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How Physicians and Patients Interact with Electronic Health Data: A Human-Computer Interaction Perspective

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Abstract. 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 interfaces that support clinicians to navigate through these growing amount of data and new innovative algorithms. Therefore, this work aims to illustrate current experiences of physicians and nurses with health data, investiate possible solutions for data-driven interfaces and ultimately discuss strategies to include new data-sources, such as self-tracking data or patient reported outcome measures.

Keywords. electronic health records, user-centered design, health informatics, interface design, hospital, HCI

1. Introduction

The digital transformation has triggered a fundamental change in the delivery of healthcare and its services. One notable example is the application of artificial intelligence (AI) that allows for innovative use cases such as drug discovery [73] , diagnosis of medical images [69] or health consultation [54]. The training of these data-driven AI systems requires large quantities of curated and annotated medical data sets. Electronic health records (EHR) pose a promising and clinically relevant data source as they contain a comprehensive longitudinal record of a patient's health information, including structured (e.g., patient demographics, diagnoses, procedures), as well as unstructured data (e.g., physician notes) [32]. Different research activities are directed towards the meaningful application of AI on such EHR datasets [4,24,14].

However, the implementation of such systems is still heterogenous and ranges from individual implementation in one single organization (e.g., hospital or care unit) or covers patients' data on a regional or national level [1,62,10]. Based on these heterogeneous circumstances, the European Commission recently proposed a draft for the European Health Data Space (EHDS) regulation [19,18]. Effectively implemented EHR systems have been associated with clinical benefits such as better decision support or improved traceability [35]. Therefore, collaboration and communication between health providers and patients need to be ensured and the presented health information made accessible to a broad range of users [8]. Usually, the data is generated by health providers, e.g., physicians or nurses, but some approaches already include patient generated data from e.g., smart wearable devices [6]. Both types of data are essential to improving health outcomes and advancing medical research.

Human-Computer Interaction (HCI) plays a crucial role in the successful integration of different datasets in electronic health records. HCI research can inform the design of user-friendly and accessible interfaces that encourage engagement with the data, and can provide insights into how to manage the complexity of health data integration in a way that supports effective decision-making. According to the European Patients' Forum initiative *DataSavesLifes*, medical breakthroughs of the future will be increasingly defined by our ability to collect, share, and understand health-relevant data in vast quantities [21]. Therefore, intelligent systems and user interfaces need to be researched and developed, that offer solutions on how to integrate health data into everyday care.

In this work, from the perspective of Human-Computer Interaction, I explore users' interaction with electronic health data. This objective is accomplished by studying, analyzing and reflecting upon users' needs in practice and providing possible solutions for user interfaces that process personal health data. Having outlined the research problem and rationale, the next sections of this research exposé will provide a more detailed plan for addressing the research topics. The *Related Work* section will critically evaluate the core concepts and existing research and finally derive gaps that this work aims to tackle. Subsequently, the *Methodology and Contribution* section describes the research approach with necessary steps and deadlines to collect and analyze data with potential expected contributions.

2. Related work

The field of Human-Computer Interaction (HCI) has been broadly defined as *"discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them"* [27]. One measurable component of HCI is usability and refers to *"the extent to which a product can be used by specified users to achieve specific goals with effectiveness, efficiency and satisfaction in a specified context of use"*[31].

Health IT systems are complex and often involve multiple interfaces and a range of functionalities that process big amounts of electronic health data. In this work, I refer to electronic health data as data collected and processed on or with the help of electronic devices and related to health conditions, reproductive outcomes, causes of death, and quality of life in relation to an individual or a whole population [60]. They can contain a wide range of data types, that can include but are not limited to patient demographic information, medical history, laboratory test results, vital signs, clinical notes, imaging data or patient-generated data [23].

2.1. Electronic health records and HCI research

The use of electronic health records (EHR) has increased rapidly in recent years, resulting in significant changes in the way physicians and patients manage care [26]. As a result, the HCI perspective on electronic health data has gained considerable attention in research, with several studies exploring the design and usability of EHRs and the impact of electronic health data on clinical workflows, patient engagement, and decision-making [64,75,51,45,47,5]. Numerous studies have reported various usability issues with EHRs, including poor design, complex interfaces, and inefficient workflows. These usability issues can affect physician-patient interactions by impeding communication and reducing the quality of care provided [68,52,66,39]. Reported examples for usability problems by clinicians include screen navigation problems [40], increased workload [59] or increased clerical burden [16]. These studies suggest, there are still gaps in the understanding of clinical needs for data-driven systems. Therefore, user-centered principles can help to better understand the current challenges when integrating health data systems into standard care and find strategies to support the actual clinical workflows.

