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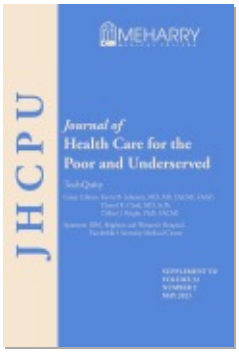
Advancing Health Equity for People Experiencing Homelessness Using Blockchain Technology for Identity Management: A Research Agenda



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Advancing Health Equity for People Experiencing Homelessness Using Blockchain Technology for Identity Management: A Research Agenda

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Abstract: People experiencing homelessness (PEH) are medically complex, with limited access to health care and unmet health-related social needs. People experiencing homelessness must access a wide range of health and social services, for which they must typically show proof of identity. Many PEH do not have original vital documents, which are highly susceptible to damage, loss, or theft. Lack of proof of identity is a major barrier to receiving services, and can exacerbate health inequities plaguing this population. Blockchain technology can be used to ensure secure and portable identity management in health care. Based on our clinical experience caring for this population, and implementation of a pilot blockchain-based identity management solution for PEH in our community, we believe blockchain can solve the identity management problem among PEH. We propose a research agenda that will help stakeholders determine how blockchain technology could be an innovative and effective techQuity solution for this pernicious problem.

Key words: Homelessness, identity, identity management, blockchain, technology, health equity, access to care, techQuity.

> *"We are not concerned with the very poor. They are unthinkable, and only to be approached by the statistician or the poet."*
>
> *—E.M. Forster*

The Health Inequities of Homelessness

There are over half a million people experiencing homelessness in the United States.[1] Compared with the general population, people experiencing homelessness (PEH) have higher rates of medical and mental health conditions, limited access to health care, higher utilization of costly acute care and crisis services, and unmet health-related social needs.[2–6] People experiencing homelessness are victims of structural violence[7]

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and intersecting with homelessness in the United States is structural racism: in every state, African Americans are disproportionately more likely than Whites to experience homelessness.[8] We know that housing is an important social determinant of health. In a 10-year prospective cohort study conducted in Boston (2000–2009), unsheltered homeless adults had an all-cause mortality rate 10 times higher than the general population, with a mean age of death of 53 years.[9,10]

Nameless Faces

In order to meet their needs, PEH must access a wide range of health and social services. However, two fundamental problems exist. First, to access these services, PEH must typically show proof of identity. However, many PEH do not have original vital documents, such as state-issued IDs or birth certificates, which are easily susceptible to damage, loss, or theft. As any homeless service provider or person experiencing homelessness themselves can tell you, this is an exceedingly common issue, and replacing vital documents or lost IDs is complex, burdensome, and time-consuming. Our prior study based on qualitative interviews with PEH in Austin, Texas, showed that at least one third of clients lacked a basic identity document when they entered the health and human services system in the city.[11] A survey of homeless service providers conducted by the National Law Center on Homelessness and Poverty revealed that the lack of a photo ID prevented PEH from receiving food stamps, social security income (SSI) benefits, Medicaid, shelter or housing services, or medical services; furthermore, ever since September 11, 2001, federal and state laws and administrative policies have made it more difficult for PEH to obtain a photo ID.[12] Second, health care and social services in the U.S. are fragmented and siloed, and in the absence of a truly person-centered and integrated approach, health care and social service systems lack interoperability and are unable to accurately collect, share, and verify even basic identity information for a person experiencing homelessness.[6,13] This puts the burden on PEH to navigate complex, duplicative, and bureaucratic requirements just to prove their identity and begin the process of accessing services.[14,15] Given these problems, PEH are often nameless faces, individuals among us in need of services but unable to benefit from them simply because they cannot prove who they are. Therefore, lack of proof of identity is a major barrier to receiving health care and social services, and can exacerbate the health inequities plaguing this population.

