

Your Health, Your Data: Combining Interdisciplinary Views, Concepts, and Practices to Empower Patients in Their Engagement With Personal Health Data

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The collection and use of personal data is increasing and new developments in Big Data Analytics allow for innovative applications. Recent developments in healthcare, such as the proposal of the European Health Data Space, point towards a more data-driven future of diagnostics and therapy. These developments lead to new challenges, especially in how to design interaction between individuals and their personal health data. With this workshop, we want to stimulate discussion about these challenges from an interaction perspective and critically ask where our health data should be kept in the future, who will be owning it, and who can interact with it and how.

Additional Key Words and Phrases: digital health, data interaction, data privacy, data sharing, human-data interaction, patient-generated data

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<https://doi.org/10.18420/muc2023-mci-ws14-117>

ACM Reference Format:

Madeleine Flaucher, Anastasiya Zakreuskaya, Katharina M Jaeger, Robert Richer, Jan David Smeddinck, Devender Kumar, Sophie Grimme, Julia Klein, Robert Hrynyschyn, Bjoern M Eskofier, and Heike Leutheuser. 2023. Your Health, Your Data: Combining Interdisciplinary Views, Concepts, and Practices to Empower Patients in Their Engagement With Personal Health Data. 1, 1 (May 2023), 4 pages. <https://doi.org/10.18420/muc2023-mci-ws14-117>

1 INTRODUCTION

The digital transformation has initiated a fundamental change in the delivery of healthcare and its services. Pioneer Big Data applications such as the diagnosis of cancer [6] or the discovery of new drugs [9] have evidently shown how growing amounts of data can be put to beneficial use. However, nowadays the data to train such models is usually distributed over several institutions and sectors and suffers from a lack of interoperability, which makes it difficult to exchange, analyze and interpret [13]. Therefore, the European Commission recently proposed a draft for the European Health Data Space (EHDS) regulation that aims to make digital health data widely available to European citizens and their physicians [4] [5]. Further standardization efforts through the development of common standards aim to support the technical integration across borders (e.g., FHIR HL7 [3]). By allowing patients to access, control, and share their own health data, individuals can be empowered to take up an active role in their own healthcare and thus be enabled to make informed decisions about their care. Notable outcomes of such enabling might include higher patient satisfaction such as reassurance, reduced anxiety, and increased awareness. Ultimately, it enables improvements in health outcomes [10, 15, 17]. With further advances in the personal health sector, the Human-Computer-Interaction (HCI) community is faced with new challenges making these advancements readily accessible and usable for patients. The research field of *human-data interaction* is emerging [7] and will play an increasingly important role in our data-driven future. In this context, the possibility to interact with personal health data is a revolutionary development

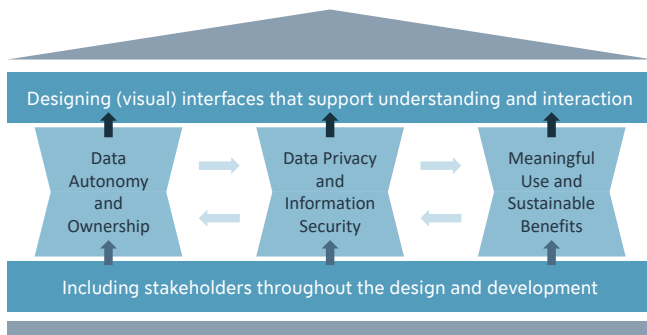


Fig. 1. Our vision for this workshop is to divide the discussed topics into three pillars framed by the basis of including stakeholders and the development of appropriate tools to visualize the concepts.

for the medical industry and the way diseases will be treated in the future. We, as a society have to ask ourselves how to shape this evolution beneficially and in the interest of everyone.

In this context, our workshop aims to shed light on the topics ‘data autonomy and ownership’ (i.e., health data needs to be in peoples control), ‘data privacy and security’ (i.e., health data needs to be protected), and finally the ‘meaningful use of sustainable benefits’. From different points of view, we want to discuss how patients can approach and interact with their personal health data. We propose that these three topics can be shaped by including stakeholders throughout the design and development of applications. Additionally, visual interfaces can help foster the interaction with personal health data [11, 16, 18].

2 WORKSHOP CONTENTS

Our vision for the discourse about how individuals will interact with personal health data in the future is to consider where this data resides and who will be in charge of it. Figure 1 summarizes this vision for the discussion during the workshop. Each of the three topics is further elaborated in the following section. During the workshop, we want to enable a discussion about how to empower patients to interact with their personal health data and control it through data autonomy and ownership, adequate privacy and security measures and finally an understanding of opportunities for creating personal value.

