

ORIGINAL RESEARCH

# Improving Transitions of Care: Designing a Blockchain Application for Patient Identity Management

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## Abstract

**Background:** The current healthcare ecosystem in the United States is plagued by inefficiencies in transitions of patient care between healthcare providers due in large part to a lack of interoperability among the many electronic medical record (EMR) systems that exist today. Both providers and patients experience significant frustration due to the negative effects of increased costs, unnecessary administrative burden, and duplication of services that occur because of data fragmentation in the system. Blockchain technology provides a potential solution to mitigate or eliminate these gaps by allowing for exchange of healthcare information that is distributed, auditable, immutable, and respectful of patient autonomy. Our multidisciplinary team identified key tasks required for a transition of care to design and develop a blockchain application, MediLinker, which served as a patient-centric identity management system to address issues of data fragmentation ultimately aiding in the delivery of high-value care services.

**Methods:** The MediLinker application was evaluated for its ability to accomplish various key tasks needed for a successful transition of patient care in an outpatient setting. Our team created 20 unique patient use cases covering a diversity of medical needs and social circumstances that were played out by participants who were asked to perform various tasks as they received care across a simulated healthcare ecosystem composed of four clinics, a research institution, and other ancillary public services. Tasks included, but were not limited to, clinic enrollment, verification of identity, medication reconciliation, sharing insurance and billing information, and updating demographic information. With this iteration of MediLinker, we specifically focused on the functionality of digital guardianship and patient revocation of healthcare information. In addition, throughout the simulation, we surveyed participant perceptions regarding the use of MediLinker and blockchain technology to better ascertain comfortability and usability of the application.

**Results:** Quantitative evaluation of simulation results revealed that MediLinker was able to successfully accomplish all seven clinical scenarios tested across the 20 patient use cases. MediLinker successfully achieved its goal of patient-centered interoperability as participants transitioned their simulated healthcare data, including COVID-19 vaccination status and current medications, across the four clinic sites and research institution. In addition to completing all key tasks designated, all eligible participants were able to enroll with and subsequently revoke data access with our simulated research site. MediLinker had a low data-entry error rate, with most errors occurring due to work-flow vulnerabilities. Our qualitative analysis of user perceptions indicated that comfortability and trust with blockchain technology, such as MediLinker, grew with increased education and exposure to such technology.

**Conclusions:** The ubiquitous problem of data fragmentation in our current healthcare ecosystem has placed considerable strain on providers and patients alike. Blockchain applications for health identity management, such as MediLinker, provide a viable solution to stem the inefficiencies that exist today. The interoperability that MediLinker provided across our simulated healthcare system has the potential to improve transitions of care by sharing key aspects of healthcare information in a timely, secure, and patient-centric fashion allowing for the delivery of consistent and personalized high value care. Blockchain technologies appear to face similar challenges to widespread adoption as other novel interventions, namely recognition, trust, and usability. Further development and scaling are required for such technology to realize its full potential in the real world and transform the practice of modern health care.

## Introduction

Transitions of patient care between healthcare providers in the United States have long been hindered by a lack of interoperability among the many different electronic medical record (EMR) systems that are in use today. This lack of interoperability creates data silos that inhibit the efficient transfer of patient's health information, leading to increased costs, unnecessary administrative burden, duplication of services, and increased frustration among patients and healthcare providers.<sup>1</sup> In fact, this siloing of healthcare information likely contributes to inaccurate or incomplete transitions of care, which ultimately may result in adverse patient outcomes, especially in the setting of hospital discharges where accepting providers may be seeing complex patients for the first time.<sup>2</sup> Although the 21st Century Cures Act (Cures Act) that was signed into law in 2016 made it mandatory for the federal government to aid in making the transfer of patient data faster and more efficient, it lacked provisions to mandate interoperability, leading to the current manifestation of EMRs that lack interoperability, often by design.<sup>3</sup>

In the complex healthcare ecosystem that exists today, transitions of patient care are a critical leverage point from which larger changes can be enacted if the structure of information flow is fundamentally changed from the status quo. Significant effort has been made to tackle issues of healthcare fragmentation over the past half-decade, with many endeavors focusing on the flow of healthcare information. Effective communication between providers who are taking care of a mutual patient is key in ensuring that the patient's care is transitioned comprehensively across the healthcare landscape. It has been shown that poor quality communication during the discharge period was identified as a major barrier to safe and effective transitions.<sup>4</sup> On the contrary, the implementation of interprofessional transitions of care programs has been shown to significantly reduce hospital readmission rates.<sup>5</sup> Safe and effective transitions of care are critical in not only avoiding adverse patient outcomes but also ensuring the cost-effectiveness of healthcare delivery.

