability of the portal (positive / negative); 3) attitude and beliefs towards patient portals in general (positive / negative); 4) mismatch of portal terminology with health literacy level of the patient; 5) mismatch of portal content with prior knowledge of the patient on the portal and 6) coordination of care communication between the patient and the provider (no problem / problem). Figure 2 and Supplementary file C indicate the number of times a theme was mentioned in the responses by patients.

3.4 Usefulness

Fifty-three respondents (40%) pointed out that MyChart was useful to them. For example, respondents appreciated that they could review their laboratory results and retrieve information about their health condition.

> *"Nice to have a look at home or elsewhere, safe feeling up till now" (female, 52y).*

They also stated the relevance of MyChart in the follow-up and planning of their health condition, most notably concerning their upcoming appointments. Eleven respondents (8%) expressed dissatisfaction with the usefulness of MyChart. Main complaints revolved around incompleteness of the information presented in the portal or the considerable time it takes before the test results are shown in the portal once the results are issued from the laboratory.

> *"It takes much too long before the results are shown in MyChart" (male, 61y)*

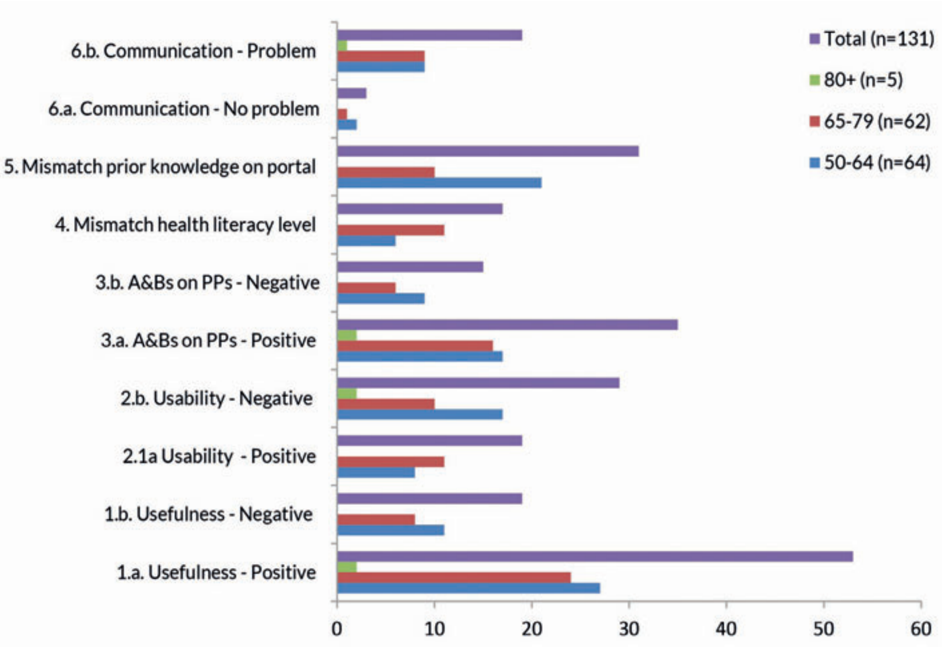

Figure 2: *Number of times of reported patient experiences per theme, per age cluster*

3.5 Usability

Nineteen respondents (15%) expressed positive comments on usability, mainly using expressions as ‘user friendly’, ‘use is easy’ and ‘clear’. However, usability problems were reported by 29 respondents (22%). For example, respondents were dissatisfied that they could not review all test results on one page; instead each result had to be opened on a different page, rendering it impossible to have an overview of the pattern of test values over time.

“Is it possible to put all lab results in one overview, then you would not need to click on each single result” (male, 55y)

The two-factor-authentication login system generated praise and criticism. Some respondents were explicitly asking for a simpler mode of access so as to minimize the numbers of passwords and codes to be remembered and entered on a (mobile) device.

“Now this is too much to remember or type and then there is also an extra notification per telephone all double double” (female, 55y)

Of the respondents who reported usability problems, 9 respondents (35%) still assessed MyChart as useful.

3.6 Attitude & beliefs

Out of 15 respondents (11%) who had a negative attitude towards patient portals in general, only 1 acknowledged the usefulness of MyChart, while 9 were clear in their disinterest; reporting that MyChart was not useful to them.

"Records are not well maintained. This has absolutely no use!!!!!" (male, 73y)

In contrast, only 1 respondent of the 35 respondents (27%) with a positive view of patient portals in general, was still skeptical as to the use of MyChart in its current development stage.

"It is very good that a start has been made with providing information to patients on their own treatment. However, much more information can be provided in MyChart, so that eventually it will become a full record to consult as a patient" (male, 61y)

3.7 Mismatch portal terminology with patient's health literacy and content to prior knowledge

Seventeen respondents (13%) indicated their inability to fully understand the terminology used in MyChart. Some deemed the use of terminology too medical. Others had difficulties with the abbreviations that were used in medical correspondence or with understanding the laboratory test values in the absence of normal range values as a reference.

"The terminology used in the results of blood tests is difficult to understand for a regular patient" (male, 70y)

Of these 17 respondents who had difficulties in understanding the terminology used in MyChart, five had a positive attitude towards MyChart, compared to 35 of total respondents with a positive overall attitude.

Insufficient prior knowledge of what MyChart entailed was a problem for 31 respondents (24%). They had higher expectations of MyChart based on their idea of what functionalities a patient portal should provide. For example, they expected their physicians' notes and historical medical information to be available in MyChart; as well as their medical images.

"My doctor always makes extensive notes in the system during a consult. Unfortunately I cannot see those" (male, 68y)

3.8 Coordination of care communication

Twenty-two respondents (17%) had explicit comments on communication with the medical staff, with 19 (15%) of them indicating a negative experience. Physicians' unresponsiveness to respondents' messages sent via MyChart was a clear source of dissatisfaction.

"Not every doctor looks at the record and it sometimes takes days or even longer before a message is answered or sometimes there is no answer at all" (female, 73y)

Nevertheless, this unresponsiveness did not seem to alter the perception of the usefulness of MyChart, since 12 (9%) of the 19 (15%) respondents still considered MyChart to be useful. Three respondents (2%) reported receiving timely replies to their questions and being satisfied with this.

"Contact with specialists is good" (female, 51y)

4. Discussion

4.1 Discussion

Over 10,600 older adult patients activated their account one year after the implementation of MyChart, 20% of all older adult patients with a hospital visit in that year. An important finding was that older adult patients with an activated account constituted 47% of all patients with a registered MyChart account. Compared to the overall Dutch population of people aged 50+ (39%) [15-16], the percentage of registered older users for MyChart seems to indicate that older adults are particularly interested in the patient portal. Other studies on patient portal registration by older adults are scarce, yet they do report that older adults currently form a large user group of patient portals. For example, a Dutch study on the usage of patient portals of 22 hospitals reports that patients aged 60-79 years account for 31-40% of users [17]. MyChart offered similar functionalities compared to the portals of these other hospitals in The Netherlands [17]. An American database study by Gordon et.al. reports that 77% of all patients aged 65-79 years of Kaiser Permanente Northern California health plan registered to their patient portal [18].

The results of the survey indicate that main contributors to patient portal use by older adults were the experienced usefulness of the portal in question as well as a positive attitude and belief towards patient portals in general. Main inhibitors were that patients had higher expectations of MyChart based on their idea of what functionalities a patient portal should provide, unresponsiveness of physicians to messages sent by patients via MyChart and experienced usability problems. Regarding the latter, consistent with previous literature this study acknowledges the importance of usability in relation to adoption of technology, especially for older adult target groups [19-21]. A main usability problem of MyChart concerned the two-factor-authentication method. Most respondents reported that it was difficult to use this method to login and suggested simpler means. An interesting finding is that about one third of patients with login problems still reported the portal to be useful to them. Lower registration rates of MyChart from 76 years and onwards might likewise relate to login usability problems experienced by this group. The rate of patients with an expired activation code (those who received an activation code, but did not activate their account in time) is higher in relation to the rate of activated accounts from 76 years and onwards. A possible explanation is that this population might find the activation and login process too difficult and thus do not attempt to register or discard their registration attempt, which leads to their code being expired.

A patient's health literacy level is an aspect that is considered to be a strong influential factor as to the patient's interest and ability to use a patient portal [22-23]. A literature review on portals and engagement confirms that patients with higher health literacy were more likely to adopt the patient portal, while those with low health (and computer) literacy would either lack the interest to use it or would use it ineffectively [23]. Another finding was that patients interacted better with the patient portal if medical abbreviations and terminology were replaced by lay language [23]. Most studies on health literacy and patient portal use do not examine specific age groups. The exceptions are a study by Taha et.al. that reported that numeracy (dis)abilities of older adults impact their (mis)understanding of medical content, for example of test results, and a study by Walker et. al. explaining that difficulties in older adults portal usage can be related to health literacy issues [24], [9]. Some older adult patients in our study mentioned that they experienced difficulties in understanding the medical terminology used in MyChart. Nevertheless, almost one-third of these patients had a positive perception of the usefulness of the portal. A possible explanation for this could be that respondents were mostly health (and computer) literate, since they were users of the portal. Patients with lower health literacy levels might not have used the portal and as such could not have responded to the survey.

The majority of respondents in our study were adamant in pointing out their discontent regarding the absence of replies of their physician to their questions asked via MyChart, yet most of them still valued the usefulness of the portal on the whole. In other words, although the portal did not facilitate or strengthen patient/provider communication, older adult patients still valued MyChart since they could review their medical data and check appointments. The previous review on patient portals and patient engagement reports that a provider's endorsement and continued engagement with the portal is of importance to encourage patients into adopting a portal [23]. Of the eight articles reviewed on this matter, none addressed the older adult patient population specifically. The principal findings of our study suggest that the experienced usefulness of the portal seems to provide enough reason for older adult patients to use the patient portal, despite the current lack of provider endorsement and engagement for the portal we investigated.

Trends are showing that patient portals and digital health tools are increasingly being used in continuing care and communication with patients with chronic diseases. For example, a growth of patient-reported outcome measures (PROMs) linked to EHRs is seen; to gather these PROMs it is preferred that patients report their health outcomes via a tethered portal [25]. Consequently, patient portals are transforming from a tool used mainly as a reference for patients to review their medical data and check appointments to an interactive tool in which patients need to actively register data on their medical health status in the portal. As this study shows, such interactive use of portals by older adults, a population in which the prevalence of chronic diseases is higher compared to younger adults, could yet be jeopardized by non-engagement of portal use at the provider side or by experienced usability problems of older adults. Future research directions should therefore concentrate on how to incorporate the benefits of patient portal functionalities as experienced by patients into the work processes of healthcare delivery teams. In addition, future research should focus on which designs, including presentation and visualization of medical data, and training efforts support older adults in their user interactions with portals. They can focus as well on training efforts to support healthcare providers in interaction with patients via patient portals.

4.2 Limitations

In this study, patient registration rates are based on quantitative reports of the EHR system. Yet, hospital staff had to provide an activation code before a patient could activate an account. At the introduction of the portal this process might have been imperfect, as the staff was still getting acquainted with how to operate the system, which might have negatively influenced the registration rates. Similar to previous studies, our study uses registration data to report on initial usage rates of the portal; frequency of use is not measured.

Using a monthly average of unique users of MyChart, we estimated the response rate of the survey at 15%. This might cause bias in our study regarding representativeness of our sample for the total older adult user population of MyChart [26]. Nevertheless, 80% of the survey respondents were older adult patients, compared to 47% of older adult patients registered at the portal.

We did not analyze the anonymous data and for this reason we might have missed relevant insights mentioned in this dataset. However, since this data did not include the age of the patient, we were not able to use this data set. We chose to use the data set in which we were certain the patients were aged 50 years and above, in order to give detailed insight on the experiences of these older adult patients' current use of a patient portal.

4.3 Conclusion

Activation rates of a patient portal amongst the older adult patient population were high; patients aged 56 to 75 years old form a large user population of this patient portal. The main factor that contributes to older adult patients' portal use, experienced by all age groups, is the opportunity to review medical record information and check the planning of upcoming appointments. Factors that inhibit portal use by older adult patients are difficulties in user interaction, annoyances regarding the difference in EHR data versus medical record data presented in the portal, and a lack a timely response from providers on patients' questions asked via the portal.

4.4 Implications

To increase adoption of patient portals by older adult patients, usability needs of these patients should be addressed in patient portal designs to further optimize user friendliness of portals for this apparently large user group. Ensuring privacy and security by means of the two-factor authentication standard is essential; yet to avoid non-adoption by older adults due to login issues they might experience, we encourage investigating new secure and user-friendly authentication options that may better suit an older population, for example by using biometrics during authentication (i.e. a photo of a patient's face, a record of a patient's voice or an image of a patient's fingerprint). As an addition to current standard functionalities and content of patient portals, additional content should preferably include medical history data and physicians' notes to meet the older adult patients' expectations. Effective patient/provider communication via a patient portal requires prompt responses of providers on questions asked by patients via the portal. Since there might be a lack of time for the physician to do so and the physician might prefer to speak to and/or see the patient in responding to questions, physicians and patients can discuss preferred communication means and response time regarding questions asked via the portal by patients during a first consult.

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5

Supplementary file A

Survey in English (for original Dutch version see text below the English version)
The questions were asked via the tool 'SurveyMonkey'

Introduction
We would like to hear your opinion regarding the service MyChart offers to you. Therefore we invite you to participate in this evaluation of MyChart. We shall collect and use your suggestions and/or compliments to improve MyChart.

It will take approximately 5 minutes to complete this survey. Your data will be confidential and we will not share this with third parties. Your identity is solely known at the MyChart team, in order to contact you in case we would like to gain more details on your given suggestions. It is an option as well to complete the survey anonymously, if you prefer so.

In case you have any questions or remarks on this evaluation, please contact us at support@amc-vumc.nl.

Thank you in advance for your help in improving MyChart.

Best,
MyChart support team

Suggestions
Please provide us with your suggestion(s). In case you do not have any suggestions, please click 'next' to provide your compliments.

My suggestions for MyChart are regarding:

- Registration / log-in
- Messages
- Appointments
- Test results
- Health summary
- Notifications
- MyChart app
- Other

My suggestion(s) for MyChart are:
....

Compliments
Please provide us with your compliments. In case you do not have any compliments, please click ‘next’ to provide us with your personal information.

My compliment(s) for MyChart are regarding:

- Registration / log-in
- Messages
- Appointments
- Test results
- Health summary
- Notifications
- MyChart app
- Other

My compliment(s) for MyChart are:
....

General information
It is optional to share your personal information with the MyChart team. If you provide us with your personal information, we can contact you regarding your suggestion(s) or compliment(s). Another option is to complete the survey anonymously.

* Do you want to share your personal information with the MyChart team (yes/no)

If yes:
We might contact you regarding your suggestion(s) and/or compliment(s). If you have provide use with the dates and times you are available, we will take that into account.

- Patientnumber
- In which hospital are you treated? (AMC/VUmc)
- Telephone number to reach you during the day (fixed number and/or mobile number)
- Available day / time

This is the end of the survey. Thank you for your participation in this evaluation of MyChart.

Best regards,

MyChart team

Survey in Dutch:

Introductie
Beste meneer/mevrouw,

Wij horen graag uw mening over de service die Mijn Dossier u biedt. We nodigen u daarom uit deel te nemen aan deze evaluatie van Mijn Dossier. Wij zullen uw suggesties en/of complimenten verzamelen en gebruiken om Mijn Dossier te verbeteren.

Het invullen van deze vragenlijst duurt ongeveer 5 minuten. Wij gaan vertrouwelijk om met uw gegevens en zullen deze niet delen met derden. Uw identiteit is enkel bekend bij het Mijn Dossier team, zodat wij eventueel contact met u kunnen opnemen om details over uw suggestie na te vragen. Als u liever anoniem suggesties doorgeeft, dan kan dit ook via de vragenlijst.

Mocht u vragen of opmerkingen hebben over de evaluatie, neem dan contact met ons op via support@amc-vumc.nl.

Alvast hartelijk dank voor uw hulp bij het verbeteren van Mijn Dossier.

Met vriendelijke groet,

Mijn Dossier-team

Suggesties
Vul uw suggestie(s) in. Heeft u geen suggesties? Klik dan op volgende om uw compliment(en) in te vullen.

Mijn suggestie(s) voor Mijn Dossier gaat over:

- Aanmelden/inloggen
- Berichten
- Afspraken
- Uitslagen
- Gezondheidssamenvatting
- Notificaties
- MyChart app
- Anders

Mijn suggestie(s) voor Mijn Dossier zijn:
....

Complimenten
Vul uw compliment(en) in. Heeft u geen compliment(en)? Klik dan op volgende om uw persoonlijke informatie in te vullen.

Mijn compliment(en) voor Mijn Dossier gaat over:

- Aanmelden/inloggen
- Berichten
- Afspraken
- Uitslagen
- Gezondheidssamenvatting
- Notificaties
- MyChart app
- Anders

Mijn compliment(en) voor Mijn Dossier zijn:
....

Algemene informatie
U kunt er voor kiezen uw persoonlijke informatie met het Mijn Dossier-team te delen. Dan kunnen wij contact met u opnemen in verband met uw suggestie(s) of compliment(en). Of u kiest ervoor de vragenlijst anoniem in te sturen.

* Wilt u uw persoonlijke gegevens met het Mijn Dossier-team delen? Ja/Nee

Bij optie ‘ja’:

In verband met uw suggestie(s) en/of compliment(en) kunnen wij contact met u opnemen. Wij zullen hierbij zo veel mogelijk rekening houden met de beschikbaarheid die u opgeeft.

- Patiëntnummer
- In welk ziekenhuis bent u onder behandeling (AMC/VUmc)
- Telefoonnummer waarop u overdag bereikbaar bent (Thuistelefoon en/of mobiele telefoonnummer)
- Geschikte dag / tijd waarop u bereikbaar bent (Dag/Tijd)

U heeft het einde van de vragenlijst bereikt. Wij danken u hartelijk voor uw deelname aan deze evaluatie van Mijn Dossier.

Met vriendelijke groet,

Mijn Dossier-team

Supplementary file B

Registration rates MyChart of patient aged 56 years and above (25th of Oct 2015 - 25th of Oct 2016)

	Age (years)					
MyChart status type	56-65	66-75	76-85	86-95	95-105	Total
Active	5,015	4,332	1,172	158	2	10,679
Expired	3,541	2,609	1,029	160	12	7,351
Declined	2,298	2,515	1,450	393	15	6,671

Supplementary file C

Number of times of reported patient experiences per theme, per age cluster

Age cluster	Usefulness Pos.	Usefulness Neg.	Usability Pos.	Usability Neg.	Attitude & beliefs Pos.	Attitude & beliefs Neg.	Mis-match health literacy	Mis-match prior knowledge	Coordination of care communication no problem	Coordination of care communication problem
50-64 (n=64)	27	11	8	17	17	9	6	21	2	9
65-79 (n=62)	24	8	11	10	16	6	11	10	1	9
80+ (n=5)	2	0	0	2	2	0	0	0	0	1
Total (n=131)	53	19	19	29	35	15	17	31	3	19

Supplementary file D

Quotes per theme - original quote in Dutch and English translation of quote

Theme	Original quote in Dutch	English translation of quote
Usefulness (positive)	"Prettig om thuis of elders ernaar te kijken, tot nu toe een veilig gevoel." Vrouw, 52 jo "Ben blij met de afspraken. Ik hoef ze niet meer te onthouden." Vrouw, 76 jo	"Nice to have a look at home or elsewhere, safe feeling up till now." Female, 52 yo "Am happy with the appointments. I don't need to remember them anymore." Female, 76 yo
Usefulness (negative)	"Uitslagen niet duidelijk en onvolledig." Man, 66 jo "Het duurt veel te lang voordat de uitslagen in Mijn Dossier terecht komen." Man, 61 jo	"Results are unclear and incomplete." Male, 66 yo "It takes much too long before the results are shown in MyChart" Male, 61 yo
Usability (positive)	"Gemakkelijk bruikbaar, helder." Man, 70 jo "Uitstekend, gebruiksvriendelijk en zelfs de service desk reageert snel." Man, 67 jo	"Easy to use, clear" Male, 70 yo "Perfect, user friendly and even the service desk replies fast". Male, 67 yo
Usability (negative)	"Is het mogelijk om alle LAB-uitslagen in een overzicht te tonen, dan hoef je niet steeds alle losse resultaten open te klikken." Man, 55 jo "Ik kan alle uitslagen van het bloedonderzoek niet in een keer uitprinten." Man, 72 jo "Waarom niet inloggen met digid code? nu is het nog teveel onthouden of te typen en nog eens melding via telefoon allemaal zo dubbel dubbel." Vrouw, 55 jo	"Is it possible to put all lab results in one overview, then you would not need to click on each single result." Man, 55 yo .... "I cannot print all results from the blood tests at once." Man, 72 yo "Why is login via DigiD not enabled? No it is too much to remember or type and then there is also an extra notification per telephone all double double." Female, 55 yo
Attitude & beliefs (positive)	"Het is heel goed dat er een begin is gemaakt met het doorgeven van informatie aan de patiënt over de eigen behandeling. Maar er kan nog veel meer informatie in Mijn Dossier, zodat het uiteindelijk een volwaardig te raadplegen patiëntendossier wordt." Man, 61 jo	"It is very good that a start has been made with providing information to a patient on their own treatment. However, much more information can be provided in MyChart, so that eventually it will become a full patient record to consult as a patient." Male, 61 yo

Theme	Original quote in Dutch	English translation of quote
Attitude & beliefs (negative)	"Dacht eerst dat dit een vooruitgang was. Echter, het maakt 't al met al alleen maar ingewikkelder omdat er toch geen reactie komt op mijn vragen." Vrouw, 72 jo "Waardeloze materie tot op heden." Man, 66 jo "Dossiers zijn niet goed bij gehouden. Dit heeft totaal geen zin !!!!!" Man, 73 jo	"Thought this would be an improvement. However, it only makes it more complicated, because there is no response to my messages." Female, 72 yo "It is worth nothing up till now." Male, 66 yo "Records are not well maintained. This has absolutely no use!!!!!" male, 73 yo
Mismatch with health literacy	"De gebruikte terminologie in de uitslagen van het bloedonderzoek is voor de doorsnee patiënt moeilijk te begrijpen." Man, 70 jo "Er worden erg veel afkortingen gebruikt waar totaal geen wijs uit te worden is." Man, 63 jo	"The terminology used in the results of blood tests is difficult to understand for a regular patient." Male, 70 yo … "Many abbreviations are used, which do not make any sense." Male, 63 yo
Mismatch with prior knowledge on portals	"Bij een consult maakt de arts altijd uitgebreide aantekeningen in het systeem. Ik kan daar helaas niet in meekijken." Man, 68 jo "Stop ook de röntgenfoto's, MRI, CT scan ook in mijn dossier." Man 58 jo	"My doctor always make extensive notes in the system during a consult. Unfortunately I cannot see those." Male, 68 yo "Also place x-rays, MRI and CT scans in MyChart." Male, 58 yo
Coordination of care communication (no problem)	"Werkt prima! Snelle actie van arts en duidelijke communicatie!" Vrouw, 50 jo "Contact met specialisten is goed." Vrouw, 51 jo	"Works fine! Quick action of doctor and clear communication!" Female, 50 yo "Contact with specialists is good." Female, 51 yo
Coordination of care communication (problem)	"Niet elke arts kijkt in dossier en het duurt soms dagen zo niet langer voordat er antwoord komt of soms helemaal niet." Vrouw, 73 jo	"Not every doctor looks at the record and it sometimes takes days or even longer before a message is answered or sometimes there is no answer at all." Female, 73 yo

Chapter 6

How do patients value and prioritize patient portal functionalities and usage factors? A conjoint analysis study with chronically ill patients

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BMC Medical Informatics and Decision Making. 2018.18:108
doi: 10.1186/s12911-018-0708-5

Abstract

Background: Patient portal use can be a stimulant for patient engagement. Yet, the heterogeneous landscape of tethered patient portals, is a major barrier to further portal development and implementation. A variety in portal access means, functionalities, usability and usefulness exists; without having accurate sight on patient perspectives. We aimed to get insights on possible coherence between patients' preferred usage factors of portals and patients' prioritization of functionalities, within the complexity of their disease management across different healthcare organizations.

Methods: A conjoint analysis questionnaire was sent to patient panels of two large patient associations in The Netherlands, centered on heart and vascular diseases and lung diseases.

Results: Of 1294 patient respondents, 81% were 55+ years old and 49% were 65+ years old. Overall respondents significantly prioritized user-friendly access to a portal, via a laptop or desktop. Patients aged <65 were less negative about using tablets to access a portal compared to the total respondents. Patients had no preference for a digital interoperable export functionality; most respondents preferred to create printable overviews. Built-in publication delay of two weeks for medical information was not preferred. Our results show no significant preference of patients between 'instant publication' versus 'publication after new information has been explained by a healthcare provider'. Overall respondents and experienced portal users had a strong preference to be able to communicate with their provider via a portal and to use a portal providing information from multiple providers. Lung patients preferred information from one provider and did not require the possibility to ask online questions.

Conclusions: Heart and vascular patients as well as lung patients prefer similar technical patient portal aspects, independent of their medical condition. Yet, in current portals consistency on this matter is lacking. It is highly assumable that offering a more consistent user-experience across the variety of patient portals could help increase patient portal acceptance, ultimately helping to stimulate patient engagement via patient portal use. We further affirm the need for customization on medical information publication and sharing information of various providers through patient portals, where information provision can be adapted to preferences of patients related to their medical condition(s).

Keywords: conjoint analysis, patient portal, elderly, patient preferences, technology acceptance

1. Background

Patients nowadays live in an information driven world, where they can get support in self-management of their health and conditions by accessing their medical record and communicating with healthcare providers via patient portals [1]. Especially older patients, chronically ill patients and patients with co-morbidities can benefit from patient portal use [1-4]. Patients can be assisted in accomplishing health-related and administrative tasks by having access to personal health information, such as laboratory test results and appointment information, as well as digital opportunities for patient-provider communication. The foremost type of a patient portal is the tethered patient portal. A tethered patient portal is an application build on an Electronic Health Record (EHR) infrastructure of a specific healthcare organization [5]. This organization manages the portal and decides which information can be accessed by the patient. In this aspect, the tethered patient portal differs from a personal health record, in which the patient can collect health data and he/she decides whether to share that data with providers or family members. Most tethered patient portals hold medical information that is derived from the EHR, such as a discharge summary, a medication and allergy list and laboratory results [4, 6-8]. Portals can include more interactive features and allow patients to send secure messages to clinical staff, schedule appointments or request prescription refills [4].

Driven by innovation goals for eHealth set by the Dutch government, the tethered patient portal is now increasingly being implemented in The Netherlands [9]. Yet, due to a lack of a clear strategy and vision on portal functionalities, many different portals exist in the Dutch market; a market-scan identified 34 portals in 2015, each varying in provided functionalities and interface [9]. This heterogeneous landscape of patient portal products is a main barrier in development and implementation activities [9-10]. Patient engagement through patient portal use is jeopardized, due to variable access and usability, creating user-friendliness problems for patients. Further, patients may have doubts regarding a portal's usefulness, since there is no standard set of portal functionalities [10]. This heterogeneity further results in interoperability problems, complicating the exchange of information between portals of different healthcare organizations. Patient engagement and interoperability problems may pose particular issues to older chronically ill patients and patients with (multiple) diseases. These patients often receive care among a variety of healthcare centers and obtain medical information from these centers. In addition, these are often older patients, experiencing motivational barriers in using eHealth [2, 6]. In managing their care with the scattered information provided by different healthcare organizations, such barriers may prevent them to use patient portals.

A solution to these problems is to design more uniform portals, meeting the disease management needs of patients defined by their characteristics and associated preferences and capacities [10]. Previous research provides insights on patient preferences in relation to patient portal functionalities and use, such as the ability to view test results via a portal [4, 11], and recognized the (feasibility) patient portal usage by chronically ill patients, such as cardiovascular or lung disease patients [3-4, 12-14]. There is nevertheless little evidence of how patient preferences on specific portal functionalities and usage factors are correlated to each other and how this is valued by patients within the context of the full portal product. Insights are further needed on how sharing of medical information through a portal, possible coherence of portal functionalities, and usage factors fit the complexity of disease management across different healthcare organizations. Our research project aimed to advance the understanding on this matter by using a conjoint analysis approach to examine how patients of the 'Harteraad' and the 'Longfonds' patient panels, two recognized Dutch patient associations respectively centered on cardiovascular diseases and lung diseases, value and prioritize specific portal functionalities and usage factors.

