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Qualitative Study of Participant Impressions as Simulated Patients of MediLinker—A Blockchain-Based Identity Verification Application

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Abstract

Objective In this study, we obtained participants' views on using MediLinker—a blockchain-based identity verification and personal health information management application. We also gathered their views about the use of blockchain technology for controlling and managing personal health information, especially in the context of a global health crisis such as a pandemic.

Methods Online semistructured interviews were conducted with 29 simulated patients (i.e., avatars) who used MediLinker between February and May 2020. Interview data were analyzed qualitatively using a phenomenological approach to thematic analysis.

Results Most of the participants noted that they do not know what blockchain is nor understand how it works. Nonetheless, in the context of the study, they trust blockchain as a technology that can enhance data protection and privacy of their personal health information. Participants noted that MediLinker is a useful application that allows patients to easily input, share, and revoke personal health information. As a proof-of-concept application, participants also noted several issues and recommendations that can serve as points of improvement when developing subsequent versions of MediLinker. In the context of using MediLinker as part of a telemedicine system during a pandemic, participants noted that it facilitates social distancing, makes clinical transactions efficient and convenient, and enhances identity verification.

Conclusion In general, the findings lay the foundation for a user-centered approach in developing future iterations of MediLinker and other patient-facing blockchain-based health information technologies. Also, the findings provide important insights into how people perceive blockchain-based health information technologies, especially during a pandemic.

Keywords
- blockchain
- COVID-19
- identity management
- personal health information
- proof of concept
- usability

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Introduction

In the United States, electronic health data are fragmented and stored in "data silos" that do not exchange information easily. One of the reasons is that health care providers store records in centralized servers that lack interoperability and data security.[1,2] One potential solution is to utilize blockchain which is a decentralized digital ledger distributed across trusted nodes.[3] In contrast to a centralized management model in which electronic health data are currently stored, researchers believe blockchain or distributive ledgers in a trusted peer-to-peer network can bridge the gaps between these "data siloes" in health care and provide patients control over their medical data.[3–10] For instance, blockchain technology can be used to store information in decentralized nodes making the patient's identity and medical information within a blockchain verifiable.[3] Such an architecture allows for greater interoperability and security.[3,4] More importantly, it puts patients in direct control of their data.[3,4]

The study presented here is part of a larger project aimed at testing the extent to which blockchain technology can help us mitigate the interoperability problem, specifically in identity management, and to explore perceptions on using blockchain for health identity management and health information management. Since 2019, our team has been developing a patient-centric decentralized identity management system using blockchain technology called MediLinker.[11] To assess MediLinker's feasibility, we conducted a simulation, where student volunteers performed defined tasks as simulated patients (i.e., avatars; see Yaeger [et al11] for more details) followed by a focus group discussion on their perception of blockchain, personal health information, and the use of MediLinker. This article reports the findings of the focus group discussion.

Overall, this study is one of the few research endeavors that examines user perceptions of blockchain-based health applications in the context of a pandemic.[12–19] To date, most studies have focused only on the development of such applications or systems with limited user testing.[12–15] Although there is a growing scholarly effort that examines how blockchain can serve as a health technology solution to the coronavirus disease 2019 (COVID-19) pandemic,[16–18] to our knowledge, none has yet provided empirical findings on users' perception of such technology when used in the context of the current COVID-19 crisis. Moreover, it is crucial that blockchain technologies be examined for both their positive and negative aspects so that such systems can be optimized to enhance their benefit and reduce risks for both patients and health care organizations.[19] Thus, in conducting this study, we hope to obtain insights that would allow us to understand user perceptions of MediLinker, especially when it is used during a pandemic. Such findings would lay the foundation for us to improve future versions of MediLinker so that it can maximize benefits and minimize risks for our intended end-users, such as patients and health care organizations.

Research Questions

In general, we answer the following research questions that cover simulated patients' views on blockchain, personal health information, and the use of MediLinker, especially during a pandemic:

RQ1: How familiar are simulated patients with blockchain?
RQ2: What are simulated patients' attitudes toward blockchain?
RQ3: What are simulated patients' views over the control and ownership of personal health information?
RQ4: To what extent do simulated patients trust blockchain to store and manage personal health information?
RQ5: What devices did simulated patients use to access MediLinker?
RQ6: What are the positive aspects of using MediLinker?
RQ7: What are issues with using MediLinker?
RQ8: What are simulated patients' recommendations to improve MediLinker?
RQ9: What are simulated patients' views on using MediLinker as part of a telemedicine system during a pandemic?