With the aging population of the United States who utilize increasing amount of healthcare resources, the lack of interoperability among healthcare providers is becoming increasingly apparent.<sup>6</sup> Combined with the advent of online patient portals and easier access to healthcare information, there has been a growing demand for individual patients to be in control of their own data.<sup>7</sup> However, to date, there have been no widespread digital options for such a tool, and in fact, many patients carry hard copies of their healthcare information across providers to manage their own transitions of care. These workarounds provide an opportunity to improve value in the delivery of healthcare services. A widely accepted framework for improving value in health

care is encompassed by the Institute for Healthcare Improvement's Triple Aim, which is comprised of better patient outcomes, improved patient satisfaction, and lower costs.<sup>8</sup> Over the past decade, there has been an increased push to pivot toward high-value health care models and to disseminate teaching strategies aimed at increasing high-value practices, but widespread adoption is lacking in the United States.<sup>9-11</sup>

Blockchain technology has the potential to deliver high-value healthcare by providing patients with control over their healthcare data while improving existing problems with interoperability. Blockchain is uniquely positioned to operate in the healthcare data environment due to its decentralized, auditable, and immutable nature that not only protects patient's confidentiality but also enhances the security of data across transitions of care. Using decentralized identification (DID), healthcare providers and patients can directly interact with one another in a secure fashion, allowing for the development of meaningful patient-provider relationships.<sup>12</sup> Once sufficiently developed, blockchain applications may be able to integrate with the existing healthcare infrastructure to bridge the interoperability gap.<sup>12,13</sup>

Our interdisciplinary team has previously described the development and testing of a prototype patient-centric blockchain identity management system, called MediLinker, to better understand the utility and viability of blockchain technology for healthcare applications. In our prior work, we created 15 use case scenarios and applied the theoretical framework developed by Bouras et al. to test the effectiveness of MediLinker in fulfilling the criteria of identity management.<sup>14,15</sup> We were able to demonstrate proof of identity and consent for sharing of personal health data during testing, although we did not evaluate user perceptions at that time. In this article, we describe the testing of the second iteration of MediLinker,<sup>16</sup> which was redeveloped as a robust custom-built iOS application to further expand on use case testing of interoperability, patient guardianship, as well as further development of patient data consenting, sharing, and revocation.

## Methods

This study examined the effectiveness of MediLinker in accomplishing various key tasks needed for a successful transition of care that generates value in an outpatient setting. Twenty study participants, each using unique simulated patient data, were asked to perform various tasks as they received simulated care across a simulated healthcare ecosystem consisting of four different clinics and a research enrollment center. Tasks included, but were not limited to, clinic enrollment, verification of identity, medication reconciliation, sharing insurance and billing information, and updating demographic information. In addition, we examined how the unique patient-centric

nature of blockchain-based technology would interact with the current healthcare ecosystem; specifically, how the patient's ability to revoke or partially share individual aspects of his or her healthcare data would affect delivery and transitions of care.

#### *MediLinker System*

MediLinker is a blockchain-based decentralized identity management solution,<sup>14</sup> which provides patients autonomy in managing their self-sovereign identity and medical information. It is designed by keeping seven scenarios in mind. Patients can securely log into the web and/or mobile application, and can enroll at a participating clinic. Patients will show their physical ID card to the receptionist who will then enroll the patient and issue a digital identity on the blockchain. Patients can then use this digital identity (without the need for the physical ID card) to verify their identity at other participating clinics. MediLinker acts as a federated system of connectivity (medical data still reside in the databases of the clinics) between multiple providers. MediLinker facilitates interoperability by allowing patients to share their medical data across multiple providers. Patients can also modify their information and consent to participate in research projects. Patients also have the option to revoke already shared information and/or consent. Revocation is different from deletion in that it does not delete the data from an institution but the desire of the patient to deny future usage of shared data is recorded on the blockchain. The shared data are then no longer verifiable. MediLinker also gives the option to have a Medical Power of Attorney (MPOA) by which a guardian can be appointed for a patient. The guardian can then act on behalf of the guarded patient and perform the required sharing of credentials. To summarize, MediLinker enables the following seven scenarios.

1. Initial enrollment at first clinic and creating validated credentials,
2. Enrollment at second clinic with only credentials,
3. Presenting/consenting personal/medical data with clinics,
4. Patient changing personal information on blockchain wallet and validating the modification,
5. Patient consent to participate in research projects,
6. Patient removing full or partial consent with clinics with credential revocation,
7. MPOA/Digital guardianship for geriatric and pediatric patients.

MediLinker is a digital wallet that can handle six different types of credentials, that is, Health ID, insurance, medication, credit card, research consent, and MPOA. Health ID credential contains profile information about the patient. Insurance credential includes insurance information of

the patient. Medication credential includes information about COVID-19 vaccination status, medications, and their corresponding dosages of the patient. Credit card credential includes information about the patient's payment method. Research consent credential is the consent issued by the patient for participation in a research project. MPOA credential is a MPOA that can be issued to a guardian to act on behalf of the guarded patient.

We established an ecosystem of trust that consists of four virtual clinics ('Community Clinic', 'Acute Care Clinic', 'Psychology Clinic', and 'Rehabilitation Clinic'), bank, insurance company, and a research institution ('Austin Community Health Research Center'). Within this network, clinics issued Health ID and Medication credentials based on persona's physical driver's license and medication prescriptions. An insurance company issued insurance cards, and credit cards are issued by the bank. Research institutions received consent credential from participants (Figure 1A). MPOA credentials are issued by a Notary (Figure 1B). These institutions formed a trust network in which participants as holders could share their synthetic data.

