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Publication Date

2022

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Peer reviewed|Thesis/dissertation

The Public's Views on Blockchain Application in Medical Data Sharing

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THESIS

Submitted in partial satisfaction of the requirements of the degree of

MASTER OF SCIENCE

in

Health Informatics

in the

OFFICE OF GRADUATE STUDIES

of the

UNIVERSITY OF CALIFORNIA

DAVIS

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2022

Acknowledgement

I would like to acknowledge and express my deepest appreciation to my thesis advisor, Dr. Katherine Kim, who provided me the opportunity and precious guidance to make this work possible. She contributed to the development of the survey questionnaire and mentored me to shape this valuable piece of work. Her continuous support, patience, and generosity in providing me with numerous opportunities for learning and career advancement throughout the course of my graduate study enabled me to grow immensely at both the academic and professional level.

I would also like to give my warm thanks to the other two members of my committee.

Dr. Tsung-Ting Kuo has provided thorough review and guidance on the technical aspects of the blockchain video script. The completion of the blockchain video could not have been possible without his expertise. Dr. Anderson has provided valuable advice along my research process from IRB logistics to results discussion of the study. It was through him, I received exposure to the field of consumer health informatics and was able to meet my mentor, Dr. Katherine Kim.

Lastly, I would like to thank my friends, co-workers, teachers from Kim's' lab, MHI cohort and beyond for being so supportive and helpful with my survey testing, participation, and dissemination. It would not have been possible for me to have a successful research experience and study life without these wonderful people.

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The Public's Views on Blockchain Application in Medical Data Sharing

Abstract: Trust is an integral part of any business to process transactions between a vendor and its consumers. In healthcare, patient data sharing is comparable to currency transactions in business. They contribute significantly to improve costs, access, quality of patient care and advances research in healthcare. However, due to a loss of public trust, patient data sharing across places is significantly lagging in the Healthcare. Without the ability to share patient data effectively across sites, the quality of patient care and advancements in medical research will be compromised. Blockchain, a reliable digital recording technology, has been recognized as a promising solution to build trust between healthcare systems and healthcare consumers. While researchers and vendors in healthcare are actively exploring its potential applications and technological feasibility, little is known about consumers' views on its application in their medical information sharing.

Objective: The study aimed to assess public trust/views and analyze the possible variables that are related to their trust/views on blockchain application in medical data sharing for healthcare and research purposes.

Methods: In this quantitative study, we distributed our survey using the Qualtrics to multiple online channels and an in-person conference associated with university and healthcare institutions using snowball sampling method. We collected a total of 62 completed responses.

Results: Respondents had generally positive views in blockchain application in medical data sharing in comparison with the traditional sharing model. There were positive correlations in their views of blockchain application between financial and medical data sharing. There was no significant correlation between their understanding of blockchain technology and their perceived usefulness of its application in medical data sharing. The only significant predictor of their perceived usefulness of its application in medical data sharing is their perceived security.

Conclusion: Blockchain technology may be useful in building trust between the public and healthcare systems. The perception of blockchain-based data sharing model as trustworthy for healthcare and medical research is promising. This study filled in the gaps from previous studies and strengthened their conclusions. By enhancing perceived security by the public may increase healthcare stakeholders' acceptance of its application in healthcare. Understanding of the public's views regarding blockchain technology and, in particular, variation in views and factors that affect security and privacy in medical data sharing are prerequisites to the public acceptance and trust in healthcare.