2. Methods

2.1 Study design: conjoint analysis questionnaire

This study used a conjoint analysis questionnaire. 'Conjoint analysis' is a survey-based statistical technique mainly used in market research that helps determine how people value different attributes of a product [15-16]. The objective of conjoint analysis is to determine what combination of a limited number of attributes is most influential on a respondent's choice or decision making. We used a discrete choice experiment conjoint analysis in our study, since is the most common type of conjoint analysis used in health economics, outcomes research, and health services research [15]. This type of conjoint analysis consists of two steps: 1) a choice experiment with respondents and 2) a statistical analysis. In the choice experiment, the attributes are used to describe a certain product and can consist of one or more levels. Different fictive profiles, possible variations of the product, can be created by combining various attributes and levels, which are then shown to a respondent to determine which combination he/she prefers. For instance, a product can be a tablet that is described by various attributes and levels of those attributes: price (levels $100, $200), screen size (levels 8.9, 10.1) and battery length (levels 14 hours, 9 hours). Fictive profiles can be presented to a respondent, such as:

A. the tablet costs $100, has screen size 10.1 and a battery length of 9 hours;
B. the tablet costs $100, has screen size 8.9 and a battery length of 14 hours;
C. the tablet costs $200, has screen size 8.9 and a battery length of 14 hours.

The respondent can choose option A, B or C in the trade-off process whether he/she would buy that tablet. This process is repeated for various fictional profiles. In the second step of the conjoint analysis, the statistical analysis of all respondents' choices for all presented profiles, the relative importance of different attributes and the trade-offs between these attributes are statistically determined [15-17]. In other questionnaire based methods to measure respondents' preferences, such as rating or interest questions, it is often not measurable to accurately value how much a certain attribute would influence a respondents' choice in preferring one attribute above the other [18-19]. However, choice-based conjoint analysis does determine which individual attributes and levels are favored over others. Conjoint analysis is gaining popularity in the health care setting [17], where it recently has been used to assess patients' preferences regarding pharmacological treatment for bipolar depression [20] and to examine how older adults rate and identify the importance of healthcare seeking and utilization aspects in the United States [21].

2.2 Study protocol

We conducted a comprehensive literature review (Supplementary file A and B) in which 42 factors were initially found influencing the use of patient portals by patients. Based on this review, four experts in healthcare discussed recurrent as well as meaningful factors that could be used as an attribute and defined the attributes and levels to be used in the conjoint analysis. Seven attributes were constructed for our conjoint analysis, shown in Table 1, each consisting of three assigned levels. The fictional profiles of patient portals presented in our questionnaire were generated using the orthogonal main effects plan: instead of presenting all possible combinations ($\text{levels}^{\text{attributes}} = 3^7 = 2{,}187$), the smallest manageable combination of profiles to test with respondents are presented - knowing that the statistical analysis will be able to balance how often a specific level is presented to a respondent. By means of 18 profiles our respondents were asked to choose their preferences for patient portals. Additional questions were asked to gain sight on respondents' demographic characteristics, health status and experience with patient portal use. A potential bias of the questionnaire could have been that respondents would not be able to envision a patient portal by the items or wordings chosen in the questionnaire. For this reason the questionnaire was validated by means of cognitive interviews with six people representative for the target group. During these interviews, eight unique problems were identified. All issues were addressed by changing several formulations and the visual design of the questionnaire. The questionnaire is shown in Supplementary file C.

2.3 Study population and data analysis

We recruited respondents by sending the questionnaire to patient panels of two Dutch patient associations: the Heart Council (HVG) and the Lung Fund (LF). Data was collected in the months April and May 2017 by means of the tool *spidox.net*. Members of the panels consisted of chronically ill patients with a cardiovascular disease and patients with a lung disease.

Table 1: *Attributes and levels used in conjoint analysis*

Attribute	Level
Accessibility	1. Portal can be accessed via a computer (laptop and/or desktop)
	2. Portal can be accessed via a tablet (for example iPad)
	3. Portal can be accessed via a smartphone (for example iPhone)
Login	1. Username and password (least secure)
	2. DigiD with SMS verification (secure)
	3. Username, password and SMS verification (secure)
Interoperability	1. No export of data
	2. Export of data to non-interoperable format (e.g. PDF)
	3. Export of data to interoperable format (e.g. Continuous Care Document)
Availability of information	1. Direct publication of information
	2. Information delayed until discussed with provider
	3. Available after 2 weeks independent if information has been discussed with provider
Content	1. Reports and basic information (e.g. medication overviews and allergies)
	2. Reports and basic information and professional summary
	3. Complete uncensored medical file
Number of providers	1. Contains information from one provider (e.g. hospital or general practitioner)
	2. Contains information from multiple providers (e.g. hospitals and general practitioner)
Patient-provider communication	1. No possibility to ask online questions
	2. Possibility to ask questions about medical data or previous visits in the portal
	3. Online in-patient consult

Of the total chronically ill patient population in The Netherlands, 16% are cardiovascular patients and 11% are patients with a lung disease [22-24]. Members of the HVG and LF patient panels were therefore representative for the Dutch chronically ill population and all respondents were eligible for data analysis. Respondents were only excluded if 1) the questionnaire was not completed; 2) response time was under four minutes; 3) response time was above 60 minutes and 4) data entries were possible spam since they had the same IP address. To calculate the minimum required sample size of this study, we used the recommendations of Orme regarding sample size determination on choice experiment conjoint analysis [25]. Orme recommends a formula for this sample size determination: $\frac{n * t * a}{c} \leq 500$.

In this formula, n is the number of minimum respondents needed, t is the number of profiles presented to the respondents (18 in our study), a is the number of options to choose from per profile (3 in our study) and c is the highest level per attribute (3 in our study). The number 500 is the threshold for representing the main-effect level of interest in the statistical analysis, yet Orme explains this number is intended to be a minimum threshold. We chose to increase that threshold, in order to be certain of sufficient representations per main-effect level. We therefore used the following formula: $\frac{n * 18 * 3}{3} \leq 2000$. This resulted in a minimum required sample size of 111 respondents. Standard to conjoint analysis, a conditional logistic regression was used to analyze the data. The data analysis was performed using RStudio version 1.1.383, using packages support.CEs(0.4-1), survival (2.41-3), lmtest(0.9-35), plyr(1.8.4).

3. Results

The questionnaire was sent to 3900 panel members; with a response rate of 34% this resulted in a total of 1307 respondents. After exclusion, 1294 respondents were included in the analysis. Table 2 shows the respondent characteristics per patient association. Most respondents are from the HVG (n=929) and 81% of all respondents are 55 years old or above. More than half of the respondents proclaimed to currently have a good to excellent health status.

3.1 Generic portal preferences

Table 3 and 4 show the overall results of the conjoint analysis, including all attributes and differences between the levels of the attributes. The most prominent and significant result is that respondents prefer to access a patient portal via a laptop or desktop above using a smartphone or tablet. Second, they prioritized to ask questions about medical data or about earlier visits to the provider via the portal. Thirdly, they dislike a delay of two weeks of their information shown in a portal as compared to direct publication of information, yet this is not a significant difference.

3.2 Difference in preferences of subgroups

3.2.1 Medical condition and usage factors

Twenty-eight percent of the respondents were lung patients. Looking at the differences with the overall respondents and these lung patients, shown in Table 5, the overall respondents prefer a portal to contain information about multiple providers (e.g. hospitals and general practitioner), whereas the lung patients showed a small disfavor of this. A similar result appeared regarding which content to display in a portal. Overall respondents prefer reports, basic information and a professional summary, whereas lung patients prefer just reports and basic information, such as medication overviews.

3.2.2 Age and usage factors

Of the overall respondents, 49% was aged 65+ and 46% was aged between 45 and 64 years old. Results of the subgroup analysis of patients aged <65 are shown in Table 5. As the table shows, <65 respondents prefer to access a portal via a laptop or desktop. They are less negative about using mobile devices compared to the overall respondent group, especially when it comes to using tablets. Patients aged <65 further prefer secure login methods and do not necessarily want to have options for patient-provider communication via a portal.

3.2.3 Patient portal experience and usage factors

Thirty percent of the respondents had used a patient portal in their daily life and were thus experienced portal users. Table 5 shows that the experienced portal users are more positive towards using a smartphone or tablet to access a patient portal compared to the overall respondents. This accounts as well for the login means, experienced users are more positive towards using a more secure login means, such as a username, password and a verification code sent to a mobile phone.

3.2.4 Gender and usage factors

Of the overall respondents, 58% were male. In Table 5 it is reported that male respondents, similar to experienced portal users, are more positive regarding the use of mobile devices to access a patient portal compared to the overall respondents. Male respondents further prefer reports and basic information presented in a portal above a professional summary or a complete uncensored medical file. Male respondents likewise prefer to have information in a portal from one healthcare organization and do not necessarily want to have options for patient provider communication via a portal.

__Table 2:__ Characteristics of respondents (n=1.294)

	Overall N=1.294	**HVG N=929**	**LF N= 365**
Age (years)			
18-34	20 (1%)	6 (1%)	14 (4%)
35-44	49 (4%)	29 (3%)	20 (6%)
45-54	177 (14%)	121 (13%)	56 (15%)
55-64	416 (32%)	281 (30%)	135 (37%)
65-74	500 (39%)	388 (42%)	112 (31%)
>75	132 (10%)	104 (11%)	28 (7%)
Gender			
Female (n) / Male (n)	549 (42%) / 745 (58%)	323 (35%) / 606 (65%)	226 (62%) / 139 (38%)
Educational level			
Low (primary/secondary)	276 (22%)	181 (20%)	69 (28%)
Intermediate (low vocational)	391 (30%)	283 (30%)	108 (29%)
High (high vocational/uni)	604 (47%)	453 (49%)	151 (41%)
Other	19 (1%)	12 (1%)	7 (2%)
Patient portal experience			
Yes / No	394 (30%) / 900 (70%)	272 (29%) / 657 (71%)	122 (33%) / 243 (67%)
Frequency of healthcare visits			
< 1 time per year	160 (12%)	132 (14%)	28 (8%)
1-4 times per year	517 (40%)	405 (44%)	112 (31%)
5-11 times per year	419 (32%)	281 (30%)	138 (38%)
1 time per month	75 (6%)	48 (5%)	27 (7%)
2-4 times per month	85 (7%)	49 (5%)	36 (10%)
> 1 time per week	38 (3%)	14 (2%)	24 (6%)
Health status			
Excellent	18 (1%)	17 (2%)	1 (0%)*
Very good	117 (9%)	106 (11%)	11 (3%)
Good	619 (48%)	517 (56%)	102 (28%)
Poor	441 (34%)	263 (28%)	178 (49%)
Bad	99 (8%)	26 (3%)	73 (20%)

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Table 3: *General conjoint analysis of all respondents | Levels 2 and 3 compared to level 1*

Attribute	**Level**	**LogLike Diff.**	**P-Value**
Accessibility	1. Portal can be accessed via a computer (laptop and/or desktop)	*	
	2. Portal can be accessed via a tablet (for example iPad)	-0.922	< 0.001
	3. Portal can be accessed via a smartphone (for example iPhone)	-1.086	< 0.001
Login	1. Username and password	*	
	2. DigiD with SMS verification	0.004	0.900
	3. Username, password and SMS verification	0.018	0.540
Interoperability	1. No export of data	*	
	2. Export of data to non-interoperable format (e.g. PDF)	0.259	< 0.001
	3. Export of data to interoperable format (e.g. Continuous Care Document)	0.165	< 0.001
Availability of information	1. Direct publication of info	*	
	2. Information delayed until discussed with provider	-0.024	0.460
	3. Available after 2 weeks independent if discussed with provider	-0.184	<0.001
Content	1. Reports and basic information (e.g. medication overviews)	*	
	2. Reports and basic information and professional summary	0.312	< 0.001
	3. Complete uncensored medical file	0.303	< 0.001
Number of providers	1. Contains information about one provider (e.g. hospital or general practitioner)	*	
	2. Contains information about multiple providers (e.g. hospitals and general practitioner)	0.290	< 0.001
Patient-provider communication	1. No possibility to ask online questions	*	
	2. Possibility to ask questions about medical data in the portal or about earlier visits	0.684	< 0.001
	3. Online in-patient consult	0.539	< 0.001

** The asterisk indicates the base value.*

Table 4: *General conjoint analysis of all respondents | Level 3 compared to level 2*

Attribute	Level	LogLike Diff.	P-Value
Accessibility	2. Portal can be accessed via a tablet (for example iPad)	*	
	3. Portal can be accessed via a smartphone (for example iPhone)	20.32	< 0.001
Login	2. DigiD with SMS verification	*	
	3. Username, password and SMS verification	0.14	0.597
Interoperability	2. Export of data to non-interoperable format (e.g. PDF)	*	
	3. Export of data to interoperable format (e.g. Continuous Care Document)	5.48	0.001
Availability of information	2. Information delayed until discussed with provider	*	
	3. Available after 2 weeks independent if discussed with provider	9.82	< 0.001
Content	2. Reports and basic information and professional summary	*	
	3. Complete uncensored medical file	0.05	0.749
Patient-provider communication	2. Possibility to ask questions about medical data in the portal or about earlier visits	*	
	3. Online in-patient consult	13.93	< 0.001

** The asterisk indicates the base value.*

Table 5: Conjoint analysis of sub groups | Levels 2 and 3 compared to level 1

Attribute	Level	LogLike Diff.				
		Total	Patient group	Age	Portal use experience	Gender
Accessibility	1. Portal can be accessed via a computer (laptop and/or desktop)	*				
	2. Portal can be accessed via a tablet (for example iPad)	-0.922	0.146	-0.301	0.376	-0.360
	3. Portal can be accessed via a smartphone (for example iPhone)	-1.086	0.228	-0.494	0.441	-0.549
Login	1. Username and password	*				
	2. DigiD with SMS verification	0.004	-0.064	-0.200	0.358	0.127
	3. Username, password and SMS verification	0.018	0.058	-0.124	0.236	0.038
Interoperability	1. No export of data	*				
	2. Export of data to non-interoperable format (e.g. PDF)	0.259	0.050	-0.217	0.297	-0.101
	3. Export of data to interoperable format (e.g. Continuous Care Document)	0.165	-0.008	0.169	0.335	0.140
Content	1. Reports and basic information (e.g. medication overviews)	*				
	2. Reports and basic information and professional summary	0.312	-0.031	-0.219	0.347	-0.099
	3. Complete uncensored medical file	0.303	0.069	-0.236	0.362	-0.045
Number of providers	1. Contains information about one provider (e.g. hospital or general practitioner)	*				
	2. Contains information about multiple providers (e.g. hospitals and general practitioner)	0.290	-0.018	-0.120	0.304	-0.113
Patient-provider communication	1. No possibility to ask online questions	*				
	2. Possibility to ask questions about medical data in the portal or about earlier visits	0.684	-0.003	-0.212	0.399	-0.158
	3. Online in-patient consult	0.539	0.005	-0.150	0.265	-0.039

* The asterisk indicates the base value.

4. Discussion

This study set out with the aim to value and prioritize patient portal usage factors reported by over 1200 cardiovascular patients and lung patients. It is interesting to note that the majority of our respondents (81%) were above 55 years old and 49% of our respondents were even aged 65 years and above. The results of this study show that our respondents prioritize user-friendly access to a portal, via a laptop or desktop, as well as being able to communicate with their provider via the portal to ask questions about their medical data or previous visits over other functionalities. Cardiovascular patients (72%) and lung patients (28%) differed in portal preferences regarding the medical information shown in a portal; lung patients prefer reports and basic information, such as medication overviews, and do not seem to require the option to contact a provider or to have a multiple provider overview.

4.1 Access and login means in relation to older patients

The results of this study indicate that aging characteristics influence patient portal preferences, especially regarding technical aspects, such as access and login means. Our respondents state a preference to access a patient portal using a laptop or desktop, rather than using a tablet or a smartphone. Nevertheless, respondents aged younger than 65 years old, the majority being between 45 and 64 years old, were less negative about using a tablet as an access means than the overall respondent group. A possible explanation for older respondents' access preference may be that the older adult and elderly target group had experience with inadequate user-interface designs of portals on small screens. Portals - both web-based and native app versions - have complex navigation structures. However, to suit the cognitive capacities of older patients and prevent usability problems, navigation complexities should be minimized [26-27]. Furthermore, irrelevant information and cluttered presentation of (medical) information on smaller screens of tablets and smartphones inhibit older patients in reading and interpreting this information [28-29]. A recent study has showed that older people increasingly do show interest in using tablets, yet they have concerns about the process of learning how to use such devices. They further worry about unclear instructions and support during that learning process [30]. Patient portal developers should take advantage of the older user interest in these devices. Albeit, in further development of mobile versions of patient portals, current knowledge on aging barriers influencing the experienced usability of mobile user-interface design [27] and portal functionalities should be taken into account.

Our analysis surprisingly showed that especially the elderly respondents preferred using a solely username and password as a login means to a patient portal. They preferred this above the more secure methods, called two factor authentication (2FA). Privacy and security are important aspects discussed in literature on patient preferences on patient portals [31-34] and the 2FA method is often mandated by governments to ensure privacy and security. The 2FA method is yet complex to use and often leads to usability problems experienced by older patients [35-36]. We encourage software engineers in the field of privacy and security together with usability experts to rethink login means to patient portals in order to create a secure as well as a user-friendly login means. They can explore the opportunities for biometric authentication for example. In doing so, it is important to take the challenges of biometric authentication into account in relation to physical effects of older adults' medical complications, such as cataracts and stroke [36]. An improved login means addressing both privacy and security as well as experienced ease of use by older patients, will likely strengthen their engagement in using patient portals.

4.2 Publication of medical information

Respondents in our study were negative about a built-in publication delay of two weeks of their medical information. Nevertheless, our results show no significant difference in preferences between the options of 'instant publication' versus 'publication after new information has been explained by a healthcare provider'. Previous studies evaluating the publication of medical information in patient portals show inconsistent results on whether publication empowers patients or if publication might harm patients when information is shown without mediating physician input [37-38]. This is especially discussed within the perspective of publication of test results [37-38]. Our study provides a strong indication that chronically ill patients do not prefer a delay in publication of their medical information in a patient portal. We therefore advise against such a delay feature in the implementation of portals of which chronically ill patients are the main user group. We further want to affirm the need for customization of medical information publication, where settings can be changed for each individual patient based on his/her preferences in obtaining medical information with or without mediating input from a physician.

The customizability of medical content in a portal is further emphasized in relation to the terminology used to publish this content in a portal. Most respondents prefer a summary of the medical information in laymen's terms, presenting less but more understandable information, above a complete uncensored medical file. Our study therefore supports the idea that patients experience difficulties in understanding the medical information and jargon published in patient portals [31-33, 39-41]. In developing patient portals, we advise to consider customized features in which the provider can manually edit the content before publication. Another possible solution, better suited to the high workload of providers, is to automatically transform medicals terminology standards into laymen terms [42].

4.3 Patient-provider communication

In our study, the option for using features to contact the healthcare provider is seen as a main priority by the respondents, which is in line with other studies claiming that such a functionality is an important facilitator for patient engagement [41, 43]. Patient-provider communication via a patient portal can yet be ineffective due to the absence or late replies from their physician [44]. This combination of findings suggest the need for further research on what patients define as a prompt response for various types of questions and how providers' workflows can allow for such prompt responses on questions asked by patients via a portal.

4.4 Patient portals and care across healthcare centers

An interesting finding of our study is that respondents showed a strong preference to use a portal with medical information from multiple providers, possibly working in various healthcare organizations. Especially experienced portal users preferred this, whereas male respondents were more in favor of obtaining medical information from one provider. Our results further show no preference for a digital interoperable export functionality and most respondents are interested in the option to create printable overviews such as in Word or PDF. Negative experiences with the cumbersome tasks of distributing health information across different centers, without any benefit of portals supporting this process, may be a possible explanation for this finding. This finding further shows that for chronically ill patients to gain more benefits from portals, the portal landscape needs to transform from 'silos' to an integrated 'ecosystem' of actors. In addition, it can be assumed that chronically ill patients currently manage their data across different healthcare centers by printing the data whereas they do want to have a holistic overview of their medical data across these centers in the future. Yet, they do not like to spend much effort in manually exporting digital information from one portal to another. In transforming portal silos to an integrated ecosystem, it is thus important to create systems that minimize the tasks of patients in creating a complete multicenter overview of their health data. A first step to achieve this is to technically facilitate the sharing of medical record information across centers by adopting interoperability standards, such as Fast Healthcare Interoperability Resources (FHIR) in the development of (future) digital environments for patients to access, manage and share their medical data [45].

4.5 Limitations

This study has several limitations. First, respondents were part of a patient panel; we can therefore assume they have a high interest in aspects related to their health and disease management. Consequently, the findings of this study cannot be extrapolated to patients with a (very) low health status and/or interest in their health. These patients might have different preferences regarding patient portal design and use. In spite of this limitation, since our study is based on a large sample of respondents from two different chronically ill patient groups, this study certainly adds to our understanding of possible coherence of portal functionalities and usage factors in relation to disease management from the perspective of chronically ill patients. Furthermore, despite of the interest of the patient panels' members in health and disease management, the majority of the respondents had no experience with patient portal use and were older people. Aspects that make them representatives of the Dutch chronically ill patient group. Second, it is possible that some words or formulations in the questionnaire were misunderstood by respondents or that respondents who had no prior experience in using a patient portal could not envision a portal based on the wording of the questionnaire. This problem was limited by validating the questionnaire before using it in practice. Third, the underlying model for a choice-based conjoint experiment is nonlinear due to the modeling using a logit function. The variance-covariance matrix which is used to generate the design is dependent on betas. Since we had no prior knowledge about these betas we chose to assume linearity just as rating-based methods and developed the choice sets using heuristics. In order to gain a more optimal design a pre-test or assuming a prior distribution would have improved the outcomes and statistical efficiency.

5. Conclusions

The current study found that preferred technical aspects by our older patient respondents, such as patient portal access via a laptop, secure login means and being able to export data via Word of PDF, are similar and independent of a specific medical condition. Yet, lung patients and heart and vascular patients do vary when it comes to preferences on usage factors related to publication of medical content and digital patient-provider communication means via a portal. It is therefore highly assumable that offering solid and user-friendly access as well as a consistent technical basis of functionalities across the variety of patient portals, could help increase patient portal acceptance by older patients; ultimately helping to stimulate patient engagement via patient portal use. By researching underlying reasons to preferences on patient portal functionalities and usage factors, future studies can gain more understanding of how to adjust patient portals to the needs of patients with specific or multiple medical conditions and their distinguishing patient journeys.

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Supplementary file A - Search strategy

To perform the literature review, two independent searches were conducted in two databases: Ovid and the Cochrane library. A predefined search strategy was used in both databases between November 15th and the 6th of December 2016. The search in the Cochrane library served as an orienting search to find high level evidence such as systematic reviews.

To build the search query used in the second search, keywords were extracted from the references and supplemented by performing an explorative search on Google (Scholar), PubMed and elicited from key papers. The second search was performed in Ovid and search results from this search were used to in- and exclude studies. Table 1 provides the used search queries for the first and second search.

Table 1. *Search queries of first and second search*

First search **Database:** Cochrane **Goal:** orienting, form correct search terms for second search	((online portal) **or** (patient portal) **or** (personal health record))
Second search **Database:** Ovid **Goal:** study in/ exclusion and data analysis with included studies	(((online portal **or** personal health records **or** ((portal **or** portals) adj5 (patient **or** patients)) **or** (health adj3 record adj3 (patient **or** patients))) and ((engagement adj5 (patient **or** patients)) **or** implementation **or** facilitator* **or** barrier* **or** (acceptance adj5 (patient **or** patients)) **or** adoption **or** (perception* adj5 (patient **or** patients)) **or** (satisfaction adj5 (patient **or** patients)) **or** ((experience **or** experiences) adj5 (patient **or** patients)) **or** (perspective* adj5 (patient **or** patients)) **or** willingness **or** need **or** needs **or** demand **or** demands **or** tethered **or** implication **or** implications **or** (electronic adj5 (patient **or** patients)))) not (portal vein **or** hepatic vein **or** portal hypertension))

Inclusion criteria were: 1) availability of English full text version; 2) article studied a patient portal; 3) study objectives were to describe possible (subjective) factors which could influence patients' usage. Exclusion criteria were: 1) study reported quantitative outcomes (e.g. number of telephone calls, clinical outcome, and number of online messages) 2) study reported solely on overall satisfaction of patients' portal usage. Articles were first screened on title and abstract. Subsequently, articles were screened on full text. Results from included studies were discussed with two other researchers to check for validity and completeness. Screenings were performed by two independent reviewers to increase screening reliability. Consensus was reached by discussing the results. Quality assessment of articles was performed by constructing a predefined appraisal list, including publication year, country, study design, key participant characteristics, setting, measurements, portal type, main functionalities of portal defined by article, possible influencing factors on use, and severe limitations.

Supplementary file B - Overview included studies

The Ovid search resulted in 1.229 resulted in unique articles. After title and abstract screening 115 articles remained for full-text screening. After this second screening, 38 articles met all inclusion criteria and were included for analysis. Most common reasons for exclusion during full text screening were; articles did not discuss any barriers/facilitators (n=10), only objectives measures were presented (n=8) or the portal was managed by a third party (e.g. patient or insurer) (n=18). The flow diagram displayed in Figure 1 shows a graphic overview of the selection process. Table 1 and 2 provide the study characteristics and reported portal functionalities and influencing factors of the included studies.

