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eHealth for all? Towards usable and effective ehealth services in different health care settings

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General Introduction

1

eHealth in a changing health care landscape

The health care landscape is evolving, which can be attributed to several key factors. First, the number of patients who need care is increasing [1]. Second, the care that patients need is becoming increasingly complex due to aging and an increasing number of chronic diseases, including obesity [2]. Third, due to high-quality health care, patients with chronic diseases also live longer, and thus, they have a growing need for care over their lifetime [3]. Beyond the impact of an aging population, there is also a greater emphasis on early diagnosis and prevention [3, 4]. Moreover, societal changes are reshaping the health care landscape, with an important shift toward the provision of care in non-hospital settings, such as homes and primary care settings. This shift is primarily driven by financial considerations and limitations in staffing [3, 4]. All of the aforementioned elements highlight the increasing demand for health care services as well as the need for transformative changes in the health care sector. This challenge is especially acute in primary care, where an aging population and a rising incidence of chronic diseases are leading to increased workloads. Consequently, there are risks of diminished health care quality, increased time constraints per patient (resulting in higher work pressure), and reduced access to health care services [5]. In short, these ongoing changes are creating an unsustainable situation for the future of health care; therefore, implementing the necessary changes is crucial to ensure the sustainability of health care [6].

A potential solution for making health care more accessible is digitization in health care (also called eHealth; see Textbox 1). Digitization has been growing in importance in society for decades. In addition, the COVID-19 pandemic improved technology in health care in both quantity and quality [7]. Factors including the changes in society and COVID-19 have increased patients' willingness to use digitization, be more in charge of their health care, and self-manage their health care [7-9].

The definition of eHealth according to Eysenbach: *"e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state of mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology."* [10]

Textbox 1. What is eHealth?

In short, problems with the accessibility of health care, high work pressure on health care professionals, and a greater willingness to use eHealth reveal opportunities for the growth of digital solutions for managing health care. eHealth provides possibilities to reduce the work pressure in (primary) care, increase patients' self-management, and improve the accessibility of care. On the one hand, eHealth can support specific

processes of care delivery, such as digital consultations or online triage, enabling care to be provided more efficiently. On the other hand, eHealth can support self-management and reduce health care demand [11]. Some potential benefits of eHealth are provided as follows through various examples. One example is the Dutch website *Thuisarts.nl* [12, 13], a non-commercial website developed by general practitioners (GPs) to enable citizens to obtain reliable health information [13, 14]. Research has demonstrated that since the launch of the website, the number of 'normal' consultations has decreased [13, 14]. Consequently, the work pressure in primary care may be lower because fewer consultations are necessary. Another example is *LIVA Health Care* [15, 16], an international digital program with online lifestyle coaching to help people change their behavior. *LIVA* helps patients to self-manage their disease and takes over some tasks from GPs. Research has indicated that the service has a positive effect on users, such as weight loss in diabetes patients, with the potential to help with the secondary prevention of chronic disease [15, 17]. These two examples illustrate how eHealth has the potential to enhance various aspects of health care, including the facilitation of self-management through a variety of services, applications, and websites and increased access to health care services [8, 16, 18].

Self-management

eHealth is expected to play a major role in increasing self-management among patients and citizens [19]. A definition of self-management is provided in Textbox 2. Increasing self-management can lead to health improvements in chronically ill patients as well as reduce their demand for health care [11]. Especially today, where much pressure exists on primary care, self-management can help to bridge the gap between patients' needs and the capacity of health services to meet those needs [20]. In addition, it can lead to more accessible health care by matching the needs of patients (eg, the provision of online information) [21]. Noteworthy, while self-management is frequently discussed within the context of individuals with chronic illnesses, its relevance also extends to the broader population of healthy citizens.

The definition of self-management according to Barlow et al.: *"The individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition."* [20]

Textbox 2. What is self-management?

Self-management focuses on education and information provision. When patients are well informed, they are better equipped to make informed decisions and adhere to their treatment plans. This, in turn, empowers patients to take a more active role

in managing their health conditions. The development of digital tools designed to aid patients in managing their health conditions could also prove beneficial for GPs. These tools can complement and support various aspects of a GP's responsibilities, ultimately enhancing the quality of care they provide. In short, self-management has the potential to enable patients to take greater control of their health and manage it or their disease more effectively. In addition, self-management can lead to increased access to health care services and a reduced need for frequent medical consultations and interventions, thereby alleviating the workload on health care professionals.

Currently, many eHealth services (hereinafter "online services") that support, empower, and help patients and citizens to self-manage their health (with or without chronic disease). However, online services are rarely extensively validated scientifically [16]. Oftentimes, developed online services end up in the metaphorical "Valley of Death," where many technologies end after research funding ends [22, 23]. This could be due to time limitations, resources, or policy [24]. Sometimes, online services are implemented but not researched, or they are researched in a research setting and not used in daily practice. The online services examined in this thesis have already been implemented or piloted in daily practice. Thus, it is possible to research them in real-life settings, as opposed to only theoretically. Consequently, they are less likely to end up in the Valley of Death.