2.2. Research on clinical workflows

Understanding clinical workflows is essential to understand the scope for the integration of health IT systems and identify deviations from ideal workflows as taught in a textbook. Therefore, numerous studies have examined the different tasks that are performed during a shift. Across different settings and units, similar findings have shown that physicians and nurses spend a considerable amount of time on the interaction with the systems, which is oftentimes referred to as *indirect care* [71,42,41,36,2,70]. Furthermore, several studies on workarounds in IT systems have shown .. [61,9,63,44].

When investigating clinicians' use of EHR systems in different domains, several activities have been identified, e.g. by Veinot et.al: "priming, structuring, assessing, informing, and continuing" [67] or by Holmgreen et. al. "notes, orders, in-basket messages, and clinical review" [28]. These tasks suggest, that EHRs are currently included for preparatory work (to obtain the necessary information about a patient's medical condition), as well as orientation during the care process by planning and ordering next steps.

The use of intelligent algorithms has the potential to support indirect care by arranging the information, make sense of the data and automating or augmenting certain workflows [15,72,7,15,57]. When introducing such algorithms to clinical settings, potential users such as users such as clinicians and nurses need to be included in a user-centered design process to ensure that these systems will support the future of care processes.

2.3. Interaction with artificial intelligence in healthcare

Artificial intelligence and machine learning tools can be a powerful support for clinicians and nurses to make use of the existing data and help to make treatment decisions. Currently, various research is directed towards the technical feasibility and accuracy of such algorithms when applied to health data [55,46]. However, to support clinicians in applying these technologies in their everyday care, further insights on the perceived usefulness and trust are required to allow for a safe clinical application. Therefore, several novice studies have investigated the view of clinicians and nurses on the use of artificial intelligence and machine learning tools [22,11,34]. Further research is needed to illustrate the potential and limitations of different use cases in clinical care.

2.4. Including the patient perspective to the data-driven care process

Beyond traditionally know practices, electronic health data can enable patients to access their health information and participate actively in their care. Such patient access to electronic health records has been found to have positive effects such as reassurance, reduced anxiety, and increased awareness [65,50,17]. However, patient engagement with electronic health data can be affected by factors such as health literacy [12,48] or privacy concerns [33,13]. Therefore, designing patient-centered EHRs that consider these factors is crucial for supporting patients in their individual needs.

2.5. My previous research in this field

Within my Bachelor thesis, I have investigated how to visualize patterns of patient journeys, that rely on finite state models, to clinicians and researchers. These models are able to illustrate progression of diseases, treatment and outcomes of populations to understand overall trends of disease progression. Usually electronic health records are chronological events and thus timelines are a very intuitive representation. While such timelines are very adequate in visualizing the progression of a single patient, they are limited with regard to conclusions about a cohort of patients. Therefore, I have proposed a visualization of probabilistic real time automata that represents health states in which patients can reside and transition from [58]. This work has been published at the 23rd International Conference of Information Visualization [74].

During my Master thesis, I have investigated the patients' perspective with the aim to explore reasons for the engagement with digital health applications. Evidence suggests that individuals with mobile health applications show significantly higher odds of using their digital device to track progress on a health-related goal or engage in health-related discussion with care providers, compared to those without [43]. This allows for a more holistic view on health data and can include data outside from medical care centers and therefore, improve knowledge about diseases and raise public health. However, the adoption rates of mobile health applications remain unequally spread. The goal of this thesis was to investigate possible data-driven methods to identify reasons for engagement with such health interventions. This work is currently in preparation for a journal submission.

Research gaps

In summary, there is still a lack of understanding about how to build accessible data interfaces for clinicians that take into account the reality of clinical workflows that also include patients as active stakeholders in the data generation process. This includes details about user-needs for data driven systems and possible solutions how to effectively incorporate intelligent algorithms in clinical care.

3. Research topics

In the light of the above discussion my work during the PhD aims to contribute to the understanding and development of accessible data-driven technologies that take user-centered principles into account. This objective is accomplished by studying, analyzing and reflecting how digital health data systems can be integrated in modern healthcare

