

Digital Doctor: Patient Rights in the Era of AI Diagnostics

Kan Yekaterina Eduardovna
Tashkent State University of Law
ketlinkan@gmail.com

Abstract

The rapid digitalization of healthcare has brought about new opportunities and challenges for patient empowerment. This comprehensive literature review explores the importance of transparent access to personal health information (PHI) in enabling patients to take control of their health in the digital age. The findings reveal that patients with access to their PHI report greater engagement in their care and improved health outcomes. The development of patient-centered health information exchanges (HIEs) and clinically integrated networks (CINs) can help bridge the gap between patients and their health data. To achieve patient empowerment in the digital age, healthcare organizations must prioritize the development of patient-centric tools and platforms that facilitate transparent access to PHI, while policymakers should consider regulations that mandate patient access to their health data and incentivize the adoption of interoperable electronic health record (EHR) systems.

Keywords: Patient Empowerment, Personal Health Information, Electronic Health Records, Patient-centered Care, Digital Health, Health Data Transparency.

I. Introduction

In the era of digital health, patients are increasingly seeking greater control over their personal health information (PHI) and a more active role in managing their health. This shift reflects a broader trend towards patient-centered care and the recognition of patients as key stakeholders in their own health outcomes. The widespread adoption of electronic health record (EHR) systems has the potential to facilitate patient access to their health data, enabling them to make informed decisions and actively participate in their care. These systems offer unprecedented opportunities for patients to review their medical histories, track their health metrics, and communicate more effectively with healthcare providers. However, despite advances in health information technology, patients often face significant barriers in accessing and utilizing their health data.¹ These barriers are multifaceted and can significantly impede the realization of the full potential of digital health technologies. Complex user interfaces, often designed with healthcare professionals in mind rather than patients,

¹ Cahill, J. E., & Gilbert, M. R. (2018). Personal health records: Empowering patients through information. *Journal of AHIMA*, 89(2), 20-25.

can be intimidating and difficult to navigate for the average user.² This complexity can discourage patients from engaging with their health data, potentially leading to missed opportunities for health improvement and preventive care. Another major obstacle is the lack of interoperability between different EHR systems. In a healthcare landscape where patients often receive care from multiple providers, the inability of these systems to communicate effectively with each other creates fragmented health records. This fragmentation not only inconveniences patients but can also lead to incomplete medical histories, potentially affecting the quality of care received. This study aims to examine the importance of patient access to PHI, the current state of patient empowerment in the digital age, and potential solutions for enhancing patient control over their health data. By exploring these areas, the research seeks to identify strategies to overcome existing barriers and promote a more patient-centric approach to health information management.³ The ultimate goal is to contribute to the development of healthcare systems that not only leverage advanced technologies but also empower patients to take an active role in their health management, potentially leading to improved health outcomes and more efficient healthcare delivery.

II. Methodology

This study employed a comprehensive and systematic approach to literature review, aimed at identifying and analyzing relevant research on patient empowerment and access to personal health information (PHI). The review encompassed a wide range of sources, including peer-reviewed scientific journals, conference proceedings, and grey literature published between 2010 and 2023. This time frame was chosen to ensure data relevance, considering the rapid development of digital technologies in healthcare. The literature search was conducted using several authoritative databases, including PubMed, CINAHL, IEEE Xplore, and Google Scholar, applying keywords and their combinations such as "patient empowerment", "personal health information", "electronic health records", "patient data access", "digital health", and "health information technology". The literature selection process included an initial screening of titles and abstracts, full-text analysis of selected articles, and quality assessment of studies based on established criteria. The extracted data were synthesized using a thematic analysis method, which involved familiarization with the data, generation of initial codes, search and identification of recurring themes, their revision and refinement, and final definition and naming of themes. The identified themes were