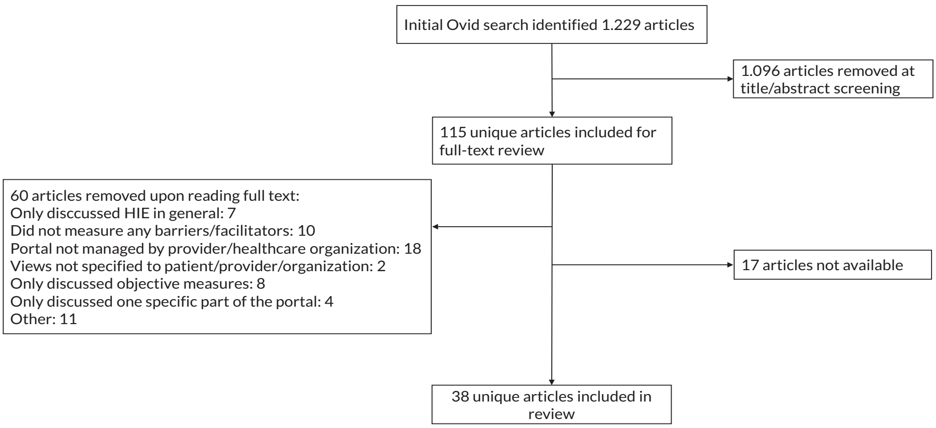


Figure 1: *Flow diagram study selection*

Table 1: *Study characteristics of included studies*

No.	Author	Year	Country	Study design	Sample size	Portal
1	White	2016	United Kingdom	Cross-sectional study using self-completed questionnaire	209	No portal used
2	Kamo	2016	United states	Description of system	0	MyVirginiaMason
3	Lyles	2016	United states	Qualitative study using ten focus groups	87	kp.org
4	Gagnon	2015	Canada	Qualitative using semi-structured interviews	35	No portal used
5	Sorondo	2016	United states	Qualitative prospective focus groups and structured interview	92	Kryptiq CareCatalyst
6	Vydra	2015	United states	Qualitative study using focus groups	5	Mychart
7	Tieu	2015	United states	Qualitative study using focus groups	16	No portal used
8	Reicher	2015	United states	Description of system	16.101	kp.org
9	Ammerlaan	2015	Netherlands	Qualitative study using semi-structured interviews	13	Reumaportaal
10	Black	2015	United states	Qualitative study using focus groups	31	Mychart
11	Ålander	2015	Sweden	Qualitative study using questionnaire	3266	My Healthcare Contacts
12	Ronda	2015	Netherlands	Qualitative study using questionnaire	632	Digitaal Logboek
13	Bush	2015	United states	Qualitative study using structured telephone interviews	9	Mychart
14	Clark	2015	United states	Qualitative study using questionnaire	1420	No portal used
15	Otte-trojel	2015	Netherlands	Qualitative study using interviews	10	Multiple
16	Hassol	2004	United states	Qualitative study using questionnaires and two focus groups	1.421 (questionnaire) 25 (focus group)	Mychart
17	Mcnamara	2014	United states	Qualitative study using questionnaire	41	No portal used
18	Latulipe	2015	United states	Qualitative study using semi-structured interviews	52	No portal used
19	Tieu	2016	United states	Qualitative study using semi-structured interviews	25	MYSFHEALTH

No.	Author	Year	Country	Study design	Sample size	Portal
20	Luque	2013	United states	Qualitative study using questionnaires and focus groups	90 (questionnaire) 8 (focus group)	No portal used
21	Alpert	2016	United states	Qualitative study using questionnaires and two focus groups	31 (questionnaire) 13 (focus group)	MyPreventiveCare
22	Turner	2015	United states	Qualitative study using semi-structured interviews	74	MyChart
23	Grunloh	2016	Sweden	Qualitative study using structured interviews	12	My Healthcare Contacts
24	Nguyen	2016	Canada	Qualitative study using four focus groups	29	No portal used
25	Harrison	2015	Canada	Qualitative study using questionnaire	63	No portal used
26	Mishuris	2014	United states	Qualitative study using semi-structured interviews	16	My HealtheVet
27	Milller	2016	United states	Qualitative study using semi-structured interviews	20	Multiple
28	Hess	2008	United states	Qualitative study using two focus groups (pre-post implementation)	39	UPMC HealthTrak
29	Mayberry	2011	United states	Qualitative study using focus groups	75	My-HealthAtVanderbilt
30	Wells	2014	New Zealand	Qualitative study using structured telephone interviews	30	Multiple
31	Ronda	2015	Netherlands	Qualitative study using questionnaire	12.793	Digitaal Logboek
32	Zarcadoolas	2013	United states	Qualitative study using focus groups	28	No portal used
33	Goel	2011	United states	Qualitative study using structured telephone interviews	159	My chart
34	Gee	2015	United states	Qualitative study using semi-structured interviews	18	Multiple
35	Britto	2013	United states	Qualitative study using semi-structured interviews	24	Multiple
36	Woods	2013	United states	Qualitative study using focus group interviews.	36	My HealtheVet
37	Yau	2011	Canada	Qualitative study using semi-structured interviews	10	mydoctor.ca
38	Dhanireddy	2012	United states	Qualitative study using focus groups	30	No portal used

Table 2: *Reported portal functionalities and influencing factors per included study*

No.	Author	Main functionalities defined by article	Influencing factors
1	White	Not applicable	Need for engagement; Health literacy/ numeracy skills; Alignment of workflow /increase of workload
2	Kamo	Appointment requests and self-schedule; Clinical messaging with providers; Test results; Medications; Allergies; Upcoming appointments; Medication refill requests	Health literacy/ numeracy skills; Proxy access; Accessibility/ completeness; Limited access to the Internet / computer; Timeliness; Alignment of workflow /increase of workload
3	Lyles	Viewing medical history; Visit summaries; Immunizations; Allergies, Laboratory results; Prescription renewals; Appointment requests; Clinical messaging with providers	Health literacy/ numeracy skills; Computer/technical skills / IT literacy; Interfere with personal relationships; Prefer talking to real person; Conservative; Security/ privacy; Registration & login process; Difficult medical content; Need for training/support
4	Gagnon	Not applicable	Health literacy/ numeracy skills; Accessibility/completeness; Limited access to the Internet / computer; Computer/technical skills / IT literacy; Conservative; Security/ privacy; (Perceived) usefulness; Support from professional; Costs/ Usage fees; Cross-platform software; Difficult medical content; Need for training/support; User interface customization; Interoperability; Remuneration; Restricted patient control of data
5	Sorondo	Problem list, Medications; Laboratory and radiology results; Appointment requests; Prescription renewals; Obtaining referrals.	Prefer talking to real person; Security/ privacy; (Perceived) usefulness; Support from professional; Technical problems; Need for training/support; Remuneration
6	Vydra	Not reported in article	Alignment of workflow /increase of workload; Training and education; Remuneration; Improved patient satisfaction
7	Tieu	Not applicable	easier means of communication; Possibility to improve the effectiveness of in-patient consult; Limited access to the Internet / computer; Proxy access; Computer/technical skills / IT literacy; Communication supplement; Interfere with personal relationships; Security/ privacy; Registration & login process; Difficult medical content
8	Reicher	Basic healthcare information; Optional access to radiology results; Clinical messaging with providers	Accessibility/completeness; Technical problems; Rapid access to new data

No.	Author	Main functionalities defined by article	Influencing factors
9	Ammer-laan	E-consult; Clinical notes; Laboratory results; Upcoming appointments; Online self-monitoring	Involvement of others; Easier means of communication; Possibility to improve the effectiveness of in-patient consult; Need for engagement; Cognitive overload; Security/ privacy; (Perceived) usefulness; Registration & login process
10	Black	Upcoming appointments; Lab results; Requesting or canceling appointments; Prescription renewals; Past AVS forms	Limited access to the Internet / computer; Computer/technical skills / IT literacy; Interfere with personal relationships; Security/ privacy; (Perceived) usefulness; Support from professional; Lack of awareness; Expectations vs experience; Alignment of workflow / increase of workload;
11	Ålander	Appointment requests and self-schedule; Request certificates; Basic medical data information; Extend sick leave; Clinical messaging with providers; Update personal data; Change house physician/family doctor; Prescription renewals and assistive tools; Order a written copy of the medical health record	Proxy access; Difficult medical content
12	Ronda	Clinic notes; Results physical examination; Laboratory results; Problem lists and treatment goals; Medications; General diabetes information	Communication supplement; Lack of awareness
13	Bush	Clinical messaging with providers; Appointment scheduling; Result reporting; Health information	Security/ privacy; (Perceived) usefulness; Registration & login process; Need for training/support
14	Clark	Not applicable	Need for engagement; Timeliness; Security/ privacy; Lack of awareness
15	Otte-trojel	Not reported in article	Health literacy/ numeracy skills; Alignment of workflow /increase of workload; Interoperability; Cost
16	Hassol	View of 25 frequently ordered laboratory tests and explanation of the results; Allergies; medications; Problem list; Past/Upcoming appointments; Health-related histories; Clinical messaging with providers; Appointment requests; Prescription renewals; Request referrals	Easier means of communication; Accessibility/completeness; Proxy access; Security/ privacy; Registration & login process; Difficult medical content; Restrict patient to access the data/ patient anxiety

No.	Author	Main functionalities defined by article	Influencing factors
17	Mcnamara	Not applicable	Possibility to improve the effectiveness of in-patient consult; Restrict patient to access the data/ patient anxiety
18	Latulipe	Not applicable	Accessibility/completeness; Limited access to the Internet / computer; Computer/technical skills / IT literacy; Communication supplement; Interfere with personal relationships; Prefer talking to real person; Conservative; Security/ privacy; (Perceived) usefulness; Registration & login process; Difficult medical content; Need for training/support
19	Tieu	Not reported in article	Computer/technical skills / IT literacy; Difficult medical content
20	Luque	Not applicable	Health literacy/ numeracy skills; Limited access to the Internet / computer; Computer/technical skills / IT literacy; Conservative; Security/ privacy; Costs/ Usage fees
21	Alpert	Laboratory results; Viewing information from the medical record, personalized recommendations	Accessibility/completeness; Communication supplement; Interfere with personal relationships; (Perceived) usefulness; Registration & login process; Difficult medical content
22	Turner	Not reported in article	Need for engagement; Limited access to the Internet / computer; Conservative; Security/ privacy; Registration & login process
23	Grunloh	Health care information; Test results; 10 eHealth services such as appointment scheduling, following referrals, Information about which provider accessed the medical record	Possibility to improve the effectiveness of in-patient consult; Communication supplement; Difficult medical content; Alignment of workflow /increase of workload; Improved patient satisfaction; Restrict patient to access the data/ patient anxiety; Fear of control
24	Nguyen	Not reported in article	Easier means of communication; Need for engagement; Health literacy/ numeracy skills; Computer/technical skills / IT literacy; Communication supplement; Security/ privacy; (Perceived) usefulness; Costs/ Usage fees; Difficult medical content; User interface customization
25	Harrison	Not reported in article	Communication supplement; Limited access to the Internet / computer; Security/ privacy; (Perceived) usefulness; Restrict patient to access the data/ patient anxiety

No.	Author	Main functionalities defined by article	Influencing factors
26	Mishuris	Download medical record; Clinical messaging with providers; Prescription renewals; Input data about health; Generic health information; Education tools	Easier means of communication; Limited access to the Internet / computer; (Perceived) usefulness; Support from professional; Lack of awareness; Need for training/support; Training and education
27	Milller	Not reported in article	Easier means of communication; Health literacy/ numeracy skills; Proxy access; Computer/technical skills / IT literacy; Communication supplement; Security/ privacy; Alignment of workflow /increase of workload; Improved patient satisfaction; Restrict patient to access the data/ patient anxiety; Easier means for communication; Low uptake
28	Hess	Test results; Medications; Problem lists; Health reminders; Communicate electronically; Education tools; User entered health data	Easier means of communication; Need for engagement; Accessibility/completeness; Communication supplement; Rapid access to new data; Registration & login process;
29	Mayberry	Not reported in article	Support from professional; Proxy access; Support from kin; Lack of awareness; Cross-platform software; Need for training/support
30	Wells	Not reported in article	Communication supplement; Lack of awareness; Alignment of workflow /increase of workload; Training and education; Remuneration; organizational vision
31	Ronda	Clinic notes; Results physical examination; Laboratory results; Problem lists and treatment goals; Medications; General diabetes information	Conservative; Lack of awareness
32	Zarcadool-as	Not applicable	Easier means of communication; Health literacy/ numeracy skills; Proxy access; Communication supplement; Prefer talking to real person; Security/ privacy; (Perceived) usefulness
33	Goel	Upcoming appointments; Laboratory results; Appointment scheduling; Prescription renewals; Viewing past AVS forms	Limited access to the Internet / computer; Communication supplement; Conservative; Security/ privacy; Lack of awareness; Registration & login process

No.	Author	Main functionalities defined by article	Influencing factors
34	Gee	Not reported in article	Possibility to improve the effectiveness of in-patient consult; Need for engagement; Health literacy/ numeracy skills; Timeliness; Communication supplement; Security/ privacy; Difficult medical content; Need for training/support; User interface customization; Accessibility/completeness
35	Britto	Demographic and contact information; Test results; Medications; Clinical messaging with providers	Interfere with personal relationships; Prefer talking to real person; Easier means of communication; Communication supplement; Difficult medical content
36	Woods	Clinic notes; Hospital discharge notes; Problem lists; Vital signs; Medications; Allergies; Appointments; Laboratory and imaging results; Education tools; Proxy access, User entered health data	Involvement of others; Possibility to improve the effectiveness of in-patient consult; Accessibility/completeness; Communication supplement; Inconsistencies in Content; Difficult medical content
37	Yau	Not reported in article	Security/ privacy; Difficult medical content; Alignment of workflow /increase of workload; Remuneration; Restrict patient to access the data/ patient anxiety; Fear of control
38	Dhanire-ddy	Not applicable	Easier means of communication; Possibility to improve the effectiveness of in-patient consult; Need for engagement; Cognitive overload; Accessibility/completeness; Communication supplement; Interfere with personal relationships; Prefer talking to real person; Security/ privacy; (Perceived) usefulness; Support from professional; Difficult medical content

6

Supplementary file C - Questionnaire

In Supplementary file C we first show screenshots of an example of the original digital questionnaire in Dutch. Then we provide the text of the questionnaire in English.

Please note: 1) only the Dutch questionnaire has been sent to the patient panels. The English text is made for this article to provide sight on the questionnaire items for non-Dutch speakers. Due to the translation into English the meaning of the text might be interpreted differently. For questions about the meaning of the original Dutch version of the questionnaire please contact the corresponding author. 2) The question on which portal the respondent prefers is asked for each questions. To show the phrasing of the question, we placed it at question 1, yet not at the other boxes.

zivver

Dit is een voorbeeld, er worden geen resultaten geregistreerd.

Vragenlijst gebruik van patiëntenportalen

Bedankt voor uw deelname, het invullen van deze vragenlijst zal slechts 10 minuten van uw tijd in beslag nemen.
De vragenlijst wordt anoniem en vertrouwelijk gebruikt. Dit betekent dat niemand weet welke antwoorden u heeft gegeven.
Ook worden uw gegevens niet met anderen gedeeld. Bij vragen en/of opmerkingen over de vragenlijst kunt u een email sturen naar frank.horenberg@zivver.com.

zivver Secure communication just got simple · amc Academisch Medisch Centrum · Universiteit van Amsterdam

Wat is een patiëntenportaal?

De meeste vragen in deze vragenlijst gaan over patiëntenportalen, het is daarom belangrijk dat u weet wat een patiëntenportaal is. Door middel van dit onderzoek wordt onderzocht welke portalen uw voorkeur heeft en hoe een patiëntenportaal in de toekomst eruit moet zien.

Een patiëntenportaal is een online omgeving (bijvoorbeeld een website) die u kunt gebruiken om uw eigen zorggegevens te bekijken. Zo kunt u een patiëntenportaal gebruiken om laboratorium uitslagen te bekijken zoals bloedwaardes, afspraken bekijken, aantekeningen van de arts lezen, online vragen stellen aan uw zorgverleners en nog veel meer.

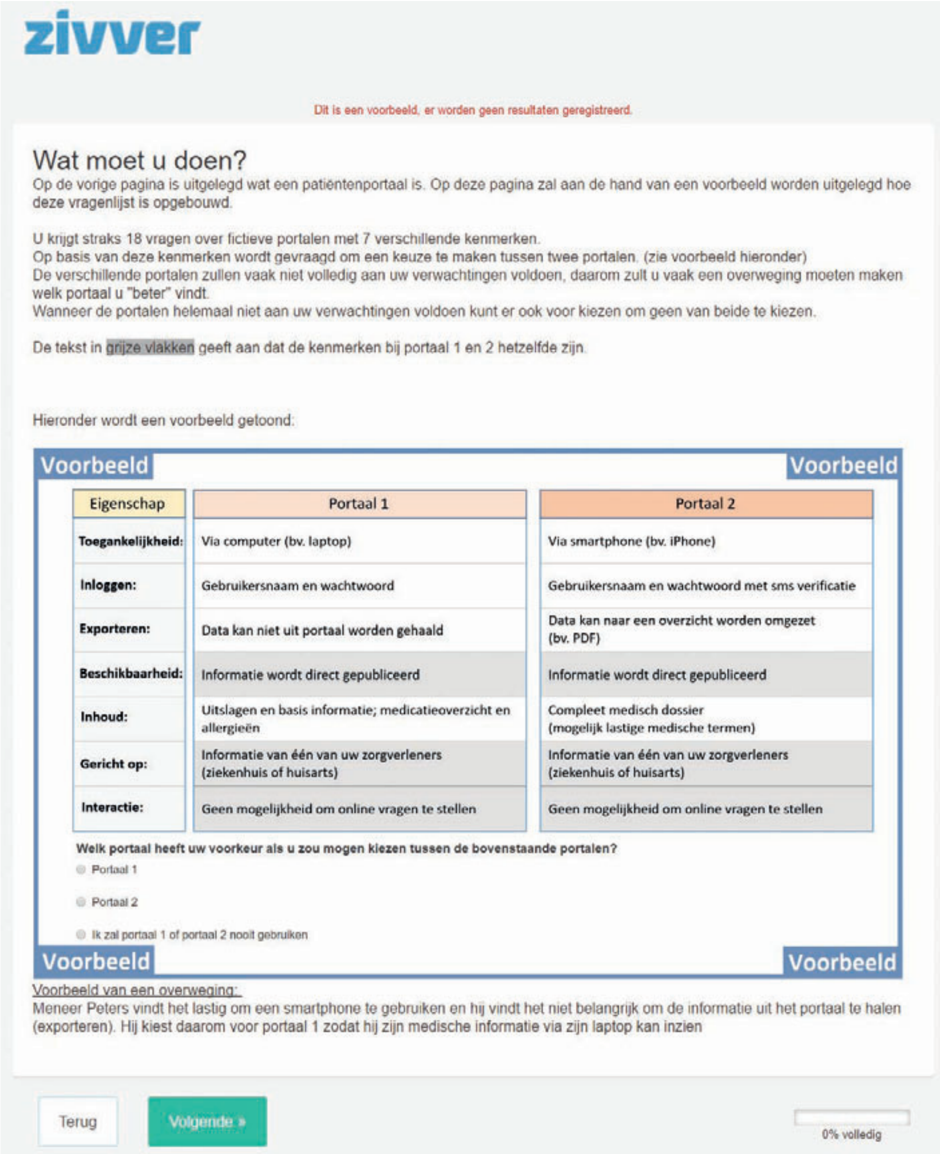
Er zijn veel verschillende patiëntenportalen in Nederland die worden gebruikt door uw huisarts of ziekenhuizen in uw regio. Elke portaal heeft ook andere functionaliteiten, zo kunt u bij sommige portalen uw gehele medische dossier bekijken en bij andere portalen slechts bepaalde delen.

Bekijk eventueel het onderstaande filmpje om in 50 seconden erachter te komen wat een patiëntenportaal is.

Werkt het filmpje niet? Klik dan hier

Volgende »

0% volledig



zivver

Dit is een voorbeeld, er worden geen resultaten geregistreerd.

Wat moet u doen?

Op de vorige pagina is uitgelegd wat een patiëntenportaal is. Op deze pagina zal aan de hand van een voorbeeld worden uitgelegd hoe deze vragenlijst is opgebouwd.

U krijgt straks 18 vragen over fictieve portalen met 7 verschillende kenmerken.
Op basis van deze kenmerken wordt gevraagd om een keuze te maken tussen twee portalen. (zie voorbeeld hieronder)
De verschillende portalen zullen vaak niet volledig aan uw verwachtingen voldoen, daarom zult u vaak een overweging moeten maken welk portaal u "beter" vindt.
Wanneer de portalen helemaal niet aan uw verwachtingen voldoen kunt er ook voor kiezen om geen van beide te kiezen.

De tekst in grijze vlakken geeft aan dat de kenmerken bij portaal 1 en 2 hetzelfde zijn.

Hieronder wordt een voorbeeld getoond:

Voorbeeld | Voorbeeld

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via computer (bv. laptop)	Via smartphone (bv. iPhone)
Inloggen:	Gebruikersnaam en wachtwoord	Gebruikersnaam en wachtwoord met sms verificatie
Exporteren:	Data kan niet uit portaal worden gehaald	Data kan naar een overzicht worden omgezet (bv. PDF)
Beschikbaarheid:	Informatie wordt direct gepubliceerd	Informatie wordt direct gepubliceerd
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht en allergieën	Compleet medisch dossier (mogelijk lastige medische termen)
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Geen mogelijkheid om online vragen te stellen	Geen mogelijkheid om online vragen te stellen

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

Voorbeeld | Voorbeeld

Voorbeeld van een overweging:
Meneer Peters vindt het lastig om een smartphone te gebruiken en hij vindt het niet belangrijk om de informatie uit het portaal te halen (exporteren). Hij kiest daarom voor portaal 1 zodat hij zijn medische informatie via zijn laptop kan inzien

Terug | Volgende »

0% volledig

zivver

Dit is een voorbeeld, er worden geen resultaten geregistreerd.

Er zullen nu 18 vragen worden gesteld waarbij u een keuze moet maken tussen portaal 1 of 2.
Tekst in grijze vlakken geeft aan dat de kenmerken bij portaal 1 en 2 hetzelfde zijn.

*1. Vraag 1 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via smartphone (bv. iPhone)	Via smartphone (bv. iPhone)
Inloggen:	Gebruikersnaam en wachtwoord met sms verificatie	Gebruikersnaam en wachtwoord met sms verificatie
Exporteren:	Data uit portaal kan in andere zorgsystemen worden gezet	Data kan niet uit portaal worden gehaald
Beschikbaarheid:	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener	Informatie wordt direct gepubliceerd
Inhoud:	Compleet medische dossier (mogelijk lastige medische termen)	Uitslagen en basisinformatie; medicatieoverzicht, allergieën en samenvattingen van consulten
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Online consult met zorgverlener	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*2. Vraag 2 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via computer (bv. laptop)	Via smartphone (bv. iPhone)
Inloggen:	Gebruikersnaam en wachtwoord met sms verificatie	Gebruikersnaam en wachtwoord
Exporteren:	Data uit portaal kan in andere zorgsystemen worden gezet	Data uit het portaal kan in andere zorgsystemen worden gezet
Beschikbaarheid:	Informatie pas gepubliceerd als is besproken met zorgverlener	Informatie pas gepubliceerd als is besproken met zorgverlener
Inhoud:	Uitslagen en basisinformatie; medicatieoverzicht en allergieën	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken	Geen mogelijkheid om online vragen te stellen

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

6

*3. Vraag 3 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via tablet (bv. iPad)	Via computer (bv. laptop)
Inloggen:	Gebruikersnaam en wachtwoord met sms verificatie	Gebruikersnaam en wachtwoord
Exporteren:	Data kan niet uit portaal worden gehaald	Data kan naar een overzicht worden omgezet (bv. PDF)
Beschikbaarheid:	Informatie pas gepubliceerd als is besproken met zorgverlener	Informatie pas gepubliceerd als is besproken met zorgverlener
Inhoud:	Compleet medisch dossier (mogelijk lastige medische termen)	Compleet medisch dossier (mogelijk lastige medische termen)
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Geen mogelijkheid om online vragen te stellen	Online consult met zorgverlener

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*4. Vraag 4 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via smartphone (bv. iPhone)	Via tablet (bv. iPad)
Inloggen:	Gebruikersnaam en wachtwoord	DigiD met sms verificatie
Exporteren:	Data uit portaal kan in andere zorgsystemen worden gezet	Data kan naar een overzicht worden omgezet (bv. PDF)
Beschikbaarheid:	Informatie pas gepubliceerd als is besproken met zorgverlener	Informatie pas gepubliceerd als is besproken met zorgverlener
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Geen mogelijkheid om online vragen te stellen	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*5. Vraag 5 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via computer (bv. laptop)	Via smartphone (bv. iPhone)
Inloggen:	DigiD met sms verificatie	Gebruikersnaam en wachtwoord met sms verificatie
Exporteren:	Data uit portaal kan in andere zorgsystemen worden gezet	Data uit portaal kan in andere zorgsystemen worden gezet
Beschikbaarheid:	Informatie wordt direct gepubliceerd	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten	Compleet medisch dossier (mogelijk lastige medische termen)
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Online consult met zorgverlener	Online consult met zorgverlener

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*6. Vraag 6 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via smartphone (bv. iPhone)	Via computer (bv. laptop)
Inloggen:	Gebruikersnaam en wachtwoord met sms verificatie	Gebruikersnaam en wachtwoord met sms verificatie
Exporteren:	Data kan niet uit portaal worden gehaald	Data uit portaal kan in andere zorgsystemen worden gezet
Beschikbaarheid:	Informatie wordt direct gepubliceerd	Informatie pas gepubliceerd als is besproken met zorgverlener
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten	Uitslagen en basis informatie; medicatieoverzicht en allergieën
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

Terug | Volgende » | 23% volledig

zivver

Dit is een voorbeeld, er worden geen resultaten geregistreerd.

Tekst in grijze vlakken geeft aan dat de kenmerken bij portaal 1 en 2 hetzelfde zijn.

*7. Vraag 7 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via computer (bv. laptop)	Via smartphone (bv. iPhone)
Inloggen:	Gebruikersnaam en wachtwoord	DigiD met sms verificatie
Exporteren:	Data kan niet uit portaal worden gehaald	Data kan naar een overzicht worden omgezet (bv. PDF)
Beschikbaarheid:	Informatie wordt direct gepubliceerd	Informatie wordt direct gepubliceerd
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht en allergieën	Compleet medisch dossier (mogelijk lastige medische termen)
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Geen mogelijkheid om online vragen te stellen	Geen mogelijkheid om online vragen te stellen

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*8. Vraag 8 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via smartphone (bv. iPhone)	Via computer (bv. laptop)
Inloggen:	Gebruikersnaam en wachtwoord	DigiD met sms verificatie
Exporteren:	Data kan naar een overzicht worden omgezet (bv. PDF)	Data kan niet uit portaal worden gehaald
Beschikbaarheid:	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht en allergieën	Compleet medisch dossier (mogelijk lastige medische termen)
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*9. Vraag 9 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via tablet (bv. iPad)	Via tablet (bv. iPad)
Inloggen:	Gebruikersnaam en wachtwoord	DigiD met sms verificatie
Exporteren:	Data uit portaal kan in andere zorgsystemen worden gezet	Data uit portaal kan in andere zorgsystemen worden gezet
Beschikbaarheid:	Informatie wordt direct gepubliceerd	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener
Inhoud:	Compleet medisch dossier (mogelijk lastige medische termen)	Uitslagen en basis informatie; medicatieoverzicht en allergieën
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken	Geen mogelijkheid om online vragen te stellen

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*10. Vraag 10 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via tablet (bv. iPad)	Via computer (bv. laptop)
Inloggen:	Gebruikersnaam en wachtwoord	Gebruikersnaam en wachtwoord met sms verificatie
Exporteren:	Data kan niet uit portaal worden gehaald	Data kan naar een overzicht worden omgezet (bv. PDF)
Beschikbaarheid:	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Online consult met zorgverlener	Geen mogelijkheid om online vragen te stellen

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*11. Vraag 11 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via computer (bv. laptop)	Via computer (bv. laptop)
Inloggen:	Gebruikersnaam en wachtwoord	Gebruikersnaam en wachtwoord
Exporteren:	Data kan naar een overzicht worden omgezet (bv. PDF)	Data kan niet uit portaal worden gehaald
Beschikbaarheid:	Informatie pas gepubliceerd als is besproken met zorgverlener	Informatie wordt direct gepubliceerd
Inhoud:	Compleet medisch dossier (mogelijk lastige medische termen)	Uitslagen en basis informatie; medicatieoverzicht en allergieën
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Online consult met zorgverlener	Geen mogelijkheid om online vragen te stellen

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*12. Vraag 12 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via smartphone (bv. iPhone)	Via tablet (bv. iPad)
Inloggen:	DigiD met sms verificatie	Gebruikersnaam en wachtwoord met sms verificatie
Exporteren:	Data kan naar een overzicht worden omgezet (bv. PDF)	Data kan naar een overzicht worden omgezet (bv. PDF)
Beschikbaarheid:	Informatie wordt direct gepubliceerd	Informatie wordt direct gepubliceerd
Inhoud:	Compleet medisch dossier (mogelijk lastige medische termen)	Uitslagen en basis informatie; medicatieoverzicht en allergieën
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)
Interactie:	Geen mogelijkheid om online vragen te stellen	Online consult met zorgverlener

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

Terug | Volgende »

46% volledig

zivver

Dit is een voorbeeld, er worden geen resultaten geregistreerd.

Tekst in grijze vlakken geeft aan dat de kenmerken bij portaal 1 en 2 hetzelfde zijn.

*13. Vraag 13 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via tablet (bv. iPad)	Via computer (bv. laptop)
Inloggen:	Gebruikersnaam en wachtwoord met sms verificatie	DigiD met sms verificatie
Exporteren:	Data kan naar een overzicht worden omgezet (bv. PDF)	Data uit portaal kan in andere zorgsystemen worden gezet
Beschikbaarheid:	Informatie wordt direct gepubliceerd	Informatie wordt direct gepubliceerd
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht en allergieën	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Online consult met zorgverlener	Online consult met zorgverlener

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*14. Vraag 14 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via smartphone (bv. iPhone)	Via tablet (bv. iPad)
Inloggen:	DigiD met sms verificatie	Gebruikersnaam en wachtwoord met sms verificatie
Exporteren:	Data kan niet uit portaal worden gehaald	Data kan niet uit portaal worden gehaald
Beschikbaarheid:	Informatie pas gepubliceerd als is besproken met zorgverlener	Informatie pas gepubliceerd als is besproken met zorgverlener
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht en allergieën	Compleet medisch dossier (mogelijk lastige medische termen)
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Online consult met zorgverlener	Geen mogelijkheid om online vragen te stellen

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

6

*15. Vraag 15 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via computer (bv. laptop)	Via tablet (bv. iPad)
Inloggen:	Gebruikersnaam en wachtwoord met sms verificatie	Gebruikersnaam en wachtwoord
Exporteren:	Data kan naar een overzicht worden omgezet (bv. PDF)	Data uit portaal kan in andere zorgsystemen worden gezet
Beschikbaarheid:	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener	Informatie wordt direct gepubliceerd
Inhoud:	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten	Compleet medisch dossier (mogelijk lastige medische termen)
Gericht op:	Bevat informatie van meerdere zorgverleners (meerdere ziekenhuizen en/of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Geen mogelijkheid om online vragen te stellen	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

*16. Vraag 16 van 18

Eigenschap	Portaal 1	Portaal 2
Toegankelijkheid:	Via computer (bv. laptop)	Via tablet (bv. iPad)
Inloggen:	DigiD met sms verificatie	Gebruikersnaam en wachtwoord
Exporteren:	Data kan niet uit portaal worden gehaald	Data kan niet uit portaal worden gehaald
Beschikbaarheid:	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener	Informatie na twee weken gepubliceerd, onafhankelijk of dit is besproken met zorgverlener
Inhoud:	Compleet medisch dossier (mogelijk lastige medische termen)	Uitslagen en basis informatie; medicatieoverzicht, allergieën en samenvattingen van consulten
Gericht op:	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)	Informatie van één van uw zorgverleners (ziekenhuis of huisarts)
Interactie:	Mogelijkheid om online vragen te stellen over uitslagen en eerdere afspraken	Online consult met zorgverlener

Welk portaal heeft uw voorkeur als u zou mogen kiezen tussen de bovenstaande portalen?