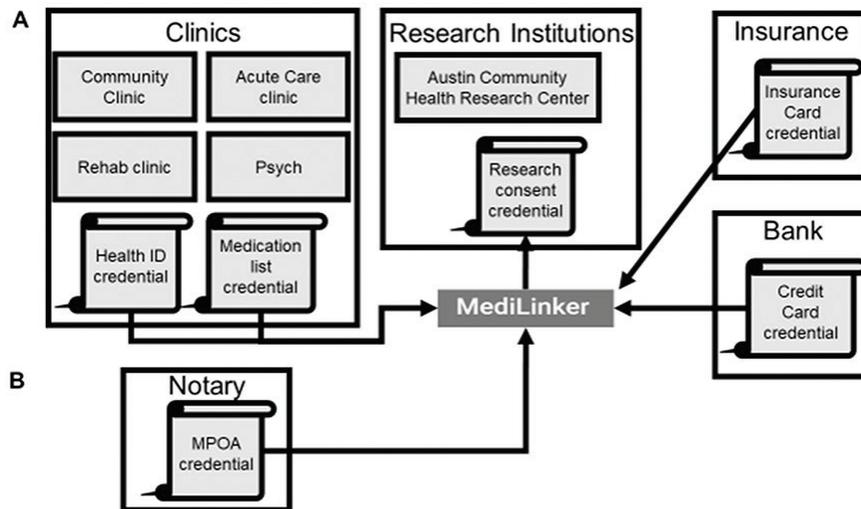
#### *Twenty Study Clinical Use Cases*

This study expanded upon previous work with MediLinker<sup>14</sup> to better simulate healthcare delivery using 20 unique use case avatars that represented a wide range of patient demographics. We expanded our testing with patient avatars focusing on guardianship and the unique challenges faced by a COVID-19 diagnosis. This was in addition to our previous work that captured the experience of individuals on housing insecurity, substance use, and undocumented status.

As shown in Table 1, the 20 use cases were composed of 9 male and 11 female cases. Due to technical limitations with the current iteration of MediLinker, additional gender identification options were not available. Five of these cases focused on guardianship and involved the testing of a MPOA function in the setting of both geriatric and pediatric patients. Two cases were COVID-19 positive patients, and the other two cases focused on patients with mental health or substance use co-morbidities. Using the MediLinker application and the patient avatars, we tested seven clinical scenarios as detailed above which involved both medical and non-medical facilities. All use cases tested fundamental tasks involving verification of identity, sharing health data, and revoking health data access. In addition, every use case incorporated the testing of research consent and enrollment at least once throughout the study period.

#### *Simulation Design*

Participants interacted with the MediLinker system at virtual clinics and shared their persona's data. The simulated



**Fig. 1.** MediLinker network of trust and credentials. (A) MediLinker framework creates a network of trust in which verifiable credentials [Health ID, medication list, insurance card, credit card, and medical power of Attorney (MPOA)] are issued by participating institutions, including clinics, insurance, and bank. Once a credential is issued, users can share these verifiable credentials within the MediLinker application to other participating institutions. Research institutions received consent credential from participants. (B) MPOA credentials issued by a Notary organization.

**Table 1.** Use case composition and characteristics

Use case	Number of cases
Geriatric Patients with a Medical Power of Attorney	1
Pediatric Patients with a Medical Power of Attorney	4
Undocumented immigrant	1
Patients with sensitive health information including mental health	2
Patients experiencing homelessness	2
Patients quarantining due to COVID19	2
Patients without complicating factors	8

information, including health identity, insurance, medication, and credit card, were provided in a pre-study packet. Participants, who were assigned as guardians, received their family member’s information and medical scenarios in their pre-study packets. The participants were instructed not to input any personal information into the system. Each persona was assigned randomly and had a unique role that tested a specific part within the MediLinker system, testing functionality and interoperability.

The study consisted of a single simulation over 4 weeks totaling eight interactions with 20 participants. Each transaction within the trust network was conducted over Zoom due to the COVID-19 pandemic. Each week, the research participants followed detailed instructions. These instructions included persona demographics or clinical updates, information sharing within and between the four fictional clinics, revoking information, and consenting to research studies. During the first 2 weeks, the participants

enrolled at multiple clinics and allowed sharing of their data. In the third and fourth weeks, patients responded to simulated data breaches at clinics and unwanted data requests from institutions to test the MediLinker system. For example, participants were presented the following scenario and instruction: ‘you were alerted by email today that the clinic had a breach and your information may be exposed. You may revoke your information from this clinic’. During the last week, the research institutions sought to make a research cohort based upon persona’s demographics and medical history, while participants were able to consent or revoke consent. Research team members operated at each institution and interacted with the participants remotely over Zoom.