A Potential TechQuity Solution

Blockchain technology can be used to ensure secure and portable identity management in health care, and holds great promise to be a techQuity solution for the problem of identity management for PEH.[11,14] Fundamentally, blockchain can be described as a distributed trust network that uses cryptography or encryption to share ledgers of transactions across a large number of nodes.[16] Each piece of information must be verified by a consensus mechanism where all participants of the network agree on the truth of each transaction. Once verified the new transaction is attached to a block of information with other verified transactions. These verified blocks of information

are then linked to the previously verified blocks of information thus creating a chain. Any change in previously verified information in any block is therefore detected easily because it changes the cryptographic code (Figure 1).[17]

The architecture of blockchain technology thus creates a set of features that ensure security and privacy along with an individual's control over their information, which is not easily established in existing health information systems.[18] Blockchain technology's characteristics that make it a unique solution for managing identities of vulnerable individuals include a very strong cryptographic security, immutability, or inability to change any entry that has been verified by a consensus, distributed information that allows transparency of transactions, and the ability to audit each entry in the network records.[19] Moreover, through the use of public and private keys it allows individuals to control when and where their information is shared.[20]

Despite being an evolving technology, blockchain technology is increasingly being used in solving real-world problems. Cryptocurrencies are being used by banks, governments, and private markets and the cryptocurrency sector is expanding rapidly.[21] Bitcoin and other blockchain-based coins have had their ups and downs but are rapidly moving beyond the early adopters to more mainstream users.[22,23] The government in Estonia has adopted blockchain technology as part of its secure identity management and transaction infrastructure for all its citizens.[24,25] Major companies such as IBM, Walmart, Whole Foods, and Chemonics are using blockchain technology for supply chain management.[26] Breakthroughs in achieving efficiency in these transactional processes are also being reported.[27]

Beyond finance and business, blockchain technology applications have also been making their mark in the social and health sectors. Blockchain applications in the social sector include the empowerment of rural farmers in Africa, Asia, and South America.[28] Similarly, blockchain has been used in the pharmaceutical industry to address the issue of counterfeit drugs,[29,30] and the FDA has a program to use blockchain for this purpose.[31] Medical and informatics literature is increasingly describing applications of blockchain in health care.[32–34] From managing medical records to tracking COVID-19 patients, blockchain's technical capabilities are being found useful across the industry.[35–37]

Recently, the City of Austin worked with the University of Texas at Austin Dell Medical School to test the feasibility of using blockchain technology to establish an identity management system for persons experiencing homelessness. The project involved social and health care service providers and patients with lived experience of homelessness.[14] The results of the study showed that blockchain technology, using an Ethereum platform, allowed PEH to create accounts, upload documents, share documents with differentiated permissions, enable service providers to share documents and information, and allow an individual to hold their personal identity information as an asset in their blockchain account.[11]

One of the key features of blockchain that may provide some innovative ways to help address inequities in health is that its foundations are based on mathematical algorithms that can be scrutinized and audited to rectify any systematic discrimination or bias. While the concern of biased algorithms is being raised more widely now, the research to address these concerns is still in its early stages.[38,39] As a peer-to-peer network, blockchain technology also allows individuals to conduct transactions without