- Portaal 1
- Portaal 2
- Ik zal portaal 1 of portaal 2 nooit gebruiken

zivver

Dit is een voorbeeld, er worden geen resultaten geregistreerd.

Over uzelf

Tot slot willen wij u 6 vragen stellen die over uzelf gaan.
Deze achtergrondkenmerken zijn belangrijk om meer inzicht te krijgen in de kwaliteit van de zorg rondom zorg voor verschillende groepen mensen.

***19. Wat is uw leeftijd?**

- ○ Jonger dan 18 jaar
- ○ 18 t/m 24 jaar
- ○ 25 t/m 34 jaar
- ○ 35 t/m 44 jaar
- ○ 45 t/m 54 jaar
- ○ 55 t/m 64 jaar
- ○ 65 t/m 74 jaar
- ○ 75 jaar of ouder

***20. Bent u een man of een vrouw?**

- ○ Man
- ○ Vrouw

***21. Wat is uw hoogst voltooide opleiding? (een opleiding afgerond met diploma of voldoende getuigschrift)**

- ○ Geen opleiding (lager onderwijs: niet afgemaakt)
- ○ Lager onderwijs (basisschool, speciaal basisonderwijs)
- ○ Lager of voorbereidend beroepsonderwijs (zoals LTS, LEAO, LHNO, VMBO)
- ○ Middelbaar algemeen voortgezet onderwijs (zoals MAVO, (M)ULO, MBO-kort, VMBO-t)
- ○ Middelbaar beroepsonderwijs en beroepsbegeleidend onderwijs (zoals MBOlang, MTS, MEAO, BOL, BBL, INAS)
- ○ Hoger algemeen en voorbereidend wetenschappelijk onderwijs (zoals HAVO, VWO, Atheneum, Gymnasium, HBS, MMS)
- ○ Hoger beroepsonderwijs (zoals HBO, HTS, HEAO, HBO-V, kandidaats wetenschappelijk onderwijs)
- ○ Wetenschappelijk onderwijs (universiteit)
- ○ Anders, namelijk:

6

*22. Heeft u zelf wel eens gebruik gemaakt van een patiëntenportaal?

- Ja
- Nee

*23. Hoe vaak heeft u contact met een zorgverlener? (schriftelijk, mondeling, telefonisch, consult)

- < 1 keer per jaar
- 1 - 4 keer per jaar
- 5 - 11 keer per jaar
- 1 keer per maand
- 2 - 4 keer keer maand
- 1 - 2 keer per week
- > 2 keer per week

*24. Hoe zou u over het algemeen uw gezondheid noemen?

- Uitstekend
- Zeer goed
- Goed
- Matig
- Slecht

25. Op de hoogte blijven van dit onderzoek? Laat dan hier je e-mailadres achter.

26. We willen de vragenlijst blijven verbeteren. We horen dan ook graag wat u van de vragenlijst vindt. Mist u iets in deze vragenlijst? Of heeft u nog opmerkingen of tips? Dan kunt u dat hieronder opschrijven.

Terug | Voltooien

100% volledig

Survey on usage of patient portals

Thank you for participating, completing this survey will only take 10 minutes of your time.

The survey will be used anonymously and confidentially. This means that nobody knows which answers you have given. In addition your personal data will not be shared with others. If you have any questions and/or remarks regarding the survey, you can send an email to frank.horenberg@zivver.com.

What is a patient portal?

Most questions in this survey will address patient portals. That is why it is important that you understand what a patient portal is. By means of this study your preferences on patient portals are examined, as well as how a patient portal should look like in the future. A patient portal is online environment (for example a website) which you can use to review your own health data. For example, you can use a patient portal to view lab results, such as blood values, or to see your appointments, notes of the doctor or to ask online questions to your healthcare providers.

There are many different patient portals in The Netherlands that are used by your general practitioner or hospitals within your region. Each portal has different functionalities. At some portals you can access your total medical record, at others just some parts of your record. You can watch the short clip (50 seconds) below to learn more on patient portals. If the clip doesn't load, please click here.

What is requested of you?

The previous page explained what is understood by 'patient portals'. At this page, an example is given on how the survey works. You will get 18 questions on 'fictive' portals with 7 different features. Based on these features you will be asked to make a choice between two portals (please see example below). The various portals might not fully comply with your expectations. That is why we ask you to consider with portal option you like most. If both of the options do not comply with your expectations, you can choose 'none of both'. The text in the grey boxes indicates that that specific feature is similar in portal 1 and 2. An example is shown below:

Example

Feature	Portal 1	Portal 2
Accessibility	Via computer (i.e. laptop)	Via smartphone (i.e. iPhone)
Login	Username and password	Username and password with SMS verification
Export	Data cannot be exported from portal	Data can be put in an overview (i.e. PDF)
Availability	Information is directly published	Information is directly published
Content	Test results and basic information; medication overview and allergies	Complete medical record (including possible difficult medical terms)
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	No possibility to ask online questions	No possibility to ask online questions

Which portal would you prefer if you could choose between the portals presented above?

- Portal 1
- Portal 2
- I will never use portal 1 or portal 2

Example of a consideration:

Mister Peters finds it difficult to use a smartphone and downloading information (export) from a portal is not of importance to him. That is why he chooses portal 1 in this example, so he can view is medical information online via his laptop.

In the following 18 questions you will have to make a choice between portal 1 or 2.

The text in the grey boxes indicates that that specific feature is similar in the portals.

1. Question 1 of 18

Feature	Portal 1	Portal 2
Accessibility	Via smartphone (i.e. iPhone)	Via smartphone (i.e. iPhone)
Login	Username and password with SMS verification	Username and password with SMS verification
Export	Data from portal can be exported to other care systems	Data cannot be exported from portal
Availability	Information is published after two weeks, regardless if discussed with health provider	Information is directly published
Content	Complete medical record (including possible difficult medical terms)	Test results and basic information; medication overview and allergies and summaries of consults
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	Online consult with health provider	Possibility to ask online questions regarding tests and previous appointments

Which portal would you prefer if you could choose between the portals presented above?

- *Portal 1*
- *Portal 2*
- *I will never use portal 1 or portal 2*

Please note: the question 'which portal would you prefer if you could choose between the portals presented above?' was asked at each question from 1 to 18. To show the phrasing of the question, we placed it at question 1 in this translation, yet not at the other boxes.

2. Question 2 of 18

Feature	Portal 1	Portal 2
Accessibility	Via computer (i.e. laptop)	Via smartphone (i.e. iPhone)
Login	Username and password with SMS verification	Username and password
Export	Data from portal can be exported to other care systems	Data from portal can be exported to other care systems
Availability	Information is published only after being discussed with health provider	Information is published only after being discussed with health provider
Content	Test results and basic information; medication overview and allergies	Test results and basic information; medication overview and allergies and summaries of consults
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	Possibility to ask online questions regarding tests and previous appointments	No possibility to ask online questions

3. Question 3 of 18

Feature	Portal 1	Portal 2
Accessibility	Via tablet (i.e. iPad)	Via computer (i.e. laptop)
Login	Username and password with SMS verification	Username and password
Export	Data cannot be exported from portal	Data can be put in an overview (i.e. PDF)
Availability	Information is published only after being discussed with health provider	Information is published only after being discussed with health provider
Content	Complete medical record (including possible difficult medical terms)	Complete medical record (including possible difficult medical terms)
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	No possibility to ask online questions	Online consult with health provider

4. Question 4 of 18

Feature	Portal 1	Portal 2
Accessibility	Via smartphone (i.e. iPhone)	Via tablet (i.e. iPad)
Login	Username and password	DigiD with SMS verification
Export	Data from portal can be exported to other care systems	Data can be put in an overview (i.e. PDF)
Availability	Information is published only after being discussed with health provider	Information is published only after being discussed with health provider
Content	Test results and basic information; medication overview and allergies and summaries of consults	Test results and basic information; medication overview and allergies and summaries of consults
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	No possibility to ask online questions	Possibility to ask online questions regarding tests and previous appointments

5. Question 5 of 18

Feature	Portal 1	Portal 2
Accessibility	Via computer (i.e. laptop)	Via smartphone (i.e. iPhone)
Login	DigiD with SMS verification	Username and password with SMS verification
Export	Data from portal can be exported to other care systems	Data from portal can be exported to other care systems
Availability	Information is directly published	Information is published after two weeks, regardless if discussed with health provider
Content	Test results and basic information; medication overview and allergies and summaries of consults	Complete medical record (including possible difficult medical terms)
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	Online consult with health provider	Online consult with health provider

6. Question 6 of 18

Feature	Portal 1	Portal 2
Accessibility	Via smartphone (i.e. iPhone)	Via computer (i.e. laptop)
Login	Username and password with SMS verification	Username and password with SMS verification
Export	Data cannot be exported from portal	Data from portal can be exported to other care systems
Availability	Information is directly published	Information is published only after being discussed with health provider
Content	Test results and basic information; medication overview and allergies and summaries of consults	Test results and basic information; medication overview and allergies
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	Possibility to ask online questions regarding tests and previous appointments	Possibility to ask online questions regarding tests and previous appointments

7. Question 7 of 18

Feature	Portal 1	Portal 2
Accessibility	Via computer (i.e. laptop)	Via smartphone (i.e. iPhone)
Login	Username and password	DigiD with SMS verification
Export	Data cannot be exported from portal	Data can be put in an overview (i.e. PDF)
Availability	Information is directly published	Information is directly published
Content	Test results and basic information; medication overview and allergies	Complete medical record (including possible difficult medical terms)
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	No possibility to ask online questions	No possibility to ask online questions

8. Question 8 of 18

Feature	Portal 1	Portal 2
Accessibility	Via smartphone (i.e. iPhone)	Via computer (i.e. laptop)
Login	Username and password	DigiD with SMS verification
Export	Data can be put in an overview (i.e. PDF)	Data cannot be exported from portal
Availability	Information is published after two weeks, regardless if discussed with health provider	Information is published after two weeks, regardless if discussed with health provider
Content	Test results and basic information; medication overview and allergies	Complete medical record (including possible difficult medical terms)
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	Possibility to ask online questions regarding tests and previous appointments	Possibility to ask online questions regarding tests and previous appointments

10. Question 10 of 18

Feature	Portal 1	Portal 2
Accessibility	Via tablet (i.e. iPad)	Via computer (i.e. laptop)
Login	Username and password	Username and password with SMS verification
Export	Data cannot be exported from portal	Data can be put in an overview (i.e. PDF)
Availability	Information is published after two weeks, regardless if discussed with health provider	Information is published after two weeks, regardless if discussed with health provider
Content	Test results and basic information; medication overview and allergies and summaries of consults	Test results and basic information; medication overview and allergies and summaries of consults
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	Online consult with health provider	No possibility to ask online questions

9. Question 9 of 18

Feature	Portal 1	Portal 2
Accessibility	Via tablet (i.e. iPad)	Via tablet (i.e. iPad)
Login	Username and password	DigiD with SMS verification
Export	Data from portal can be exported to other care systems	Data from portal can be exported to other care systems
Availability	Information is directly published	Information is published after two weeks, regardless if discussed with health provider
Content	Complete medical record (including possible difficult medical terms)	Test results and basic information; medication overview and allergies
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	Possibility to ask online questions regarding tests and previous appointments	No possibility to ask online questions

11.. Question 11 off 18

Feature	Portal 1	Portal 2
Accessibility	Via computer (i.e. laptop)	Via computer (i.e. laptop)
Login	Username and password	Username and password
Export	Data can be put in an overview (i.e. PDF)	Data cannot be exported from portal
Availability	Information is published only after being discussed with health provider	Information is directly published
Content	Complete medical record (including possible difficult medical terms)	Test results and basic information; medication overview and allergies
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	Online consult with health provider	No possibility to ask online questions

12. Question 12 of 18

Feature	Portal 1	Portal 2
Accessibility	Via smartphone (i.e. iPhone)	Via tablet (i.e. iPad)
Login	DigiD with SMS verification	Username and password with SMS verification
Export	Data can be put in an overview (i.e. PDF)	Data can be put in an overview (i.e. PDF)
Availability	Information is directly published	Information is directly published
Content	Complete medical record (including possible difficult medical terms)	Test results and basic information; medication overview and allergies
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from several health providers (i.e. various hospitals and/or general practitioner)
Interaction	No possibility to ask online questions	Online consult with health provider

13. Question 13 of 18

Feature	Portal 1	Portal 2
Accessibility	Via tablet (i.e. iPad)	Via computer (i.e. laptop)
Login	Username and password with SMS verification	DigiD with SMS verification
Export	Data can be put in an overview (i.e. PDF)	Data from portal can be exported to other care systems
Availability	Information is directly published	Information is directly published
Content	Test results and basic information; medication overview and allergies	Test results and basic information; medication overview and allergies and summaries of consults
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	Online consult with health provider	Online consult with health provider

6

14. Question 14 of 18

Feature	Portal 1	Portal 2
Accessibility	Via smartphone (i.e. iPhone)	Via tablet (i.e. iPad)
Login	DigiD with SMS verification	Username and password with SMS verification
Export	Data cannot be exported from portal	Data cannot be exported from portal
Availability	Information is published only after being discussed with health provider	Information is published only after being discussed with health provider
Content	Test results and basic information; medication overview and allergies	Complete medical record (including possible difficult medical terms)
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	Online consult with health provider	No possibility to ask online questions

15. Question 15 of 18

Feature	Portal 1	Portal 2
Accessibility	Via computer (i.e. laptop)	Via tablet (i.e. iPad)
Login	Username and password with SMS verification	Username and password
Export	Data can be put in an overview (i.e. PDF)	Data from portal can be exported to other care systems
Availability	Information is published after two weeks, regardless if discussed with health provider	Information is directly published
Content	Test results and basic information; medication overview and allergies and summaries of consults	Complete medical record (including possible difficult medical terms)
Aimed at	Information from several health providers (i.e. various hospitals and/or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	No possibility to ask online questions	Possibility to ask online questions regarding tests and previous appointments

16. Question 16 of 18

Feature	Portal 1	Portal 2
Accessibility	Via computer (i.e. laptop)	Via tablet (i.e. iPad)
Login	DigiD with SMS verification	Username and password
Export	Data cannot be exported from portal	Data cannot be exported from portal
Availability	Information is published after two weeks, regardless if discussed with health provider	Information is published after two weeks, regardless if discussed with health provider
Content	Complete medical record (including possible difficult medical terms)	Test results and basic information; medication overview and allergies and summaries of consults
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	Possibility to ask online questions regarding tests and previous appointments	Online consult with health provider

17. Question 17 of 18

Feature	Portal 1	Portal 2
Accessibility	Via tablet (i.e. iPad)	Via smartphone (i.e. iPhone)
Login	DigiD with SMS verification	DigiD with SMS verification
Export	Data can be put in an overview (i.e. PDF)	Data cannot be exported from portal
Availability	Information is published only after being discussed with health provider	Information is published only after being discussed with health provider
Content	Test results and basic information; medication overview and allergies and summaries of consults	Test results and basic information; medication overview and allergies
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	Possibility to ask online questions regarding tests and previous appointments	Online consult with health provider

18. Question 18 of 18

Feature	Portal 1	Portal 2
Accessibility	Via tablet (i.e. iPad)	Via smartphone (i.e. iPhone)
Login	DigiD with SMS verification	Username and password
Export	Data from portal can be exported to other care systems	Data can be put in an overview (i.e. PDF)
Availability	Information is published after two weeks, regardless if discussed with health provider	Information is published after two weeks, regardless if discussed with health provider
Content	Test results and basic information; medication overview and allergies	Test results and basic information; medication overview and allergies
Aimed at	Information from one of your health providers (i.e. hospital or general practitioner)	Information from one of your health providers (i.e. hospital or general practitioner)
Interaction	No possibility to ask online questions	Possibility to ask online questions regarding tests and previous appointments

Regarding yourself.

To conclude we would like to ask you 6 questions regarding yourself. These characteristics are important to get more sight on the quality of care for different groups of people.

*19. What is your age?

- Younger than 18 years
- 18 till 24 years
- 25 till 34 years
- 35 till 44 years
- 45 till 54 years
- 55 till 64 years
- 65 till 74 years
- 75 years and above

20. Are you male or female?

- Male
- Female

*21. What is your highest completed education? (Education completed with a degree or a certificate)

- No education (primary school: not finished)
- Lower education (primary school, special primary school)
- Lower or preparatory vocational education (such as LTS, LEAO, LHNO, VMBO)
- Middle-level secundary education (such as MAVO, (M)ULO, MBO-kort, VMBO-t)
- Middle-level vocation education (such as MBOlang, MTS, MEAO, BOL, BBL, INAS)
- Higher secundary education (such as HAVO, VWO, Atheneum, Gymnasium, HBS, MMS)
- Higher vocation education (such as HBO, HTS, HEAO, HBO-V, candidates scientific education)
- Scientific education (university)
- Other, please specify:
  ....

22. Have you ever used a patient portal yourself?

- Yes
- No

*23. How often are you in contact with a healthcare provider? (written, face-to-face, by telephone, via a consult)

- < 1 time per year
- 1 - 4 times per year
- 5 - 11 times per year
- 1 time per month
- 2 - 4 times per month
- 1 - 2 times per week
- > 2 times per week

*24. In general, how do your describe your health?

- Excellent
- Very good
- Good
- Poor
- Bad

25. Would you like to be updated on this research? If so, please register your email address.

26. We would like to improve the survey. For this reason we would like to hear your opinion on the survey. Was something lacking in the survey? Do you have any remarks or tips regarding the survey? You can give your feedback in the box below.

Part 3

Patient-centered eHealth research for older adults

Chapter 7

The impact of patient-centered eHealth applications on patient outcomes: a review on the mediating influence of Human Factor issues on study results

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Yearbook of Medical Informatics. 2016, Nov 10;(1):113-119
PMID: 27830238

Abstract

Objectives: To examine the evidence on the impact of patient-centered eHealth applications on patient care and to analyze if and how reported human factor issues mediated the outcomes.

Methods: We searched PUBMED (2014-2015) for studies evaluating the impact of patient-centered eHealth applications on patient care (behavior change, self-efficacy and patient health related outcomes).

Results: Of the 348 potentially relevant papers, 10 papers were included for data analysis. None of the 10 papers reported a negative impact of the eHealth intervention. Seven papers involved a randomized controlled trial (RCT) study. Six of these RCT's reported a positive impact of the eHealth intervention on patient care. The Systems Engineering Initiative for Patient Safety (SEIPS 2.0) model was used as a guidance framework to identify the reported human factors possibly impacting the effectiveness of an eHealth intervention. All 10 papers reported on human factor issues *possibly* mediating effects of patient-centered eHealth. Human factors involved patient characteristics, perceived social support and (type of) interaction between patient and provider.

Conclusion: While the amount of patient-centered eHealth interventions increases, many questions remain as to what and to what extent human factors mediate their use and impact. Future research should adopt a formal theory-driven approach towards human factors, when investigating those factors' influence on the effectiveness of these interventions. Insights could then be used to better tailor the content and design of eHealth solutions to different patient user profiles, so as to enhance eHealth interventions impact on patient behavior, self-efficacy and health related outcomes.

Keywords: eHealth, health related outcome, behavior change, self-efficacy, patients, impact

1. Introduction

To improve healthcare delivery, governments and healthcare organizations worldwide are investing considerable resources in health information technology (HIT). These technologies indeed have proven to optimize patient care, prevent medical errors, increase the efficiency of care and reduce unnecessary costs [1-5]. Despite these benefits, HIT use in daily healthcare practice has likewise revealed unanticipated– so-called *unintended consequences*. The plethora of studies, showing the extent and importance of unintended consequences, for the most relate to *physician's* usage of electronic health records and computerized provider order entry systems in relation to their *ease of use* [6-11]. Herewith these studies neglect two important aspects related to usage of HIT: HIT usage is not solely related to ease of use, HIT needs to be placed within a, often complex, healthcare system setting (1). A growing segment of HIT is eHealth and eHealth services used by both physicians ánd patients (2). If these eHealth services are to become fully effective, a more complete understanding of the influence of human factors on eHealth's integral usage within the healthcare system is needed, including patient factors possibly influencing the impact of eHealth.

First, many of the unintended consequences flow from *interactions* between the introduced HIT, physical and technical infrastructures of the healthcare organization and the often highly complex healthcare environments [12-20]. They concern issues regarding workflows, communication, cognitive aspects, and an organization's culture and social interactions [12-20]. Within the field of HIT, these aspects are researched within the domain of Human Factors Engineering (HFE). HFE is defined as 'the scientific discipline concerned with the understanding of interactions among humans, 'healthcare' professionals or patients', and other elements of a system and the profession that applies theories, principles and methods to HIT design in order to optimize user well-being and overall system performance' [21-22]. HFE thus has specific benefits applied to healthcare and HIT, such as efficiency improvement in care processes and improved patient outcomes [23].

Secondly, eHealth services have been available to patients for more than a decade [24]. Over time, eHealth services have become emerging tools for supporting patients to directly engage in their health, through stimulating health behavior changes and self-management of their disease [24-25]. This is especially interesting for chronically ill patients, since a health engaged lifestyle can reduce the burden of their chronic disease [25]. HFE aims to ensure that eHealth services are developed that meet the intended health needs, prevent designs that are susceptible to misuse, identify usability issues, minimize input error and enhance safety. Previous research within the field of patient-centered eHealth services shows that HFE approaches are nearly always adopted in the design and development of these HIT interventions [21]. Furthermore, insights on human factors that influence the acceptance, usability and implementation of patient-centered eHealth services have grown [26-30]. However, evidence on how human factors, such as patient characteristics, mediate the use and *impact* of these eHealth services on patient behavior changes, self-efficacy and health related outcomes is scarce [21, 25]. From 2006 onwards several studies and reports have examined the impact of eHealth solutions [31-33]. These studies address the impact of eHealth on the economics of healthcare systems, the possible improvements of quality and safety of healthcare and how eHealth affects low income countries [31-33]. The impact of eHealth on health related outcomes at patient level are seldom addressed. A meta-analysis of evidence-based research on the impact of patient- centered eHealth interventions on patient behavior changes, self-efficacy and health related outcomes, in relation to human factors issues influencing, these outcomes is needed to explore how these interventions can become maximally effective in healthcare and to drive the further development of these innovations [24].

This survey paper summarizes the overarching themes as emerging from the literature of the last two years on the impact of patient-centered eHealth solutions on patient behavior changes, self-efficacy and health related outcomes and mediating human factors and discusses them within the overall context of unintended consequences of HIT. This is of importance since it enables researchers to pinpoint human factors issues influencing the effectiveness of patient-centered eHealth. This knowledge provides insights in how to discover ways for developing better tailored eHealth solutions and maximizing their benefits. We focus on patient-centered eHealth requiring communication and collaboration with healthcare professionals and healthcare organizations as a means of achieving better patient outcomes [34]. The survey paper concludes with recommendations on research questions to be addressed within the field of human factors in relation to impact studies of patient eHealth interventions on behavior change, self-efficacy and health related outcomes.

2. Methods

We searched PUBMED for studies reporting on patient-centered eHealth applications. We performed two searches. For the first search we combined MeSH term 'patients' with keywords 'patient' or 'patients' in title or abstract, keyword 'ehealth' in title or abstract or all fields, keyword 'factors' in title or abstract and limited our search to papers in English published in 2014 and 2015. For the second search we combined MeSH term 'patients' with keywords 'patient' or 'patients' in title or abstract, keyword 'eHealth' in title or abstract or all fields, keyword 'impact' in title or abstract and limited our search to papers in English published in 2014 and 2015. Together the searches resulted in a total of 350 potentially relevant papers. Results from both searches were deduplicated afterwards. Based on the titles and abstracts the first author screened all papers for relevancy. To assess inter-rater reliability, all included and excluded papers were examined by the first and second author. Any disagreements or difficult cases were discussed amongst the two authors until consensus was reached. Papers were included if they reported on an eHealth application targeted at patients ánd presented the effects of this application on patient care from a patient's perspective. Since we wanted to learn more on the *impact* of eHealth on patient outcomes and how human factors mediated the impact, we excluded papers that reported on a general status update of eHealth usage, the potential of eHealth, technical issues related to eHealth, eHealth implementation, acceptance or ethical aspects of eHealth usage or if the paper reported on a mobile (mHealth) application. Reviews, commentaries, letters and conference abstracts were excluded. This resulted in the rejection of 330 papers and left 20 full papers for full examination. Full text versions of 2 of the 20 papers were not found and 8 papers were excluded after reading the full text version. This resulted in the inclusion of 10 papers for final data-analysis.

The first phase of the data processing involved an analysis of the studies' research design and the reported impact of the eHealth intervention. The results sections of the papers were analyzed and the impact of the eHealth intervention per paper was categorized using the following categorization: a positive effect of intervention on defined outcomes (+), a neutral effect, meaning no differences (overtime) in effects of intervention on defined outcomes compared to non-users (+/-) and a negative effect of the intervention on at least one of the defined outcomes (-). In the second phase of the data processing we analyzed if the study methods included a formal human factor framework to frame the study results. If not, we analyzed the discussion section of the paper in search for details on how human factors could have influenced the impact of the eHealth intervention on defined outcomes. The Systems Engineering Initiative for Patient Safety (SEIPS 2.0) model [35] was used as a guidance framework to identify the reported human factors possibly impacting the effectiveness of an eHealth intervention. We used a bottom-up analysis to identify human factors that corresponded with SEIPS 2.0 elements, respectively: persons(s) and tasks (system elements) and physical, cognitive, social and behavioral processes (process elements). Human factors within a specific SEIPS element were clustered among recurrent themes: patient characteristics, perceived social support and patient provider interaction.

3. Results

3.1 General characteristics of included studies

Of the 10 included studies, 7 studies involved a randomized controlled trial (RCT). Six of these RCT's reported a positive impact of the eHealth service on (one of) the outcomes: patient behavior change, self-efficacy or health related outcomes. A post-implementation study and quasi experimental study reported a positive impact on the eHealth service on these outcomes well. In 1 RCT and in 1 pre/post implementation study, the eHealth service did not or only partially improve (one of) the defined outcomes. None of the 10 studies reported a negative impact of the eHealth service. Table 1 provides an overview of all 10 papers.

3.2 Human factors and possible influence on impact of eHealth intervention

Nine of the 10 papers did not use a formal approach to frame and analyze human factor issues; proof on the human factor issues mediating the impact of patient-centered eHealth thus was not made evident in these papers. The remaining one study hypothesized that the human factors self-efficacy and social support would mediate patients' health outcomes and reported a positive impact of these human factors. Table 2 provides an overview of the human factors and their possible influence on impact of the eHealth intervention. Human factors that were most often discussed as possibly mediating the eHealth's impact on defined outcomes are: patients' characteristics, such as social- & cultural background and gender, patients' self-efficacy and cognitions (1) perceived social support (2) and the (type of) interaction between patients and their provider, including individual feedback from provider to patient (3).

First, in a study by Safran Naimark et. al. [41] a web-based app providing tools for monitoring while encouraging (healthy) diet and physical activity proved to be successful in promoting a healthy lifestyle among participants. App users significantly increased the quality of their diet and their weekly duration of physical activity, and lost more weight than the control group not exposed to the tool. Sixty-four percent of the app users were well-educated Caucasian females. In another study by Sepah et. al. [45] active promotion and use of an internet-based lifestyle intervention led to significant reductions of body weight in diabetes patients. The socio-economic status of patients was equally spread, eighty-three percent of the participants were female and more than half of the participants had an ethnicity referred to as 'white' in the paper. In both studies these patient characteristics might have influenced the intervention's impact, since this female participant group might be concerned with their health in general regardless of the specific intervention.

Regarding self-efficacy, a study by Borosund et.al. [38] compared the effect of a web-based illness self-management support system, Internet-based patient provider communication service and usual care among breast cancer patients on symptom distress, anxiety, depression, (primary outcomes), and self-efficacy (secondary outcome). Patients offered the web-based self-management system reported significantly lower symptom distress, anxiety and depression, while patients offered the Internet-based communication service only reported significant lower depression scores compared with the usual care group. Though no significant differences in self-efficacy were found among the study groups, a tendency towards increased self-efficacy of patients offered the self-management support system was seen. Gomez-Zuniga et. al. [44] assessed whether a web-based program aimed at raising awareness of the importance and promotion of physical activity in managing diabetes led to changes in blood sugar levels and insulin use of diabetes patients and whether these changes were related to patients own perceptions of self-efficacy and social support. Those patients who reduced their blood glucose levels after performing the physical exercise the least were those with lower self-efficacy and lower perceived social support.

Perceived social support was also studied by Allam et. al. [36]. They analyzed the effect of a web-based intervention including social support features and gamification on physical activity, healthcare utilization, medication overuse and knowledge on rheumatoid arthritis of patients suffering from this condition. The major features of the social support concerned a forum and a chat room for exchanging experiences and information with other patients and healthcare providers. Game features introduced a competition-like environment where patients' actions were rewarded. Patients having access both to the social support and gaming features of the intervention gained more empowerment, increased their physical activity and decreased their use of healthcare utilization and medication overuse over time.