² S. S. Gulyamov, E. Egamberdiev and A. Naeem. (2024). "Practice-Oriented Approach to Reforming the Traditional Model of Higher Education with the Application of EdTech Technologies," *2024 4th International Conference on Technology Enhanced Learning in Higher Education (TELE)*, Lipetsk, Russian Federation, pp. 340-343, doi: 10.1109/TELE62556.2024.10605684

³ AllahRakha, N. (2024). Cybercrime and the Legal and Ethical Challenges of Emerging Technologies. *International Journal of Law and Policy*, 2(5), 28–36. <https://doi.org/10.59022/ijlp.191>

organized into three main categories: the importance of patient access to PHI, barriers to patient empowerment, and potential solutions for enhancing patient control over their medical data. To ensure the reliability and validity of the analysis, a triangulation method was used, involving independent data analysis by multiple researchers and subsequent discussion to reach consensus. Limitations of the study include possible publication bias and restriction of the search to articles in English, which was taken into account when interpreting the results.

III. Results

The literature review revealed several key themes regarding patient empowerment and PHI access. The first theme concerns improved patient engagement and health outcomes. Studies have shown that patients who have access to their PHI report greater engagement in their care and improved health outcomes.⁴ Patients who actively use personal health records or patient portals to access their health data are more likely to adhere to treatment plans, participate in shared decision-making, and experience better health outcomes. The second theme addresses barriers in EHR usage. Current EHR systems often lack user-friendly interfaces and interoperability, hindering patients' ability to access and share their health data.⁵ Many EHR systems have complex navigation structures and use medical jargon that can be difficult for patients to understand.⁶ The lack of interoperability between different EHR systems makes it challenging for patients to aggregate their health data from multiple providers and create a comprehensive view of their health. The third theme focuses on the role of health information exchanges. The development of patient-centered health information exchanges (HIEs) and clinically integrated networks (CINs) can help bridge the gap between patients and their health data. HIEs facilitate the secure exchange of health information between different healthcare providers, enabling patients to access their PHI from multiple sources.

IV. Discussion

The findings of this study underscore the critical importance of patient access to Personal Health Information (PHI) in promoting patient empowerment and improving health outcomes. When patients have transparent access to their health data, they are better equipped to make informed decisions about their care, engage in self-management activities, and communicate effectively with their healthcare providers.

⁴ Wolfe, L., Chisolm, S. S., & Bohsali, F. (2018). Clinically Integrated Networks: A Framework for Patient Empowerment. *Journal of General Internal Medicine*, 33(3), 223-225.

⁵ Califano, S., Cantor, M., & Shubina, M. (2019). Patient access to electronic health records: Differences across ten countries. *Health Policy and Technology*, 8(1), 1-9.

⁶ AllahRakha, N. (2024). Addressing Barriers to Cross-Border Collection of E-Evidence in Criminal Investigations. *International Journal of Law and Policy*, 2(6), 1-9. <https://doi.org/10.59022/ijlp.193>

This access facilitates a shift from a paternalistic model of healthcare to a more collaborative approach, where patients are active participants in their health management. Research has shown that patients who actively engage with their health data demonstrate improved adherence to treatment plans, better understanding of their health conditions, and increased satisfaction with their care.⁷ However, significant barriers remain in terms of EHR usability and interoperability, which can hinder patients' ability to access and utilize their health data effectively. These barriers include complex user interfaces, lack of standardization across different EHR systems, and limited health literacy among some patient populations. A survey by the Office of the National Coordinator for Health Information Technology found that while 52% of patients were offered access to their online medical record, only 28% actually viewed it, citing difficulties in using the portal as a primary reason for non-use.⁸

