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Returning for Round Two: Data Platforms and Ecosystems in Healthcare

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Abstract

This minitrack, for the second time, deepens understanding of data sharing, data ecosystems, data platforms, data spaces, data hubs, and repositories. It emphasizes diverse perspectives, covering technical, organizational, social, and regulatory aspects, and examines multiple levels, including system, individual, community, and societal dimensions. This minitrack fosters discussions on emerging technologies and is open to insights on repurposing existing technologies for data-driven care coordination and research, involving increasing data over extended periods.

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

1. Introduction

Recent years have highlighted the need for efficient healthcare systems where relevant health data is readily accessible wherever and whenever needed. This growing need is coupled with the increasing amount of sensitive and personal health data collected daily by various mobile solutions (e.g., apps, wearables, sensor-equipped devices). The convergence of these trends is rendering siloed approaches to health data increasingly inefficient and challenging (Seastedt et al., 2022).

It is crucial to ensure health data integration and accessibility, potentially through strategies like multisite health data sharing (Thiebes et al., 2023) or the utilization of emerging health data sharing platforms and data spaces. Such integration is essential to inform and impact care coordination, data-driven care research, and population health, and create better (digital) treatments and interventions, and evaluate their risks and benefits based on real-world data (Sunayev et al., 2015; Fürstenau et al., 2021; Scheibner et al., 2021; Fürstenau et al., 2023).

Apart from technology and interoperability issues, individuals and organizations face regulatory, organizational and institutional hurdles (Witte et al., 2020), often hesitating to share health data openly due to fears of surveillance, stigma, or misuse by third parties (Thiebes et al., 2017). In this context, it is critical to devise health data sharing methods that benefit patients and their support networks while ensuring privacy and data utility (Scheibner et al., 2021), requiring swift policy formulation to capitalize on digital advantages.

This minitrack focuses on health data ecosystems – multi-stakeholder networks enabling value through platforms for secure, privacy-preserving, and FAIR health data storage, sharing, and reuse. We seek contributions on data's role and privacy preservation in healthcare platforms and ecosystems, particularly those stressing practical healthcare applicability.

Topics of interest included, but were not limited to:

- Data sharing and data donation in healthcare
- (Open) health data repositories
- Health data spaces and initiatives for data lofts, data communities, and data collectives
- Sustainable, circular data-driven value creation in healthcare ecosystems
- Cases on the emergence, design, and evolution of (open) data platforms in healthcare
- 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
- Data governance and its relation to social value
- AI-powered solutions on (open) health data
- Patient and stakeholder engagement strategies

2. Research Papers

This year, we are hosting the minitrack for the second consecutive time. Out of a total of 8 submissions,

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we accepted 4 papers for presentation at HICSS. We would like to thank the Healthcare track organizers for their ongoing support and express our excitement about the sustained interest in our minitrack. While definitional questions were primarily the focus in the first year, this year's discussion is partially shifting towards the prerequisites and outcomes of data platforms and ecosystems.

The first paper, "Lean Study Host: Towards an Automated Pipeline for Multi-Center Study Hosting," provides a comprehensive description of a health data platform's design for managing data in medical studies across multiple sites, especially in image analysis. The proposed solution, "Lean Study Host" (LSH), is an open-source approach tailored to the specific needs of clinical practitioners, researchers, and data protection officers. LSH seeks to reduce technical, administrative, and legal complexities, allowing studies to devote more resources to research efforts. It accomplishes this through a cloud-native, microservice-based architecture, incorporating de-identification processes and on-premises hosting to preserve data sovereignty within the local institution.

The second paper, "Data Size Matters: The Impact of Message Framing in Different Health Scenarios on the Donation of Personal Health Information," focuses data donation from a patient perspective, underscoring the importance of message framing. The study investigates how factors such as benefit appeals, attribute framing, and specific health conditions can affect individuals' willingness to donate their personal health information. Conducted through an online vignette experiment with 208 participants from Germany, the study determines that benefit appeals, attribute framing, and health conditions indeed sway individuals' readiness to engage in health data donation. This research broadens our comprehension of the intricate benefit structures in health data donation.

The third paper, "Leveraging Large Language Models for Simplified Patient Summary Generation, Literature Retrieval, and Medical Information Summarization: A Health CASCADE Study," details how effective models (e.g., for accurately generating patient profiles) can be trained and deployed based on health data from such platforms. To this end, the paper presents an innovative system that employs natural language processing techniques to extract information from electronic health records and create simplified patient summaries. The authors suggest that their system has the potential to significantly improve clinicians' access to patient information, ultimately enabling them to concentrate more on patient care, which could lead to enhanced patient outcomes.

The fourth paper, "Privacy and User Satisfaction in Digital Health Applications," discusses the impact of privacy considerations and user satisfaction on the effective use of mobile health apps as a promising future data source for data platforms. In this effort, the authors review over 90,000 health apps from the Apple App Store and employ propensity score matching to explore the effects of various privacy settings within these apps on user satisfaction. The paper's findings challenge prevailing assumptions in the literature, indicating that collecting user data does not always correlate with decreased user satisfaction. The authors suggest this could be due to the necessity of gathering specific user data to offer certain services within health apps.

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