On (type of) interactions between patient and provider, a study was performed involving Chronic Obstructive Pulmonary Disease (COPD) patients using a self-management tool offering them personalized advice by the service helpline based on their daily recorded symptoms and pulse oximetry measurements. The study indicated that the tool not only heightened their awareness of their condition but likewise raised their confidence to make self-management decisions [43]. Some patients however avoided using the tool because it reminded them of their disease at times they did not experience any severe symptoms. These patients discontinued using the tool unless the need arose when their symptoms worsened. Most patients became sufficiently confident in their self-management that they did not need their healthcare professionals' opinion. In a study by Ralston et. al., patients suffering from uncontrolled essential hypertension who, in addition to usual care, were offered a home blood pressure monitor in combination with online communication with their pharmacists, were more likely to have standard blood pressure levels than patients offered a home blood pressure monitor only [40]. The online communication supported patients and their pharmacist in monitoring of an action plan concerning a patient's lifestyle goals and medication regime. These results indicate that a blended care model, combining online care management, including online feedback from providers to patients, with self-monitoring of symptoms by patients can be more successful than self-monitoring on its own. Another study assessed the feasibility, acceptability and impact of a patient portal supporting shared decision making by parents of children with asthma and their children's caregivers on asthma

Table 1: *English papers published in 2014-2015 on patient-centered eHealth applications and their impact on patient care, ranked by study design.*

Study design	**eHealth intervention** **Patient group**	**Reported impact**	**Ref #**
RCT	Oneself: information website with online social support and experimental gamification features *Rheumatoid Arthritis patients*	+ Patients having access both to social support and gaming features gained more empowerment, increased physical activity and decreased use of healthcare utilization and medication overuse over time	[36]
	ESRA-C: web-based program for self-monitoring of symptoms and Quality of Life, self-care education and customized coaching on how to report to physicians *Oncology patients*	+ Intervention group had a decrease in their level of distress	[37]
	WebChoice: web-based illness management support system *Oncology patients with breast cancer*	+ Intervention group reported significantly lower symptoms of distress, anxiety and depression. +/- No significant differences were found among study groups regarding self-efficacy	[38]
	MyAsthma: I linked patient portal supporting shared decision making for pediatric asthma *Family of asthma patients in pediatric care*	+ Both parents and the pediatric asthma patients missed fewer days from work and school respectively + Parents reported use of portal improved their ability to manage their children's asthma condition	[39]
	Home blood pressure monitoring with and without secure web-based pharmacist messaging and phone visits *Patients with hypertension*	+ Patients offered a home blood pressure monitor in combination with online communication with their pharmacists had more standard blood pressure levels then patients offered solely a home blood pressure monitor	[40]
	eBalance: web-based app to promote healthy lifestyle *N.A.*	+ Intervention group significantly increased the quality of their diet, their weekly duration of physical activity and had more reduction in weight than control group	[41]
	Module to guide sick-listed employees to return to work *Patients with mental disorders*	+ 9 months after baseline significantly more participants of the intervention group achieved remission	[42]
Pre-post study	Light Touch service: self-management intervention *COPD patients*	+ Users of the service indicated higher awareness of their condition and increase in confidence to make self-managed decisions +/- Patients avoided use of service, because it reminded them on their condition even when not experiencing severe symptoms	[43]

Study design	eHealth intervention Patient group	Reported impact	Ref #
Post study	Big Blue Test: raise awareness of physical activity *Diabetes Mellitus (type I and II) patients*	+ Patients with higher self-efficacy and access to social support reduced their blood glucose level after exercise best	[44]
Quasi experi-mental study	Prevent: Internet-based diabetes prevention program *Diabetes Mellitus patients*	+ Intervention group showed significantly higher reduction of weight than control group and achieved a long-term weight maintenance effect even after the effective intervention ended	[45]

Table 2. ***Human Factors discussed and their possible influence on impact of eHealth intervention***

SEIPS 2.0 elements Work system processes	Reported Human Factor	Possible influence on impact of eHealth intervention	Ref #
Person(s) physical	*Patient characteristics gender*	Patients' gender might influence their willingness to participate in the study (within the none RCT's)	[41]
Person(s) cognitive	*Patient characteristics cognitions*	Patients' awareness, knowledge and judgement of available methods for dealing with health issues might influence their health behavior change	[42]
	Patient characteristics self-efficacy	Patients' extent or strength of one's belief in one's own ability to complete tasks and reach goals might influence their health behavior change	[38], [44]
Person(s) social	*Patient characteristics socio- cultural, educational background*	Patients' background might influence participation within the study as well as perception and experience of technology and content of the intervention depending on their health- & computer literacy level	[37], 45]
	Perceived social support by patient	Patients' access to social support (as part of intervention or by informal caregiver) might positively influence their engagement with the intervention	[36], [38], [44],
Tasks behavioral	*Patient/provider interaction (individual feedback from provider)*	Bi-directional provider patient communication was part of the intervention and might enhance patients' engagement with intervention positively.	[39], 40], [43]

control, healthcare utilization and days missed from school (children) or work (parents) [39]. Parents reported that use of the portal improved their communication with their children's clinicians, awareness of the importance of ongoing attention to their children's treatment and their ability to manage their children's asthma. Both parents and their children missed fewer days from work and school respectively.

4. Discussion

Evidence-based research on the impact of patient-centered eHealth on patient behavior changes, self-efficacy and health related outcomes is emerging, though few randomized controlled trials have yet been performed. Whereas formal HFE frameworks are applied within the interaction design of patient-centered eHealth, often before implementation of the intervention, a formal approach on human factors mediating the use and effects of these eHealth interventions is scarcely adopted in outcome studies on patient-centered eHealth. Consequently, potential unintended consequences related to human factors mediating the impact of patient-centered eHealth are hard to identify. As a first step, this survey provided insight in several human factors potentially influencing use and impact of patient-centered eHealth interventions, by using the SEIPS 2.0 model as a guidance framework to identify reported human factors via a bottom-up analysis of the discussion section of the eHealth papers.

First, patients may differ in the degree to which they want to be involved in technology-based health intervention programs to support behavior change and self-efficacy, with female, higher educated patients and patients with better clinical conditions being more likely to seek this kind of involvement. In the study by Safran Naimarak [41], the key parameter for success was the frequency of app use, and being a woman likewise predicted success. The sample comprised predominantly adult, well educated, white females. The intended effect of the program by Berry [37] was likewise modified by frequency of its use which was mediated by personal demographics and clinical characteristics. Working cancer patients, patients who had more than high school education and radiation oncology patients voluntarily used the web-based program more than other patients. These patients might have had a better clinical condition, more likely to know how to use a computer or understand health-related information as provided by the program.

Interestingly, the web portal of Fiks [39] was widely used by both suburban white families and urban African American families regardless of socioeconomic status and the internet-based lifestyle intervention of Sepah [45] by a socioeconomically diverse population of people. Whether these eHealth interventions attained similar results regarding impact on patient care in these diverse groups is yet unclear. Overall these findings show that evidence on demographic differences mediating the impact of patient-centered eHealth interventions is scarce. The ability of patients to benefit from eHealth interventions may be constrained by their limited education, clinical condition, and digital or health literacy. Digital literacy refers to a patient's skills to and knowledge needed for productive interaction with HIT. Health literacy refers to a patient's ability to not only locate but also understand, contextualize and interpret health information. eHealth interventions that fail to consider requirements they impose on a user' abilities could lead to unintended consequences like under- or improper use, misinterpretation of health information or advice provided. Understanding the demographic determinants mediating use and impact of patient-centered eHealth services is thus needed for designing effective eHealth interventions. The questions here are whether and to what extent these factors influence patients' ability to use eHealth tools and what design considerations are important when creating eHealth tools for certain targeted patient populations differing in these characteristics.

A similar plea can be made for understanding the psychological determinants of a self-behavior change process as these can clearly impact behavior changes achieved by patients. Three of these psychological determinants are a patient's self-efficacy, cognitions and social support. Perceived self-efficacy refers to a person's confidence in his or her abilities to perform required actions and achieve desired results. In a healthcare context, perceived self-efficacy concerns a patient's confidence in his abilities to change certain unhealthy behavior patterns or appropriately self-manage his disease. Cognitions refer to a person's mental processes like reasoning by which he acquires certain knowledge. In a healthcare context, cognitions could concern a patient's awareness, knowledge and judgement of available methods for dealing with his health issues. Two studies indeed showed that a patient's perceived self-efficacy level can guide behavior changes concerning diet intake and physical activity [36, 44] and one that patients' cognitions on how to handle daily- work issues given their impairments guided them to return to their work [42]. Some patients may however not be able to take an active role in changing their health-related behaviors due to low a self-efficacy state that does not encourage them to use eHealth aiming at health behavior changes by the eHealth intervention itself. Theory-driven eHealth interventions, mastery experiences and continuous monitoring of behavior changes seemed to motivate users and encourage these changes in the studies of [36, 40, 44]. The question here is how and to what extent eHealth interventions, preferably theory-driven, can contribute to raising self-efficacy as perceived by these patients.

Along with self-efficacy and cognitions, perceived social support can be a very important psychological variable in promoting behavior changes as these changes are encouraged through interaction and support of relevant persons in one's environment. Allam et. al.

[36] indicate that the social support features of their web-based intervention might have increased patients motivation to return to the website, eventually improving their sense of empowerment in dealing with their rheumatoid arthritis. Sharing their experiences and knowledge online with other patients and healthcare professionals even substituted for the need to use real healthcare services. eHealth interventions aiming at health behavior changes that fail to consider the role of social support in facilitating healthy behavior could lead to unintended consequences like unmotivated patients, attrition of users potentially leading to earlier onset or worsening of disease symptoms. Greater elucidation of the details of the relationship between social support structures provided by eHealth interventions and health behavior changes is yet needed to apply knowledge for designing effective patient-centered eHealth interventions. The question here not only is which social support structures work, but also how to integrate those in eHealth interventions so as to enhance patient users 'motivation to change their (unhealthy) behavior patterns and maintain healthy behaviors.

Another method for enhancing users' motivation to change unhealthy or risky behavior may be gamification of eHealth interventions. Gamifying eHealth interventions may not only engage users, increase and continue their participation and motivation but even empower them in handling their health issues. The study of Allam et. al. [36] indeed proved positive effects of a game-based approach in the direction on patients' health-related behavior and outcomes. These authors suggest that patients' participation in a competition-like environment where their actions were rewarded may have increased their motivation and confidence in acquiring and processing the disease related information provided by the eHealth tool. This could eventually have empowered these patients in dealing with their disease. The question here is which gaming mechanisms would affect engagement and empowerment of users in eHealth interventions aimed at self-management of health issues and how.

5. Limitations

We solely included studies that reported on the impact of patient-centered eHealth interventions on patient care. Studies reporting on the implementation or acceptance of patient-centered eHealth were excluded from this meta-analysis whereas in these studies, the mediating influence of human factors on study outcomes is often considered.

Current trends in eHealth are patient-centered mHealth applications, using mobile communications like smartphones for patient health services and patient information. We excluded impact studies of mHealth applications on patient care from the current meta-analysis of the literature but will include these studies in a follow-up meta-analysis.

6. Conclusion

While the amount of patient-centered eHealth interventions is increasing, many questions remain as to what extent and how human factors mediate their effectiveness within the healthcare system and impact on patient health related outcomes. In the search for evidence-based research on the impact of patient-centered eHealth on patient behavior changes, self-efficacy and health related outcomes, only ten studies were included of which the majority reported positive results on (one of these) outcomes. As with any HIT, positive effects of eHealth interventions may however be accompanied by unintended consequences like underuse or misuse. Particularly since most patient-centered eHealth interventions significantly change the role and responsibilities of the patient in dealing with his disease. Most patients and their relatives are interested in gaining greater access to and are ready to embrace eHealth solutions, but others may not be sufficiently motivated, empowered or experience difficulties in using eHealth tools. Future research should incorporate a formal theory on human factors to study how human factors influence the effectiveness of these interventions. The resulting insights can be used to better tailor the content and design of eHealth solutions to different patient user profiles, so as to enhance their impact on patient behavior changes, self-efficacy and health related outcomes.

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Chapter 8

The equity paradox: older patients' participation in patient portal development

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International Journal for Quality in Health Care
Accepted for publication

Abstract

Purpose: This paper reflects on ethical concerns to patient portals design and evaluation approaches and provides a comprehensive overview of methodological considerations to advance patient participation of older patients to patient portal research and development.

Reflection: Barriers to the use of current patient portals experienced by older patients are concentrated on access issues and difficulties with interpretation of medical content. As patient portals' functionalities are being expanded by means of co-creation and user-testing such barriers often remain unrecognized. A main challenge of these patient participation efforts is namely to include a variety of older patients; foremost autonomous patients seem to participate. By selecting autonomous participants in co-creation or user-testing, design solutions are proposed that specifically benefit the autonomy of that patient, whereas it does not do justice to values and interests of patients who are less independent and are confronted with a wider variety of use barriers. Consequently, there is a risk of widening the gap between those who can use and benefit from patient portals and those who cannot. To prevent this from happening, we propose three main methodological aspects to consider in co-creation and user-testing activities that aim to optimize patient portal functionalities.

Implications: We encourage policy makers and patient portal developers to use present-day's momentum to include older patients' abilities, needs and context in the decision-making and investments in further advancing patient portals. We further stimulate future research that aims to improve methods to overcome challenges of older patients' participation regarding design and evaluation of eHealth systems.

Keywords: Human Factors, patient-centeredness, equity in healthcare, patient-provider information

1. Introduction

A pivotal role is allocated to patient portals in improving quality of care and as such the deployment of patient portals is promoted by Western governments and healthcare delivery systems [1-3]. A patient portal is an internet-based aid and foremost an application build on an Electronic Health Record (EHR) infrastructure of a specific healthcare organization, often offering patients basic functionalities. Such functionalities can be tools to schedule appointments, view laboratory results and personal medical information, request repeat medication prescriptions and send secure messages to their healthcare team [4-5]. By means of these functionalities portals aim to position patients at the center of care and promise to offer remote digital access to healthcare provision for all; thereby these portals aim to improve important components of quality in health care for the 21st century, such as patient-centeredness, efficacy and equity [3].

Older patients are a major target group of patient portals, since they typically need more healthcare services related to the high prevalence of chronic diseases amongst older people. The above mentioned functionalities of patient portals can therefore be useful to these older patients especially. For example, being able to communicate with a healthcare team from home and performing administrative health tasks digitally, instead of in the hospital, could benefit those who are less mobile. Studies reporting on various user groups of patient portals confirm these benefits [6-7]. These studies explain that users of patient portals are affected by several (chronic) medical conditions and are often 55+, or even 65+, years old [6-7]. Nevertheless, 60% of people aged 65+ are affected by one or more chronic medical condition(s). Compared to this percentage, the rate of current active users within this population remains low [6, 9]. Growing evidence does suggest that older patients are interested in using a patient portal, either themselves or with help of their caretaker, yet they currently experience barriers to this use [9].

In advancing patient portals to reach their aims to support older as well as general patient populations, patients' participation in its design is viewed as essential to accustom portals to patients' preferences: involving patients and physicians early and continuously in the iterative development process [10]. Activities for instance exists of end-users being involved in discussing new healthcare planning and delivery processes supported and redesigned by a patient portal implementation. Methods to involve end-users in co-creation of patient portals are: interdisciplinary sessions in which especially appointed client counsels interact with physicians and designers; interviews or patient focus groups; or by appointing consumer leaders as staff. End-users can also be involved in improving a patient portal's usability, i.e. by user-based tests and evaluations. Nevertheless, a major problem is that older patients are often not thoroughly involved in those activities. Patients who are able and motivated to participate in co-creation and user-testing are contributing to the advancement of patient portals' design by expressing their needs [11]. Yet, as a consequence the needs and abilities of older patient populations, especially older disadvantaged patients, seem not to be adequately addressed in patient portal design due to an under-representation of these populations in co-creation and user-testing. This negatively influences their adoption of portals or similar eHealth products and increases the complexity for them of engaging in healthcare [12].

This paper therefore reflects on methodologies used to improve and implement patient portals from the perspective of the older patient target group. Conform [13], we performed a critical review of literature on advances in patient portal developments, its barriers for older patients and their challenges in co-creation and user-testing. This is combined with extensive experiences within the field of co-creation and user-testing with end-users regarding eHealth and patient portal use, consisting of over 10 years of research activities within this field (LP, MJ, GW) and 5 years of eHealth implementation activities in two major hospitals in The Netherlands (GW). By means of this abductive research strategy [14], we provide a comprehensive overview of methodological considerations in advancing patient portal research, development and use. We have observed a gap in emerging theory and practice, regarding the ethical concern of patient portal implementation and use for older patients: diversity aspects of older patients seem to be neglected in current advances of patient portals, thereby jeopardizing equity since this may widen the gap between those whom can benefit from portal use and those who cannot. The purpose of this paper is to offer insights and suggestions for improvement regarding this ethical concern.

2. Advances in patient portal developments and its barriers for older patients

Given the increased development of patient portals, in our experience there is a trend that portals are transforming from merely a 'service to patients' into a means that are expected to fulfill a major role in integrated care for patients' self-management of their disease. This is supported by literature, explaining that instead of solely providing medical information on diagnosis, the basic functionalities of patient portals are expanded with usage functions for patients to monitor and manage symptoms and signs of their medical condition and assess the impact of their condition on their physical, emotional, occupational and social functioning [15-18]. Portals further aim to advance functionalities by providing patients with access to educational materials, (video) communication means to take part in e-consults with physicians and tools to monitor their own health indicators such as blood pressure and medication intake. Tethered patient portals are foreseen to include patient reported outcomes, such as medication side effects, progress towards treatments goals and concerns regarding treatment [18]. Within the context of older patients, self-management is seen as a central aspect of integrated care for them, because of the increased occurrence of chronic conditions and need for medical care in older populations [19]. Being supported on this matter by means of a patient portal can thus be particularly useful tools for older patients.

Reported barriers of older adults to using patient portals are focused on (willingness to) access and interpretation of medical data in the portal. Older patients have limited technology or internet access or need help in using the internet or a patient portal [5, 9, 20-22]. Regarding older patients' willingness to access a portal, privacy and security are important aspects discussed in literature; if privacy and security are not ensured, older patients are less motivated to access a portal [20, 23-25]. Other reasons for not attempting enrollment are connectivity obstacles, for example of older African Americans [26]. They have the feeling that a portal would not be useful for them and they worry the portal could undermine their existing in-person relationships with their healthcare team [26]. Lower health literacy and numeracy levels, socio-economic status, less education, internet experience and cognitive abilities as well as older age influence patient portal use negatively [9, 20, 27-28].

3. Challenges of co-creation and user-testing

Consumer co-creation to optimize healthcare is an increasingly well-recognized management initiative in the health sector aiming at generating user-driven innovative solutions to real-world problems [29-31]. Advantages of co-creation are that it brings different parties together to produce a mutually valued outcome and that it builds upon the understanding of users' existing and future needs [29-31]. Within the development of software products to be implemented in healthcare settings, the need for conducting user tests with targeted end-users to improve the interface of these products is strongly supported in literature [32], and policy [33].

Yet, patient participation in co-creation and user-testing activities is affected by a key challenge: Patients must be willing and able to interact with representatives of a healthcare institution and other co-creation participants, such as physicians, to contribute to the process [31]. A review by Martínez-Cañaz et. al. explains that predicting engagement in co-creation activities, participants' autonomous decisions such as ethical values and their need to benefit society play an important role, apart from intrinsic (i.e. hedonic motivations) and extrinsic needs (i.e. financial rewards) [31]. In user-testing it is foremost challenging to select participants who resemble the target group in terms of health status and technology experience. Mostly healthy patients, with good cognitive and verbal skills are selected, due to the requirements of end-user tests [34-35]. Regarding healthcare co-creation in general, it has been suggested that too much patient autonomy may lead to poor intervention choices, possibly resulting in a reduction of outcomes, and standardization across patients might be challenging [29]. This also accounts for portal design adjustments. An autonomous co-creation or user-testing participant can lead to design solutions that specifically benefit the autonomy of that patient, whereas it might not be suitable and beneficial to patients who are less independent. In that case, the gap between those who benefit from portal use and those who cannot may thus widen due to portal design adjustments derived from co-creation and user-testing. Consequently, instead of contributing to a more equitable healthcare system, co-creation in patient portal deployment might jeopardize equity by neglecting diversity aspects and thus missing the view of sub-groups of potential end-users whom would benefit from portal use.

4. Methodological considerations in co-creation and user-testing of patient portals

To tackle the barriers of older patients in patient portal use and to optimize patient portals functionalities in such a way that they are beneficial to older disadvantaged patients, we propose three main methodological considerations in co-creation and user-testing of patient portals: 1) diversity in co-creation and user-testing participants; 2) efforts to stimulate participation of disadvantaged patients and 3) research into the contextual issues surrounding potential end-users to validate proposed information needs, functionalities and benefits.

4.1 Diversity in co-creation and user-testing participants

To better understand the intrinsic aspects to barriers of older adults in patient portal use and adoption rates and to tackle these barriers in (future) patient portal developments, diversity in co-creation and user-testing participants is needed. Older and younger patients differ regarding their information and communication needs, which is relevant to the design of information and communication functionalities of a portal. For example, older people need more time to recall information that is presented via digital text compared to younger people [36] and unfulfilled information and communication needs of older (oncology) patients influence their quality of life more negatively compared to younger patients [37]. Regarding such aging differences, we identified four main aging barriers by means of a scoping review that may make it difficult for older people to use eHealth and mobile health: cognition, physical abilities, perceptional and motivational barriers [38]. In addition, medical conditions, for instance diabetes or a stroke, may serve as a catalyst to increase these aging barriers [38]. Since most EHR patient portals serve a broad target group, it is important to create an inclusive design of interfaces and functionalities that is appropriate to a variety of users, both younger and older as well as with a diversity of medical conditions and knowledge about these conditions. For both co-creation and user-testing it is therefore important that the principles of Human Factor Engineering are pursued, in which the significance of including *representative* samples of end-users in the design process is stressed [33] and that an appropriate mix of participants is present in order to ensure representation of all stakeholder groups and interests in reflecting upon how healthcare aspects can be improved [39]. For example, a recent user-testing study including older patients with various health literacy levels, showed that their design solution of presenting health information in an audiovisual format, bridged the information processing gap between the low and high health literate participants [40]. The recall differences on the presented health information between the two groups were eliminated, whereas the presentation format did not negatively influence high health literate audiences [40].

4.2 Efforts to stimulate participation of disadvantaged patients

In our experience it is difficult to reach this type of diversity in these patient participation activities. In current co-creation and user-testing activities in relation to patient portal use, there are implicit expectations of participants. They have to be able to eloquently speak their opinion on healthcare services, their role in self-management and the role of physicians therein. Furthermore, they should be able to reflect on and express their ethical values regarding (improving) healthcare. If physicians are part of the co-creation activities, the patient's motivations and capacities should be strong enough to refute those of the physicians, who are often still regarded as a higher authority. Such physicians often want to collaborate with patients to hear their specific needs and beliefs, as opposed to what providers think from their own mental framework what would suit patients best. However, regarding patient participation in general, it may be difficult for patients to articulate their emotions and concerns due to, for instance, fears of burdening their provider or disrupting the therapeutic alliance [41]. As a consequence, less autonomous and disadvantaged patients are less likely to participate in these processes and a diverse group of participants is not easily reached. We therefore encourage organizers of such activities to put effort and time into reaching out to older and disadvantaged patients to include them as participants and to help them being able to participate effectively. This can be done by providing communication skills training to participants, similar to such trainings that are given to promote patient participation in healthcare interactions [41]. Although communication skills training targeted at patients' active participation behavior may not be appropriate for every patient, we nevertheless advise to consider such a training in co-creation activities since it can help to give patients essentials skills in expressing their emotions and concerns that they would normally not easily disclose [41]. Furthermore, in-service courses can be provided to patient portal (software) developers regarding how to best perform co-creation and user-testing activities with older patients and how to adjust portal designs to their needs thereafter.

Several studies have reported on lessons learned while conducting intervention research with these populations, of which several are valuable for performing co-creation research [42-43]. It is important to have a stable point of contact for study participants within the development team, who communicates with the participants frequently and consistently during the project to avoid participant loss [42]. For the participants to openly express their health lifestyle and (digital) needs and to support appropriate self-disclosure, it is particularly important for the team to remain non-judgmental and to build trust [42-43]. Participants might additionally come to see the development team as a resource for solving problems that may not directly relate to the co-creation project; therefore it is important to define the scope of the project and to prevent the blurring of roles throughout the project [42]. These aspects seem to call for multidisciplinary teams that can optimally support and stimulate participation of disadvantaged older patients.

4.3 Research into the contextual issues surrounding potential end-users

Co-creation or user-testing requiring the participation on location of sample populations, such as 'lab' or 'creative workshop' sessions, can be an extra obstacle for some patients. In addition, these settings provide little sight on how patients use a portal in their own context at home and during their daily life. Other co-creation techniques are focused on obtaining information from participants in their own habitat. Studies have asked participants to keep a diary on their experiences in using a digital health tool or went to their homes to perform interviews on web-based self-management support [44-45]. By this means data on the natural context of use is collected, which is an important design consideration when designing for older and disadvantaged patients [33]. For example, in a natural context it might become apparent which types of connectivity problems exist and which assistance and training on patient portals use is needed to support meaningful use by older patients. In addition, it is important to engage family caregivers since they often act as a proxy to older (disadvantaged) patients. A literature review by Byrne commissioned by The Change Foundation shows that the needs of family caregivers and co-creation involving caregivers were often the springboard for development of (digital) support initiatives to engage caregivers and healthcare providers [46].

5. Conclusion

With healthcare organizations' efforts to expand patients portal functionalities, they aim to improve the quality of care for patient groups who frequently need healthcare services. In this reflective exploration on ethical aspects related to patient portal development we argue that present barriers of vulnerable patient groups, such as disadvantaged older adults, seem to be overseen in current patient portal designs. These patients' connectivity obstacles, old

age and multiple (chronic) diseases as well as disease specific barriers to technology use and context-of-use issues, hamper their chance to benefit from patient portal use. Patient participation activities, such as consumer co-creation and user-testing, to advance patient portals can address those barriers, yet currently there is an under-representation in participation of disadvantaged older patient populations in these efforts. As the phase of pilot projects with patient portals has passed and the deployment of portals is maturing, the decision-making and investments process on further advancing patient portals' incorporation in healthcare practices will take place in the upcoming years. To encourage researchers, policy makers and patient portal developers to use this momentum for including older patients' abilities, needs and context in portal use, we proposed three methodological considerations:
1) diversity in co-creation and user-testing participants; 2) efforts to stimulate participation of disadvantaged patients and 3) research into the contextual issues surrounding potential end-users. Further research in this field would be of great help in improving methods on how to overcome challenges of co-creation and user-testing with older patients regarding eHealth systems. Insights on this matter are highly important in advancing patient portals to the needs and characteristics of older patients and ultimately for patient portals to reach their aims in improving quality of care for these patients.

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Chapter 9

How to approach user-based testing of eHealth with older patients: insights from an expert-based workshop

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Journal of Biomedical Informatics
Submitted

Abstract

Background: Involving representative participants in user-tests of eHealth is a central aspect of user-centered design approaches of (new) eHealth interventions. Older patients might especially benefit from these interventions. Yet, barriers exist that hamper adequate user-testing with this user group.

Purpose: To create awareness on how aging barriers influence the performance of user-based evaluation studies and to propose recommendations on how to perform user-tests of eHealth suited for older patients.

Methods: A consensus-seeking process was performed based on an expert workshop, where experiences and insights on how characteristics of older patients influence (usability) evaluation studies and user-testing were shared.

Results: In total, the experts provided nine recommendations for user-testing of eHealth with older patients. Three main themes were identified: 1) empathetic approach and trust-building; 2) new requirements to testing and study design and 3) adjustments to user evaluation methods for testing with older patients. The overview of recommendations gives support and advice on aspects needing attention at the design, planning and execution phase of user-based evaluations of eHealth with older patients.

Conclusion: The recommendations presented aim to support the performance of user-testing of eHealth interventions with older patients to ultimately enhance the usability and effectiveness of these innovations. Application of these recommendations in practice will enhance execution of user-testing studies on this matter, and ultimately lead to a better eHealth design quality. These recommendations are an important step towards building stronger evidence on usability of health innovations for older patients, key for sustainability of eHealth amongst this target group.