Definitions

Trust

Trust is an integral part of any business to process transactions, promote collaboration, and enable productivity. Trust is a “bilateral relationship in which one has to trust and another one to be trusted”.[1] There are four variables in the trustworthiness equation introduced in the book *Trusted Advisor*. The variables are: credibility, reliability, intimacy, and self-orientation. Credibility is related to expertise, describing whether one is knowledgeable about the subject. Reliability is related to action, describing whether one will do what he said he would do. Intimacy describes how secure one feels in entrusting the other one with his personal information. Self-orientation refers to how much one focuses on his own interests without aligning it with others. These four variables can be grouped into one trustworthiness equation: $\text{Trustworthiness} = (\text{Credibility} + \text{Reliability} + \text{Intimacy}) / \text{Self-Orientation}$. The higher the measure of credibility, reliability, and intimacy along with the lower the value in self-orientation, results in higher perceived trustworthiness.[1]

Blockchain

Blockchain, initially created in the financial world to build trust among stakeholders, is a digital recording technology with several transferable characteristics such as immutability, trackability, transparency, and decentralization.[2] Immutability refers to the unchanging nature of valid transaction records in the network. Immutability is assured by the proof-of-work protocol of blockchain. Trackability refers to the ability to establish the order in which digital assets are being transacted and is accomplished through the specialized timestamping mechanism of blockchain. Transparency refers to the ability to see every transaction record by all users, enabled by the decentralized ownership of blockchain records. This decentralization

feature which automatically processes and records every transaction in the network supports peer-to-peer transactions and while lowering the risk of single-point failures.

The best-known blockchain application is cryptocurrency, made well known by the launch of Bitcoin. The distributed ledger capability was added with smart contracts for managing digital properties. This type of application of blockchain is known as Blockchain 2.0. Blockchain 3.0 refers to non-financial applications that can be implemented either permission-less, which is publicly accessible, or permissioned to restrict public access.[2] Applications of blockchain technology covers a broad range of domains including insurance, supply chain, healthcare, copyright protection, and identity management.[3]

Healthcare Terms

Electronic patient health data generated from healthcare services are digital assets which can be shared across settings. These data are grouped into different categories based on purpose and scope. In general, "health data" refers to "any data related to health conditions, reproductive outcomes, death causes, and life quality for an individual or population. Health data includes clinical metrics along with environmental, socioeconomic, and behavioral information related to health and wellness". Healthcare providers utilize a patient's health data to deliver "health care," an action or process through which providers meet health needs of a patient or target population. Any data resulting from health care processes can be described as "healthcare data".[4] On the other hand, the healthcare system refers to "an industry or system by which people get the health care they need". Healthcare delivery refers to "a conglomerate that combines insurance companies, employer groups, providers of care and government agencies that work together to provide health care to a population" .

A systematic collection and storage of patient's health and healthcare data by healthcare providers or other medical staff in healthcare systems is referred to as electronic health record

(EHR) or electronic medical record (EMR). Patients play an active stakeholder in accessing, modifying, and managing health-related data to support their care.[5] Since the federal government invested substantially to encourage EHR adoption in healthcare through the Health Information Technology for Economic and Clinical Health (HITECH) in 2009, EHR adoption reached 96% in general medicine and surgical hospitals in the US.[6] Evidence has demonstrated that EHRs can improve healthcare quality.[7] The personal health record (PHR) is the patient's version of EHRs or other personally-maintained health records systems. In this paper, "patient data", "medical data" or "medical information" are used interchangeably and cover any of the data types defined above. Information sharing may refer to electronic transactions of any of the data forms mentioned above.

Introduction and Background

Patient Data Sharing in Healthcare

Sharing patient data plays a critical role in improving care quality, access, cost, and research in healthcare.[6] To enhance patient data sharing across institutions, HITECH funded Health Information Exchange (HIE) to securely share patients' EHR data across health entities in a standardized format. Through HIE, providers can access patient's EHR with other providers who have an appropriate need and are connected to the same HIE. In addition to EHR, healthcare entities also seek to integrate other sources of patient health data such as PHR to improve patient care delivery. Besides data sharing for patient care, HITECH also incentivized the development of clinical distributed research networks to promote data sharing for healthcare research to gain insights to better future patient care quality and medical advancements.[7] New models of healthcare delivery are also seeking ways to achieve such a mutually beneficial goals for both healthcare consumers and healthcare vendors by reengineering their systems and research networks.[7,9] However, despite the high national EHR adoption rate and rapid digitization of healthcare, patient data sharing across institutions is still significantly lagging according to the statistics from the US government.[10]