Methods

Development and Testing of MediLinker

In 2019, the Dell Medical School and School of Information of the University of Texas at Austin (UT Austin) collaborated with Austin Blockchain Collective to develop MediLinker, a blockchain-based identity management application for patients. The overall objective of developing MediLinker is to allow patients to prove their identity to health care providers without the need of showing government-issued ID on each visit. The requirements and workflows were derived from health information technology experts, clinicians, and literature review.[11] Moreover, MediLinker is built on the principle that patients should be able to decide what information they want to share with a clinic and should also be able to revoke access to their information (see ►Fig. 1 for screenshots of MediLinker). The patient's information is intended to be secure, confidential, and auditable in the blockchain network.

The proof of concept (PoC) of the MediLinker project was successfully implemented and tested in two sprints (i.e., a sprint is equivalent to testing MediLinker for a month) conducted between February and May 2020 (i.e., Sprint 1: February 24–March 27, 2020; Sprint 2: April 6–May 5, 2020) on 15 simulated patients each with simulated personal health information. Participants used the MediLinker web application to enter and edit their medical data or patient identity during in-person visits at simulated institutions. Once their data were verified and issued to the blockchain, data could be shared between institutions. Due to the COVID-19 pandemic, Sprint 2 was conducted in a virtual clinical setting over Zoom (Zoom Video Communications, San Jose, California, United States). We used simulated patients because we did not want to expose actual patient data and want

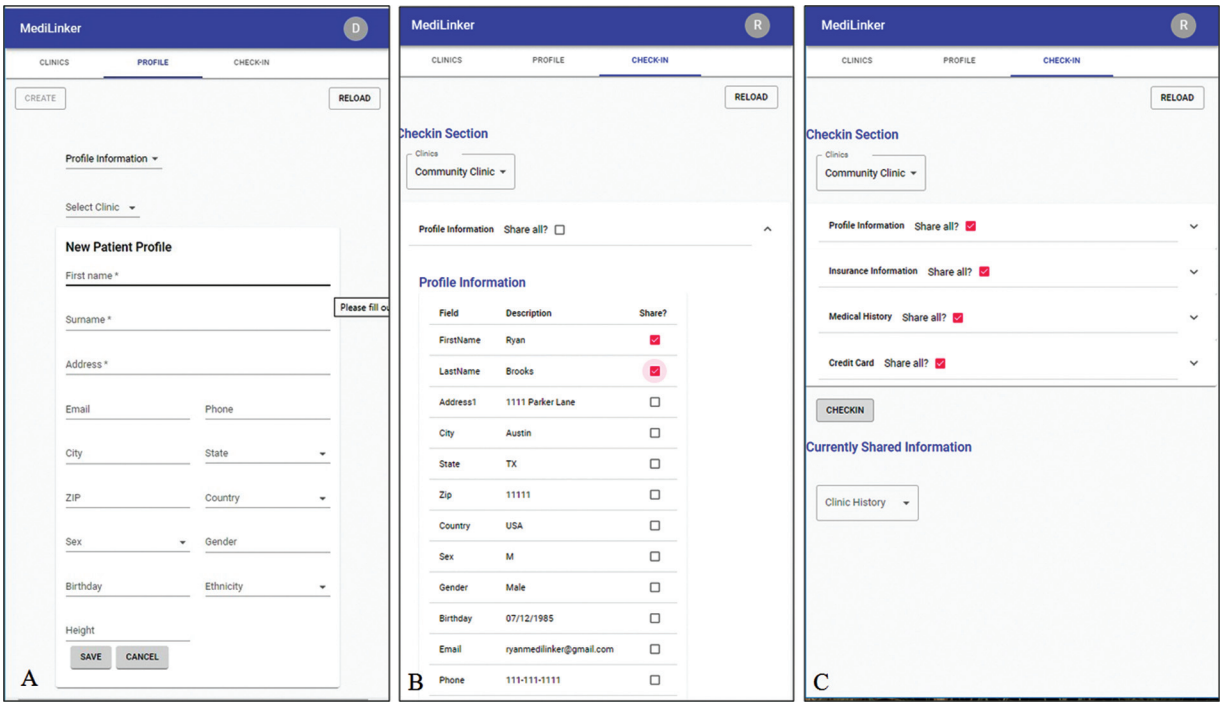

Fig. 1 MediLinker screenshots. (**A**) Profile creation page. (**B**) Check-in page with ability to share selected information with clinic. (**C**) Check-in page with ability to share all information with a clinic.

to protect human subjects, while testing MediLinker. We believed that at this stage having users who may help us test the functionality of the MediLinker application will inform a more human-centered technical design, which once refined can be tested with real patients to capture other aspects of patient experiences in using the application.

