SoK: Analysis of User-Centered Studies Focusing on Healthcare Privacy & Security

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Motivation

- Security and privacy integration in healthcare: essential to protect patients' data
- Healthcare data: notoriously difficult to monitor after a breach.
- Healthcare data: lucrative on the black market avg: of $40-50 per record

Overview

Systematic literature review including 129 papers published up to December 10, 2021 of user studies with a focus on privacy and security of healthcare patients' data

Methods

Identification: Databases: ACM Digital Library (DL), Google Scholar, SSRN, ScienceDirect, IEEE Xplore, PubMed, MEDLINE Papers (n = 129) → **Screening**: Full text screening (n = 80) → **Included**: Card-sorting Exercise (n = 26)
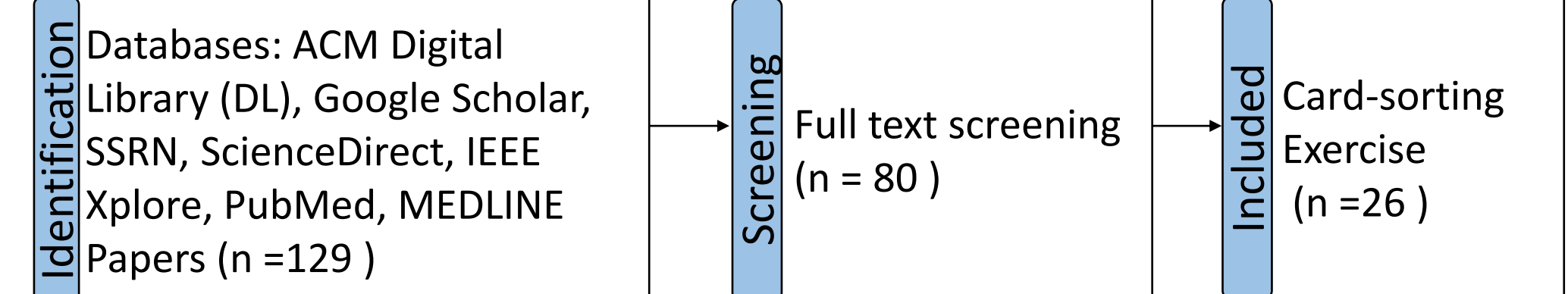
Table1: Key information about the card sorting papers including the number of participants, location of study, population, type of study, and labels

