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

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Summary

The health care landscape is evolving due to increasing demand, the complexity of care, and a shift toward early prevention, in addition to changes in health care settings. To address these challenges, eHealth (electronical health) is gaining importance, as it offers opportunities to reduce health care professionals' work pressure, enhance patient self-management, and improve health care accessibility. Yet, eHealth services must be validated to ensure that they fulfill their intended purpose. In addition, online services must also be practical and user-friendly. This thesis studied online services that have already been implemented or piloted in the health care landscape. It assessed their usability and effectiveness at helping patients and citizens with self-management and improving the accessibility of health care. In **Chapter 1**, the challenges in health care and the role of eHealth in patient self-management are described in detail. In addition, the thesis objectives are presented. The general objective was 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. Next, **Chapters 2 through 5** specifically investigate the use and usability of direct access to various diagnostic test services. Then, **Chapter 6** 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. Lastly, **Chapter 7** presents a discussion of the findings and concludes the thesis.

Chapter 2 evaluates the availability and utilization of direct online access to diagnostic tests and result services. A review was conducted that focused on patients having direct access to online triage, ordering tests online, performing tests at home, and receiving the results digitally. The review encompassed 31 different services, which were predominantly focused on sexually transmitted infections (STIs). Users rated the usability of these services as well as their acceptability positively. Testing for STIs at home had higher user rates compared with clinic-based testing, as it reduces the barriers to getting tested. In addition, performing a diagnostic test at home was demonstrated to be acceptable, safe, and convenient for users. Moreover, after users received positive test results for a sexual infection, follow-up care was available. Direct access to diagnostic test and result services could potentially reduce the barriers to testing, improve efficiency, and reduce the workload of general practitioners (GPs) as patients would be able to assume a more active role in their care.

Chapter 3 compares the advice of an online triage tool for STIs with the advice of GPs. In this qualitative study, 10 GPs were asked to provide advice for six different patient vignettes about whether to perform an STI test. These vignettes were identified as patient cases structured around risk factors associated with STIs. Specifically, different aspects were considered to calculate the risk of an infection, such as unsafe sex and different complaints. Furthermore, factors such as age, gender, and relationship status

were considered, and they differed for each vignette. The advice of the online tool for each vignette was compared with the advice offered by the GPs. In addition, this study sought insights into the decision-making process behind the GPs' advice; specifically, it examined why they advised or did not advise an STI test for a particular patient case (a vignette in this study). The results revealed that in three out of the six vignettes, the advice for testing offered by the online triage tool and all GPs was the same. For the remaining three vignettes, discrepancies were observed between the online tool and the GPs as well as among the GPs themselves. Consistency between the online tool and GPs was more prevalent when risk factors for STI testing were unequivocally evident, such as in cases involving men who have sex with men. The decision-making process of GPs was influenced by patient-related factors, including the anxiety levels of the patient, patient preferences, and age. Additionally, some GPs expressed an inclination to ask further questions or conduct physical examinations before advising patients to be tested. From these findings, it could be concluded that the GPs tended to adopt a comprehensive and holistic perspective, considering various aspects of the patient, while the online tool tended to align more closely with medical guidelines. The online triage tool demonstrated potential as a substitute for in-person consultations in the future. However, this tool needs to provide safety, effectiveness, and user friendliness, and more research is required to ensure this. Furthermore, incorporating more holistic inquiries into the triage tool, developed in collaboration with GPs, could be advantageous.

The online triage tool researched in Chapter 3 is also among the online services researched in Chapters 4 and 5. **Chapter 4** examines an online service's usability, for which focus group sessions were conducted. A total of 19 participants were interviewed to assess the service's usability, identify user needs, and identify factors that either facilitate or impede its utilization. The online service allows citizens to independently order diagnostic tests, such as those for STIs, without the involvement of health care professionals. Nevertheless, health care professionals were involved in the service's development. The focus group participants emphasized the importance of clarifying that the service aimed to enhance their health care, as this was not adequately conveyed to them on the website. Moreover, a lack of information on privacy and a commercial appearance acted as barriers, discouraging citizens from using the service. Participants stressed the need for a suitable amount of clear information to improve the service's usability and encourage its adoption. Moreover, this research found an imbalance between the wishes of the health care professionals involved in the service and those of the citizens. Specifically, the health care professionals involved in the service desired highly detailed information on the website about the diagnostic tests, while the citizens wanted clearer and more concise information about the diagnostic tests. Co-creation with end-users and medical professionals is required to solve this imbalance. In addition, future research could focus on the effect of test results on user behavior.