Six main functionalities were implemented during testing per sprint (see Yaeger et al[11] for more details):

- Patients can enroll at a first clinic using a government-issued identity and a health ID can be created on the blockchain network.
- Patients can enroll at a second clinic using a health ID generated during the first visit (without the need of government issued identity).
- Patients can share personal and medical information with clinics.
- Patients can revoke access to personal and medical data.
- Patients can update personal information.
- Patients can provide consent to participate in research projects.

Study Design and Data Collection

Interview data were collected from UT Austin students who participated as simulated patients in two sprints of testing MediLinker. Collecting data through in-depth interviews can provide a rich understanding on users' perspectives and insights regarding health information technologies,[7,20] such as blockchain.[21] Besides, considering that MediLinker has just completed initial development at the time of data collection, recruiting students who would act as simulated patients provides a safe and controlled environment to test MediLinker and obtain preliminary feedback before real-world testing.

Each sprint had 15 participants in which they used MediLinker for 4 weeks. During orientation, participants in sprint 1 (i.e., February 24–March 27, 2020) were told that MediLinker is a health information sharing app and were not informed that it is based on blockchain. On the other hand, those in sprint 2 (i.e., April 6–May 5, 2020) were told that MediLinker uses blockchain during orientation. Creating two groups would allow us to determine differences in attitudes and perceptions toward the use of blockchain for health care purposes.

At the end of each sprint, semi-structured interviews were conducted where we used an interview guide (see ►**Supplementary Appendix A**, available in the online version) that has questions regarding participants' perspectives toward blockchain in health care and their experience of using MediLinker (from their own point of view and as simulated patients). The interviews also provided an opportunity for participants to learn more about how blockchain is used in MediLinker. To account for modifications in Sprint 2 due to the COVID-19 pandemic (e.g., shifting clinic interaction from personal to online), we added questions about the utility of MediLinker when integrated in a telemedicine system during a pandemic.

A total of six focus groups and a personal interview were conducted among 29 of the 30 participants who used MediLinker (see ►**Table 1**). All interviews were conducted online over Zoom. The interviews lasted about 1 hour, and they received a cash incentive at the end of the interview. All interviews were video-recorded with the participants'

Table 1 Simulated patients' characteristics and interview schedule

Simulated patients' characteristics			Interview schedule	
Name (subsequent final name)	Sex	Age	Sprint 1	Sprint 2
1. Abdul-Azeem Nabhan Naeem	M	25	Focus group 2	Focus group 3
2. Adam Lopez	M	11	Focus group 3	Focus group 1
3. Amy Austin	F	22	Focus group 3	Focus group 1
4. Barbara Jones	F	62	Focus group 3	Focus group 2
5. Deveon Barkley (Wyche)	M	72	Focus group 3	Focus group 1
6. Evan Sellis	M	25	Focus group 2	Focus group 1
7. Jack Johnson	M	34	Focus group 2	Focus group 1
8. John Ross	M	29	Focus group 2	Focus group 2
9. Jose Alcantara Ramirez Delos Santos (Santoski)	M	45	Focus group 1	Focus group 2
10. Laura Bennet (Benet)	F	35	Focus group 2	Focus group 2
11. Mary Gown	F	28	Focus group 1	Focus group 3
12. Meagan Shilling (Bucanon)	F	34	Focus group 3	Did not participate
13. Ricardo Escalara	M	25	Focus group 2	Personal interview
14. Ryan Brooks	M	35	Focus group 3	Focus group 3
15. Xavier Jimson	M	25	Focus group 1	Focus group 2

consent and later transcribed for analysis. The study received an exempt approval from the Institutional Review Board of UT Austin.

Data Analysis

To answer the research questions, a phenomenological approach to thematic analysis was conducted because it is an applicable approach when it comes to examining users' experiences of using health care technologies.[22,23] Initially, interview transcripts and notes were imported to MAXQDA 2018 (VERBI GmbH, Berlin, Germany). Then, interview data were read by the research team to obtain preliminary insights of potential codes and themes. We then performed an iterative process of open (i.e., breaking down data into codes) and axial (i.e., breaking, lumping, and relating codes) coding to uncover sub-themes and themes that arise from the data.[24] During coding, we also wrote memos to keep track of potential nuances arising from the data (e.g., differences between sprints and simulated patient characteristics). Weekly meetings were performed to discuss the progress of the analysis and review key aspects of the findings in relation to the research team's experience of facilitating the testing of MediLinker. These meetings were also instrumental to decide that data saturation has been reached and additional codes or interviews were not required. Names of simulated patients and sprint numbers were added to provide context.

Results

In this section, we organize our qualitative findings based on our nine research questions.