Title	# Participants	Location	Population	Type of Study	Risk Perception	Data Sharing	EHR	Risk Awareness	Technology Adoption	Regulatory Compliance	Individual Differences	Secure Communications	Mobile Applications	Social influence	Privacy	Contact tracing
Why employees (still) click on phishing links: investigation in hospitals	397	USA		Online survey	●	–	–	●	–	●	–	●	–	–	–	–
Are participants concerned about privacy and security when using short message service to report product adherence in a rectal microbicide trial?	187	Peru		Computer-assisted self-interview	●	●	–	●	–	●	–	–	–	–	–	–
Cybersecurity in Medical Private Practice: Results of a Survey in Audiology	131	USA		Survey	–	–	●	–	●	●	–	●	–	–	–	–
Security practices and regulatory compliance in the healthcare industry	250	USA		Telephone survey	●	–	●	–	●	●	–	–	–	–	–	–
Structural Model of the Healthcare Information Security Behavior of Nurses Applying Protection Motivation Theory	252	South Korea		Survey	●	–	–	●	–	●	–	●	–	–	–	–
Privacy management of patient physiological parameters	93	China + Pakistan		Questionnaire	–	●	–	●	–	–	–	–	●	–	●	–
Physicians' knowledge, perceptions, and attitudes related to patient confidentiality and data sharing	221	Jordan		Survey	–	●	–	●	–	–	–	●	–	–	●	–
Privacy and data security in E-health: Requirements from the user's perspective	19104	Germany		Focus group & Survey	●	●	–	●	–	●	–	●	–	–	●	–
Public Perspectives of Mobile Phones' Effects on Healthcare Quality and Medical Data Security and Privacy: A 2-Year Nationwide Survey	1000	USA		Telephone Survey	●	–	–	●	–	–	–	–	●	–	●	–
Machine Learning–Based Analysis of Encrypted Medical Data in the Cloud: Qualitative Study of Expert Stakeholders' Perspectives	14	Sweden + Italy + UK + Ireland + Australia		Semistructured interviews	●	●	–	●	●	–	–	●	–	–	–	–
Do data security measures, privacy regulations, and communication standards impact the interoperability of patient health information? A cross-country investigation	773	Europe		Interviews or online questionnaires	●	●	–	●	–	●	–	●	–	–	–	–
Sustaining patient portal continuous use intention and enhancing deep structure usage: Cognitive dissonance effects of health professional encouragement and security concerns	117	†		Online Survey	●	–	●	–	●	–	●	–	–	●	–	●
Examining How Internet Users Trust and Access Electronic Health Record Patient Portals: Survey Study	394	USA		Mturk Survey	●	–	●	–	●	–	–	–	–	–	–	–
Patient perspectives on the linkage of health data for research: insights from an online patient community questionnaire	3516	USA		Online Questionnaire	–	●	–	–	–	●	–	–	●	–	–	–
Exploring medical identity theft	133	USA		Survey	–	–	●	–	–	–	●	–	–	●	–	–
Cyber-risk in healthcare: Exploring facilitators and barriers to secure behaviour	50	Italy + Greece + Ireland		Focus Groups	–	–	●	–	●	●	–	●	–	–	–	–
Healthcare and Security: Understanding and Evaluating the Risks	14	USA		Observation & interview	–	–	●	–	●	–	●	–	–	–	–	–
Psychological factors shaping public responses to COVID-19 digital contact tracing technologies in Germany	4357	Germany		Cross-sectional survey	●	–	–	●	–	●	–	●	–	–	–	●
Hopeful and concerned: public input on building a trustworthy medical information commons	75	USA		Community advisory panel	●	–	●	–	●	–	–	–	–	–	●	–
Investigating mental health service user opinions on clinical data sharing: qualitative focus group study	22	England		Focus Groups	●	●	–	●	–	–	–	–	–	–	●	–
Co-creating social licence for sharing health and care data	80	England		Focus Groups	–	●	–	●	–	–	–	–	–	–	●	–
Trust, perceived risk, perceived ease of use and perceived usefulness as factors related to mHealth technology use	80	USA		Focus Groups	–	–	–	●	●	–	●	–	●	–	–	–
Improving individual acceptance of health clouds through confidentiality assurance	260	Germany & Switzerland		Survey	–	–	–	●	●	–	●	–	●	–	–	–
HIPAA-based Analysis on the Awareness Level of Medical Personnel in Indonesia to Secure Electronic Protected Health Information (ePHI)	100	Indonesia		Online Survey	–	–	●	●	–	●	–	–	–	–	–	–
Violations of medical confidentiality: opinions of primary care physicians	508	Switzerland		Questionnaire	–	–	–	●	–	–	●	–	–	●	–	–
Privacy vs usability: a qualitative exploration of patients' experiences with secure Internet communication with their general practitioner	15	Norway		Interview	●	–	●	●	–	●	–	●	–	–	●	–

Evaluation: ● = Label Detected; – = Label not Detected; † = not enough information.