Keywords: user-based evaluation, methodology, elderly, eHealth, Think Aloud protocol

1. Introduction

To support the aging population, the interest and development of eHealth technologies for older patients is on the rise [1-2]. Such eHealth interventions, including mobile health (mHealth) and digital health devices, are increasingly being designed to assist older patients in independent living and self-management of (chronic) illnesses. These interventions may for example provide medication assistance by prompting alerts, provide self-care advice for diabetes patients, assist heart failure patients in monitoring their blood pressure, promote independent living as well as identify and alleviate fall risk factors [3-5]. In the development of such eHealth interventions, existing research recognizes the critical need to involve older end-users to ensure high usability and alignment of the eHealth intervention within the actual user context of the older patient [6-7]. Perceived usability and usefulness are of importance to allow for sustainability of eHealth interventions for older patients, as shown in a recent scoping review on mHealth advances by Matthew-Maich et al [6]. This review indicated that an intervention will not be used if it is perceived to be "more trouble than it is worth" [8-9], too time-consuming [10], unreliable [8], or generally burdensome [11-12]. Taken together, there is a potential of innovative eHealth interventions to support successful management of chronic conditions and health behavior. However, most publications mainly show case studies on pilot implementations or systems' feasibility assessments [3], whereas especially regarding mHealth, usability barriers to sustainability have limited the number of successful and evidence-based interventions for older patients beyond this pilot or feasibility stage [6].

A range of usability engineering methods (UEM's) can be applied to provide sight on the user interface and/or functional problems end-users encounter when interacting with a system. Involving end-users within UEM's can be done by means of user-tests, in which problematic issues in the design of a tool or technology are identified by end-users. Amongst others means, user-tests can consist of usability tests, interviews and surveys. Using such UEM's can improve eHealth, mHealth and medical device designs as these methods aim to align them with needs and characteristics of their user population [13], given that they are applied with participants that are representative to the intended user group of the eHealth intervention. However, a main challenge faced by research and development teams in performing user-tests with eHealth interventions for older patients, is to involve a representative group of older patient participants in user-tests. Examples of barriers that have been observed in previous research on this matter firstly report that it proves to be difficult to recruit older participants for user-testing within the project timeline [14], since older patients' willingness to participate in such studies seems to be low. Secondly, age-related and disease-related barriers may pose limitations to include older patients for user-testing. Older patients often have multi-morbidity related physical and perception impairments, such as problems with the eyesight, deafness [15], or more severe disabilities related to stress induced factors that could make inclusion of older patients difficult. Cognitive or physical impairments may also lead to being excluded from user-testing as patients might not be able to attend the evaluation sessions. Excluding older patients with these impairments is a major problem in performing accurate user-testing to assess the usability and effectiveness of eHealth interventions, since then these interventions are not tested with participants that are representative to their intended user group. This is especially of concern when these interventions are aimed at chronically ill patients, considering that important user-context issues such as the age-related and disease-related impairments, for example eye-sight problems of diabetes patients, which influence the eHealth intervention's use might then remain under-recognized.

When older patients are nevertheless included in user-tests, cognitive impairments pose further limitations to the performance of a well-known technique performed during user-testing: the Think Aloud protocol. This method provides a unique source of information on cognitive processes in many cases: it generates direct data on the ongoing thought processes during task performance [16]. As such, this methodology relies heavily on the cognitive capacities of participants, such as communication, attention and speed of comprehension, whereas it is exactly these cognitive capacities that decline with aging. These cognitive skills, especially attention, are deeply solicited by the Think Aloud protocol, preventing people with cognitive limitations such as older patients to have sufficient remaining attention for using the product under evaluation. These barriers to inclusion of representative older patient participants in user-testing and execution of these tests with them, might lead to solely considering the needs of (younger or more autonomous and less disease-dependent) patients who are more easily involved in user-testing. As a result, eHealth interventions might remain cumbersome and ineffective in use for (chronically ill) older and less autonomous patients.

Although the need for applying user-tests as a central aspect of user-centered design approaches in eHealth development and evaluation is thus clear, little attention has been paid to the above mentioned barriers of older patient participants and on how to adapt user-tests to such barriers. New evaluation studies and trials on eHealth interventions could benefit from an overview of methodological recommendations on this matter that can be applied within their eHealth development context. This paper therefore gives an expert-based overview of recommendations to user-testing UEM's that are adapted to user-testing with older patients with the ultimate aim to improve the alignment of the evaluated eHealth technology to older user populations.

2. Methodology - Expert workshop

A workshop was held during the 18th Medical Informatics Europe Conference, where health information technology (HIT) evaluation experts were invited to funnel the expertise on user-testing studies on HIT involving older patients. The workshop project was endorsed by the EFMI Working Group on Human and Organizational Factors of Medical Informatics (HOFMI). The aim of the workshop was to share experiences and insights on how characteristics of older patients influence user-testing, and to jointly propose methodological approaches via a consensus-seeking process to improve user-testing with older patients.

The level of expertise of the participants was assessed based upon the number of relevant experiences and publications in the field. Participants were divided in groups during the workshop, where each group contained multiple senior researchers to ensure a sufficient level of expertise per group. Each group addressed one main perspective in relation to older adults' involvement in user- testing, respectively: eHealth, mHealth and medical devices and was hosted by one of the authors. The groups were provided with a persona of a typical older patient (65+ years old) by the host. Each group discussed what participants' thoughts were on how to overcome barriers to user-testing with older patients and thus how to best approach user-testing with this population. In each group, participants started answering these questions by writing their answers on index cards, which were collected and pinned onto a pin board. Each participant explained for his or her cards what the answers entailed. The role of the host was to rekindle the discussions, as well as to help participants synthesize and structure their answers. Once all the index cards were collected and discussed, participants clustered them in a joint effort guided by the host. Each card stating a barrier was discussed among the participants regarding its relevancy to the usability methodology cards. For instance, whether the statement fitted with mentioned problems, or whether it represented a new idea that would provide a recommendation for adapting existing methodology or provide a new approach to HIT evaluation with older patients. A plenary discussion was then held by the groups' hosts on overarching themes and proposed recommendations on appropriate methodologies that were put forth by each group. The workshop was finalized by gaining consensus on the recommendations provided.

3. Results

Table 1 shows the experience level of the workshop participants per expert group. In total 10 participants joined the workshop, of which 7 had a high level of expertise. Table 2 shows the themes that emerged during the group discussions, in which groups these themes were mentioned and which barriers to user-testing with older patients would be solved. Despite the different topics addressed in each group, the resulting themes mentioned were similar across the groups. The results are therefore explained per main theme in section 3.1 to 3.3, respectively 'empathetic approach and trust-building', 'new requirements to testing and study design' and 'adjustments to UEM's for testing with older patients'.

3.1 Empathetic approach and trust-building

All expert groups mentioned it was especially important to have an empathetic approach towards the older patients throughout the whole scope of the evaluation project. This approach is of importance in order to build trust; if the older patients trust the evaluators it is more likely they will share their true experiences with the eHealth intervention. Aspects mentioned as part of this approach are: giving attention to the patients, listening to them and making them feel comfortable. It is important to understand that usability testing for older patients is a social experience, not just an experience where researchers get new information on for example an interface design. Experts agreed that such an approach would increase older patients' motivation to participate in user-testing and their genuineness in expressing experiences with the tested intervention.

3.2 New requirements to testing and study design

Experts coincided that setting additional requirements for the testing phase would benefit the quality of the test to be performed. In doing so, pre-testing would be a new phase in the planning and performance of the evaluation study. The experts expressed that pre-testing could lead to easier recruitment of older participants, more accurate inclusion and exclusion of older participants as well as provide sight on which contextual issues and organizational aspects might need to be (re)arranged to perform user-tests that are adapted to the aging needs of the participants. Overall, four add-ons to plan and perform a usability test with older patients were specified by the experts in the groups. A prerequisite foremost to older patient participation and stated by all expert groups was: 1) ensure pre (beta)testing. It is essential that the technology is 'bug' free, to prevent older participants' early withdrawal during a test. Even in testing during an early design phase, focus is needed on minimal complexity for older participants when interacting with the interface to prevent the burden of stress. Next, 2) to support older participants in feeling confident throughout the whole scope of the evaluation process, involvement of their family and caregivers in a contextual setting is considered useful. Having a family member or friend present during the test is likely to support the older patient and again will reduce stress and enhance comprehensibility of the evaluation tasks to be performed by participants. In addition, suggestions were given by the experts on performing certain methods in user-testing such as interviews or surveys with the family members as well, i.e. an interview with both a family member and the older participant present as well as interviews separate from each other. Direct involved caregivers such as nurses are additionally recommended to be part of the evaluation team: they are a consistent factor and contact person for the older patient and can help in making older patients more comfortable during participation in user-testing. According to the experts an 3) intake meeting and 4) context analysis of patient characteristics that are specific to the actual use of the eHealth innovation may help to gain sight into the organizational aspects that developers need to take into account during the user-test. Experts mentioned that in performing such analysis, it could be helpful to use a theoretical framework that recognizes age-related and disease-related barriers possibly influencing eHealth's use, such the MOLD-US framework [15]. The MOLD-US framework, mHealth for older users, provides a visual and accessible overview of motivational, cognitive, physical ability and perception barriers to eHealth use; and more specifically to mHealth use. According to the experts it can be used as a guide to recognize these aging barriers in the context analysis.

3.3 Adjustments to UEM's for testing with older patients

Experts mentioned several adjustments of current used-based evaluation methods to improve testing with older patients. First, conduct a usual user-test yet adapt the instructions and locations for testing to the older patient participant. These adjustments focus on recognizing cognitive barriers of older patients by adapting the length of the test and the set-up of the test. For example, instead of having one longer usability test session in which several tasks are evaluated, a set of multiple short sessions can be performed. Where each session consists of one brief task, followed by a brief interview to obtain relevant information from the participant on that task. Usability evaluations likewise can be performed in a set of several evaluations in for instance a week's time. This allows for an unrushed execution of usability tasks. During the evaluation(s) it can be emphasized multiple times that any interaction the participant has with the intervention is correct; explaining that the design of the intervention is being tested instead of how well the older participant uses the intervention. Experts further stated that is important to frequently emphasize why the older patient's involvement in this type of research is important. In doing so, the social impact can be explained and the difference between (the scope of) the research project and care activities can be addressed in more detail. Older patients may not be aware of this difference and may have trouble understanding research activities. Another adjustment, related to the comfort of older patients, is to explicitly explain them why the evaluation might be recorded and to only record after patients' consent while avoiding recordings of patients' faces. Other recommendations here related to the location of the evaluation. As a golden standard it was described that evaluators should go to the homes, the usual physical environment, of the older participants to perform the evaluations or to shadow the patient there for a short period of time. If this is not possible, it was mentioned to perform user tests in 'living labs', laboratories fully equipped with camera and microphone to observe the behavior of the participants and whose layout reproduce the setting of an older person's physical environment. For example, living labs can consist of older people equipped apartments or even elements of cities that closely mimic or represent how older people experience that environment. Performing evaluations at settings that are unfamiliar to older people or look like a (clinical) lab or office atmosphere, should be avoided.

Other adjustments aim to adapt the user-testing method to allow for collective testing. These main additions were related to the social aspects older participants experience when acting as participants in usability evaluations. In the Think Aloud usability evaluation, the participant get user-tasks to perform in the eHealth intervention, such as 'go to appointment schedule and find the time of a hospital appointment'. The participants then needs to verbalize the interaction steps he/she is taking in the eHealth intervention to perform that task. This is done individually by the participant, which might put the older participant under pressure and also might not coincide with their actual use. Therefore, as a variant to an individual user-test including the Think Aloud method, the 'peer discovery' method was suggested. In this variant, the older patient participant can interact with the technology together with a family member or caregiver. The idea behind this approach is that they can help each other during the Think Aloud as they would in their personal context. When peers work together they express their impressions, frustrations, and thought processes more naturally; therefore, this variant yields a clearer picture of how a technology is used and where users struggle. In relation to this, experts mentioned the concept of 'peer community' user-testing as an addition to UEM methods. In this variant the older patient participant can use the technology together in a group setting with other older patient participants, again to stimulate a more natural expression of their impressions, frustrations, and thought processes in interacting with the eHealth intervention. Lastly, suggestions were given to use a different method than user-testing: shadowing, observing an older patient's use of the evaluated eHealth technology in his/her own environment for a period of time. Experts expressed this may give more accurate sight on their daily interactions with the eHealth intervention as well as causes to moments when the technology is not used.

Table 1: *Overview of workshop participants' experience per group*

Workshop group	Title	Amount of papers published (author/co-author) in field of user-testing in healthcare
1) eHealth	Professor	> 80
	Senior researcher	> 20
	Junior researcher	-
2) mHealth	Professor	> 80
	Professor	> 80
	Senior researcher	n.a.
3) Medical devices	Professor	> 30
	PhD candidate	< 5
	Senior researcher	< 5
	Junior researcher	-

Table 2: *Themes and recommendations on user-testing with older patients, applicability in phase of test italicized.*

No	Theme/sub-theme	Mentioned in group	Key elements mentioned by experts	Addressed barriers
1.	Empathetic approach and building trust *Total scope of project*	eHealth mHealth Medical devices	- Trust of participant towards evaluators of importance - Making participants feel comfortable - Prevent stress of participant during evaluation	Patients' motivation to and genuineness in expressing experiences
2.	Pre-testing and study design *Pre-test phase*			
2.1	Beta testing	eHealth mHealth Medical devices	- Analysis of beta eHealth technology on alignment with intended user goals (possibly through observations) - Perform a beta test to ensure eHealth technology is bug free	Patients' motivation to test and continuity of testing
2.2	Involving family and caregivers	mHealth Medical devices	- Recruitment of participants via family or caregivers - Include family and nurses as part of participants in evaluation interviews (together and separate of older patient participants)	Recruitment of patients
2.3	Intake and older participants' capacities and skills	eHealth Medical devices	- Intake meeting at home of participant before test	Aging barriers to inclusion or exclusion of patients
2.4	Analysis of patient characteristics and context specific to user-test	eHealth mHealth Medical devices	- In-depth needs analysis of participants' social context and physical environment - Assessment of cognitive, perception and physical abilities - Specify user- and organization requirements needed for usability evaluation	Aging barriers to be recognized in organization of user-test

No.	Theme/sub-theme	Mentioned in group	Key elements mentioned by experts	Addressed barriers
3.	Suggested adjustments to UEM's for testing with older patients *During test phase*			
3.1	Peer discovery	mHealth	- eHealth technology is used together with a peer (i.e. family member)	Patients' motivation to test
3.2	Peer community session	Medical devices	- eHealth technology is used in a group session with other older patient participants	Patients' motivation to test
3.3	Living lab	eHealth Medical devices	- Resemble physical environment of patients to perform test (if test cannot be done in actual home)	Diminishing contextual barriers influence on results of test
3.4	Adapted instructions and guidelines	Medical devices	- Attune evaluation set-up to cognitive capacities of participants - Have brief tasks, each followed by short interview - Perform several short evaluations in for instance a weeks' time - Record only relevant information and explain why evaluation is recorded - Emphasize importance of participants' involvement	Diminishing cognitive barriers influence on results of test Patients' motivation to test
3.5	Shadowing	mHealth	- Observe how patients' uses eHealth technology in own environment for a period of time	Diminishing contextual barriers influence on results of test

4. Discussion

The recommendations provided in this paper to user-testing with older patients, aims to support evaluators, healthcare professionals, decision makers, software developers and other HIT stakeholders in performing user-based evaluation studies of eHealth interventions for older patients. The overview gives support and advice on aspects needing attention at the design, planning and execution phase of these evaluations. The recommendations in the overview have been developed through a consensus-seeking process during an expert workshop in which experiences and insights on how characteristics of older patients' influence user-testing were shared. By sharing these expert experiences and by exposing current issues on this matter, this paper aimed to contribute to creating awareness on aging barriers influencing the performance quality of user-based evaluation studies. The recommendations in this paper further aimed to raise the level of quality of user-based evaluation studies and thus to contribute to the accumulation of the scientific evidence base for eHealth interventions.

4.1 Benefits of proposed recommendations to redesigns

The recommendations can be applied to any eHealth user-based evaluation involving older patients to support a user-centered design. Insights from user-centered design processes with older patients may improve various design aspects that are especially relevant for perceived usability and usefulness of a product by older people [17]. For example, the presentation of information can be adjusted in such a way that is easily readable and interpretable by older people. This includes how to best present texts, buttons and icons as well as their dependencies; creating a clear distinction between texts, buttons and icons. Further, the navigational levels of an interface design can be adjusted such that it is compatible with older people's cognitive capacities. Another important design aspect of older people's technology use is related to how they should use a device to enter and review data, for example minimizing the number of steps to take in doing so and ensuring consistency in input/output features [17]. This is particularly relevant for minimizing older patients' burden in obtaining an overview of multiple data devices or sources, such as data from multiple healthcare organizations, and maximizing the interoperability between eHealth interventions and medical devices used by older patients. In addition, older people indicate that they prefer clear instructions and support in using technologies and eHealth [17-18]. It is highly assumable that applying the recommendations of this paper to user-testing with older patients, can improve insights on how to best design these aspects of information presentation, navigational structure, interoperability design and clarity of instructional support for older (chronically ill) patients. To assess the validity of the recommendations on this matter, as well as on their clarity and completeness, we encourage researchers and eHealth developers to report on how they integrated these recommendations in their application and use in user-tests with older patients. We advise to involve a multi-disciplinary team in doing so; not only consisting of Human Factor researchers and eHealth IT developers, but also of healthcare professionals and geriatricians. Especially the latter can provide more sight on the older patient population and may provide in-depth knowledge on the age-related and disease-related barriers as mentioned in the MOLD-US framework [15]. This is relevant to possibly expanding the identified issues of this population to user-testing and further developing the overview of recommendations to solve such issues.

4.2 Proposed recommendations aiding representative project management

Some of the recommendations emerging from this expert workshop relate specifically to project management of user-based evaluations. Recommendations mentioned, such as performing a thorough beta-test, undertaking an intake meeting and an assessment of older patients' capacities and skills, observing or shadowing the participants and having multiple test moments, are especially labor as well as time intensive. Furthermore, an intake meeting to assess older patients' capacities and skills might give sight on their limitations to participate, such as mobility issues when participating in user-tests and evaluations on location. Often these issues are encountered during the execution of the project, leading to higher expenses and/or a delay in the project timespan. The recommendations given in this paper can therefore help in the set-up of a representative project management plan at the initial phase of a new eHealth development. For example, by taking these recommendations into account in listing the staffing resources and budgetary aspect of a project proposal, such as allowing the budget to reimburse taxi costs of participants, aids a more accurate estimate of project costs. Regarding the length of a project involving end-users in user-centered design processes, previous research has shown that the contribution of end-users significantly altered the ultimately designed technological intervention from the initial prototype. Yet as a consequence of end-users' involvement, it took longer than expected to develop the intervention [19]. User-testing with older patients requires more time than user-tests with younger populations due to the added elements during the preparation and execution phase of the test, such as the intake meeting or performing several test sessions instead of one. It is thus likewise important to allocate a sufficient timespan in the initial project proposal to iteratively redesign the intervention based on the end-users insights gained through the user-tests. Paradoxically, both financial resources and sufficient development time is scarce in eHealth development projects. We nevertheless want to make a plea for investing finances and time for the involvement of older end-user participants in a user-centered design process. This can improve the quality of user-based evaluation studies leading to accurate redesign solutions, ultimately improving the success rate in uptake of the eHealth intervention for this target group.

4.3 Challenges of proposed recommendations related to standardization in user-testing

The proposed recommendations in this paper make an important contribution to the performance of UEM's for a specific user population. These insights on how to approach user-testing with older patients can lead to more accurate insights resulting from such tests, improving eHealth designs for older patients as well as the project management approach to involve patients in the development of eHealth, as is described in section 4.1 and 4.2. Nevertheless, the proposed recommendations are challenging to standardization in user-testing. User-testing research, specifically usability research, is strengthened when scientific requirements are met that aid reproducibility of the user-test, such as a standard means to execute the research or using validated usability questionnaires to gather data [20]. As this paper argues, requirements of standardized user-testing in eHealth pose constraints and limitations to older patient participants, resulting in less valid and valuable data on usability of the eHealth technology under evaluation. Yet, by not complying with scientific requirements of standardization in eHealth user-testing, a comparison overtime and with other eHealth technologies on usability for older patients may become problematic. In user-testing studies with older patients we suggest paying special attention to finding the balance between scientific constraints of user-testing and barriers in older participants' participation. Future research is therefore recommended on how to empirically compare standardized user-test results of eHealth in which older patients participated with user-tests performed via these recommendations on performing user-tests with older patients.

5. Conclusion

A comprehensive overview of recommendations to user-test evaluations of eHealth with older patients has been developed by means of experts insights. The overview contains nine recommendations, related to the pre- and execution phase of user-test studies. These recommendations facilitate eHealth evaluators and stakeholders in eHealth development regarding recruitment as well as in- and exclusion of older participants to user-tests. Further, the results of such studies will become more robust when the recommendations are applied, contributing to an important step towards evidence-based eHealth for older patients.

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Chapter 10

General discussion and conclusion

This thesis aimed to provide new insights on needs and use of mHealth and patient portals by older patients, with the overall aim to improve patient-centeredness for these patients within the development and evaluation of eHealth. In particular, this thesis:

1. Synthesized knowledge on older adults' use of mHealth and patient portals and provided a structured overview of barriers and facilitators identified in scientific literature;
2. Validated identified barriers and facilitators by means of case studies with (chronically ill) older adults to give sight on relevant factors influencing mHealth's and patient portals' development and use;
3. Explored user-centered design methods with older adult patients to enhance eHealth's effectiveness.

In this chapter the principal findings will be discussed via the themes of this thesis, respectively for mHealth (part 1, focusing on aim 1 and 2), patient portals (part 2, focusing on aim 1 and 2) and methodology (part 3, focusing on aim 3). Per theme, an overview of practical implications and recommendations is given on how to improve patient-centeredness for older patients in a digitalizing healthcare context. This is followed by the general conclusions of this thesis and directions for future research.

Part 1: Current mHealth designs for older adult patients

Principal findings

A synthesis of the literature **(chapter 2)** provided an in-depth exploration of the aging barriers influencing usability of mHealth. Based on this synthesis, a framework was developed of four influencing aging barriers that may negatively impact older adults' interaction and communication with mHealth interfaces and functionalities; cognitive, motivational, physical abilities and perceptional barriers. The MOLD-US framework, mHealth for older users, provides a visual and accessible overview of these barriers. It can be used for systematic empirical testing and analysis of mHealth usability issues, as it enables results to be classified and interpreted based on impediments intrinsic to usability issues experienced by older adults. To assess the usefulness and utilization of the framework in classifying usability results, usability evaluations were performed on two mHealth case-study apps for older adult patients **(chapter 3)**. Usability issues of older adult patients interacting with the two apps were identified by using the think-aloud method; in total 28 high severe issues were identified. Aging barriers intrinsic to these issues were then classified by means of MOLD-US, through which it was found that half of the issues were provoked by motivational barriers, such as a patient's low knowledge on how to use unknown smart device functionalities or a low trust in one's own capacities in doing so. One-third of the issues were provoked by cognitive barriers; for example, users did not know how to return to previously shown relevant information due to an unclear hierarchy in the apps. This research further shows that existing knowledge from user interface guidelines on perception, cognitive and physical ability barriers of older adults is currently not applied to the fullest in designing mHealth interfaces. Aging barriers might additionally influence end-users usability evaluations performed with older patients. Specific adjustments to these methods are recommended so that they become better suited to user-testing with older adult patient populations. Part 3 of this thesis therefore examined methodologies used to develop and evaluate eHealth from the perspective of older patients and provides recommendations on these kind of adjustments.

Practical implications and recommendations

The insights resulting from part 1 of this thesis can aid project teams during the development and evaluation of mHealth for older patients, particularly regarding the specification of requirements, analyses of usability issues and creation of interface (re)design solutions. To prevent usability issues for older patients in the use of mHealth, it is important to apply existing guidelines on how to best design interfaces for older people. For example, by distinguishing buttons from other visual display features in the interface design and by creating consistency in navigational structures, aligned with expectations of older patients. Further, clear instructions as well as feedback messages should support an older patient when the patient has made an interaction error while using an app. These insights have foremost shown that usability is especially important within the older adult user context of mHealth as aging barriers may influence usability of mHealth negatively. mHealth designs will be more apt to older patients' needs when the development of mHealth is realized from a user-centered design (UCD) perspective, as is described in part 3 of this thesis. Using such an approach and adjusting mHealth designs to aging barriers may result in more natural interactions and communication patterns of older patients with the provided mHealth functionalities. Presumably, more natural interactions and communication patterns will enhance older patients' possibilities and willingness to engage with mHealth. Such engagement with mHealth will allow them to take advantage from mHealth use, such as taking control in managing their health by monitoring their own biometrics, leading to improved patient-centeredness and care benefits.

In the development of mHealth services, researchers are thus encouraged to thoroughly analyze usability issues and consequences of these issues in relation to older adult users. Based on this thesis' insights we further suggest to (re)design mHealth based on the outcomes on older adults' needs and capacities accordingly. The MOLD-US framework provides a reference model for these activities. The overview presented in MOLD-US of older adults' (medical conditions related to) degradation of sensory, physical and cognitive abilities can assist researchers in setting inclusion criteria of study participants, assuring representativeness of the overall user population, and selecting specific usability metrics relevant to user-based usability testing by the user population. MOLD-US further adds value to existing classification tools used to interpret usability testing results, because it is unique in integrating aging barriers and categories of usability aspects that (may) influence user-experience. This framework can thus be used to classify and interpret usability issues based on older adults' impediments intrinsic to these issues and contribute to creating awareness on aging barriers and disease complexities of older adults amongst stakeholders involved in mHealth development. In creating awareness on these aging barriers, we emphasize to mHealth development teams to be aware in general that motivational barriers to the use of mHealth are a central issue in the user-experience for older patients. Despite older adults' interest in using smartphones and tablets, most of them indicate they need support in the process of learning how to use new (functionalities on) smart devices. This is especially relevant within the context of mHealth, which often involves using functionalities that are new to older users, mostly paired with using multiple smart devices, such as a blood pressure monitor connected to a smartphone. To lower the motivational barriers of older patients in using these innovations, we endorse the use of clear instructions on how to use the technology. We advise to create instructions that are easily comprehended by older patients with declining cognitive and visual perception skills, as well as speak to patients with no decline in cognitive skills. This can for instance be done by using animated videos combined with spoken word. These communication means are explained in more detail in the recommendations given in part 2. We likewise advise to ensure the availability of reliable and accessible technical support that can answer questions that older patients may have regarding the technology. General strategies accepted by industry, suggest to answer users' ad-hoc questions on a technology via computer-generated chats. Such chats make use of artificial intelligence in responding to the users' questions. Taken together, the results of this thesis suggest that such strategies might not be applicable to helping older patients in the use of mHealth. Providing older patients with a technological solution to answer questions on (motivational) problems they experience in the use of a technology, may have a counter-effect in actually helping these patients. Therefore, the advice based on this thesis is to provide technical support to older patients' use of mHealth by means of a support team that is available to patients per telephone and/or in-person. Further, we advise to involve older patients in co-creation and user-testing activities in order to optimize the usability of mHealth innovations. Methodological considerations on how to adjust these activities in order to involve older patients are described in part 3 of this thesis.

Recommendations - improving patient-centeredness by adjusting mHealth designs to older adult patients:

- Specify age clusters of the target group of an mHealth innovation;
- Analyze aging barriers possibly influencing usability of an mHealth innovation (MOLD-US framework can be used as guidance);
- Use insights and knowledge from existing guidelines on how to design mHealth for older adult patients [1-3];
- Take motivational barriers of older adults into account in designing mHealth by creating a forgiving interface design and by providing a reliable and accessible technical support team that can answer questions that older patients may have regarding the mHealth product.