Trust Issues in Patient Data Sharing

Lack of trust among patients in healthcare systems is a problem. Privacy and security concerns, low transparency of data usage and lack of patient control are factors that affect the public's lack of trust in healthcare systems.[7,11] Privacy and security concerns regarding EHRs and data sharing from EHRs have been frequently reported in previous studies.[7,12] Concerns about the potential "abuse of power" due to the centralized management of EHR and HIE servers has also been reported.[13,14] Many studies found that the public has low awareness

and transparency regarding how medical records are accessed and used.[15] Without the trust of patients, healthcare systems will not be able to effectively collect accurate health information from patients.[16] It will not only harm care quality individual patients receive but also the advancement of the industry in the long run. Thus, building trust between healthcare consumers and healthcare vendors is essential to facilitate data sharing for a mutually beneficial relationship and sustainable growth in the healthcare industry.[7] Various approaches have been attempted to address this need including policy constructions, technology implementations and third-party agencies. However, this remains a challenge due to the inherent complexity of the healthcare sector, sensitivity of patient health data, and the ever-changing digital environment.

Blockchain in Healthcare:

Blockchain, a democratically owned digital ledger is recognized as a valuable addition to a trustworthy backbone for patient data sharing across healthcare institutions.[2] According to the trustworthiness equation, blockchain is capable of building trust due to its potential to provide healthcare consumers unchangeable data access and use records, traceability of medical digital assets, individual control over data usage, and peer-to-peer sharing with redundancy. At the same time, the transparency feature of blockchain may pose new challenges to the privacy of patient data throughout the sharing processes.[2] Nevertheless, blockchain may be deemed worthwhile for patients who are willing to trade-off privacy for individual control.[7] Blockchain may also be useful for data analysis and validation among stakeholders, and improve the speed and cost of data movement for the high volume of transactions and data maintenance requirements in healthcare.[17] There are a number of blockchain use cases being researched in healthcare including EHR management, remote patient monitoring, biomedical research, drug / pharmaceutical supply chain, insurance claims, and other areas that need a

robust and trustworthy recording backbone.[3] Blockchain research in healthcare is rapidly growing and evolving. The successful adoption of blockchain applications may revolutionize the traditional operation models in healthcare.[17]

Given the complexity of the blockchain technology, misunderstanding and controversial opinions regarding its feasibility in healthcare are not uncommon in the general public.[3] Many researchers identified that human factors can be more challenging than technological difficulties for the widespread adoption of blockchain application in healthcare.[2,17] The use of proposed blockchain applications in healthcare is still being conceptualized with prototypes and implementations emerging. To minimize potential failures, it is important to understand the public's views before proposed use-cases proceed into the next stage. Blockchain must be perceived as a trustworthy technology by stakeholders, particularly patients, in order to accomplish the intended value for building trust between patients and healthcare systems. This is especially essential for the patient-centered applications which require consumers' willingness and support.[7]

Research Gap on Public Views

Little has been studied about the perceived trustworthiness of blockchain technology for patient data sharing in healthcare from consumer's perspectives. A few studies, published in recent years, that have looked at patients' views on blockchain-based HIE mechanisms. Lee, et. al., conducted semi-structured interviews in which researchers verbally described envisioned blockchain-based HIE mechanism to interviewees, reporting that patients (n=7) generally expressed positive attitudes toward its adoption.[18] Another controlled web-based experimental study, conducted by Esmaeilzadeh, et. al., also found that consumers (n=2013) generally hold positive attitudes toward blockchain-based HIE models. In this study, respondents' views were tested in different HIE models with a variety of patient health data at

different sensitivity levels and strong and weak privacy policies.[19] Both studies provided descriptions of proposed blockchain applications. However, neither study compared or distinguish the same individuals' attitudes toward blockchain's application in financial data sharing and medical data sharing. There is no clear way to determine whether respondents' blockchain knowledge or their views on its financial application affect their views on its application in healthcare. It is also not clear how respondent's characteristics and prior technology experiences shape their attitudes toward blockchain applications. One study reported that consumer's blockchain knowledge is a predictor for the acceptance of blockchain applications among consumers in the commercial world.[20] However, there is no study investigating whether such relationship extends to its application in the healthcare domain.