**Participant Recruitment and Cohort**

This study recruited 20 UT students to act as personas and simulate our healthcare identification management platform. No Health Insurance Portability and Accountability Act (HIPPA) or Family Educational Rights and Privacy Act (FERPA) data were used during this study. These students were recruited via listserv emails to undergraduate and graduate students from the University of Texas at Austin’ Dell Medical School, Health Leadership Apprenticeship program, College of Engineering, College of Natural Science, and School of Information. Students received compensation of \$120.00 each.

In a pre-study survey, our participant cohort of students expressed familiarity with technology such as smartphones and had experience using one portal, mobile application, or website to share medical information. Eight of 16 respondents reported a nervous feeling about

security of their medical data online. Furthermore, 8 of 16 respondents had personally or their relative/friend experienced a type of data breach. (Appendix A: Weekly MediLinker Usability Survey Questions)

#### *Assessing Feasibility (Scenario Handled, Accuracy, Interoperability, Survey Results)*

We assessed MediLinker's feasibility as an electronic verifiable healthcare identification management system using both quantitative and qualitative measures. The feasibility was evaluated quantitatively with the following measures: (i) to what extent are participants able to setup a validated profile and determine the accuracy of data entered and (ii) to what extent are participants able to share their profile with multiple healthcare entities. In addition, we evaluated the percentage of patients who entered data correctly compared with expected values as specified in their instructions. Interoperability was assessed by recording the distribution of each participant's data across the five institutions. To evaluate the system's usability qualitatively, mini-weekly surveys were designed to provide insights with Likert scores ("Very Easy," "Easy," "Neutral," "Difficult," "Very Difficult"). (Appendix A: Weekly MediLinker Usability Survey Questions). Survey questions were distributed weekly before the start of the study and at the conclusion of each week's activities. The survey results mentioned in this article are part of a larger study, including other survey questions and log data.

#### *Ethical Considerations*

All medical data entered into MediLinker in this study were from simulated patient identities, which minimized the risk of revealing the participants' private information. Participants' real private information was not used in the analysis; hence, the Institutional Review Board determined this study to be nonhuman subjects.

## **Results**

We quantitatively evaluated application functionality and participant ability to complete these tasks successfully and examined associated errors that occurred during the study period. Once completed, we qualitatively assessed participant views regarding MediLinker usability, trust, and perceived effectiveness. We found that all 20 participants were able to complete the key tasks designated and successfully transition medical care across the four clinic groups involved. In addition, all eligible participants were able to enroll in and subsequently revoke data access with our simulated research enrollment center. Similarly, key healthcare information such as COVID-19 vaccination status and current medications was successfully shared across clinics. Most errors were due to inaccurate data entry because of work-flow vulnerabilities and were corrected upon subsequent review.

#### *MediLinker Accomplished Seven Real-world Clinical Scenarios and Provided Patient-Centered Interoperability between Virtual Clinics*

Throughout the simulation, all 20 participants were able to accomplish all seven scenarios as described above using the MediLinker application. Throughout the study period, 20 participants interacted with four clinical sites, as well as a research enrollment center. As detailed above, each clinical scenario was successfully completed, indicating that the participants were able to share and modify their healthcare information via MediLinker across all the sites tested, which demonstrated full interoperability within the virtual healthcare ecosystem that was created for this simulation. In addition to healthcare data being shared among the participating clinical sites, all participants successfully enrolled in research studies and were able to transfer their information seamlessly. Similarly, all participants successfully demonstrated revocation of data at least once throughout the study period demonstrated by the fact that revoked data were not propagated nor shared with new organizations.

#### *Accuracy of Data Entry in MediLinker*

The number of data-entry errors made by patients is shown in MediLinker, as listed in Table 1. The *Credential Type* column lists the type of credential. The *Number of Patients* column lists the total number of patients with the respective credential and the *Number of Attributes* column lists the number of attributes for each credential. *Number of Data Entries* shows the total entries made across all patients, and the *Number of Incorrect Data Entries* column lists the total number of mistakes made by patients for each credential. The *Error Rate* column shows the error rate for each credential, and the *Accuracy* column shows the accuracy with respect to each credential:

$$\text{Number of Data Entries} = \text{Number of Patients} \times \text{Number of Attributes}$$

$$\text{Error Rate} = \frac{\text{Number of incorrect Data Entries}}{\text{Number of Data Entries}} \times 100$$

$$\text{Accuracy} = \frac{\text{Number of correct Data Entries}}{\text{Number of Data Entries}} \times 100.$$

All 20 enrolled participants completed the study. We calculated data-entry errors made by participants in completing the tasks assigned to them using MediLinker. Health ID credential had 12 attributes, and a total of 240 individual entries were checked for accuracy. We found that there were seven incorrect entries, with a 97.08% accuracy for Health ID credential. Insurance credential had nine attributes, and a total of 180 individual entries were checked for accuracy. We found that there were four

incorrect entries, with a 97.78% accuracy for insurance credential. Medication’s credential had 10 attributes and a total of 200 individual entries were checked for accuracy. We found that there were five incorrect entries, with a 97.50% accuracy for the medication’s credential. Credit card credential had four attributes and a total of 80 individual entries were checked for accuracy. We found that there were two incorrect entries, with a 97.50% accuracy for credit card credential. Although we did not get 100% accuracy for any credential, these results are much better than that in phase 1 of the simulation study.<sup>14</sup> All errors occurred during data entry and verification, which were categorized as workflow vulnerability rather than an error with MediLinker.