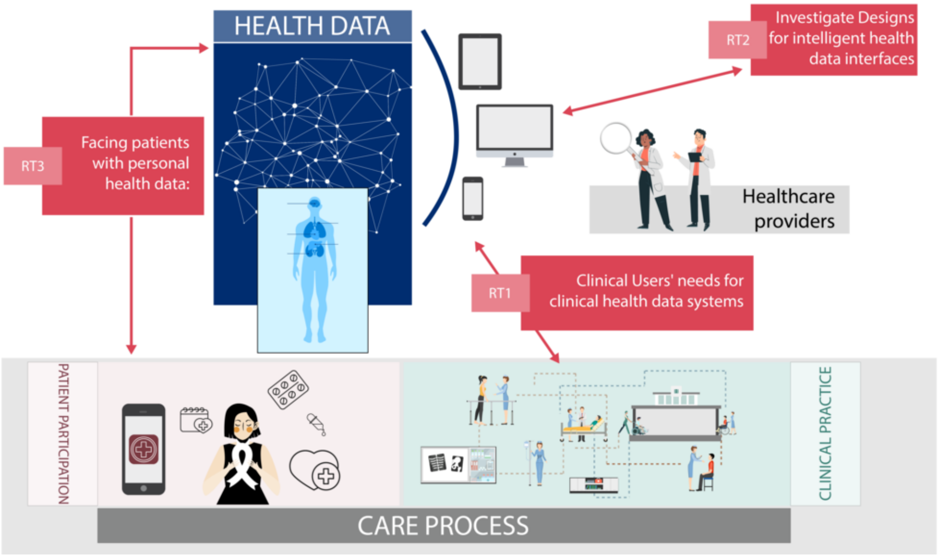

Figure 1. The overall picture of my PhD project with the respective Research Topics (RT).

practice. Therefore, I consider two user groups, which are (1) healthcare providers and (2) patients. To meet the proposed goal, I have divided my work into three research topics, which are further elaborated in this section. The details and specific research questions will be defined within the research process and in collaboration with several partners.

3.1. Clinician's experience of health data integration in care processes

One key factor that influences user satisfaction is usability. Clinical health data systems should be designed to be intuitive, efficient, and easy to navigate, allowing users to access the relevant information quickly. To achieve this, user-centered design principles must be incorporated, considering the distinct needs and expectations of different user groups. Therefore, questions in this research topic include how and under which circumstances clinical includes the information from health data during the care process in a shift (i.e, which information from EHR is necessary, how is this information obtained, where are barriers to obtain this information). Based on this user journey, the question arises, if and how interaction with health data systems can be improved and if recommendations can be derived.

Expected contribution: The expected contribution of this question is to identify user journeys for the access of health data in a hospital setting for physicians and nurses of one care unit. This includes the consideration of Human Factors, such as cognitive factors like memory and decision making and the organizational context, such as location or technical equipment.

3.2. Explore solutions for intelligent clinical health data interfaces

As healthcare continues to incorporate technology and artificial intelligence, there is a growing need for interfaces,that are designed to support clinicians in making informed decisions and support collaboration between different health provider groups. Based on the identified challenges in the previous research topic, the aim of this topic is to investigate different design attributes. Therefore, their impact on user experience and personal attitudes of clinical staff is evaluated in a laboratory setting.

Expected contribution: The expected contribution of this work is to develop and compare different solutions for the visualization of electronic health data and give guidance on how to incorporate intelligent algorithms to clinical care from an HCI perspective.

3.3. Augment health records with new data-sources

Future data driven systems will incorporate different data sources that are created not only by clinical staff but can also include information that has either been collected automatically or through the patient. Within this question, I want to investigate how patients can be empowered to interact and contribute to their personal health data and enable informed consent.

Expected contribution: The expected contribution of this work is to evaluate strategies to include patient-reported outcomes into traditional care practice and give recommendations how this patient-generated data can be used in clinical care. Ultimately, this work aims to bridge the clinical needs and preferences from previous studies and investigate possible strategies how to include the patient's perspective in the clinical interfaces.

Research topics summary

The overarching objective of this thesis is to address a variety of problems in human-computer interaction centered around how user groups perceive, use and benefit from health data. The findings aim to increase the impact of digital health technologies by allowing for a more nuanced understanding of the specific user preferences and needs. The overall picture with the respective research topics and their connection are visualized in Figure 1.

4. Methodology and Contribution

My planned research is based on various methods for the given questions and objectives. Furthermore, reflective practice and writing as analytic activities are a fundamental part of this research. The following section provides a summary of the planned methods and research sites for the planned studies in a chronologic order.

4.1. Research methods

This work is divided in three subsequent studies with different methods that aim to (1) understand the requirements of physicians for data-driven solutions in clinical care, (2) test different solutions to these requirements and (3) explore possible augmentations of electronic health records through other data sources such as self-tracking data or patient reported outcome measures.

4.1.1. Ethnographic observational study

The observations are conducted non-participatory with a structured template and field notes. Therefore, clinical shifts of physicians and nurses are followed over multiple weeks between April and July. Advantages of this approach include detailed insights into the everyday use of the health data systems that can reveal nuances which would not be tangible by other research methods.

4.1.2. Design and creation research strategy

The goal of a design and creation research strategy is to develop new interfaces or products, i.e. artifacts [49]. Within study 2 the artifact to be developed is an user interface for electronic health data that aims to visualize different data sources for health data. Furthermore, different approaches for the visualization of intelligent algorithms for clinical decision support are tested and compared in order to provide a clinical solution that helps to incorporate Big Data into standard care.

