Data Platforms and Ecosystems in Healthcare

Daniel Fürstenau
IT University of Copenhagen | Charité
daniel.fuerstenau@itu.dk

Anne-Katrin Witte
University of Hagen
anne-katrin.witte@fernuni-hagen.de

Scott Thiebes
Karlsruhe Institute of Technology
scott.thiebes@kit.edu

Ali Sunyaev
Karlsruhe Institute of Technology
sunyaev@kit.edu

Abstract

This minitrack provides a venue for all work (qualitative, quantitative, computational, and design) in relation to better understanding health data platforms, data repositories, data sharing, data governance, and ecosystems. It highlights various perspectives, including technical, organizational, social, and regulatory ones and considers multiple levels, such as the system, individual, community, and societal level. This minitrack encourages work on emergent technologies, while it is open to learn how existing technologies may be repurposed for data-driven care coordination and research using increasing amounts of data over long periods of time.

Keywords: data sharing in healthcare, health data platforms and ecosystems, health data openness, individual privacy preservation in healthcare.

1. Introduction

The past two years of the COVID-19 pandemic have painstakingly highlighted the demand for efficient healthcare systems in which relevant health data are readily accessible wherever needed and whenever needed. The amount of sensitive and personal health data collected every day by a variety of mobile and medical devices (e.g., smartphones, wearables, implants) fosters the emergence of large data repositories and platforms at scale (Beverungen et al., 2015; Sunyaev et al., 2015). However, it is essential to integrate and make this data accessible, such as through multisite health data sharing, so that it can be used to inform and impact care coordination, data-driven care research, and population health (Oborn & Barrett, 2016; Fürstenau et al., 2021; Scheibner et al., 2021). In this context, healthcare systems frequently struggle to realize nation-wide information infrastructures (Aanestad & Jensen, 2011) and make data accessible to those healthcare stakeholders who can act upon the knowledge generated from it (Oborn & Barrett, 2016). Beyond technological interoperability barriers, there are challenges on the individual, organizational, and societal level (Witte et al., 2020), such as the unwillingness to share health data openly due to fears of surveillance or misuse by third parties (Thiebes et al., 2017). In this context, it is critical to design health data sharing in a way that simultaneously preserves individual privacy and data utility (Scheibner et al., 2021), and to quickly find appropriate policies to do so while leveraging the benefits of digitization (Anderson & Agarwal, 2011).

The minitrack puts a focus on the emergence, design, and evolution of *health data ecosystems*, generally defined as multi-stakeholder networks that enable value creation via platforms and other structures connecting data allowing various types of health data to be stored, shared, and reused (Oliveira et al., 2019) in a secure, privacy-preserving, and FAIR manner (Wilkinson et al., 2016). The minitrack is welcoming to qualitative, quantitative, computational and design contributions that shed light on the critical role of data and individual privacy preservation in and through healthcare data platforms and ecosystems. In this context, it especially encourages papers that strongly emphasize practical applicability within the healthcare environment.

Topics of interest include, but are not limited to:

- Data sharing and data donation in healthcare
- (Open) health data repositories
- Health data spaces and initiatives for data lofts, communities, and collectives
- Data-driven value creation in healthcare ecosystems
- Cases on the emergence, design, and evolution of (open) data platforms in healthcare

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- Design principles for privacy-preserving data platforms in healthcare
- Use of health data platforms for data-driven care research and artificial intelligence
- Openness and governance of biomedical data

2. Research Papers

The papers in this minitrack consider these topics from two different but important perspectives. One paper adopts a socio-technical view and empirically investigates a proposed large-scale project to develop an open healthcare platform, while the other paper takes an economics of information perspective and provides a conceptual analysis. Both papers point out the lack of an interoperable health information infrastructure on a broader, e.g., national, level.

The first paper "Exploring the Emergence of Open Platforms in Healthcare: Design Considerations and Experiences from an Initial Case in Norwegian Primary Care" addresses the challenge of health information technology interoperability using a proposed platform initiative in Norway. The authors apply a socio-technical lens to *critically assess the architecture of the proposed platform case* and *synthesize key considerations in developing requirements for an open platform in healthcare*. As a result, they highlight four key areas that resulted in conflict and tensions: procurement strategy and vendor neutrality, the platform's ability to facilitate flexible use, the use of standards and separation of application and data, and strategies for the development and governance of standards.

The second paper "On the Economic Nature of Medical Information: Implications for the Development of Information Infrastructures in the Healthcare Sector" highlights the challenge of information infrastructure development and slow information technology adoption in the healthcare sector. The authors apply the theory of collective action to information components, as opposed to information infrastructures as a whole, to answer the research question: *What is the economic nature of medical information making up a health information infrastructure?* As a result, they provide an explanation that could shed light on the difficulties of setting up nationwide electronic patient record systems based on the theoretical analysis of information subtractability.

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