Part 2: Patient portal use by older adults

Principal findings

To get insight into what inhibits and stimulates older patients' use of patient portals, literature on barriers and facilitators to older adults' patient portal use was synthesized **(chapter 4)**. After an extensive search process, 8 out of 245 potentially relevant studies were included. Factors were classified by textual analysis of the included studies via the themes of the Unified Theory of Use and Acceptance of Technology (UTAUT) model. This study reported that a main barrier consists of a lack of facilitating conditions, such as limited access to technology and internet or privacy and security concerns. Another barrier is involuntariness to use a patient portal as some patients prefer face-to-face contact with their physician and patients may have a limited health literacy. Main facilitator to portal use was patients' expected usefulness of patient portals; older adults appreciated a means to have access to their own medical data for reviewing their health problems and overseeing the planning of appointments. Patients with a positive attitude towards patient portals further find the beneficial aspect of being able to digitally ask questions to their treatment team via a patient portal appealing. These identified barriers and facilitators were evaluated in a case study on experiences of older adult patients with the use of a patient portal implemented in the Amsterdam University Medical Center **(chapter 5)** and a cross-sectional study with two large Dutch patient associations on preferences of chronically ill patients on patient portal functionalities **(chapter 6)**. Main facilitators from the literature review were confirmed: reviewing medical information and appointments via a portal is indeed experienced as useful by older patients, as is being able to communicate via a portal with their healthcare providers. In doing so, older patients prefer to have multi-provider access, across different healthcare organizations. Yet, overviews of medical information do not have to be digitally exportable for older patients, since they prefer to print such overviews. Regarding the barriers to portal use, older adults experience usability problems, in particular at the authentication and login stage. Instead of preferring the most secure login method, which verifies the identity of users via a minimum of two security factors, older patients indicated their need for user-friendly access to portals and thus preferred using solely an username and password to log in. They further favor accessing a portal via a desktop instead of via smart devices. Additionally, reported barriers to portal use were related to patients' expectations regarding presented content and communication via a portal. A delay of two weeks to publish medical content in a portal is received negatively by older patients and patients expect a more extensive overview of medical content than solely their registered diagnoses, medications and allergies. Nevertheless, patients prefer a summary of the medical information presented in laymen's terms above a complete uncensored medical file. Furthermore, we showed that if there is no response to patients' sent messages via a portal, the option to communicate with providers via a portal becomes a barrier to patient portals in improving patient-centeredness; patients were currently dissatisfied due to unresponsiveness of providers on this matter.

Practical implications and recommendations

Continuous use of patient portals can increase the sense of patient-centeredness for patients, through having more control on their own medical data and by being able to digitally communicate with their healthcare team. The studies as described in part 2 of this thesis, have progressed knowledge on an effective strategy that could lead to higher continuous use rates of patient portals by older adults, relevant to the exponential growth of patient portals being implemented [4-8]. Study results from chapter 5 are consistent with those of other studies confirming that older adults are a large use group registering to patient portals [7], implying older adults' willingness to use portals. Nevertheless, adoption rates of patient portals by older adults seem to be low [7, 9-10]. Based upon our insights from part 2, this matter is approached from two perspectives: 1) older adults' readiness level regarding patient portal *technology use* and 2) older adults' digital needs regarding *healthcare communication*. Regarding the first technological perspective the focus is on tackling barriers, such as the lack of access to technology and internet in some circumstances as well as experienced usability problems. Regarding the second communicative perspective, the focus is on design solutions for digital communication with patients supplementary to patient/provider communication via a patient portal.

On older adults' readiness level regarding technology use, insights from the studies in part 2 show that the preferences and needs of these patients concerning patient portal use foremost seem to rely on solid and user-friendly access to basic functionalities of a portal. Technology and internet access among older adults are relatively high in The Netherlands [11]. Nevertheless, it is important to verify if the main target group of patient portals, chronically ill (older) patients, has access to up-to-date smart devices and reliable internet services. To illustrate, in The Netherlands chronic illnesses are more prevalent and more severe amongst low educated people and non-western migrants [12], often with a low socio-economic status [13]. Such contextual issues of the target group are important to bear in mind within the development and implementation of patient portals, since patients with a low socio-economic status often own outdated technology and their internet connection at home is poor [14]. This issue raises an intriguing question regarding how to minimize the digital divide in access to patient portals and eHealth in general. One solution could be to make the functionalities of an eHealth technologically available to older operating systems and devices. This would require reducing designs and functionalities of a patient portal that need 'state-of-art' technologies, whereas it are these technologies that can offer smart design solutions to current experienced barriers to the use of eHealth. An example of such a design solution is to use a patient's biometric data for login to prevent usability problems at this stage, as is described in the next paragraph. Another approach to make eHealth more accessible could be to provide (older) patients with the needed technology for eHealth in case they do not own this themselves. An investment on this matter may be worthwhile for stakeholders involved in lowering healthcare costs; foremost healthcare insurers and municipalities in a Dutch context, since they are key stakeholders in coordinating care and accompanying costs [15]. Dutch health insurers' current role in eHealth is related to reimbursement: applying an eHealth innovation as part of care can be reimbursed when proven to be appropriate and effective [16]. Paradoxically, evidence-based eHealth research on effectiveness in supporting improved health for older patients is jeopardized by under-recognizing barriers to eHealth use by this target group as is shown in part 3 of this thesis. By providing those patients who do not have the means with the needed technology for eHealth, Dutch health insurers could take a step in lowering a main barrier to eHealth use, ultimately increasing chances for its effectiveness. Within a broader perspective of *digital inclusion*, a similar plea could be made for Dutch municipalities. They can provide technological access to (older) people to minimize the digital divide and help civilians to become more self-reliant in our digital society as is likewise recommended by the municipality of Amsterdam [14]. A note of caution is due here, since a lack of technological access is not the only barrier of older adults to eHealth use. Providing technological access to these patients can work when combined with providing solutions to other issues these patients encounter in eHealth use, solutions such as adjusting the designs of mHealth to older adults' aging barriers as described in part 1 of this thesis and involving older patients in the development of eHealth, as described in part 3 of this thesis.

Similar to the insights discussed in part 1 of this thesis, studies of part 2 showed that an optimal usability is crucial to the user-experience of older adults in patient portal use. Adding to the practical implications from part 1 on this matter, we want to emphasize that user-experience of patient portals is further jeopardized by the variety of usability of different healthcare institutions' patient portals. Whereas older patients often receive care from multiple institutions and prefer to have a multi-provider overview on medical data, as is shown in chapter 6, portals are offered to patients as silos per healthcare institution. Each portal for example has its own type of authentication, login and functionalities. Current developments within the field of personal health records (PHR) support patients on this matter by creating a multi-provider overview in one digital environment [17]. These developments are supported and development teams within this field are encouraged to minimize aging patients' burden in obtaining a complete multicenter overview of their health data by creating interoperable systems. We encourage the development of authentication methods that are simplified in usability, yet safe in ensuring privacy, to provide easy access to such overviews. For example, by using a scan of a patient's face or voice during authentication and login, instead of probing older patients' decreasing cognitive and physical abilities in manually registering usernames, passwords and numeric authentication codes.

Regarding the communication processes supported by patient portal use, this thesis has shown that the beneficial aspect of portals in facilitating one-on-one patient/provider communication outside of consultation moments is a key driver for patient portal use by older patients. A possible explanation for this is that patients may feel to be placed at the center of their care if providers give an interpretation of the often complex health information published in the portal. However, for successful patient/provider communication via a portal, it is crucial to engage providers in responding promptly to patients' sent messages as well as to enable these providers to be able to do so during their work schedule. We encourage patient/provider communication via patient portals, yet it is best combined with smart design solutions to present and explain complex medical data and information in a portal in order to minimize the workload of providers in individually explaining health information to patients. One of these smart design solutions is to apply information processing theories in the presentation of complex, abstract or numeric medical content [18-19]. These information process theories, such as the duel-process theory, the duel-coding theory or the cognitive theory of multimedia learning [18-19], describe that several cognitive systems are involved in information processing, including intuitive processing and converting non-verbal information as well as analytical processing and converting verbal information. By stimulating a combination of these cognitive systems, information is processed more easily and more extensively [18-19]. In presenting complex medical data in a patient portal, video animations that explain the interpretation of this data by means of simple line drawings and spoken word could be used. A recent study on providing cancer screening information to older adults showed that such spoken animations are the best way to communicate complex health information to older adults with low health literacy, whereas they suit people with high literacy levels as well [20]. The spoken animations proved to be more effective in recalling the presented information and creating a positive attitude towards the message given, compared to solely non-animated illustrations [20]. Using this communication means may not only help the processing of information by older patients with diminishing cognitive skills, the spoken word may also help older patients with diminishing visual capacities; thereby providing a solution to two important aging barriers of older patients' digital health use as described in part 1 of this thesis. We thus advise to add context to textual and numeric data by using visual aspects, preferably animated and supported by a spoken explanation.

Another smart design solution to decrease complexity in the presentation of medical data and information, is to customize patient portals' functionalities to the needs and preferences of (older) patients and specific groups sharing similar patient characteristics. This is in line with the insights on older patients' preferences on this matter as described in chapter 6 of part 2, where it is reported that especially regarding medical information publication's timing and terminology, preferences differ per patient group. A means to enable sophisticated customizability is to create different user-profiles in a patient portal, each varying in which functionalities they offer to patients. It is best to tailor these functionalities per profile to the needs and preferences of specific patient groups, for example by using the UCD method of creating 'personas'. Such personas can correspond to different patient clusters, for example differing on health literacy level and type or stage of their disease, with various preferences for the presentation of medical data and information. By this means, profiles can differ in how and when they present this data and information. Providing customized user-profiles as well as apt presentation of contextual information to published medical content, is not only relevant to facilitate patient portal use; these formats can be applied to facilitate the use by older patients of any other eHealth services providing similar functionalities as a portal.

Recommendations - improving patient-centeredness by stimulating older adults' patient portal adoption:

- Tackle main barriers to older adults' patient portal continuous use by:
    - facilitating technological access to portals and portal functionalities for patients with a low socio-economic status;
    - providing multi-provider overviews, for example via a personal health environment;
    - simplifying and adjusting usability of authentication and login to portals and personal health environments to aging needs and characteristics by using biometrics, while adhering to privacy and security standards.
- Facilitate the provision of context to medical data provided in a portal by:
    - engaging providers in patient/provider communication via a portal;
    - apt presentations of (complex) medical data and information, preferably using a combination of animated visual aspects and spoken words that add to the numeric and textual medical data as well as using user-profiles to offer information tailored to users' needs and preferences.

Part 3: Patient-centered eHealth research for older adults

Principle findings

To examine the effectiveness of eHealth in supporting improved health for older patients, Part 3 begins with a literature analysis of studies showing effectiveness of eHealth services **(chapter 7).** Of the 348 potentially relevant papers, 10 studies were included. The studies each examined the effect of an eHealth intervention on either patients' behavior change, self-efficacy or health-related outcomes. The Systems Engineering Initiative for Patient Safety model (SEIPS 2.0) was then applied to classify possible Human Factors reported in these studies that might have influenced the resulting measured effectiveness of an eHealth service**.** It was found that a formal approach towards measuring the potential influence of Human Factors on eHealth's effectiveness was lacking in these studies, whereas the studies did report Human Factors' influence on eHealth's effectiveness. For example, patients' characteristics as a person's confidence in his or her abilities to perform required actions and achieve desired results, had a positive impact on eHealth's effectiveness. Part 3 of this thesis continues with a reflection upon an important possible reason why Human Factors are often not an integral part of eHealth research **(chapter 8)**. Using co-creation activities of patient portal development as an example, chapter 8 argues that one of the main challenges in the development phase of portals, is that barriers of older patients to patient portal use often remain under-recognized. Patient portals thus seem to be effective in use while older patients may not benefit from the use of these portals. A reason for this is that patient participation efforts used to develop portals, such as co-creation and user-testing, are often performed with autonomous and younger patients that are willing to participate in such efforts. Consequently, proposed (re)design solutions specifically benefit eHealth use suited for those patients, whereas it does not do justice to needs and capacities of less independent (older) patients. As is shown in part 2 of this thesis, there are several barriers of older adults hampering their use of patient portals that eHealth design teams should consider. Not acknowledging these barriers in the development of patient portals increases the risk of widening the digital divide in patient portal use; the gap may grow between those who can use and benefit from the effects of patient portal use and those who cannot. It is therefore proposed to consider methodological aspects in co-creation and user-testing activities with these patients to get better insights on barriers to eHealth use during the development phase **(chapter 9)**. These methodological considerations were constituted by means of consensus-seeking process during an expert workshop, in which expert experiences and insights were shared on how characteristics of older patients influence (usability) evaluation studies and user-testing. Through transcript analysis, three main themes and 9 recommendations emerged for such methodological considerations. The first theme focused on having an *empathetic approach and trust-building* and understanding that partaking in user-testing is a social experience for older adults. The second theme focused on *new requirements to testing* *and study design*, such as beta-testing of the technology, involvement of family and care takers and an intake meeting to get sight on older participants' characteristics, context and needs to specify the organizational requirements for user-tests. The MOLD-US framework can be used here to get sight on aging barriers possibly influencing these tests. The third theme focused on *adjustments to user evaluation methods for testing with older patients*. Suggestions were for example to adjust standard evaluation methods by including more social elements, such as peer discovery in which older adults can test the technology together with a family member or care taker. The overview of recommendations can give support and advice on aspects needing attention at the design, planning and execution phase of user-based evaluations of eHealth with older patients.

Practical implications and recommendations

The studies described in part 3 of this thesis aimed to create awareness on the importance of involving older patients in the development of eHealth in order to attain eHealth's effectiveness for this population. The insights from part 3 can support eHealth evaluators and stakeholders in eHealth's development regarding recruitment as well as in- and exclusion of older participants to user-tests. More importantly, these insights contribute towards more greater 'evidence-based eHealth' for the older patient, since results of user-tests will be more robust when applying the recommendations on how to best approach such tests with older people. For over 25 years 'evidence-based healthcare' (EBHC) has become the norm to drive modern healthcare forward [21]. EBCH is defined as the "conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" [22]. In doing so, it consists of three elements: 1) clinical expertise; 2) best scientific evidence and 3) patients' values and expectations [22]. Within this EBHC setting, the randomized controlled trial (RCT) is used as a golden standard study design. Nevertheless, as seen in chapter 7, the amount of RCT's performed to study the evidence on eHealth's effectiveness on outcomes remains low. This may be explained by the fact that evidence-based eHealth research via RCT's is challenging to conduct. This type of study design does not easily allow for a rigorous analysis on the third element of EBCH, the influencing contextual factors of the various eHealth users possibly influencing their values and expectations, such as age and related visual, cognitive, perception, and motivational barriers as shown in this thesis. Specifically for mHealth, the constantly and rapidly changing technological environment further does not match the rigor of studying a variety of mHealth interfaces, content and social interactions triggered by mHealth [23]. Yet, as this thesis has shown, to guide and evaluate eHealth innovations upon evidence-based insights within the perspective of older adults' eHealth usage, it is especially relevant to include an analysis of older adults' interaction and contextual factors on eHealth in the study design. Not only do older adult eHealth users' interactions and contexts differ from those of middle-aged and younger adult users, the means to involve older adults in research to develop and evaluate eHealth differ as well: it is needed to take these interdependencies between technology, human characteristics, and the socio-economic environment into account in order to demonstrate the effectiveness of eHealth accurately [24-25]. This thesis therefore aimed to provide clear guidelines on how to best involve older patients in research on contextual factors surrounding their values, expectations and experience in using eHealth. It is advised to use the instructional guidelines on user-testing with older adults within the field of eHealth development and evaluation. Performing rigorous analysis of interactions and contextual aspects of eHealth users as part of study protocols on evidence-based eHealth research is encouraged. Whereas current standards of the International Standards Organization (ISO) in Europe do state that a usability analysis and documentation should be part of the study protocol in case a *medical device intervention* is to obtain a Conformité Européenne (CE) mark [26], specific guidelines on methodology to be used to perform such an analysis are not given and a lot of *eHealth innovations* do not require such an CE mark. To gather robust and evidence-based insights on usability of eHealth innovations, this thesis proposes the use of methodological guidelines for involving older patients in the development and evaluation of eHealth. It is suggested to include usability tests with end-users as well as context analyses of anticipated end-users for each eHealth innovation as parts of those guidelines. These tests and analyses should involve a variety of anticipated end-users with different age ranges and (health) backgrounds in order to obtain better quality insights on how to tailor the innovation to the anticipated end-users' needs.

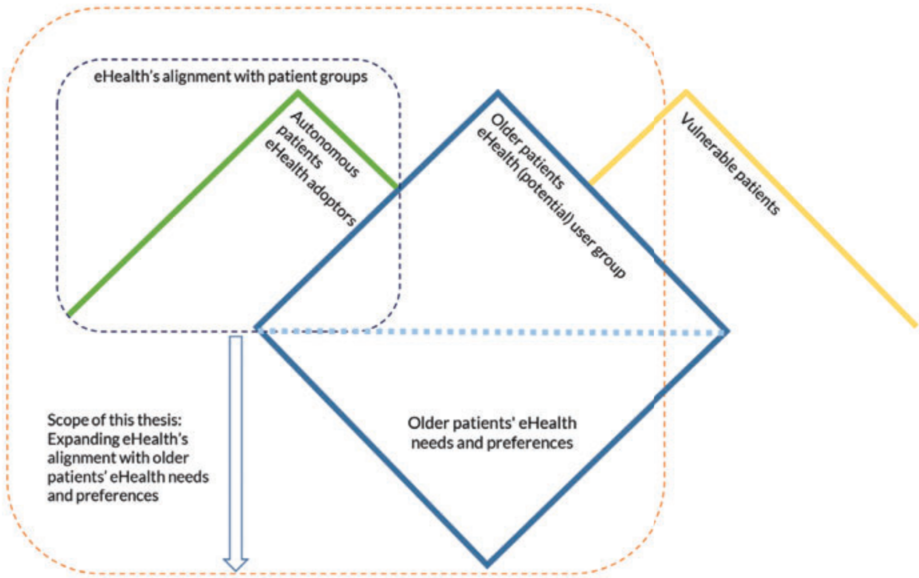
Recommendations - improving patient-centeredness by modifying methods used to develop and evaluate eHealth to aging barriers:

- **Use the instructional guidelines provided in this thesis on user-testing with older adult patients within the field of eHealth development and evaluation;**
- **Formalize methodological guidelines on usability testing and user-context analysis in eHealth study protocols.**

Conclusions of this thesis and directions for future research

This thesis 'Design speaks: Improving patient-centeredness for older people in a digitalizing healthcare context' contributes to our understanding of usability and contextual influences of eHealth's adoption by older patients. Taken together, over the last decades eHealth technologies gained traction among autonomous (younger) patients coinciding with their increasing (smart) technology use. This paved the way for a growth in development of eHealth, specifically of mHealth and patient portals, two main eHealth domains examined in this thesis. Besides the younger adopters of eHealth, eHealth technologies have the potential to place a large group of older patients at the center of care through sharing their medical data with them and digitally tailoring care to their individual information needs. Despite eHealth's benefits for these older patients, especially chronically ill patients, adoption of eHealth by older patients is low. The evidence from this thesis has shown that aging barriers inhibit interaction and adoption of these technologies by older patients, yet, their willingness to use such services is growing. It thus seems to be the right momentum to stimulate continuous use of eHealth by this large potential older user group. In doing so, the current data in this thesis highlights the importance of designs that optimally support older users' interactions and communication, of eHealth's interfaces as well as functionalities. The fast pace of innovations within the field of eHealth risk an imbalance with the (digital) needs of our aging populations. In developing and evaluating eHealth it is therefore important to preserve a balance between the technical possibilities of the eHealth service and the design and functionalities adjusted to aging barriers and capacities. Such a balance can be achieved by using smart design solutions, such as animated videos to explain complex health information and user-profiles with customized features to better tailor eHealth functionalities to the needs of the variety of older patients. Using such smart design solutions does do justice to older patients in improving their patient-centeredness in a digital context. Patient-centeredness in this form must be approached with some caution for vulnerable older patients, such as those with severe mental illnesses, extreme low socio-economic conditions or elderly of very old age. For these patients attention to their individual needs and preferences might entail in-person contact rather than patient-centered care through eHealth. Notwithstanding, the scope of this study was outlined by examining how to improve patient-centeredness through eHealth designs for potential older adult eHealth users, as is shown in the *Concluding Figure* of this thesis. In this Concluding Figure, the three clusters of patient groups, autonomous patients which are adopting eHealth, older patients as a (potential) eHealth user group and vulnerable patients are represented by the three triangles. Older patients' needs and preferences on eHealth are mirrored below the triangle of this patient group. The blue dotted square represents current eHealth's alignment with these patient groups. The orange dotted square represents the possible eHealth's alignment with these patient groups, when eHealth would be adjusted to older patients' needs and preferences. The scope of this thesis was to perform research and provide recommendations on how to expand eHealth's alignment with its first adopters to alignment with the older patient group.

Future research can focus on how to best preserve the balance in patient-centered eHealth for younger and older patients that works together with (equally patient-centered) non-digital safety nets for non-eHealth users. In doing so, we encourage researchers to further expand knowledge on mobile interface designs for older patients and to examine whether some barriers are disease specific as well, regardless of age. This can for instance be assessed by expanding the MOLD-US framework with disease specific barriers, correlations between age-related and disease-related barriers and by adding design suggestions accordingly. Further research could likewise determine how to best support patient/provider communication in a digital context attuned younger, older and vulnerable patients; balancing online and offline communication. We further stimulate future research that addresses aging and patients' aspects in formalizing methodological guidelines on usability testing and user-context analysis in research on effectiveness within the field of eHealth.



Concluding Figure: *Scope of this thesis in relation to eHealth (non)user patient groups*

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Appendices

Summary
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PhD portfolio
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Acknowledgements

Summary

Digital 'eHealth' innovations for patients aim to offer patient-centered care; a contemporary characteristic of good care, where care is tailored to the individual needs and preferences of a patient. Patient portals and mobile health apps (mHealth) are examples of eHealth and are seen as important components in facilitating patient-centered care. Patient portals and mHealth can give patients access to medical records, including appointments with their treatment team and information regarding their health problems and medicines, through which patients can obtain more control over their health and treatment. In addition, these innovations make it possible for patients to facilitate the measurement of their biometrics at home. These innovations can be of value particularly for patients with chronic illnesses. Such patients frequently have a relatively high use of care, often spread amongst several health-care organizations. Patient portals and mHealth can support these patients in maintaining an overview on their own health issues and with performing self-management activities within their individual treatment process. For these reasons, the use of patient portals and mHealth is growing. In The Netherlands, there are more than 30 active patient portals, and worldwide there are more than 325.000 mHealth apps available. This thesis focusses on patient portals and mHealth in relation to providing patient-centered care, specifically concerning older adult patients aged 50 years and above.

The growing number of available patient portals and mHealth tools is occurring alongside aging populations. In Western countries this is also includes overall increases in patient lifespans; coinciding with a high prevalence of chronic illnesses, because prevalence of chronic illness is high amongst older people. More than 60% of people aged 65+ have one or more chronic illness. The value proposition of patient portals and mHealth makes older patients a large potential target group of these innovations. While older adult patients are showing interest in these innovations, continuous use of patient portals and mHealth by them remains low. A possible reason for this is that the intended patient-centeredness of these innovations is still insufficiently tailored to the needs and preferences of older adult patients. During the development of these innovations, the specific aging-related characteristics of these patients are often not taken into account. To gain insight on user characteristics, including specification of functionalities, user-centered design (UCD) methods can be used; typically these methods place the patient at the center of the design, development and evaluations of innovations. This thesis, therefore, approaches patient-centeredness from the perspective of user-centered design. The central aim is to understand the alignment between the design of patient portals and mHealth in relation to the characteristics and needs of older adult patients, in order to improve patient-centeredness for these patients in the development and evaluation of eHealth.

This thesis consists of three parts: part 1 describes research on designs of current mHealth apps for older adult patients, part 2 provides in-depth insight into the use of patient portals amongst this target group, and part 3 critically assesses the methodologies used to develop and evaluate eHealth from the perspective of older patients.

Part 1 begins with **chapter 2**, which provides an overview of aging barriers via the MOLD-US (mHealth for older users) framework. A synthesis of literature was performed on reported physical and functional aging barriers related to the use of digital (mobile) health applications. Aging barriers mentioned in the literature were mapped against prominent usability aspects to explain their influence on the user-experience of mHealth. Cognitive, physical ability, perception and motivation barriers of older patients, were identified as key aging barriers that can have a negative impact on interactions and communication with mHealth interfaces and functionalities. In **chapter 3**, the MOLD-US framework is applied in the analysis of two mHealth apps. It is examined whether the MOLD-US framework is useful in analyzing usability issues of mHealth experienced by older adults. Older participants verbalized their thoughts during their interactions with the mHealth apps, a prominent research method to detect usability issues. From the 28 severe issues that were identified, the MOLD-US framework showed that half of these issues were related to a low motivation of older adult patients to use of mHealth. Older patients often have a lack of trust in their own abilities to use a smartphone or tablet and therefore did not use all functionalities of the researched apps. One-third of the issues were related to cognitive barriers of older patients, through which they, for example, experienced issues in navigating through the researched apps. Older patients also experienced usability issues related to physical and perceptual barriers. These findings reveal that current scientific guidelines for interface design suitable for older adults are not yet applied to the fullest in the design of the researched mHealth apps.

Recommendations from part 1 emphasize the importance to taking aging barriers into account, especially those of older patients regarding their motivation and cognitive capacities to use mHealth, and to more comprehensively apply the existing guidelines for designing interfaces for older people in the design and development of mHealth. For example, this includes providing clear (visual and audible) instructions on the use of a mHealth app, and keeping the navigation structure consistent while minimizing the number of clicks needed in order to navigate through the app. Since the MOLD-US framework provides insight into the barriers that can have most impact on a design, it is advised to use this framework in (iteratively) evaluating an interface during the development of mHealth. In particular, this framework helps to identify which aging barriers are intrinsic to usability issues experienced by older adults, thereby allowing more accurate design solutions to these problems.

Part 2 begins with **chapter 4** which gives an overview of facilitators and barriers influencing the use of patient portals by older adult patients. A prominent database of medical literature was searched for studies from the years 2010 up to 2016 that evaluated the technological acceptance, adoption and user-friendliness of patient portals among older adult patients. Of the total of 245 studies screened, 8 were included in the analysis. Facilitators primarily relate to expectations and added value of a patient portal, such as the ability to have an overview of a patient's appointments, the possibility to review a patient's own medical record and the option to contact healthcare providers via a portal. Foremost barriers primarily relate to gaining access to a patient portal; although the computer and internet use is growing amongst older people, there are older patients who do not have the means to access and login to a patient portal. In addition, some older patients have the impression that using a patient portal may be too complicated for them, due to the multitude of functionalities and the complex medical information that is displayed in a patient portal. **Chapter 5** and **chapter 6** evaluate via case studies whether these facilitators and barriers from literature are present amongst older Dutch patients as well. This is done by analyzing the user-experiences of older adult patients of the Amsterdam University Medical Center (Amsterdam UMC, location AMC) patient portal and via a cross-sectional study amongst chronically ill patients from two large Dutch patient associations (Heart Council and the Lung fund), respectively. Key insights regarding facilitators and barriers identified in these case studies relate to medical content, communicative and technical factors in the area of presentation and interpretation of medical information and access to a portal. Regarding medical content and communication, patients expressed interest in obtaining an overview of information from multiple providers. However, they did not necessarily desire automatic release of medical information after a specific time period; patients stated no clear preference for direct release of information or release after the information had been discussed between patient and provider. Patients preferred a summary of medical information in laymen's terms above a fully uncensored medical file and it is important that healthcare providers answer a question asked via a portal within a short period of time. Regarding technical factors, older patients prefer to access a patient portal via a computer, but indicate that there is a need for a more user-friendly means to log-in than currently available. In The Netherlands, the 'two-factor-authentication' is a standard means to login to a patient portal, having two moments to verify the identity of a user. Yet older patients mostly did not prefer this method, indicating a lack of user-friendliness for this group.

Recommendations from part 2 focus on addressing technical and communication barriers that hamper the continuous use of patient portals by older adult patients. This includes simplifying authentication and login methods, facilitating technical access to patient portals for people with lower socio-economic backgrounds and improving the presentation of complex medical information in a patient portal. Regarding authentication and login methods, there are opportunities to make greater use of biometric data, such as a fingerprints, for identity verification. It is further advised to align the access to medical information and communication means via patient portals with the needs of older patients. For example, by using short animated videos that make complex medical information more understandable and by incorporating the answering of patients' sent messages via a portal in the work processes of healthcare providers. Recent developments to offer one portal compiling an individual's medical records from multiple healthcare organizations are encouraged, such as a personal health record (PHR). It is important to be able to seamlessly exchange medical data between the website or app of a PHR system and the electronic patient file (EPD) systems of healthcare organizations. Initiatives such as the 'MedMij' program in The Netherlands, in which information standards and agreements are made to achieve interoperability between PHRs, EPDs and other healthcare information systems, are beneficial in this regard.

Part 3 begins with **chapter 7** which examines the effectiveness of eHealth in supporting improved health of older patients. This chapter shows that knowledge in the area of human capacities, skills and limitations (that is, 'Human Factors') can influence the effectiveness of eHealth positively or negatively, but are not yet structurally analyzed in research into eHealth. **Chapter 8** therefore reflects upon an important possible reason why Human Factors are often not an integral part of eHealth research related to the initial development phase of an eHealth innovation. In this phase, methods such as co-creation and user-testing are increasingly used to tailor innovation to the needs and preferences of intended users. However, mostly autonomous and young or middle-aged adults participate in these design activities, which results in barriers faced by older adults, as described in part 2, remaining under-recognized. This creates a risk that eHealth designs suit the needs and preferences of autonomous patients, while neglecting the needs and preferences of less autonomous (particularly older) patients. Consequently, older patients may be less likely to benefit from the innovation. To detect barriers to eHealth use by older adults at an early phase, **chapter 9** presents an overview of recommendations regarding how to best approach user-testing with older patients. The overview is developed by experts within this field and contains 9 recommendations related to the preparation and execution phase of user-testing. Themes covered in this overview are: an empathetic approach and trust-building, new requirements to testing and study design and adjustments to user evaluation methods for testing with older patients.

