

Understanding patient perspectives

Citation for published version (APA):

Thielmann, R. R. L. C. (2023). *Understanding patient perspectives: online access to medical records*. [Doctoral Thesis, Maastricht University]. Maastricht University. <https://doi.org/10.26481/dis.20231205rt>

Document status and date:

Published: 01/01/2023

DOI:

[10.26481/dis.20231205rt](https://doi.org/10.26481/dis.20231205rt)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

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Summary

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

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

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

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

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

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

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

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