Distinguishing and understanding the public's opinions regarding blockchain technology and factors that may affect their opinions is important for public acceptance of blockchain-based, person-centered medical data sharing mechanisms. Without this critically important understanding to the public views, proposed applications may fail to gain public support.

This thesis addresses this gap, reporting on a survey of the public's views in blockchain applications and analyzing the variables that related to their views. This study is among the first to assess the public's views and investigate how the public's blockchain knowledge, technology experiences, views of its financial application and other characteristics relate to their trust in its application in medical data sharing for healthcare and medical research purposes.

Research Objectives

The primary research questions addressed by the survey reported here were:

1. What are the public's views on blockchain application in medical information sharing?
2. Do public perceptions of blockchain technology differ or correlate between medical and financial applications?
3. How does respondents' understanding of the blockchain technology relate to their rating of the usefulness of the blockchain applications?
4. What characteristics of participants relate to their rating of the usefulness of blockchain applications in medical info

Materials and Methods

The target population of this study were US healthcare consumers, anyone who has a need to share data between places to receive healthcare or participate in medical research. Since everyone may be a patient at some point, anyone in the United States who was over 18 was eligible to participate.

The data were collected online via an online survey application, the Qualtrics, through multiple channels: UC Davis study page, UC Davis Public Health email list, Facebook, and attendees at the American Medical Informatics Association (AMIA) Annual Symposium in San Diego. For the UC Davis study page and Facebook, the survey was available to the public. For the UC Davis Public Health email list, a flyer was distributed with the help of the program coordinator. At AMIA, attendees were approached in person to participate in the survey via an electronic QR code. Respondents were encouraged to share the survey with others who might be interested using a snowball sampling method. Many respondents were in the healthcare workforce in information technology, healthcare professions, research, and students, as well as being a patient. The survey was anonymous and only demographic data was collected. All participants were screened for eligibility. The study was approved by the Institutional Review Board at University of California, Davis and deemed exempt from informed consent requirements.

The study consisted of an introductory video explaining blockchain technology and questions related to factors identified from previous papers including blockchain knowledge, technology experiences and perception of blockchain applications. The video explained the immutability, trackability, transparency and decentralization of blockchain technology and provided an example of its potential application in medical information sharing for healthcare and medical research. Blockchain knowledge questions measured respondents' understanding of blockchain

technology. Technology experience questions asked about online money transaction, electronic medical information sharing, and blockchain use. Trust questions include perceived security and usefulness of blockchain applications. Other items related to demographics were selected from other national surveys. The accuracy of the video content was verified by a blockchain expert at UC San Diego and the survey was developed with the help of the survey expert at UC Davis. The survey was pre-tested for clarity via online meetings with 5 UC Davis students (1 medical student, 1 graduate student, 3 undergraduate students). The survey instrument consisted of the video and 16 items: 1 blockchain knowledge question, 3 technology use experience questions, 4 trust questions and 8 demographics questions.

The analysis consisted of tabulation of response frequencies and descriptive statistics. Differences in views were assessed with two-sided paired t-test, or Pearson correlation coefficient as appropriate with significance was set at $p \leq 0.05$. Linear regression was applied to understand which characteristics were associated with perceived usefulness of blockchain. Analyses were conducted using IBM SPSS v.28.01.

Results

The survey sample included a total of 62 completed responses from October 22nd to November 12th, 2021.