4.1.3. User-Centered Design Process

The design approach which places emphasis on involving users in the design is called user-centered design (UCD) [29,30]. The foundation of this process is to understand and specify the context of use and then repeat design and evaluation until the user is satisfied with the design and usability requirements are achieved. In study 3 various co-design workshops and a user study with patients and clinicians aim to investigate, how to bridge the data from patients and experts to a holistic image of the physiological and physical state of a patient to provide optimal care.

4.2. Research sites and cooperations

Within this research, several institutions are involved in order to answer the presented questions and meet the objectives. The following section describes the currently anticipated collaboration sites for the dissertation project and their role my research plan.

4.2.1. Machine Learning and Data Analytics Lab, Friedrich-Alexander-Universität Erlangen-Nürnberg

The chair Machine Learning and Data Analytics Lab (MaD Lab) provides over a decade of experience with data analysis and machine learning in the field of digital medicine and a variety of topics in human-computer interaction. Research areas include real-time analysis of sensor signals, sensor data fusion, data mining, modeling, data visualization and user-friendly interfaces. This expertise has already been brought to the end user and into the clinical practice through several spin-offs and participation in the development of digital health applications. My overall research project is based at the MaD Lab which provides a stimulating research environment with many opportunities for cross-disciplinary collaboration and innovation. Within this context, HCI research can help to make Machine Learning and Data driven approaches more accessible and usable. Especially for non-experts in this field, Machine Learning can be a complex and inaccessible topic. By incorporating HCI principles into the design of ML interfaces and tools, the research results can be made more accessible to a broader range of users. Inversely, the current topics at the MaD Lab and experts in fundamental and application-related

ML algorithms help me to understand possible application scenarios for a clinical setting and facilitate the bridge between data driven research and standard care (examples of research: [3,20,38,56]).

4.2.2. Klinikum Landkreis Erding - Teaching Hospital of the Technical University Munich

The municipal hospital of Erding has been an official teaching hospital of the Technical University of Munich since mid-2008. This large and well-equipped facility offers a wide range of medical services, including emergency care, surgery, intensive care, internal medicine and obstetrics. Patients can expect to receive high-quality medical care with state-of-the-art medical technology and facilities, including diagnostic equipment such as MRI and CT scanners, as well as modern operating theaters and intensive care units. The internal department for cardiology and pneumology treats patients who suffer from a wide range of conditions, including heart attack, heart failure, arrhythmia, asthma, COPD, and lung cancer, among others. The care provided in this department is typically focused on diagnosing and treating these conditions, as well as providing ongoing support to patients as they manage their conditions over time. For comprehensive care, the department works closely with other disciplines both internally and externally. Therefore, data from various sources are accumulated for this purpose (e.g., imaging techniques, patient monitoring, assessment by scores, etc.). Within study 1 as presented above, physicians and nurses from the cardiology and pneumology department will be observed to identify how they interact with health data during a shift. The goal to examine these processes from an HCI perspective is to identify potential complications to manage and analyze the accumulating information and derive user needs for data-driven systems in a clinical setting.

4.2.3. Center for Healthcare Innovation and Delivery Science, New York University

The Center for Healthcare Innovation and Delivery Science (CHIDS) of NYU Langone Health is a leading research institution that develops innovative solutions in an interdisciplinary team to improve healthcare delivery. Several experts with different backgrounds such as medicine, informatics, computer science, economics, social science, and engineering team up with the aim to build innovative applications for clinicians and patients. One part of this research focuses on the visualization of health information and how to make complex data from various sources more accessible and understandable for healthcare providers, patients or other stakeholders. Using a interdisciplinary approach, a broad range of perspectives and insights can be included in the development of user-centered data visualizations. I would like to use benefit from this collaborative and dynamic research environment by conducting a study with clinicians with the aim to evaluate different visualizations of machine learning algorithms and representation of complex health data sets. Therefore, I will receive support from the predictive analytics unit who provide profound experience in the application of artificial intelligence on electronic health records [53,25,37] and research how to translate the information into clinical practices.

5. Conclusion

Recent advances and trends in Big Data Analysis and Deep Learning have the potential to change the way care and therapy is delivered today, as it becomes possible to automatically identify previously hidden patterns and gain insight into patient health. Furthermore, new data sources are constantly emerging, providing new insights for continuous monitoring and preventive measures. With my work, I hope to contribute to the understanding of patients' and physicians' interaction with data-driven health technologies. Ultimately, within my research, I hope to contribute to the discussion on how to integrate data-driven technologies in today's healthcare system and provide solutions that achieve acceptance and trust in the interaction with health data.

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