Participant Population: 👥🔒 =Hospital privacy and security managers; 👥 =Hospital or Physician's Office Employees; 👥 =General Public; 👤 =Nurses; 👨 = Doctors; 👤 = Patients; 🧑 =Technical Experts; ⚕ =Pharmacists; 🏥 =Healthcare providers
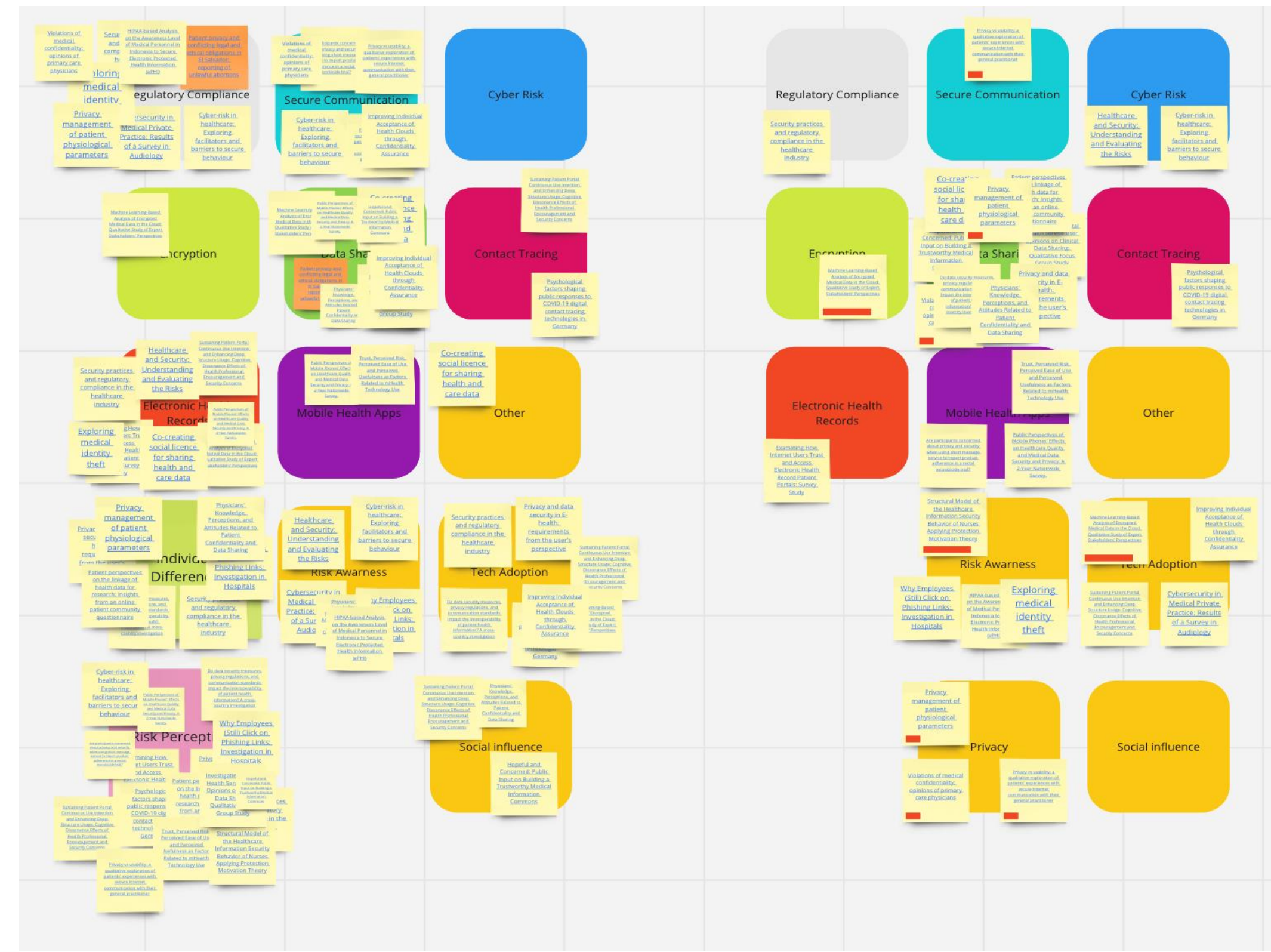

Figure 1: A snapshot of the card-sorting exercise used to analyze the paper repository

Takeaways

- The studies we analyzed focused primarily on hospitals and other significant medical settings, even though those represent a narrow view of all healthcare workplace settings
- Among the user studies we analyzed, the majority have focused on understanding the risk perceptions of patients and the security behaviors of healthcare workers. However, privacy awareness and confidentiality uptake were largely disregarded.
- Most studies analyzed reported the need for more tailored security and privacy awareness education for medical providers and staff
- More research is needed to understand the challenges to healthcare security and privacy fully.

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