Familiarity with Blockchain

Most of the participants noted that they do not know what blockchain is nor understand how it works. Such a trend is the same for participants in Sprint 1 (the study orientation did not specify that MediLinker uses blockchain) and Sprint 2 (the study orientation specified that MediLinker uses blockchain). For some, it is just another "buzzword" (Xavier, Sprint 1) or "fancy word" (Jose, Sprint 1) that represents a new technology. One noted that she heard about blockchain in relation to bitcoin or cryptocurrency (Barbara, Sprint 1). Although some participants knew what blockchain is and understand some of its components (e.g., built on a decentralized platform) and features (e.g., provides enhanced data security and difficult to hack), they are not aware of its application to health care:

> *"From what I know, blockchain could be helpful to share all the information because they are built on a decentralized platform. But I do not see that blockchain is reflected in this application [MediLinker]. I don't realize that until you [moderators] told us that it is based on blockchain."* (Evan, Sprint 1)

Attitudes toward Blockchain

Participants expressed both positive and negative attitudes toward blockchain, with the majority expressing the former. No differences in attitudes were found regardless of whether participants were informed that MediLinker is based on blockchain technology. In terms of positive attitudes, most of them noted that a system that uses blockchain gives them greater control on their personal health information:

"I do [feel in control]. It sounds pretty reasonable to me especially because since everything is being logged, everything goes down as a transaction." (Jose, Sprint 1)

Some participants also noted that the decentralized nature of blockchain makes their personal health information less susceptible to hacking or unauthorized access:

"I feel having decentralized data reduces the chances of a data breach. And since all of the information is not stored at any single location, there are less chances of all of my information being exposed to some kind of hackers in the first place." (Abdul-Azeem, Sprint 2)

In terms of negative attitudes, some participants noted that although blockchain is designed to have greater security features, there is still a possibility of untoward events, such as hacking or data breaches, that can lead to some having feelings of uncertainty:

"I don't feel quite safe because it could be still hacked. I don't know how effective the encryption is, how easy is it to crack." (Evan, Sprint 2)

Besides, one participant explained why older people are more likely to hold negative attitudes than younger people:

"I think my avatar, being more middle aged, would probably be somewhat speculative and probably a little fearful because if you are slightly older, the things you see on the news like Cambridge Analytica or things like that with data breaches, your first perception of something like this will go directly to that." (Jack, Sprint 1)

Control and Ownership of Personal Health Information

There is a consensus among participants that patients should have overall control and ownership of their personal health information, and a technology such as blockchain fulfills that idea. As noted by some participants, control of patient health information should be controlled by patients because such information is theirs to begin with:

"I think it should be controlled by the patient. It's information about yourself and it's also private. It's about your health and your medical conditions, your prescriptions." (Deveon, Sprint 1)

Although patients should have overall control of their personal health information, there is also consensus that sharing or co-ownership of such information with medical institutions is essential to facilitate better access to health care:

"There should be some kind of co-ownership between the patient and the medical institutions. Some of the more medically relevant things like what medication you've been taking, what surgeries you had in the past, etc. is more practical to be co-owned by the hospital as well." (Adam, Sprint 1).

Since personal health information should be shared or co-owned with medical institutions to access health care, some participants noted several responsibilities that medical institutions should uphold as stewards of patients' personal health information. ►**Table 2** lists these responsibilities.

Trust in Blockchain

The participants outlined several conditions in which they would trust blockchain to store and manage personal health information. ►**Table 3** summarizes these "trust conditions." For most participants, they would only trust blockchain if information on how it works is available.

Devices Used to Access MediLinker

Most of the participants used their laptop to access MediLinker in both sprints (►**Fig. 2**). However, a few participants in Sprint 1 (personal clinic sessions) used their smartphones out of convenience (e.g., no need to bring out a larger device during clinic visits) or availability (e.g., they only have their smartphones during clinic visits). On the contrary, considering that Sprint 2 conducted clinic sessions over Zoom, all Sprint 2 participants used their laptop to access MediLinker out of convenience (e.g., Zoom is already installed in their laptops for their coursework) or multitasking opportunity (e.g., simultaneously check emails and view instructions during clinic sessions).

Positive Aspects of Using MediLinker

Participants noted five positive aspects of using MediLinker: (1) useful and needed in today's health care system., (2) gives security and control to personal health information, (3) easy to use, (4) interface is neat and simple, and (5) facilitates convenience. ►**Table 4** summarizes these positive aspects.

Issues with Using MediLinker

Although participants noted several positive aspects of using MediLinker, they also mentioned several issues that can serve as points of improvement. ►**Table 5** shows a summary of these issues. In general, these are categorized as issues related to (1) user, (2) data privacy, (3) account and log-in, (4) interface, (5) information submission, and (6) data input. ►**Supplementary Appendix B** (available in the online version) shows the representative quotes for each issue.