Challenges to the usability and accessibility of online services

Scientific research could contribute to the investigation of (a) the efficacy of online services; (b) the alignment of their intended purpose (ie, do they do what they are intended to do?); and (c) the impact of these services on quality health care [16]. Other reasons to scientifically validate online services are user-centered – namely to increase reliability and overcome barriers for users [25]. Some known barriers to the use of online services for users are security problems, low usability, and complexity [25, 26]. Addressing such barriers before such services are implemented on a larger scale can increase their usability. The usability of an online service for health care professionals is equally significant when it is deployed. The online service must fit within the organization and in the daily routine of the health care professional [27].

Accessibility also presents a barrier to the adoption and utilization of online services. Due to factors that influence citizens' access to online services, their use can exacerbate disparities in health care access [28, 29]. Differences in people's educational level and age play roles in their use of online services [30]. In general, higher age and lower educational level result in lower use of online services [28, 30]. Although older people who use online services are increasing in number, they remain the group that uses online services the least [28]. Moreover, income is a factor that contributes to the use of online services; that is, low income leads to fewer possibilities for Internet

access [28]. To ensure that online services work in practice, they should be accessible to everyone and not increase health care differences.

All of the services examined in this thesis are researched as services in real-life settings, which makes it an interesting and relevant study. On the one hand, it is imperative to examine whether online services fulfill their intended purpose. On the other hand, ensuring that the online services are practical, user-friendly, and used as intended is also crucial to this thesis. This thesis aims to collect additional insights regarding the characteristics of online service users and their experiences. It delves into the usability of the various services across diverse patient and citizen groups in various health care settings. The online services researched in this thesis have the potential to empower patients and citizens by enhancing their self-management capabilities and supporting health care professionals in their daily efforts.

Thesis objectives

The general objective of this thesis is to investigate whether different online services that offer direct access to care are usable, effective, and safe for patients and citizens for self-managing their health care with or without the involvement of health care professionals. Chapters 2 through 5 specifically investigate the use and usability of direct access to different diagnostic test services (in)dependent of a health care professional. Then, Chapter 6 specifically investigates the effectiveness of an online self-management and support tool for asthma and chronic obstructive pulmonary disease (COPD) patients supported by health care professionals.

Thesis outline

This thesis primarily focuses on evaluating online services for enhancing self-management among patients and citizens through various online services. What unites all of these online services is their shared objective of assisting patients or citizens in effectively managing their health and/or disease.

The remainder of this thesis is organized as follows. Chapter 2 presents an overview of methods available to patients for direct online access to diagnostic testing and results independent of a health care professional in primary care. This systematic review includes studies that have focused on digitization in one or more phases of laboratory diagnostic testing, namely (a) triage and advice on diagnostic testing, (b) testing itself, and (c) the communication of test results.

Chapter 3 researches the first phase of direct access to diagnostic testing, namely the triage service. This **online triage service** is also part of the services researched in Chapters 4 and 5. Chapter 3 compares the online triage service with the decision-

making process of GPs. The online triage service advises whether and what types of diagnostic tests fit a patient's complaints. Such an online service makes laboratory diagnostic testing accessible and has the potential to reduce the work pressure for GPs, as a patient could perform the triage online instead of visiting their GP. If the online triage tool confirms that no consultation is required, unnecessary consultations with the GP can be avoided. To allow direct access to a diagnostic test service with an online triage work in practice, the advice of the online tool must be in line with the advice of the GP. A qualitative vignette study is presented that compares the advice of the online service with that of GPs and to identify their decision-making factors. The online triage tool can be used in primary care settings as well as in services for citizens independently of a health care professional.

Chapter 4 discusses the service **Directlab Online**, where the online triage service is included. Directlab Online is an online service that enables citizens to request diagnostic tests online, such as diagnostic tests for sexually transmitted infections, without the involvement of a health care professional. Through self-testing and self-sampling, individuals can access information about their health and make informed decisions about whether they want to consult a health care provider. It is important for citizens to pay for the service themselves, and the results are communicated to them online [31]. The chapter evaluates the experiences of Directlab Online through focus groups with potential users. In addition, facilitators, barriers, usability and needs related to the use of such a service are identified.

Chapter 5 examines **Homelab**, which is comparable with Directlab Online but embedded in the GP's online environment. Only patients of general practices affiliated with Homelab can request a diagnostic test online. The GP of a patient can see what tests have been ordered and approve or decline the request. Patients can only perform a diagnostic test with the approval of the GP. The results are communicated to the patient and GP online. It is always the responsibility of the GP to ensure that the patient receives and understands the results. The diagnostic services of Homelab are covered by health care insurance in the Netherlands. A quantitative questionnaire implemented after patients used Homelab was used to research the use, usability, and user characteristics of Homelab. In addition, the research aimed to evaluate whether Homelab could replace an appointment with a GP.

Chapter 6 focuses on the assessment of the effectiveness of a platform called **SARA**, which is intended for patients with asthma or COPD. SARA is an online self-management portal developed by the Dutch pharmacy company Service Apotheek. SARA provides information about inhaled medication and its usage as well as supports patients when they have any questions about their medication or disease. While SARA was initially developed for asthma and COPD patients, the platform's core concept could apply to various chronic diseases and their corresponding medications. Chapter 6 examines whether this self-management support system could contribute to patients' improved health. The service is fully embedded in the health care system of

patients. A pre–post study that employed medication dispensing data was conducted to calculate exacerbation rates and medication adherence among patients who used SARA and those who did not.

To conclude, Chapter 7 provides a main summary of the findings and puts the results into context. In addition, it describes the study’s strengths and limitations, its implications, and suggestions for further research.

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