Master Research Proposal

Topic   Which aspects of user guidance increase the intention for personal (health) data sharing, taking privacy and acceptance measures into account.

Background:

Studies suggest that there is a trade-off between system privacy and usability [1]. However, there is limited research on privacy in conjunction with usability in mobile systems and most especially in mHealth systems. Even though some external and influencing factors have been researched in the literature, only few solutions have been provided to solve this issue.

Patient-centered health care information systems (PHSs) aim to give patients access to their health information share it with other stakeholders for a common collaboration in care. Benefits include the insight into patient-generated data and the combination of different data sources. As summarized in [2], PHS can be implemented, using centralized databases, distributed ledger technology or a peer-to-peer technology (P2P). In P2P PHSs all endpoints (patients) have equal rights and responsibilities and are not further controlled by a higher instance (e.g., server). This implies for new user management as new interaction methods are possible.

The intention for personal health data sharing is complex and depends on various factors, such as privacy perception of the users and the usability of the system [3], [4], [5].

This master thesis aims to investigate, how different components (e.g., chat, timeline, status, requests, etc.) of user guidance influence (and increase) the intention for personal health data sharing in a decentralized system. Therefore, a special focus will be directed towards privacy and acceptance variables.

Research Questions (to be further defined and refined):
- Which factors influence perceived privacy in decentralized health data systems?
- Which user flow promotes the intention to share personal health data?

The proposed work consists of the following parts:
- Literature research: identify relevant studies and researched evidence for the intention of data sharing (focus on perceived privacy, usefulness, intention for data sharing)
- Conceptualize different user flows, taking the literature results into account: how can patients be guided through the system,
- Create corresponding user interfaces (focus on frontend), which can be connected to a decentralized backend
- Pilot Study: compare and evaluate the user interfaces regarding the intention for data sharing; measure and consider privacy and acceptance measures

German native-level language proficiency is required for conducting the Pilot study.

Supervisors:
Anastasiya Zakreuskaya (anastasiya.zakreuskaya@fau.de), René Raab (rene.raab@fau.de)

References:

[1] Katusiime J, Pinkwart N. A review of privacy and usability issues in mobile health systems: Role of external factors. Health Informatics J. 2019 Sep;25(3):935-950. doi: 10.1177/1460458217733121. Epub 2017 Oct 9. PMID: 28992749.

[2] Abdullahi Yari I, Dehling T, Kluge F, Geck J, Sunyaev A, Eskofier B. Security Engineering of Patient-Centered Health Care Information Systems in Peer-to-Peer Environments: Systematic Review. J Med Internet Res. 2021 Nov 15;23(11):e24460. doi: 10.2196/24460. PMID: 34779788; PMCID: PMC8663665.

[3] Lu C, Batista D, Hamouda H, Lemieux V. Consumers' Intentions to Adopt Blockchain-Based Personal Health Records and Data Sharing: Focus Group Study. JMIR Form Res. 2020 Nov 5;4(11):e21995. doi: 10.2196/21995. PMID: 33151149; PMCID: PMC7677023.

[4] Jahn MA, Porter BW, Patel H, Zillich AJ, Simon SR, Russ AL. Usability Assessment of Secure Messaging for Clinical Document Sharing between Health Care Providers and Patients. Appl Clin Inform. 2018 Apr;9(2):467-477. doi: 10.1055/s-0038-1660521. Epub 2018 Jun 27. PMID: 29949815; PMCID: PMC6021963.

[5] Larson K, Sim I, von Isenburg M, Levenstein M, Rockhold F, Neumann S, D'Arcy C, Graham E, Zuckerman D, Li R. COVID-19 interventional trials: Analysis of data sharing intentions during a time of pandemic. Contemp Clin Trials. 2022 Feb 16;115:106709. doi: 10.1016/j.cct.2022.106709. Epub ahead of print. PMID: 35182738; PMCID: PMC8847110.

Supervisors:
Anastasiya Zakreuskaya (anastasiya.zakreuskaya@fau.de), René Raab (rene.raab@fau.de)