Recommendations to Improve MediLinker

We asked for several recommendations that can be done to improve subsequent versions of MediLinker and to overcome most of the issues shared by the participants. In general, these recommendations are related to (1) user access, (2) interface, (3) data input, (4) submission of information, and (5) notification. ►**Table 6** summarizes these recommendations along with relevant issues that each recommendation would resolve. ►**Supplementary Appendix C** (available in the

Table 2 Medical institutions' responsibilities as stewards of personal health information

Medical institutions' responsibilities as stewards of personal health information	Representative quotes
Medical institutions need to ask permission from patients and declare as much details as to how they intend to keep and use such information	*"The medical institutions can have the option to keep their data and should notify the patient how long they will keep their medical data. They should also notify when they need to share their medical data to other parties."* (Mary, Sprint 1)
Medical institutions should safeguard patients' personal health information from data breaches or unauthorized access	*"I think the medical institution should be very transparent about how they're using the data. If they're storing it officially in a safe way, and within the medical institution, making sure that that data is not extremely easy to access by anyone in the hospital. It should be controlled in a safe way."* (Abdul-Azeem, Sprint 1)
Medical institutions should have mechanisms to obtain access to personal health information when the patient is unable to provide consent	*"I suppose there are also situations where a patient might need to get data to a facility, but they can't consent to pass that data along. Maybe there should be some sort of fail-safe that should be activated. I don't know exactly how that would be implemented, but I can imagine like somebody's unconscious and they need their medical information."* (Xavier, Sprint 1)
Medical institutions should respect patients' decision to revoke access	*"When the patient wants to revoke and take back their data, I don't think the medical institution should force them to stay with them and they should just allow them to revoke their data. Because at the end of the day, a person is a person, and they're willingly giving the medical institution their data."* (John, Sprint 1)

Table 3 Blockchain trust conditions

Blockchain trust conditions	Representative quotes
Will trust it if information on how it works is available	*"I don't know if they necessarily trust it at first. But if it's explained in the way that it is to us, I think people would come around to trusting it just because it is more secure and that it gives you control over your information rather than a central system."* (Barbara, Sprint 2)
Will trust it if others trust it	*"As a layman, I would trust something that the public trusts. So, if it's a well-established system like we all trust, like email and other technology which whatever we use nowadays. But blockchain seems like something upcoming. So, once it is something well established, I feel like people would start trusting it."* (Jose, Sprint 1)
Will trust it if benefits are explained	*"Maybe there's no need to explain how everything works as long as you just make the association that blockchain meets extra privacy and extra safety. That'd be good."* (Xavier, Sprint 1)
Will trust until something bad happens	*"For me, I'm still not too familiar with blockchain technology and how it all works. But I'll probably trust that anyway until something bad happens."* (John, Sprint 2)
Will not trust it all	*"I think for my avatar, he might not be as trusting of technology and maybe sees it as more foreign, so I think those might be put into consideration"* (Ricardo, Sprint 1)

online version) shows the representative quotes for each recommendation.

Views on Using MediLinker as Part of a Telemedicine System during a Pandemic

Although it is not designed to be part of such a system, the university's enforcement of social distancing measures due to COVID-19 during Sprint 2 testing served as an opportunity to simulate how MediLinker can be integrated in telemedicine during a pandemic. ►**Table 7** summarizes Sprint 2 participants' views on using MediLinker in such a situation.

Discussion

Familiarity and Trust in Blockchain-Based Health Information Applications

In general, very few participants are familiar with blockchain and are mostly unaware of its use for health care. This supports recent work which shows that patients are generally not aware of blockchain's use for health care purposes.[21] This suggests that there is a need for more education and transparency on how it works as it becomes relevant to consumers, such as in the case of adopting it to manage personal health information. This suggestion is also based on

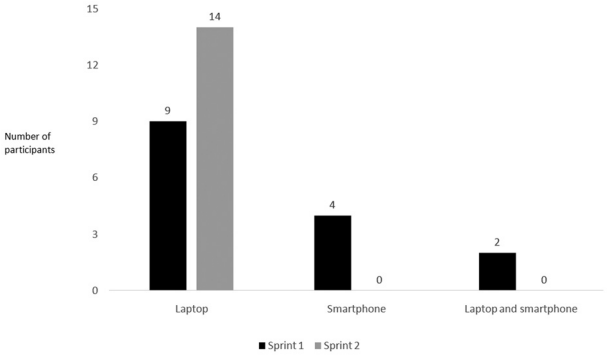

Fig. 2 Devices used to access MediLinker ($n = 15$ per sprint).

the finding that some participants will only trust blockchain to store their personal health information if details on how it works are available (see ►**Table 2**). Thus, it is crucial for application developers and clinicians to be able to explain among patients what blockchain is and how it is used to enhance the security of personal health information.[21,25,26]

Patient-Centric Control and Management of Personal Health Information

The results indicate that participants want control over their personal health information but are willing to share access with medical institutions if they follow certain responsibilities (see ►**Table 3**). Our findings are in line with previous work.[27,28] Echoing the suggestions of several scholars,[29,30] our findings serve as a call for medical institutions to adopt new technologies, such as blockchain, that can enhance data privacy and security to assure patients that they can continue to be good stewards of personal health information.