Recommendations from part 3 focus on improving the quality of co-creation and evaluation methods to develop eHealth for older adult patients so that eHealth better meets the needs of this patient population. In particular, a better fit between eHealth design and their actual contexts of use by older patients could increase their usage rates, thereby increasing the likely effectiveness of eHealth for this target group. Achieving this would require the involvement of older patients with varying attributes, such as age and degree of autonomy, in co-creation sessions and user tests. Involving older patients in such activities deserves particular attention to the context within which these patients actually use eHealth, which might involve meeting with them individually to explain the set-up of a user test and to get a better view of their current living environment. In addition, understanding social aspects surrounding the use of eHealth by older patients is also important, and methods such as involving family members and other important contacts in setting up and performing the user tests can help to motivate older people for such activities. These recommendations are time and money intensive. However, the findings of this research indicate that such investments are likely to be crucial for successfully designing eHealth to serve older patients.

In conclusion, there is a critical need to take a user-centered approach in the development of patient-centered eHealth innovation tailored specifically to older patients, particularly to their age-related barriers and their contexts of use. Patient-centered approaches to eHealth for older patients are typified by design that aligns interface interactions, communication and functionalities with the capacities and needs of older patients. This requires allocating adequate time, budget and attention to involving older patients in co-creation and user-testing activities. Recommendations of this thesis support evidence-based development and evaluation of eHealth innovation, to improve patient-centeredness for older patients in a digitalizing healthcare context.

Nederlandse samenvatting

Digitale 'eHealth' innovaties voor patiënten in de zorg beogen 'zorg op maat' aan te bieden, een hedendaags kenmerk van goede zorg, waarbij de zorg is afgestemd op de individuele behoeften en wensen van een patiënt. Patiëntportalen en mobiele apps (mHealth) zijn voorbeelden van eHealth en worden beschouwd als belangrijke componenten in het realiseren van deze zogenoemde patiëntgerichte zorg. Patiëntportalen en mHealth kunnen patiënten onder andere toegang geven tot hun medisch dossier, inclusief afspraken met hun zorgverleners, informatie over hun aandoeningen en medicatiegebruik, waarmee zij meer regie krijgen over hun zorg en gezondheid. Ook maken deze innovaties het thuis meten van gezondheidswaarden door patiënten zelf mogelijk. Vooral voor patiënten met chronische aandoeningen kunnen deze innovaties meerwaarde bieden. Deze patiënten hebben vaak een relatief hoog zorggebruik en komen veelal in contact met meerdere zorginstanties. Patiëntportalen en mHealth kunnen deze patiënten ondersteunen in het houden van overzicht op hun eigen gezondheidsproblematiek en bij het uitvoeren van zelfmanagementactiviteiten gericht op hun individuele behandeltraject. Om deze reden groeit het aanbod van patiëntportalen en mHealth gestaag, in Nederland bestaan er meer dan 30 actieve patiëntportalen en wereldwijd zijn er meer dan 325.000 mHealth apps op de markt. Dit proefschrift richt zich daarom op patiëntportalen en mHealth in relatie tot het aanbieden van zorg op maat, in het bijzonder voor vijftigplussers en oudere patiënten.

Het toenemende aanbod van patiëntportalen en mHealth speelt zich namelijk af namelijk tegen het decor van een vergrijzende samenleving. In Westerse landen vindt daarin ook een vergrijzing plaats van patiëntpopulaties, gekenmerkt door patiënten met veelal chronische aandoeningen. De prevalentie van chronische aandoeningen is met name groot onder ouderen, meer dan 60% van mensen van 65 jaar en ouder heeft één of meerdere chronische aandoeningen. Dit maakt hen een grote potentiële doelgroep van patiëntportalen en mHealth. Hoewel vijftigplussers en ouderen interesse tonen in deze innovaties, blijft het (continue) gebruik van patiëntportalen en mHealth door hen laag. Dit komt mogelijk doordat de beoogde patiëntgerichte ondersteuning van deze innovaties nog onvoldoende aansluit bij de behoeftes van vijftigplussers en ouderen en er tijdens de ontwikkeling van deze innovaties in het ontwerp nog onvoldoende rekening wordt gehouden met karakteristieken van deze patiënten. Om hier meer zicht op te krijgen kunnen gebruikersgerichte ontwerp methodes worden ingezet; typerend voor deze methodes is dat deze de patiënt centraal zetten in het ontwerp, de ontwikkeling en de evaluaties van innovaties. Patiëntgerichtheid wordt in dit proefschrift daarom benaderd vanuit dit perspectief van gebruikersgericht ontwerp. De aansluiting tussen het ontwerp van patiëntportalen en mHealth in relatie tot de karakteristieken en behoeftes van vijftigplussers en ouderen wordt in dit proefschrift onderzocht, met als doel het verbeteren van patiëntgerichtheid voor deze oudere patiënten in de ontwikkeling en evaluatie van eHealth.

Dit proefschrift is opgedeeld in drie onderdelen: deel 1 beschrijft het onderzoek gericht op het ontwerp van huidige mHealth apps voor vijftigplussers en ouderen, deel 2 geeft zicht op het gebruik van patiëntportalen onder deze doelgroepen en in deel 3 worden de methodieken die worden gebruikt om eHealth te ontwikkelen en evalueren tegen het licht gehouden vanuit het perspectief van de oudere gebruiker. Vijftigplussers en ouderen worden in het resterende gedeelte van deze samenvatting aangeduid als ‘oudere patiënten’ om de leesbaarheid van de samenvatting te bevorderen.

Deel 1 start met **hoofdstuk 2,** waarin een overzicht is gegeven van verouderingsbarrières via het MOLD-US raamwerk, *mHealth for older users*. Er is een literatuur analyse uitgevoerd om de gerapporteerde fysieke en functionele leeftijdsbarrières gerelateerd aan het gebruik van digitale (mobiele) gezondheidstoepassingen te synthetiseren en samen te vatten. Verouderingsbarrières vermeld in de literatuur werden in kaart gebracht op prominente bruikbaarheidaspecten om hun invloed op gebruikerservaring van mHealth te verklaren. Cognitieve, fysieke, perceptie en motivatie barrières van oudere patiënten werden via deze methode geïdentificeerd als verouderingsbarrières die een negatieve impact kunnen hebben op de interacties en communicatie met een mHealth interface en functionaliteiten. In **hoofdstuk 3** is het MOLD-US raamwerk vervolgens toegepast in het analyseren van twee mHealth apps op gebruikersvriendelijkheid. Hiermee is beoordeeld of het MOLD-US raamwerk bruikbaar is in het analyseren van mogelijke problemen die ouderen ervaren in het gebruik van mHealth. Oudere deelnemers verbaliseerden in dit onderzoek hun gedachtes tijdens hun interacties met de mHealth apps, dit is een prominente onderzoeksmethode om gebruikersvriendelijkheidsproblemen te achterhalen. Van de 28 serieuze problemen die geïdentificeerd werden, is het via het MOLD-US raamwerk inzichtelijk gemaakt dat de helft van deze problemen gerelateerd was aan een lage motivatie van oudere patiënten om mHealth te gebruiken. Oudere patiënten hebben vaak weinig vertrouwen in hun eigen competenties om een smartphone of tablet goed te kunnen gebruiken en gebruikten daardoor niet alle functionaliteiten in de onderzochte mHealth apps. Eén derde van de problemen was gerelateerd aan cognitieve barrières van oudere patiënten, waardoor zij bijvoorbeeld problemen hadden in het navigeren door de onderzochte interfaces van de apps. Ook ondervonden oudere patiënten gebruikersvriendelijkheidsproblemen gerelateerd aan fysieke en perceptie barrières. Uit ons onderzoek komt naar voren dat (wetenschappelijk vastgestelde) ontwerp richtlijnen, opgesteld door experts en bedoeld om een interface meer geschikt te maken voor gebruik door ouderen en/of patiënten, nog niet goed zijn toegepast in het ontwerpen van de onderzochte mHealth apps.

Aanbevelingen vanuit deel 1 richten zich daarom op het benadrukken van het belang om verouderingsbarrières, met name barrières van ouderen op het gebied van motivatie en cognitieve capaciteiten om mHealth te gebruiken, mee te nemen in het ontwerpen van mHealth apps en de bestaande richtlijnen voor het ontwerpen van interfaces voor ouderen beter toe te passen in het ontwerp en de ontwikkeling van mHealth. Dit kan onder andere gerealiseerd worden door duidelijke (visuele en auditieve) instructies aan te bieden over het gebruik van een mHealth app en de navigatiestructuur te laten bestaan uit een consistent menu met zo min mogelijk doorklikopties. Aangezien het MOLD-US raamwerk goed zicht geeft op de barrières die de hoogste impact kunnen hebben op een ontwerp, wordt aangeraden dit raamwerk te gebruiken in het (tussentijds) evalueren van een interface tijdens de ontwikkeling van mHealth. Dit raamwerk geeft zicht op verouderingsbarrières die intrinsiek zijn aan ondervonden gebruikersvriendelijkheidsproblemen door oudere patiënten in het gebruik van de onderzochte mHealth apps. Hiermee kan er een meer accurate ontwerp oplossing voor deze problemen worden gevonden.

In deel 2 geeft **hoofdstuk 4** een overzicht van faciliterende en belemmerende aspecten die van invloed zijn op het gebruik van patiëntportalen door oudere patiënten. Een prominente database met medische literatuur is doorzocht voor studies uit de jaren 2010 tot en met 2016 die de technologische acceptatie, adoptie en gebruikersvriendelijkheid van patiëntportalen onder oudere patiënten evalueerden. Van de in totaal 245 potentieel relevante studies, zijn er 8 gebruikt voor analyse. De voornaamste aspecten die het gebruik van deze applicaties bevorderen, zijn gericht op het voorziene nut en toegevoegde waarde van een patiëntportaal, zoals het hebben van een afspraken overzicht, de mogelijkheid om eigen medische gegevens in te zien en de gelegenheid om via het portaal contact op te nemen met zorgverleners. Belemmerende aspecten focussen zich onder andere op het verkrijgen van toegang tot patiëntportalen: hoewel het computer- en internetgebruik onder ouderen groeit, zijn er ook oudere patiënten die niet beschikken over de technische middelen om in te loggen op een patiëntportaal. Daarnaast hebben sommige oudere patiënten de indruk dat het gebruiken van een patiëntportaal mogelijk te ingewikkeld voor hen is, door de veelheid aan functionaliteiten en de complexe medische informatie die vertoond wordt in een patiëntportaal. **Hoofdstuk 5** en **hoofdstuk 6** evalueren via case studies of deze faciliterende en belemmerende aspecten uit de literatuur ook spelen bij Nederlandse oudere patiënten, aan de hand van een analyse van gebruikerservaringen met het patiëntportaal van het Amsterdam Universitair Medisch Centrum (Amsterdam UMC, locatie AMC) en via een peiling onder chronisch zieke patiënten vanuit twee grote Nederlandse patiëntenverenigingen (Harteraad en het Longfonds). De belangrijkste nieuwe inzichten ten opzichte van de literatuur die naar voren komen in deze case studies zijn gericht op faciliterende en belemmerende aspecten ten aanzien van medische inhoud, communicatieve en technische factoren op het gebied van respectievelijk presentatie en interpretatie van medische informatie en toegang tot een portaal. Wat betreft de medische inhoud en communicatie geven patiënten aan geïnteresseerd te zijn in het terug zien van hun medische informatie vanuit meerdere zorginstanties. Patiënten vinden het daarentegen niet gewenst om een automatisch ingestelde periode in stellen voor het publiceren van hun medische informatie in een portaal; patiënten geven geen duidelijke voorkeur aan voor het direct publiceren van deze informatie of het publiceren zodra de informatie is besprokken tussen de patiënt en zijn zorgverlener. Patiënten geven de voorkeur aan een samenvatting van hun medische gegevens in begrijpelijke taal en is het belangrijk dat zorgverleners binnen een korte periode antwoord geven op gestelde vragen door patiënten via het portaal. Ten aanzien van de technische aspecten gebruiken oudere patiënten het liefst een computer om in te loggen op een patiëntportaal, waarbij ze aangeven dat er behoefte is aan een gebruikersvriendelijkere manier om in te loggen dan die er momenteel voor handen zijn. In Nederland geldt de 'twee-factor-authenticatie methode' als standaard om in te loggen op een patiëntportaal, met twee momenten waarop de identiteit van de gebruiker wordt geverifieerd. Deze methode is veelal niet gebruikersvriendelijk voor oudere patiënten.

Aanbevelingen vanuit deel 2 richten zich daarom op het onder handen nemen van de technische- en informatievoorzieningsbarrières die het continue gebruik van patiëntportalen door oudere patiënten belemmeren, zoals het versimpelen van authenticatie en inlogmethodes en het faciliteren van technische toegang tot patiëntportalen voor bijvoorbeeld mensen met lagere socio-economische omstandigheden en het verbeteren van de presentatie van complexe medische informatie in een patiëntportaal. Met betrekking tot authenticatie en inlogmethodes kan bijvoorbeeld meer gebruik worden gemaakt van biometrische gegevens, zoals een vingerafdruk voor identiteitsverificatie. Ook wordt aangeraden de inzage in medische gegevens en communicatie via patiëntportalen beter te laten aansluiten bij oudere patiënten. Hierbij kan gedacht worden aan het inzetten van korte animatie video's die complexe medische informatie begrijpelijker maken en het inpassen van het beantwoorden van patiëntberichten verstuurd via patiëntportalen in de werkprocessen van zorgverleners. Ook het aanbieden van één portaal dat eigen medische gegevens vanuit meerdere zorginstanties weergeeft wordt aangemoedigd, bijvoorbeeld via een persoonlijke gezondheidsomgeving (PGO). Daarin is het belangrijk om medische gegevens tussen de website of app van een PGO omgeving en de elektronische patiëntendossier (EPD) systemen van zorgorganisaties probleemloos en veilig te kunnen uitwisselen. Initiatieven zoals het 'MedMij' programma in Nederland, waarin informatiestandaarden en afspraken worden gemaakt om interoperabiliteit tussen PGO's, EPD's en andere zorginformatiesystemen te bewerkstellingen, kunnen daarbij helpen.

Deel 3 gaat met **hoofdstuk 7** in op een literatuur analyse van de effectiviteit van eHealth in het ondersteunen van gezondheid voor oudere patiënten. Dit hoofdstuk toont aan dat kennis op het vlak van menselijke capaciteiten, vaardigheden en beperkingen, *Human Factors*, die effectiviteit van eHealth positief of negatief kunnen beïnvloeden, nog niet structureel worden geanalyseerd in onderzoek naar eHealth. **Hoofdstuk 8** gaat daarom in op een mogelijke reden dat Human Factors in onderzoek naar eHealth veelal nog over het hoofd worden gezien en reflecteert daarbij op de fase van het ontwerp van een eHealth innovatie. Tijdens deze fase worden methodes als co-creatie sessies en gebruikerstesten meer en meer ingezet om de eHealth innovatie te laten aansluiten bij de behoeften en wensen gebruikers. Echter, het zijn veelal autonome en volwassenen van jongere of middelbare leeftijd die deelnemen aan deze activiteiten. Hierdoor loopt men het risico dat het ontwerp van de eHealth innovatie meer aansluit bij de autonomie en wensen van deze doelgroepen dan bij de wensen en behoeften van oudere patiënten. Het gevolg kan zijn dat oudere patiënten de innovatie minder snel zullen gebruiken en dus ook geen voordeel in effectiviteit van de innovatie kunnen ondervinden. Om hier verandering in te brengen biedt **hoofdstuk 9** een overzicht van aanbevelingen hoe men gebruikerstesten met oudere deelnemers het best kan ondernemen. Het overzicht omvat 9 aanbevelingen die gerelateerd zijn aan de voorbereidings- en uitvoeringsfase van gebruikerstesten, ontwikkeld door experts op dit vlak. De thema's die naar voren komen zijn: een empathische aanpak en het opbouwen van vertrouwen, nieuwe eisen voor (het ontwerpen van) gebruikerstesten met oudere patiënten en aanbevelingen ten aanzien van toe te passen evaluatie methoden voor het uitvoeren van gebruikerstesten met oudere patiënten.

Aanbevelingen vanuit deel 3 richten zich daarom op het verbeteren van de kwaliteit van co-creatie en evaluatie methodes om eHealth voor oudere patiënten te ontwikkelen zodat eHealth apps beter aansluiten bij deze patiëntpopulatie. Het is aannemelijk dat een betere aansluiting van eHealth ontwerpen meer toegevoegde waarde van eHealth aan oudere patiënten biedt, wat kan leiden tot frequenter gebruik van eHealth door oudere patiënten. De effectiviteit van eHealth voor deze doelgroep zal daarmee eveneens toenemen. De voornaamste methode om dit te bereiken is het betrekken van diverse gebruikers, variërend in leeftijd en autonomie, in co-creatie sessies en gebruikerstesten. Het betrekken van oudere patiënten in dergelijke activiteiten verdient vooral persoonlijke aandacht naar deze patiënten toe. Daarin is het belangrijk om zicht te krijgen op hun actuele context waarin zij eHealth gebruiken. Dit kan bijvoorbeeld door individueel met hen af te spreken om de opzet van een gebruikerstest uit te leggen en een beter zicht te krijgen op hun actuele leefomgeving. Daarnaast is begrip voor de sociale aspecten rondom het gebruik van eHealth door oudere patiënten van belang en kunnen methodes zoals het betrekken van familieleden en andere voor hen belangrijke contacten in het opzetten en uitvoeren van de gebruikerstesten helpen om ouderen te motiveren voor zulke activiteiten. Deze aanbevelingen zijn tijd- en geldintensief. Desalniettemin, de resultaten van dit onderzoek wijzen erop dat zulke investeringen waarschijnlijk cruciaal zijn in het maken van een succesvol eHealth ontwerp waar oudere patiënten gebaat mee zijn.

Concluderend, er is een kritieke noodzaak om een gebruikersgerichte aanpak te hanteren bij de ontwikkeling van patiëntgerichte eHealth innovaties voor oudere patiënten, waarbij er rekening wordt gehouden met hun ouderdomsgerelateerde barrières en hun gebruikscontexten. Patiëntgerichte benaderingen van eHealth voor oudere patiënten worden gekenmerkt door een ontwerp dat interface interacties, communicatie en functionaliteiten afstemt op de capaciteiten en behoeften van oudere patiënten. Dit vereist toewijzing van voldoende tijd, geld en aandacht voor het betrekken van oudere patiënten bij co-creatie en gebruikerstesten. Aanbevelingen van dit proefschrift ondersteunen *evidence-based* ontwikkeling en evaluatie van eHealth innovatie, om zorg op maat voor oudere patiënten in een digitale zorgcontext te verbeteren.

List of publications

Publications in this thesis

Published/accepted for publication – ordered by date:

Wildenbos GA, Peute LW, Jaspers MW. *The equity paradox: older patients' participation in patient portal development*. International Journal for Quality in Health Care (Accepted for publication)

Wildenbos GA, Horenberg F, Jaspers MW, Peute LW, Sent D. *How do patients value and prioritize patient portal functionalities and usage factors? A conjoint analysis study with chronically ill patients*. BMC Medical Informatics and Decision Making. 2018.18:108. doi:10.1186/s12911-018-0708-5

Wildenbos GA, Maasri K, Jaspers M, Peute L. *Older adults using a patient portal: registration and experiences, one year after implementation*. Digit Health. 2018 Sep 2;4:2055207618797883. doi: 10.1177/2055207618797883

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Wildenbos GA, Peute L, Jaspers M. *Facilitators and Barriers of Electronic Health Record Patient Portal Adoption by Older Adults: A Literature Study*. Stud Health Technol Inform. 2017;235:308-312. Review.

Wildenbos GA, Peute LW, Jaspers MW. *Impact of Patient-centered eHealth Applications on Patient Outcomes: A Review on the Mediating Influence of Human Factor Issues*. Yearb Med Inform. 2016 Nov 10;(1):113-119. Review.

Submitted for publication – ordered by date:

Wildenbos GA, Marcilly R, Jaspers MW, Peute LW. *How to approach user-based testing of eHealth with older patients: insights from an expert-based workshop.*

Submitted to: Journal of Biomedical Informatics

Wildenbos GA, Jaspers MW, Schijven MP, Peute LW. *Mobile health for older adult patients: using an aging barriers framework to classify usability problems.*

(Revised version) submitted to: International Journal of Medical Informatics

Other publications

Published – ordered by date:

Wildenbos GA, Peute LW, Jaspers MW. *Influence of Human Factor Issues on Patient-Centered mHealth Apps' Impact; Where Do We Stand?* Stud Health Technol Inform. 2016;228:190-4. Review.

Wildenbos GA, Peute LW, Jaspers MW. *A framework for evaluating mHealth tools for Older Patients on Usability*. Stud Health Technol Inform. 2015;210:783-7.

PhD portfolio

Name PhD student: Gaby Anne Wildenbos
Promotor: Prof. dr. M.W.M. Jaspers
Copromotores: dr. L.W. Peute

PhD training	**Year**	**Workload (ECTS)**
General courses		
Scientific Writing – Graduate School AMC	2016	1.5
Didactical Skills – Graduate School AMC	2017	0.4
FameLab – Graduate School AMC	2018	1.0
Specific courses		
The Informal leader – De Baak	2015	1.5
Medicine & Human Rights from a cross cultural perspective - UvA	2017	3.0
Start-up incubator program – ACE / IXA	2018	1.5
Seminars, workshops and master classes		
Mobile healthcare day, Amsterdam	2016	0.1
Ethics and eHealth day, Utrecht	2017	0.1
Presentations		
AMC 'Promovendi day' - III	2015, 2016, 2017	1.5
Webinar TRIPLL Institute Cornell University, Ithaca NY State	2016	0.75
Collaboration CIC-IT, Lille University	2016	0.5
HEAL project – Medical Informatics department	2017	0.25
(Inter)national conferences		
Medical Informatics Europe (MIE), Madrid	2015	0.5
Medical Informatics Europe (MIE), Munich	2016	0.5
Medical Informatics Europe (MIE), Manchester	2017	0.5
Medical Informatics Europe (MIE), Gothenburg	2018	0.5
Teaching		
BA Medical Informatics 'eHealth' – II	2014, 2015	0.5
MA Medical Informatics 'Biomedical research and evaluation methodology' - IV	2015, 2016, 2017, 2018	3.25
MA Medical Informatics 'eHealth' – III	2016, 2017, 2018	0.75
MA Medical Informatics 'Research methods in medicine and mi'	2017	0.25
MA Medical Informatics 'Academic Skills 2 – Management Communications'	2018	4.0

PhD training	Year	Workload (ECTS)
Tutoring, mentoring		
Scientific Research Project MA students Medical Informatics – III	2015, 2016	6.0
Internship (pre)MA students Medical Informatics - VI	2015, 2016	6.0
Thesis master student Media Technology - Leiden University	2017	1.0
Other		
Speaker at Master Medical Informatics information day - III	2014, 2015	0.75
Speaker at launch of academic year Medical Informatics BA & MA	2015	0.25
Co-organizer of Science Slam MIE, Gothenburg	2018	0.75
Occasional reviewer at journals: 'BMC Medical Informatics and Decision Making' and 'Journal of Applied Clinical Informatics'	2016, 2018	1.0
Prizes and awards		
Winner 3rd prize Science Slam - MIE, Munich	2016	
Winner 3rd prize Science Slam - MIE, Manchester	2017	
Winner 'AMC Jong' eHealth pitch presentation	2017	
Total		**38.60**

About the author

Gaby Anne Wildenbos was born the 13th of June, 1983, in Rotterdam. She graduated from the Sint Laurens College high school in 2001, and started a bachelor in Theatre, Film and Television studies at the University of Utrecht. Her bachelor thesis focused on the success of i-mode, comparing Japan and The Netherlands. At the same university she completed a master's degree in New Media and Digital Culture in 2005. Her graduation thesis, entitled "The Western notion of digitalization', was based on her internship in Tokyo. After these studies, she travelled for nine months through New Zealand, Australia and South-East Asia.

Subsequently, she started her career as a digital media specialist at the marketing agency LBi Lost Boys. After three years and a course as a media coach for children and youth, she switched to working in the non-profit sector as a project lead at the Cinekid Foundation. During her work at Cinekid, she developed an interest in how digital (media) technologies can be applied in a healthcare setting. In pursue of this interest she started a (pre)master Medical Informatics (MI) at the University of Amsterdam (UvA) in 2012 and acquired a job at the implementation team (EVA) of the electronic health record at Amsterdam UMC (AMC and VUmc).

After finishing her master MI in 2014, including a TOP Traineeship on the usability and evaluation of a healthcare app for older patients, she started her part-time PhD study on eHealth and patient-centeredness. She continued to work as a project coordinator at EVA, focused on the implementation of a patient portal and several mobile health apps. She further coordinated the provision of information to the client councils of the AMC and VUmc hospitals on the electronic health record implementation. When the implementation activities came to an end, she focused on the final stage of her PhD study. Alongside she provided assistance in lecturing the academic skills management communications course of the MI master at the UvA.

Given her ongoing interest in how digital technologies can be applied in healthcare to improve patient-centeredness, Gaby currently works as a eHealth project coordinator at the Dutch Burns Foundation. She coordinates the development and implementation of a personal health portal for people with burns, including a shared decision making tool on scar tissue treatment. This portal and shared decision making tool will be implemented at the Dutch burn centers in Beverwijk, Groningen and Rotterdam.

A thousand and one thanks to all of you!

22 maart 2019

Acknowledgements

The studies described in this thesis and performed over the last years were a team effort. This illustration represents my gratitude that goes out to all of you. Its amount of colorful balloons show that so many of you were part of the team and have left a mark, figuratively and/or literally, on my thesis. Thank you so much for helping me with gathering data, structuring thoughts, reviewing articles, giving me a chance to apply my knowledge in practice, and supporting me throughout these years. It's been quite a ride and I certainly wouldn't have been able to obtain a PhD degree without your help!

Special thanks to:

All patients that participated in these studies: I hope I've put the right words to your needs and ideas

Linda: The insights and advice you have given me as my co-promotor have made it possible for me to successfully finish my PhD. Looking back at my PhD years I will think of us brainstorming, writing, discussing and, above all, laughing. I'm grateful beyond words that you've become such a close friend.

Monique: I couldn't have wished for a better promotor. Your positive attitude, prompt replies to emails, reviews to papers and especially your warm heart are much appreciated. Thanks for your enthusiasm, all your wise words and charisma.

Marlies: Your efforts to develop and implement eHealth are tremendous. Thanks for your guidance on this matter throughout the years.

Romaric: Highlights of my PhD years were both visits to Lille, especially August 2017. Merci beaucoup de nous avoir invités!

All committee members: Thank you for your reviewing and discussing my thesis with me.

Mikki, Hester, Priya, Victor, Lisette, Stef, Karim, Hélène, Steven and Frank: Without you this thesis wouldn't have been possible. Thank you so much for all your hard work.

Collaborations partners: Hospitality App team, Focus Cura and ZIVVER. Thanks for our research collaboration.

My managers at EVA: Maurits and Nynke especially, thanks for giving me the opportunity to work at EVA.

Team MyChart: Forever 'Talking about ...MyChaaart, MyChart!' ♫ ♫

Vivian: Calm and steady in hectic times. I enjoy our lunch breaks :)

Inge: I admire your work ethic and above all, your approach to life.

Client councils of AMC and VUmc: Thanks for sharing your thoughtful insights

KIK colleagues and roomies: Thanks for the support and laughter during coffee breaks / evening drinks.

Danielle: All praise of the conjoint analysis research goes out to you and Frank.

KIK secretary: Without you, we would all be lost!

Birgit: This page is beautiful because of you, thanks for your creativity.

Colleagues at Dutch burns care and association for people with burns: I feel privileged to coordinate the 'nazorg portal' activities.

Ella: Thanks for being my paranymph and good friend from highschool onwards! You're a great physician ánd it's lovely to see you being so happy with your three little ones and Jeroen.

Dianne: Another great paranymph, colleague and friend! Thanks for sharing your thoughts about work and life with me.

I'm further blessed with many friends, family and a boyfriend that I all hold dear to me. I'll have lots of coffee moments to thank them personally for their love and support throughout my PhD years.

“I carry a log – yes. Is it funny to you? It is not to me. Behind all things are reasons. Reasons can even explain the absurd. Do we have time to learn the reasons behind the human being’s varied behavior? I think not. Some take the time. Are they called detectives?

Watch – and see what life teaches.”

Log Lady | Twin Peaks, episode 1, 1990