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Enhancing sharing of personal health information for privacy and social utility:

Towards design principles for a blockchain tool informed by theories of motivation

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A recent New York Times article reported that Electronic Health Record (EHR) vendors that impede data-sharing — a practice called information blocking — could be fined up to $1 million per violation. Additionally, doctors accused of information blocking could be subject to a federal investigation [1]. New regulations by the Department of Health and Human Services (HHS) and the Centers for Medicare and Medicaid Services (CMS) aim at empowering patients through the access of their health information. These new regulations will result in the proliferation of data sharing platforms and applications which utilize EHR to improve health outcomes and reduce costs.

However, data sharing platforms will not be successful unless enough patients agree to participate. Research on sharing health information for medical research indicates that willingness to share information depends on anonymity, intended use, trust of the intermediary, transparency around personally controlled health records' access and use, and payment. The decision to share sensitive health information on these platforms depends on the perceived benefits versus the perceived privacy risk. Hence, a system designed to preserve user privacy and bolster social utility may significantly enhance sharing of health information on online platforms. In this paper, we address the following research question: how do privacy, transparency, and auditability features affect the propensity of sharing sensitive health information in online platforms.

Following a design science research approach, we draw on the theories of motivation to develop design guidelines for platforms that would allow for the sharing of both patient-reported outcomes and extracts of the patient health record. We develop a blockchain-enabled design framework that provides social utility information and increases the patients' control over information sharing that increase users' perceived privacy and social utility and enhances patient motivation to share health information. In collaboration with an oncologist and non-profit cancer survivor organization, we designed an experimental study to test the framework.

References

[1] N. Singer, "When Apps Get Your Medical Data, Your Privacy May Go With It," *The New York Times*, 03-Sep-2019.