Useful, Easy to Use, Secure, and Convenient—Even During a Pandemic

Participants noted that MediLinker is useful and easy to use (see ►**Table 4**)—views that are essential for the acceptance and adoption of technologies.[31] Participants also noted that MediLinker gives them security and control to personal health information as well as convenience when accessing health care services. Such findings are consistent with previous work where ensuring control, security, and convenience can entice users in using blockchain-based systems to

Table 4 Positive aspects of using MediLinker

Positive aspects	Representative quotes
Useful and needed in today's health care system	*"I do think there's a need for this. I hear doctors constantly complaining about different EMR systems and them being hard to use. And there isn't really a way to have all your data consistent across everyone. So, if you change providers, it's a mess to get all your data moved over. If you have an emergency and you need go to another hospital, they're fumbling to find your data. So, I think there is definitely a need for something like this that is kind of globalized to the point where your data is going to be everywhere. And whoever needs that, whenever can have it."* (Jack, Sprint 1) *"I think it would definitely be useful because being able to share your data just overcomes a lot of hurdles when it comes to getting care because a lot of the times when you switch to a new clinic or you go to a different specialist, they want to obtain your medical records and sometimes if it's something more intense like an MRI or something like that, it's a lot easier just to share it than have to kind of go through that process again. So, I definitely think it is needed in our present system."* (Laura, Sprint 2)
Gives security and control to personal health information	*"I feel like I was able to choose what to share and then I was able to choose what to revoke in my information. I felt like that was really beneficial."* (Deveon, Sprint 1) *"I think that system is really good based on blockchain platform. So, I think that I have total control of my medical data so that makes me feel secure that the medical agencies are not using my data for their benefit. And as a person suffering PTSD [refers to his avatar], I got to share my situation with everyone that I need medical."* (Ryan, Sprint 2)
Easy to use	"*I think it was pretty simple to use. Everything was straightforward and it sent everything to the clinics right away. So, I thought it was like a good platform to have. It was pretty simple to use."* (Ryan, Sprint 1) *"I feel that the system is quite easy to use and I was able to share and revoke the information that I wanted to, and it was quite instant... the method, like the verification of information that I shared through my account. So, the system seems quite easy to use."* (Abdul-Azeem, Sprint 2)
Interface is neat and simple	*"I think I really like the fact that the interface is really clean and not very complicated. So, anyone with just a rudimentary knowledge of operating electronic devices should be able to figure out what to do."* (Jose, Sprint 1) "*My experience was pretty smooth. I thought the application was easy to navigate through*." (Adam, Sprint 2)
Facilitates convenience	*"I appreciated not having to fill out forms and forms and forms every time I went to a new clinic."* (Deveon, Sprint 1) *"I definitely think it is efficient and convenient. Instead of having to, at every new clinic, explain everything or redistribute documents or carry them with you. You're able to just share automatically and more than that you're able to share whatever proportion of the information you would want to."* (Mary, Sprint 2)

Abbreviations: EMR, electronic medical record; PTSD, posttraumatic stress disorder.

Table 5 Issues with using MediLinker

General Issues	Specified
User	• Limited access to technology by have-nots
	• Language barriers
	• Poor grasp of technology
Data privacy	• Data breach
	• Hacking issues
	• Revocation may not actually revoke information
Account and log-in	• Account not available in other clinics
	• Cannot reset or modify account
	• No option for endorsement leading to account switching
Interface	• Cannot see revoke button
	• Difficult to navigate
	• Interface is not optimal in smartphones
	• No activity summary page
	• No in-application instructions
	• Need to click reload to refresh information
Information submission	• Blank form bug
	• No instant information refresh
	• No notification upon check-in
	• No "revoke all" button
	• No "share all" button
	• Notification not in application but via email
	• Submit button working without clinic selection
Data input	• Need to input all information again when editing details
	• No autofill or predictive text function
	• No dropdown options
	• No instructions when inputting name

manage personal health information.[13,25] Besides, providing users control over their health information is crucial since it promotes autonomy—an ethical principle that is often violated when patients' information in electronic medical records is accessed or shared without permission.[32,33]

MediLinker was also viewed positively by the participants because of its utility during a pandemic. For instance, as the COVID-19 pandemic forced health care institutions to limit face-to-face interactions, enabling patients to access, add, or revoke personal health information remotely in a secure, efficient, and convenient manner is something that enticed participants to hold positive attitudes toward it. In general, our findings suggest that the participants positively viewed the PoC version of MediLinker and there is strong justification to further develop it for commercialization.