Chapter 5 examines another service in which the online triage tool from Chapter 3 was implemented. Specifically, it investigates the usability of an online service called Homelab, which enables patients to order diagnostic tests online with the permission of their GP. Thus, GPs can monitor their patients. Homelab provides a range of diagnostic tests, including tests for STIs and hair loss. Within Homelab, an online triage tool guides patients on which tests to request. Homelab aims to minimize visits to a GP, enabling patients to conveniently request tests online and access their results digitally. Nonetheless, if the results are abnormal, it remains the GP's responsibility to communicate this fact to the patient. In Chapter 5, the usability of Homelab was assessed through a post-usage questionnaire that was completed by 74 participants. The most ordered test package was called 'Am I still healthy?'. The results indicated that Homelab primarily attracted well-educated and employed users. They used Homelab instead of going to the GP, and more than 80% were willing to reuse Homelab in the future. Moreover, the users found Homelab easy to use, particularly younger ones. Homelab thus demonstrated its potential to alleviate the workload of GPs by reducing patient visits. Moreover, it could enhance patient self-management and accessibility, particularly among younger patients, by offering them greater control over the management of their health without the need to wait for specific appointments.

Chapter 6 investigates the effectiveness of an online self-management service for patients with asthma and the use of medication for chronic obstructive pulmonary disorder (COPD). The study aimed to examine whether the service was able to decrease exacerbation rates (lung attack) and increase medication adherence. The online self-management tool was called SARA. SARA provides information about medication use and entails follow-up support by pharmacists. Medication dispensing data were used from 382 pharmacies across the Netherlands. In total, 9,452 participants were included, of whom 2,400 were SARA users. Their average age was approximately 61 years. Exacerbation rates were determined by the short-course oral corticosteroids dispensed. Medication adherence was assessed by calculating the proportion of days covered by dispensed inhalation maintenance medication. The outcomes were analyzed for the year before and after SARA implementation, and SARA participants were compared with control patients. The results revealed an increase in mean exacerbation rates for both SARA and control participants. However, this increase was significantly lower among the SARA participants. For participants who used medication for asthma and COPD for a longer period, medication adherence was found to be increased in both the SARA and control groups, although the increase was significantly higher for the SARA group. These findings suggested that SARA holds promise for potentially decreasing exacerbation rates and increasing medication adherence. Furthermore, SARA could potentially have its efficacy extended to the management of other chronic diseases that require medication for disease control and symptom improvement.

Lastly, **Chapter 7** discusses the findings of all of the studies. In addition, it discusses the lessons learned and provides suggestions for future research. The findings suggested that, overall, patients and citizens – particularly younger ones – display receptiveness to online services aimed at aiding their self-management of health and disease. Furthermore, these services were often perceived as user-friendly. Nonetheless, certain obstacles hinder their widespread adoption. Hence, it is imperative to promote collaboration among all stakeholders to improve these services' usability and guarantee that they effectively fulfill their intended purpose and objectives. Throughout this thesis and the implementation of the online services, several lessons were learned. To start, the reliability and ease of use of these services proved to be crucial. In addition, implementing online services is a time-consuming process. Furthermore, it is vital to include all stakeholders in the development and implementation of an online service to increase its usage as well as the chance that it does what it is intended to do. Further research could focus on long-term usage aspects, such as whether users feel more in control of managing their health. A limitation of this research lies in the duration of scientific research compared with the pace of innovation. The tools examined in this thesis could already be outdated by the time research is conducted. It is vital to consider the duration required for both research and implementation in contrast to the rapid pace of technological advancements. Future studies should explore effective methodologies for researching online services. Moreover, upcoming research endeavors might prioritize the validation of the efficacy of online triage tools and the assessment of their comprehensibility among patients. A pivotal aspect is to ensure that patients can interpret and adeptly grasp these online triage tools. The use of online triage tools holds potential for facilitating direct access to health care services, provided that they are comprehensible and well-interpreted by patients. Additionally, services such as Homelab contribute to enhancing health care accessibility. Rather than transitioning everything directly into the digital realm, tools like online triage and services like Homelab can function as intermediaries. Nonetheless, it remains crucial for health care professionals to be actively engaged in these services. In summary, while eHealth offers opportunities for accessible and effective health care, scientifically validating these services is paramount.