Table 2 presents details of all data-entry errors made by patients. The *Credential Type* column lists the credential name, and the *Attributes* column lists the corresponding attributes for each credential. The *Expected* column shows

the correct information, and *the Actual* column shows the information entered by the patient. Health ID credential had the most errors, which may be because it had the most attributes. Five patients made one or more mistakes in entering their profile information. One patient entered an incorrect city, while another patient made a mistake in entering both his/her phone number and date of birth. One patient made a spelling mistake in his/her last name, while another incorrectly entered his/her zip code. Another patient entered his/her gender incorrectly and made a mistake in entering his/her zip code. Four patients made mistakes in entering their insurance information. One patient entered an incorrect expiration date for their insurance card. One patient made a spelling mistake in the insurance provider’s name. One patient made a mistake in entering his/her copay information, while another made a mistake in entering his/her deductible information. Four patients made mistakes in entering their medication information. The medication

**Table 2.** Accuracy of data entry in MediLinker

Credential type	Number of patients	Number of attributes	Number of data entries	Number of incorrect data entries	Error rate	Accuracy (%)
Health ID credential	20	12	240	7	$\frac{7}{240} * 100 = 2.92\%$	97.08
Insurance credential	20	9	180	4	$\frac{4}{180} * 100 = 2.22\%$	97.78
Medication’s credential	20	10	200	5	$\frac{5}{200} * 100 = 2.50\%$	97.50
Credit card credential	20	4	80	2	$\frac{2}{80} * 100 = 2.50\%$	97.50

**Table 3.** Data-entry errors found in MediLinker

Credential type	Attributes	Expected	Actual
Health ID credential	City	San Antonio	Austin
	Phone	5123569231	5123599231
	DOB	04-10-1976	04-13-2021
	Zip code	78710	78720
	Last name	Antonov	Autonov
	Gender	Female	Male
	Zip code	78751	78717
Insurance credential	Provider	BCBS	BCS
	Copay	100	75
	Expiry date	4-21-21	4-23-21
	Deductible	200	250
Medication’s credential	Dosage	Apply twice daily	Apply once daily
	Dosage	10 units	5 units
	Dosage	Once	As needed
	Dosage	16	8
	Dosage	Apply topically	As needed
Credit card credential	Last name	Choudhury	Choudhurry
	Number	5085580575754848	5058580575754840

names were always entered correctly. Three patients entered one (of the five) medication dosages incorrectly, while another patient entered two (of the five) medication dosages incorrectly. Two patients made mistakes in entering their credit card information. One patient made a spelling mistake in his/her last name, while another patient entered an incorrect credit card number.

#### Participants Reported Positive Perception of MediLinker's Usability

Our study results have shown that our 20 participants using the MediLinker iOS application were able to successfully complete the seven clinical use cases and managed their medical data. In addition, throughout the study, the participants reported in weekly surveys (Appendix A: Weekly MediLinker Usability Survey Questions) an overall positive user experience with the majority selecting 'Very Easy' or 'Easy' for each task (Table 3). Of the seven use cases, the initial setup of MediLinker accounts and credentials including connecting with clinic, creating credentials, and sharing data with first clinic showed most difficulty, with 29.41, 35.29, and 23.53% ( $n = 17$ ), respectively, reporting a neutral or negative experience. One of the participants reported the need for biometrics on their iOS device during MediLinker setup caused delays and user hesitancy. After the initial setup, participants reported a 'Very Easy' or 'Easy' user experience ranging from 85.72 to 100% for each activity.

#### Discussion

In this second iteration of MediLinker, we further expand on previous work demonstrating the utility of

blockchain-based patient-centric identity management applications in a healthcare environment.<sup>14</sup> Our use cases simulated a wide range of patient demographics to emulate the interactions that occur in a real-world healthcare ecosystem. We demonstrated again the ability of MediLinker to share dynamically updated healthcare data elements across multiple providers. The results of this study further support the potential use of blockchain applications in improving interoperability once integrated with the existing healthcare infrastructure while maintaining patient-centric data control.

#### Improving Interoperability Aids in the Delivery of High-Value Care

Blockchain applications for health identity management, as observed with MediLinker, provide a viable solution to the data siloing that exists due to our fragmented healthcare ecosystem. Both patients and providers have long been frustrated by the inefficiencies that stem from operating in such an environment. Without the ability to control their own data, patients must rely on healthcare administrative staff to share relevant information with providers who do not have access to specific EMRs. This process of sharing information is usually not optimized, and many times results in provider offices printing out substantial portions of the EMR to send over to the requesting party, diluting relevant information, and further scattering the patient's pertinent healthcare data.<sup>17</sup> Patients have derived their own workarounds to mitigate this problem by carrying around their own records in paper or digital formats, which are also likely not compatible with the provider's EMR. Although this methodology may provide more relevant information, this leads to