Resolving Issues for a Commercial-Ready Product

Although the participants held positive views on MediLinker, they also noted several issues with it as well as the corresponding recommendations to address those issues (see ►Table 5). Aside from technical issues that are expected (i.e., data privacy, account and log-in, interface, and data input), the participants highlighted user-related issues (i.e., access to technology by have-nots, language barriers, and poor grasp of technology) that reflect social issues that hinder the adoption of technologies, such as the digital divide that stems from income and educational inequality.[34] Such acknowledgment of user-related issues is needed to develop future versions of MediLinker that is inclusive. For instance, adding Spanish as a language option within the application can enhance adoption considering that this language is the most spoken non-English language in the MediLinker.[35] This would enable more people to use it and ensure its viability as a commercial product.

The findings also suggest that the next appropriate step for MediLinker is to develop it as a mobile application so that it can leverage current smartphone features to facilitate greater functionality and security. Currently, the application can be accessed in both web and mobile browsers, but most participants used their laptop to access MediLinker because the user interface was not optimized for mobile devices (see ►Fig. 2). However, consistent with previous work,[36,37] participants think that such an application needs to be developed also as a mobile application because patients are likely to have a smartphone and bring it during clinic visits. Besides, recent work shows that Americans primarily seek health information using mobile devices.[38,39] To foster inclusivity, developing MediLinker as a mobile application is needed to reach disadvantaged populations. In fact, 58% of homeless adults in the MediLinker own a smartphone, thus providing a mechanism for them to access MediLinker in their devices.[40] Nonetheless, considering that MediLinker can also be accessed as a web application, those without smartphones can access it through internet-connected computers in public libraries.[41] On the security perspective, creating an optimized mobile application for MediLinker would enable us to incorporate robust security (e.g., two-factor authentication and biometrics log-in) and input features (e.g., image recognition for credit cards and predictive text) that are being deployed in contemporary mobile applications. In general, for subsequent versions of MediLinker to be a commercial-ready product, it needs to have a well-designed user interface in both web and mobile versions.

Limitations and Future Research Directions

The study has several limitations that can serve as future research directions. First, the study participants consisted of university students who acted as simulated patients and were provided tasks on using MediLinker. Hence, the insights provided by these participants may contrast with real patients who would use MediLinker to manage real-world health conditions. Although the findings from simulated patients provided valuable information in improving the current version of MediLinker, subsequent research will be

Table 6 Recommendations to improve MediLinker

General and specific user recommendations	Issues that can be resolved
User access	
• Allow users to log-in using a clinic device	• Have-nots • Poor grasp of technology
• Fingerprint log-in	• Data breach • Hacking
• Give permission to representative to access account	• No option for endorsement leading to account switching
• Two-factor authentication	• Data breach • Hacking
Interface	
• Add information, graphics, and visuals	• Difficult to navigate
• Add language options	• Language barriers
• Add tech support	• Cannot reset or modify account • Poor grasp of technology
• Detailed in-application instructions	• Blank form bug • Cannot reset or modify account • No in-application instructions • No instructions when inputting name • Poor grasp of technology
• Develop as a mobile app	• Interface not optimal in smartphones
• Interface compatibility across platforms	• Interface not optimal in smartphones
• More effort to have a user-friendly interface	• Cannot see revoke button • Difficult to navigate • Interface not optimal in smartphones
Data input	
• Allow to edit individual fields	• Need to input all information again when editing details
• Connection to database	• No autofill or predictive text function
• Image recognition	• No autofill or predictive text function
• Predictive text	• No autofill or predictive text function • No dropdown options
Submission of information	
• Flexible share/revoke all/some button	• No “revoke all” button • No “share all” button
• In-application notification on submission	• Submission notification not in application but via email
• Instant information refresh after submission	• Need to click reload to refresh information • No instant information refresh
• Lock submit button to avoid multiple submission	• No notification upon check-in • Submit button working without clinic selection
• Password confirmation for every transaction	• Hacking
Notification	
• Add activity summary	• Difficult to navigate • No activity summary page
• Add calendar notification	• No activity summary page
• Notification on user access based on location	• Data breach • Hacking • No notification upon check-in

Note: Issues with no recommendation: (1) revocation may not actually revoke information, and (2) account not available in other clinics.

geared toward recruiting real patients to uncover additional issues beyond those identified in this study. One issue that needs further examination in future work is to identify workarounds when patients do not have government-issued identification since such a document is required to start the use of MediLinker.