Data Autonomy and Ownership. While individuals have a right to control their own personal information, the legal framework surrounding ownership of personal data is complex and still evolving. In some cases, personal data may be considered the property of an individual, while in other cases it may be considered the property of the organization or entity that collected the data [1]. Data autonomy refers to the ability of individuals to control their own personal health data and make informed decisions about how it is collected, used, and shared [2]. Aspects that can be addressed to this topic can include but are not limited to:

- Conceptualize access solutions for personal health data

- Explore potential contextual, cultural, and even individual differences in the preference for autonomous choices in data management
- Address the boundary condition for autonomy and ownership in the face of rapidly evolving technologies

Data Privacy and Information Security. Linked to the question of how to achieve autonomy and full control in the management of personal health data, concerns about privacy, security, and the potential for misuse of sensitive health information arise. Data privacy is understood as the amount of personal information that people allow others to access about themselves [12]. Data security furthermore relies on the technical, physical and administrative safeguards that protect personal information [14]. Aspects that can be addressed to this topic can include but are not limited to:

- Assess possible techniques to empower individuals to control their personal health data and make informed decisions about how it is collected, used and shared
- Think of possible best-practice examples for protecting the privacy and security of personal health data in different settings, such as healthcare providers, research institutions, and digital health platforms
- Address challenges for the privacy and security of personal health data in the face of global and cross-border data flows, fast-changing environment and heterogeneity of users

Meaningful Use and Sustainable Benefits. The use of personal health data can lead to a variety of beneficial outcomes, such as the support of medical decisions, which leads to a more personalized and effective care for patients or empowering patients to gain confidence in decision-making regarding their own health [8]. Therefore, it is necessary to not only democratize the data but to democratize data science itself to (1) give people the necessary tools and (2) make sense of their own data. Therefore, we need to discuss how to empower individuals to understand and use their data that can benefit themselves and society as a whole. Aspects that can be addressed to this topic can include but are not limited to:

- Propose awareness-raising measures (e.g., educational content) to communicate the meaningful use of personal health information
- Discuss the role of (digital) health literacy for the understanding of health data benefits
- Assess possible implications for medical decisions based on the confrontation with personal health data

3 INFORMATION FOR THE ORGANIZATION OF THE WORKSHOP

This workshop is organized as a half-day event by an interdisciplinary and inter-institutional expert group. We welcome researchers, students, and practitioners from different backgrounds. We expect that participants with all different levels of experience in health data interaction can contribute since the workshop topic relates to a wide variety of people not only in the professional environment but in the personal environment as well. This workshop will especially benefit from this variety by including all kinds of viewpoints and different stakeholders already in the discussion.

The workshop is divided into three parts. The first part will be a brief presentation about the topic and process of the workshop by the organizers. Afterward, attendees will be split into smaller groups for the discussion on the proposed sub-topics. This will be conducted as a gallery walk in combination with conversations. The third part includes short presentations to share important findings with all participants and the possibility to recap the impressions. The workshop will end with giving the attendees a challenge: The groups are asked to create a short sketch (e.g. paper prototype) for the concept of a visual interface that suggests a creative solution to the discussed problems. These sketches are collected and structured by the organizers and sent out to all participants after the conference for visibility and further discussion.

4 CONCLUSION

We propose this workshop as an effort to bring interdisciplinary researchers from the Human-Computer Interaction community to a table and discuss challenges and approaches to solutions for the design of interaction with personal health data. During this workshop, we want to foster a shared understanding of the topic of data control and ownership. We assert that patients should have the right to know which information is collected about their health state and be informed about the ownership of their data. Beyond dealing with data, we want to discuss solutions on how to empower patients to engage with their personal health data and be able to make informed decisions. Therefore, this discussion is divided into three sub-topics, which are 'data autonomy and ownership', 'data privacy and security', and finally, the 'meaningful use of sustainable benefits'. The frame of this discussion is the consideration of how to include stakeholders throughout the design cycle and represent the discussed ideas visually. Ultimately, we hope to contribute to the discussion on how to support patients in a digitalized health-care system and initiate an interdisciplinary collaboration toward patient-centered care.

5 BIOGRAPHIES OF THE ORGANIZERS

Madeleine Flaucher is a doctoral candidate at the Machine Learning and Data Analytics Lab at the Friedrich-Alexander-Universität Erlangen-Nürnberg. In close cooperation with the women's hospital in Erlangen, she is working on the digiOnko project, funded by the Bavarian State Ministry of Health and Care. Her research interests include digital health, women's health, and human-data interaction. Additionally, she is co-responsible for the course Human-Computer-Interaction lecture at FAU Erlangen-Nürnberg.