Table 4. Participant perception of the MediLinker system

MediLinker use case	MediLinker task	Very easy <i>n</i> (%)	Easy <i>n</i> (%)	Neutral <i>n</i> (%)	Difficult <i>n</i> (%)	Very difficult <i>n</i> (%)
Setup MediLinker account at first clinic ( $n = 17$ )	Connecting with clinic	5 (29.41)	7 (41.18)	5 (29.41)	0 (0.00)	0 (0.00)
	Creating credentials	4 (23.53)	7 (41.18)	5 (29.41)	1 (5.88)	0 (0.00)
	Sharing data with first clinic	5 (29.41)	8 (47.06)	3 (17.65)	1 (5.88)	0 (0.00)
Sharing data with second clinic ( $n = 16$ )	Sharing Health ID	8 (50.00)	8 (50.00)	0 (0.00)	0 (0.00)	0 (0.00)
	Sharing medication list	9 (56.25)	7 (43.75)	0 (0.00)	0 (0.00)	0 (0.00)
	Sharing insurance card	9 (56.25)	7 (43.75)	0 (0.00)	0 (0.00)	0 (0.00)
	Sharing credit card	8 (50.00)	8 (50.00)	0 (0.00)	0 (0.00)	0 (0.00)
Updating credentials ( $n = 16$ )	Updating Health ID	6 (40.00)	8 (53.33)	1 (6.67)	0 (0.00)	0 (0.00)
	Updating medication list	9 (56.25)	7 (43.75)	0 (0.00)	0 (0.00)	0 (0.00)
	Updating insurance card	8 (50.00)	8 (50.00)	0 (0.00)	0 (0.00)	0 (0.00)
	Updating credit card	8 (53.33)	7 (46.67)	0 (0.00)	0 (0.00)	0 (0.00)
Creating and managing research consent ( $n = 7$ )	Creating research consent credential	3 (42.86)	4 (57.10)	0 (0.00)	0 (0.00)	0 (0.00)
	Sharing medical data with research institution	3 (42.86)	4 (57.10)	0 (0.00)	0 (0.00)	0 (0.00)
Revoking credentials ( $n = 7$ )	Patient removing full or partial consent with clinics with credential revocation	3 (42.86)	3 (42.86)	0 (0.00)	1 (14.29)	0 (0.00)
MPOA/Digital guardianship ( $n = 2$ )	Switching between guardian and dependent wallets	0 (0.00)	2 (100.00)	0 (0.00)	0 (0.00)	0 (0.00)

additional administrative burden as these outside records require sorting and then eventual incorporation into the native EMR, usually in the form of scanned documents that are not easily searchable.

While improving interoperability addresses some of the systemic faults of the modern-day healthcare ecosystem, understanding the social dynamics of health care is also critical in the pursuit of delivering high-value care services. Patients who rely on a caregiver, such as pediatric and geriatric patients, depend on providers who give timely access to their records so that the caregiver can stay up to date on clinical instructions, medication regimens, and follow-up appointments. Traditionally, caregivers usually accompany patients to their provider visits and are authorized to manage the patient's care, either verbally or with formal documentation. However, this relationship is not necessarily shared across providers, which further impedes a proper transition of care. Blockchain technology can be used to securely communicate these relationships across a network of providers to ensure smooth transitions of care. The current inefficiencies of data propagation during transfers of care likely contribute to a poor patient experience, especially in these vulnerable populations like the elderly who expect ongoing and tailored communication with providers regarding their care.<sup>18</sup> Providing patients the ability to share their own data with multiple providers may significantly improve the lack of care coordination that has developed due to siloed EMR systems.<sup>19</sup> An additional benefit of providing patients with easier access to their healthcare data is that they may feel more invested in their health, with studies showing that patient participation may depend on being invited to plan the care transition.<sup>20</sup> Taken together, blockchain technologies can aid a patient or a trusted caregiver to access and share pertinent medical information confidentially, while providing avenues to assist with transitions of care in an otherwise fragmented healthcare ecosystem for the delivery of consistent high-value care.

In addition to providing a platform for enhanced patient-centric care, blockchain technology has the potential to create increased value and interoperability in the processes of many adjacent healthcare-related fields. Other healthcare use cases that have been studied include management of healthcare provider accreditation,<sup>21</sup> clinical trials,<sup>22</sup> and supply chains.<sup>23</sup> When examining management of patient health information specifically, many proposed methods are still in their infancy when compared with the existing healthcare infrastructure.<sup>24</sup> Compared with MediLinker, many blockchain-based patient identity or data managing systems are undergoing prototyping to develop the fundamental infrastructure needed to integrate information across a wide range of stakeholders in health care. While the specific approaches may differ, comparable work in developing patient-centric blockchain-based healthcare

information systems are guided by the same principles of interoperability, trust, and patient autonomy.<sup>25</sup> Existing issues that are currently being addressed by many blockchain solutions include, but are not limited to, challenges with integration, mainstream adoption, economic factors, ethical regulations, and scalability.<sup>12</sup> Improving interoperability remains a central focus for many blockchain solutions as it may generate value by avoiding the same limitations noted in our current healthcare ecosystem.