Table 1.
Respondent Characteristics

Variable	% (N)	Total Reponses
Gender		
Male	51.6 (32)	62
Age		
18-34	67.7 (42)	62
35-64	25.8 (16)	62
65 or older	6.5 (4)	62
Education		
High school graduate or GED	1.6 (1)	62
Some education after high school	4.8 (3)	62
College graduate	51.6 (32)	62
Post-graduate degree	41.9 (26)	62
Race		
White	21 (13)	62
Black or African American	11.3 (7)	62
American Indian or Alaska Native	1.6 (1)	62
Asian	51.6 (32)	62
Other	11.3 (7)	62
Multiple	3.2 (2)	62
Hispanic/Latino		
Yes	16.1 (10)	62
Geography		
CA	61.3 (38)	62
Primary Language		
English	82.3 (51)	61
Health	Mean(with 1 being poor, 4 being excellent)	SD
	3.23	0.61
		Count
		62

Table 2.**Prior Technology Experience**

Variable	% (N)
Total Responses	100.0 (62)
Ever sent or received money online	
Yes	91.9 (57)
NO	6.5 (4)
Don't Know	1.6 (1)
Ever used blockchain system	
Yes	30.6 (19)
NO	41.9 (26)
Don't Know	27.4 (17)
Ever shared medical information electronically	
Yes	56.5 (35)
NO	29.0 (18)
Don't Know	12.9 (8)

Table 3.**Perceptions of Blockchain for Medical and Financial Applications**

Variable (0 = not at all, 6 = extremely)	Mean	SD	Count
Usefulness for medical information sharing	4.71	1.14	62
Security for medical information sharing	4.1	1.14	62
Usefulness for financial information sharing	4.47	1.26	62
Security for financial information sharing	3.97	1.13	62
Tutorial Comprehension	4.43	0.94	61

Research Question 1. What is the public's view on blockchain application in medical information sharing?

Respondents have generally positive views regarding the security (n=62, mean=4.10, sd=1.14) and usefulness (n=62, mean=4.71, sd=1.14) of blockchain application in medical information sharing. Ratings of perceived security and usefulness of blockchain in managing medical information sharing requests across hospitals were on a scale of 0 to 6, where 0 is extremely negative, and 6 is extremely positive.

Research Questions 2. Do public perceptions differ or correlate between blockchain applications in financial and medical information sharing?

Respondents rated blockchain applications as useful for both medical (n=62, mean=4.71, sd=1.14) and financial (n=62, mean=4.47, sd=1.27) information sharing. The rating for medical information sharing is slightly higher but with no significant difference between the two purposes (p=0.17). There is a weak, significant positive correlation between two purposes (r=0.35, p=0.006).

Respondents rated blockchain applications as somewhat secure for both medical (n=62, mean=4.10, sd=1.14) and financial (n=62, mean=3.97, sd=1.27) information sharing with no significant difference between the two purposes (p=0.24). There is a strong, significant positive correlation between two purposes (r=0.71, p<0.001)

Research Questions 3. How does respondents' understanding of the blockchain technology relate to their rating of the usefulness of its applications?

There was no significant correlation between the understanding of blockchain technology and usefulness of blockchain application in medical information sharing (r=0.16, p=0.22).

There was a significant, moderate positive correlation between their rating of understanding of blockchain technology and usefulness of blockchain application in financial information sharing ($r=0.37$, $P=0.003$). Respondents were asked to rate how well they understood blockchain technology on a scale of 0 to 6 after watching the tutorial.

Research Questions 4. What characteristics of respondents predict their rating of the usefulness of blockchain application in medical information sharing?

The factors included in the linear regression model assessing the outcome of usefulness of blockchain for medical information sharing were: gender, age, education, race, geography, health condition, technology experiences, blockchain knowledge and perceptions on blockchain technology. The only predictor of respondents' rating of the usefulness of blockchain application in medical information sharing was their perception of the security ($p=0.04$).

Discussion

The results reported in this study represent a preliminary investigation of the public's views on blockchain application in medical information sharing and addressed the gaps in previous studies using different methods.