Anastasiya Zakreuskaya works as a doctoral candidate at the Machine Learning and Data Analytics Lab at the Friedrich-Alexander-Universität Erlangen-Nürnberg. She is working on the TEAM-X project, funded by the Federal Ministry for Economic Affairs and Climate Action and her research interests include the interaction with personal health data from a clinicians' and patients' perspective. Additionally, she is co-responsible for the course Human-Computer-Interaction lecture at FAU Erlangen-Nürnberg.

Katharina M. Jaeger is a doctoral candidate at the Machine Learning and Data Analytics Lab at the Friedrich-Alexander-Universität Erlangen-Nürnberg. In close cooperation with the women's hospital in Erlangen, she has been working on the SMART Start project, funded by the Federal Ministry of Health. Her research interests include digital health, women's health, and wearable computing in the field of physiological biosignals.

Robert Richer is a doctoral candidate at the Machine Learning and Data Analytics Lab at the Friedrich-Alexander-Universität Erlangen-Nürnberg. Since 2023, he is head of the Digital Health - PsychoSense group of the Machine Learning and Data Analytics Lab, FAU, Germany. His research interests focus on the intersection between health psychology and data analytics.

Jan David Smeddinck is the current scientific Co-Director and Principal Investigator for the programme lines in digital health interventions and data analytics at the Ludwig Boltzmann Institute for Digital Health and Prevention. He has formerly led the Digital Health Cluster at Open Lab and acted as Degree Programme Director for the MSc in Human-Computer Interaction at the School of Computing at Newcastle University. He is a human-computer interaction (HCI) researcher and practitioner with a passion for digital health.

Devender Kumar is a postdoc researcher at Ludwig Boltzmann Institute for Digital Health and Prevention. His research interests lie in the intersection of context-aware and explainable AI, physiological sensing, mHealth, and HCI. With a keen emphasis on reducing the 'annotation dependency' in MedAI, some of his ongoing research involves applying semi and self-supervised learning methods on physiological health data.

Sophie Grimme is a research associate and doctoral candidate at OFFIS Institute for Information Technology in Oldenburg, Germany. She is working on the Health-X dataLOFT project, funded by the Federal Ministry for Economic Affairs and Climate Action. Her research interests are in the HCI discipline of women's health and user-centered design for data authority of private health data.

Julia Klein is a researcher with a background in health economics and health sciences, currently working in the research group on information security and compliance at the University of Göttingen. Her primary research focus is centered on health data donation and privacy questions, with a goal to address critical issues surrounding the use and protection of personal health data.

Robert Hrynyschyn is a Ph.D. candidate at the Institute of Health and Nursing Science at Charité-Universitätsmedizin Berlin and has a background in Public Health. His current research focuses on challenges in developing and evaluating digital health applications. He is currently working on developing and evaluating a virtual reality application for alcohol prevention in children and adolescents.

Bjoern M. Eskofier is a professor and head of the Machine Learning and Data Analytics Lab at Friedrich-Alexander-Universität Erlangen-Nürnberg. Currently, his lab has 40 co-workers, who research in the fields of wearable computing systems and machine learning algorithms for engineering applications at the intersection of sports and health care. His digital health research philosophy is that only multidisciplinary teams of engineers, medical experts,

industry representatives, and entrepreneurs will have the tools to actually implement changes in Healthcare.

Heike Leutheuser is a postdoc at the Medical Data Science Group at ETH Zurich, Switzerland. She is further affiliated with the Machine Learning and Data Analytics Lab at the Friedrich-Alexander-Universität Erlangen-Nürnberg (FAU), where she heads the Digital Health – Biosignals group. Previously, she coordinated the CRC 1483 EmpkinS integrated Research Training Group and was managing science director. Both positions required her to organize various events and workshops, bringing together researchers from different disciplines with industry experts and clinicians. Her research focuses on biomedical signal processing, exploratory physiological time series analysis, digital health, and wearable health monitoring.

ACKNOWLEDGMENTS

This work is supported by the Bavarian State Ministry of Health and Care, project grant number PBN-MGP-2010-0004-DigiOnko, the Federal Ministry of Health on the basis of a decision by the German Bundestag (grant number 2519DAT400) and the Federal Ministry for Economic Affairs and Climate Action of Germany (BMWK) under Grant No. 68GX21004F (TEAM-X).

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