#### *Blockchain Technology Allows for Personalized Healthcare Delivery*

In an increasingly data-driven society, there is more demand for the delivery of personalized healthcare services that integrate information from all aspects of a patient's life. Many patients now expect their providers to comment on information that is obtained outside of the clinic from their smart devices, such as vital signs, sleeping patterns, electrocardiography tracings and other detailed medical data. This only exacerbates the current problems with interoperability as each of these devices has their own, usually inadequately secured, method of data storage and sharing. Because of this, many providers opt not to incorporate such data into their clinical practice, which limits the potential information that could contribute to the overall health of the patient. Blockchain technology has been proposed to manage protected health information (PHI) generated by such smart devices.<sup>26</sup> From the results of this study, it would be conceptually possible to integrate this PHI into the wider healthcare ecosystem, thus bridging the interoperability gap for information that may come from nontraditional sources.

#### *User Perceptions of Blockchain Technology*

Although the widespread use of blockchain technologies would be profound, any new technology will have to overcome the issues of user adoption and ultimately develop trust among the user base to be successful. Blockchain, in a broader sense, has had a mixed public reaction with many being introduced to the term in the context of a hyped news cycle without understanding the significance of the underlying technology, leading to potential disillusionment.<sup>27</sup> We surveyed perceptions about blockchain and online medical data security and examined how they evolved with our study participant group. It was not surprising that less than a third of our participants initially felt comfortable with the security of medical data online, as about half of them indicated that they or someone they knew had experienced a data breach. However, after completion of our study and interim education about blockchain technology with exposure to the MediLinker platform, none of the participants indicated that they felt nervous about the security of medical data online. In fact, a large majority of the participants felt more in control

of their medical data using MediLinker, indicating that perhaps increased exposure to blockchain technologies and education about their functions may improve public perceptions and acceptance of such novel technology.

#### *Data Entry Changes Lead to Accuracy Improvements*

This second iteration of MediLinker showed an increased accuracy from prior versions due to additional workflow changes and data field verification measures. In our prior iteration, the participants who performed the use cases were tasked with completing data entry and subsequent updates, which resulted in degradation of data accuracy over the study period.<sup>14</sup> With this latest iteration, we changed the process, such that only trained staff would input the pertinent data, with patient verification once the data were entered. In addition, our data-entry fields were updated to have preset options as well as limiting inappropriate inputs, such as allowing only 16 numerical digits in credit card fields and preventing digits to be typed into name fields, respectively. After these changes, our accuracy throughout the study period remained greater than 97%.

Our study results showed that trained staff inputting data may lead to higher accuracy when compared with having patient data entry alone. Additional work remains to improve the efficiency of this process by mitigating sources of error, which in our case were due to work-flow vulnerabilities. Future work in this area could examine the use of image recognition to pull data directly from hard copy or scanned documents, as well as integrating outside information sources with patient authorization. Additional errors could be avoided by having multiple steps of verification across the data-entry process, although this may impede efficiency depending on how it is implemented. Altogether, our work provides some fundamental and practical approaches to improving data accuracy for patient identity management.

#### **Study Limitations**

One of the major limitations of this study was regarding the education level of the individuals who participated. All participants had at least an undergraduate level of education and were familiar with the use of mobile applications, which may have allowed for easier use of the MediLinker platform. In addition, it was difficult to emulate all aspects of the patient use cases, including all the challenges associated with unstable housing, given the demographics of our participants. We had limited resources regarding the number of simulations that could be run simultaneously, thus restricting our ability to evaluate scalability. Similarly, synthetic medical data were used as opposed to real patient data, which did not encompass all data elements of what would be contained in a patient's medical record. Examples of data elements that were not tested in the use cases include radiographical findings,

provider documentation, and vital signs. Although we expanded on the types of uses cases tested, additional patient scenarios still exist, which we did not test.

#### **Future Research**

This second iteration of MediLinker once again demonstrates the utility of blockchain technologies for patient identity management and provides further evidence on how such tools can be used to improve transitions of care and interoperability in an otherwise fragmented healthcare ecosystem. Additional study of usability, accuracy improvement, data management, and security are needed to fully characterize the utility of blockchain technologies in a live setting. Similarly, testing a more detailed healthcare dataset is needed to examine how such data elements interact in the blockchain environment. These elements include data such as radiographic images and other large files that are currently stored and managed by the respective institutions who obtained or interpreted them. In addition to examining different data elements, it will be critical to examine potential methodologies and barriers for integration of blockchain technologies with existing EMRs, as well as evaluate the various regulatory and legal circumstances surrounding the use of blockchain technology for healthcare data. Assessing the scalability of this technology will be needed to create a foundation for the practical implementation of such tools.

As mentioned earlier, understanding the social dynamics and user perceptions of blockchain technologies will be crucial for understanding how best to implement such novel tools in an industry that is usually reluctant to change. There appears to be significant differences in patients' perceptions of healthcare information exchange mechanisms based on blockchain.<sup>28</sup> Additional detailed research studies surrounding patient trust and comfortability in all demographic groups are also needed to establish if such technology is ready for mainstream adoption. Similarly, provider perspectives will be crucial in understanding how such technology will be used in both the inpatient hospitalized setting and the outpatient clinic setting.