Respondents' Views in Medical Information Sharing

In line with other studies, respondents hold generally positive views about blockchain application in medical information sharing across entities for healthcare and medical research.[15,16] While Lee, et. al., asked participants to express their general attitudes and concerns in interviews, we asked respondents to rate their perceived usefulness and security separately. In our study, respondents gave a higher average rating for perceived usefulness than perceived security of its application in medical information sharing. It was not clear whether their perceived security was affected by the privacy challenge posed by the transparency feature of blockchain.

Financial vs. Medical Information Sharing

Respondents' views did not differ between blockchain applications in financial and medical information sharing. In fact, there were close correlations in their views between the two types of applications. The correlation between their perceived security was stronger than the correlation between their perceived usefulness of its applications. It may be that blockchain mechanisms that work in the back-end of systems without a user interface are too removed for the general audience to mentally assess. User-facing features such as individual control and record tracking are more tangible and respondents may be able to visual their usefulness in different scenarios in daily life. In addition, the video did not offer much detail about security alternatives between the two types of application.

On the other hand, given that blockchain was initially created for the financial world, it was interesting that respondents had higher perceived usefulness of its application in medical information sharing than in financial. There are currently more third-party applications in the market for financial assets than for medical information. This may have contributed to a perception that there was greater need for a reliable third-party application for medical information sharing.

Blockchain Knowledge vs. Respondents' Views

No significant correlation was found between respondents' understanding of blockchain technology and perceived usefulness of its application in medical information sharing. Like in other studies, we also found significant, positive correlation between their understanding and their perception of blockchain application in financial information sharing. Such correlation did not extend to its application in medical information sharing. The sample in this study included many respondents who work in healthcare which may account for results that differ from other studies.

Predictors of Usefulness

In the linear regression analysis, none of the respondents' demographics, technology use experiences or perceptions in financial application significantly predict the perceived usefulness of blockchain application in medical information sharing. The only significant predictor was perceived security of its application in medical information sharing. This result suggests that by enhancing the perceived security of blockchain application in medical information sharing may help increase public acceptance of blockchain applications in medical information sharing.

Suggestions for Future Studies

In the future, studies should be conducted to examine factors that may affect public's perceived security of blockchain application in medical data sharing. An experimental study would also be useful to determine the effectiveness of educational interventions to increase the public's acceptance of blockchain applications in medical data sharing. It would also be interesting to explore to what extent respondents would be willing to trade-off their privacy risk for the advantages such as data use monitoring and individual control enabled by blockchain.

Limitations

This study was designed as a preliminary assessment of views of healthcare consumers to gauge the potential of blockchain application in medical data sharing and to inform future research. Although the survey was freely distributed through multiple channels, all the recruitment channels were limited to a convenience sample associated with the university and a professional conference. This sampling method led to a non-representative sample which may limit the generalizability of the respondents' responses to the public. In particular, the sample has considerable healthcare experience and a high education level with most respondents having a college graduate or postgraduate degree. These respondents may have differential professional and academic exposure to issues related to medical information sharing and technology. More than half of respondents indicated that they had shared medical information electronically and one third of respondents indicated that they had used blockchain systems before. However, we did not distinguish what type of medical information sharing experience they had and to what extent respondents used what type of blockchain systems or products. Lastly, this survey did not compare the respondents with the general US population's demographics and technology use experience.

Conclusion

Blockchain technology may be useful in building trust between the public and healthcare systems. The perception of blockchain-based data sharing model as trustworthy for healthcare and medical research is promising. Understanding of the public's views regarding blockchain technology and, in particular, variation in views and factors that affect security and privacy in medical data sharing are prerequisites to the public acceptance and trust in healthcare.

Public Impact

The findings of this study may have impact on the public good in several ways. First, the results may help healthcare researchers, healthcare technology developers, and leaders understand where the state of public acceptance of blockchain technology. Second, this study may contribute to the understanding of the potential of blockchain applications among healthcare consumers. Finally, the implications of this study inform future research in patient-centered blockchain-based applications, especially for individually-controlled healthcare and research use of data.

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