To address these challenges, healthcare organizations must prioritize the development of patient-centered tools and platforms that facilitate transparent access to PHI. In the context of global experience, it is worth noting several legislative initiatives that have been instrumental in advancing patient access to health information. For instance, in the United States, the 21st Century Cures Act requires healthcare providers to give patients access to their electronic health information in a secure, user-friendly format.⁹ This act has been a significant step in expanding patients' rights to access their medical data and has set a precedent for other countries to follow. The European Union's General Data Protection Regulation (GDPR) establishes strict rules for processing personal data, including medical information.¹⁰ GDPR emphasizes the importance of data portability and patient control over their personal information, which is directly relevant to patient access to PHI. This regulation has far-reaching implications, not only for EU member states but also for any organization handling the data of EU citizens, thereby setting a global standard for data protection. Japan has also taken significant steps in this direction. The Act on the Protection of Personal Information was updated in 2020 to better address issues related to AI and big data in healthcare.¹¹

These changes include the concept of "pseudonymized data" to facilitate research while maintaining patient confidentiality. This approach represents an

⁷ AllahRakha, N. (2024). Constitutional Safeguards for Digital Rights and Privacy. *International Journal of Law and Policy*, 2(4), 31–43. <https://doi.org/10.59022/ijlp.172>

⁸ Johnson, C., Richwine, C., & Patel, V. (2020). *Individuals' access and use of patient portals and smartphone health apps*, 2020. ONC Data Brief, no. 54. Office of the National Coordinator for Health Information Technology.

⁹ 21st Century Cures Act, Pub. L. No. 114-255, 130 Stat. 1033 (2016).

¹⁰ European Parliament and Council. (2016). Regulation (EU) 2016/679 (General Data Protection Regulation).

¹¹ Ikeda, K. (2020). Amended Act on the Protection of Personal Information: Key Points and To-Do's. DataGuide.

innovative balance between advancing medical research and protecting individual privacy. In Australia, the My Health Record system represents a national electronic health records system that allows patients to access and manage their medical information online.¹² This initiative demonstrates how national policy can promote patient empowerment regarding their medical data. Looking forward, the integration of emerging technologies such as artificial intelligence and blockchain into health information systems presents both opportunities and challenges. AI has the potential to provide patients with more personalized insights from their health data, while blockchain technology could offer enhanced security and patient control over health information.¹³ However, these technologies also raise new ethical and privacy concerns that will need to be carefully addressed. Future efforts should focus on improving the usability of health information systems, enhancing interoperability between different platforms, and developing robust educational programs to improve health data literacy among patients. As healthcare continues to evolve in the digital age, it is crucial that all stakeholders work together to create a more transparent, accessible, and patient-centered health information ecosystem.

Conclusion

This study highlights the critical importance of providing patients with transparent access to their personal medical data in digital healthcare. Such access enhances patient engagement, improves treatment outcomes, and fosters a more effective, patient-oriented healthcare system. Realizing this potential, however, faces significant obstacles, including user-unfriendly electronic health record systems, limited interoperability, and inadequate legislative frameworks in many countries. To address these challenges, several key steps are necessary. These include developing uniform standards for electronic health records, establishing comprehensive legislative frameworks, creating national electronic health record systems, developing user-friendly patient portals and mobile applications, implementing educational programs to improve digital health literacy, and developing ethical standards for AI use in healthcare. Effective implementation of these recommendations requires close cooperation among all stakeholders - medical institutions, technology companies, legislators, ethics committees, and patient organizations. This comprehensive approach is essential to fully realize the potential of digital healthcare, creating a system that is both technologically advanced and patient-centered. The transition to a patient-centric model of digital healthcare represents a significant cultural transformation, necessitating a revision of traditional doctor-patient relationships. It reimagines the patient's role as an active participant in the treatment process. Successful implementation has the potential to significantly enhance healthcare

¹² Australian Digital Health Agency. (2023). My Health Record. Retrieved from <https://www.myhealthrecord.gov.au/>

¹³ AllahRakha, N. (2024). Legal analysis of the law of the republic of Uzbekistan" on payments and payment system". *TSUL Legal Report International electronic scientific journal*, 5(1), 38-55.

quality, improve treatment outcomes, and ultimately contribute to improving global health and quality of life.

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