#### **Conclusions**

Transitions of health care are challenging times for both patients and providers partly due to the lack of interoperability that exists in our current fragmented healthcare ecosystem. Blockchain applications for health identity management, as observed with MediLinker, provide a viable solution to the data siloing that is the root cause of such problems. By placing control of healthcare data in the hands of the patients in a secure and auditable manner, MediLinker and similar tools have the potential to improve interoperability by allowing for the timely delivery of accurate healthcare information across a trusted healthcare network. In a healthcare system designed in part without the ability to communicate across providers,

patient-mediated interoperability and data control may be the best solution for the delivery of consistent high value care. Although the integration of blockchain applications with the existing healthcare infrastructure has immense potential, further development, research, and scaling of their use are needed for their benefits to be achieved in the real world.

### Competing Interests

The authors declare no potential conflicts of interest.

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### Contributors

Mustafa Abdul-Moheeth, Muhammad Usman, and Daniel Toshio Harrell designed the feasibility study and clinical scenarios investigated. Mustafa Abdul-Moheeth, Muhammad Usman, and Daniel Toshio Harrell drafted the manuscript with revisions from Anjum Khurshid.

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## Appendix A: Weekly MediLinker Usability Survey Questions

### Pre-Study Survey

Please answer all of the following questions about the study you have agreed to participate in regards to health identity management. These questions relate to your experience of using the MediLinker system. Your responses will remain confidential.

- How comfortable are you in using mobile phones to accomplish various tasks?  
 1 (Very Uncomfortable)      2 (Uncomfortable)      3 (Neutral)      4 (Comfortable)      5 (Very Comfortable)
- Have you ever used any online portal, mobile application, or a website for sharing medical information?  
 (Yes)      (No)      (Unsure)
- How do you feel about the security of your medical data online? (Choose one)  
 1 (Very Uncomfortable)      2 (Uncomfortable)      3 (Neutral)      4 (Comfortable)      5 (Very Comfortable)
- Have you or someone from your relatives/friends ever had any type of data breach (e.g., hacking or unauthorized access)?  
 (Yes)      (No)      (Unsure)

### Week 1: Setting up MediLinker accounts

These questions relate to your experience using the MediLinker system. Your responses will remain confidential.

- I found the process of connecting with the clinic to be \_\_\_\_\_. (Choose one)  
 1 (Very Difficult)      2 (Difficult)      3 (Neutral)      4 (Easy)      5 (Very Easy)
- I found the process of getting credentials to be \_\_\_\_\_. (Choose one)  
 1 (Very Difficult)      2 (Difficult)      3 (Neutral)      4 (Easy)      5 (Very Easy)
- I found the process of sharing data to be \_\_\_\_\_. (Choose one)  
 1 (Very Difficult)      2 (Difficult)      3 (Neutral)      4 (Easy)      5 (Very Easy)

### Week 2: Sharing with another clinic and Updating information

These questions relate to your experience using the MediLinker system. Your responses will remain confidential.

- I found the process of sharing Health ID with the second clinic to be \_\_\_\_\_. (Choose one)  
 1 (Very Difficult)      2 (Difficult)      3 (Neutral)      4 (Easy)      5 (Very Easy)
- I found the process of sharing credit card with the second clinic to be \_\_\_\_\_. (Choose one)  
 1 (Very Difficult)      2 (Difficult)      3 (Neutral)      4 (Easy)      5 (Very Easy)
- I found the process of sharing insurance card with the second clinic to be \_\_\_\_\_. (Choose one)  
 1 (Very Difficult)      2 (Difficult)      3 (Neutral)      4 (Easy)      5 (Very Easy)
- I found the process of sharing medication list with the second clinic to be \_\_\_\_\_. (Choose one)  
 1 (Very Difficult)      2 (Difficult)      3 (Neutral)      4 (Easy)      5 (Very Easy)

5. I found the process of updating Health ID to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

6. I found the process of updating medication list to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

7. I found the process of updating insurance card to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

8. I found the process of updating credit card to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

**Week 3: Revoking information with another clinic**

*These questions relate to your experience using the MediLinker system. Your responses will remain confidential.*

1. I found the process of revoking access to my MediLinker and medical data with another clinic to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

**Week 4: Managing consent for research and Medical Power of Attorney (MPOA)**

*These questions relate to your experience accepting and revoking consent for research studies with your MediLinker system. Your responses will remain confidential.*

1. I found the process of creating the research consent credential to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

2. I found the process of sharing the medical data with the research institution to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

3. If applicable, I found the process of revoking the research consent credential to be \_\_\_\_\_ . (Choose one)

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |

4. For those who acted with a Medical Power of Attorney (MPOA), how did you find switching between wallets?

- |                  |             |
|------------------|-------------|
| 1                | 2           |
| 3                | 4           |
| 5                |             |
| (Very Difficult) | (Difficult) |
| (Neutral)        | (Easy)      |
| (Very Easy)      |             |