Second, considering our research design, the findings are limited to perceptions on using MediLinker. Although

Table 7 Views on using MediLinker as part of a telemedicine system during a pandemic

Impressions	Representative quotes
Facilitates social distancing	*"I think this app will be really helpful in these times because you don't have to make contact with those receptionists when you actually go in person visit the clinic. You can just check-in virtually and the only appointment that you have is with the doctor. So yeah, it helps in mitigating contact."* (Evan, Sprint 2) *"It's great that the patients wouldn't have to make contact with the receptionist in real life. It's great to bring things online, especially during times like this."* (Jack, Sprint 2)
Makes clinic transactions much convenient	*"Being able to do all of this [share personal health information] and get advice and care from your doctor when you're supposed to be home. I think that makes it a lot easier for people to access the clinic, especially if they have time constraints or must take care of a child or something at home."* (Laura, Sprint 2) *"Being at home and being able to like check-in really quickly in like 5-10 minutes, 15 minutes. That's a really good benefit."* (Xavier, Sprint 2)
Efficient sharing of personal health information	*"Since we can share the information and make appointments online with whatever information we want to share, it speeds up the process, especially in cases where [COVID-19] testing is required. So, having a system like MediLinker would make the process more efficient."* (Abdul-Azeem, Sprint 2) *"I definitely think there's a benefit to using a system like this because you're able to automatically share information with clinics instead of perhaps making phone calls back and forth or needing to request that they fax over information from another clinic."* (Mary, Sprint 2)
Efficient verification of identity	*"I think it's great to have a way to verify your identity and maybe how to contribute to increase medical care through online, especially during times you can't show up into the clinic."* (Jack, Sprint 2) *"It would be beneficial because I think it'd be easier [to verify identity] with a really, really big influx of patients coming in [because of COVID-19]. It would be easier for them [patients] to control their own information instead of having to make the medical institutions worry about it."* (Ricardo, Sprint 2)

conducting interviews after 4 weeks of using MediLinker provide findings that allow us to improve subsequent versions of MediLinker, our findings do not include quantitative metrics for assessing usability (e.g., time it took to set up a user profile) which is often conducted in a laboratory.[42] Therefore, future research will be aimed at assessing the usability of MediLinker in a laboratory to complement the findings of this study.

Third, the study only focused on testing MediLinker without the presence of similar health information management technologies. Comparing blockchain- and nonblockchain-based technologies to manage health information can provide insights to improve the former's usability. Thus, future research can be directed toward testing two systems at the same time (e.g., A/B testing with other similar technologies such as Consent2Share[43]).

Finally, as a PoC, the goal of the study was to understand participant views as simulated patients of MediLinker to maximize its benefits and minimize risks.[44] Based on the results, there is a need to further enhance the security features of MediLinker. This is needed because subsequent research that would rely on live clinical data requires secure systems considering that such data could potentially be transferred from one system to another. Therefore, future work will be geared toward further improving MediLinker to be more secure and usable before live clinical testing.

Conclusion

MediLinker is a blockchain-based identity verification and personal health information management application. Based on interviews with simulated patients who tested MediLinker, it is a useful application that allows them to easily input, share, and revoke personal health information, especially during a pandemic. As a PoC application, participants also noted several issues that can serve as points of improvement when developing subsequent versions of MediLinker. Overall, the study contributes important insights into how users perceive blockchain-based health information technologies. Practically, these insights are valuable to improve the usability of such technologies in the future.

Clinical Relevance Statement

The findings lay the foundation for a patient-centered approach in developing future iterations of MediLinker and other patient-facing blockchain-based health information technologies. Also, the findings provide important insights into how users perceive blockchain-based health information technologies, especially during a pandemic.

Author Contributions

A.K. and D.T.H. conceptualized the study and obtained funding. J.R.B., D.T.H., E.T.M., L.H., and A.K. designed the study. J.R.B., M.U., D.T.H., I.D., J.A., C.C., L.H., and C.H. collected data. J.R.B., M.U., and D.T.H. performed data analysis. J.R.B., M.U., E.T.M., and A.K. wrote and edited the manuscript. All authors approved the final version of the manuscript.

Protection of Human and Animal Subjects

The study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human

Subjects. Participants provided written and verbal consent prior to interviews. The study received an exempt approval from the Institutional Review Board of MediLinker.

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Conflict of interest

None declared.

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