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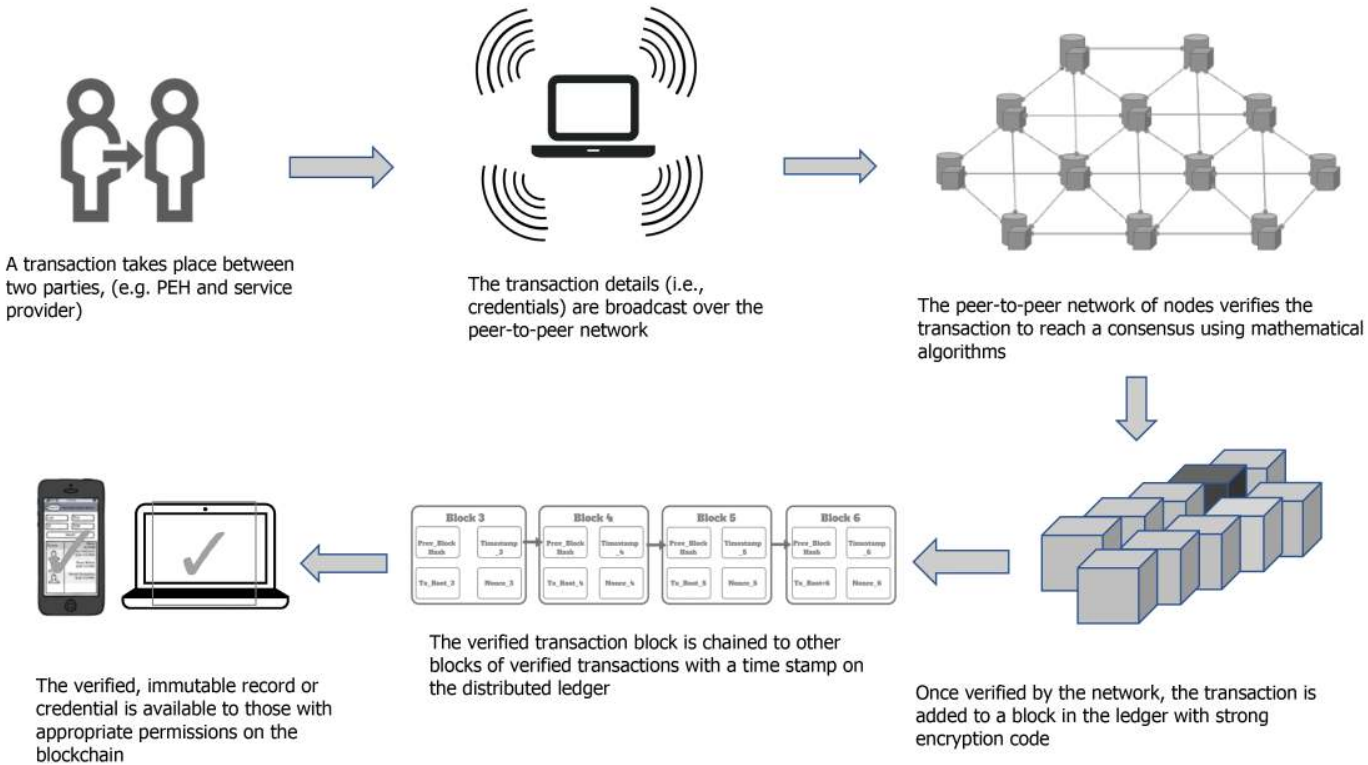

Figure 1. A conceptual model of blockchain's distributed ledger.
Source:
The authors, adapted from Khurshid and Gadnis, 2019 (Ref #14).

an intermediary who could impose any personal or institutional bias on the nature or scope of such transactions. The system works on agreed-upon principles or consensus and brings transparency and auditability that can prevent judgmental or stereotyped interpretation or implementation of rules. It also protects an individual's privacy and identity by sharing validated credentials without having to share complete identification records. For instance, if an individual must prove that they are over 18 years old, that information can be validated through blockchain's immutable record without having to share the full identity document or even date of birth.

Individual PEH preferences and comfort level with the various options for log-in mechanisms (password, QR codes, biometrics), affordable devices (e.g., Android, iOS), and literacy levels are factors that are important for future adoption of blockchain technology for health equity. Similarly, business process changes and acceptance of these trust mechanisms by institutions may be influenced by existing law and regulatory requirements that must be updated. Validation and verification of data and issuance of identity documents when multiple public and private agencies are engaged in multiparty transactions may have competing solutions.

Despite the promise of blockchain technology to address identity management in health care and social services, much remains unknown about the scope of the problem, how blockchain technology could be applied to address it, and how this might translate into addressing the health inequities that result from it. Therefore, we propose a research agenda that will help key stakeholders determine how blockchain technology could be an innovative and effective techQuity solution for the problem of identity management for PEH.

Unanswered Questions Abound: A Research Agenda

While practical examples of blockchain applications in health care are being reported at an increasing rate, according to two recently published systematic reviews, very little empirical research has been conducted so far.[18,40] Much of the published literature consists of opinion pieces discussing the fragmentation of electronic health records systems and the potential applicability of blockchain in solving this problem, drawing from its use in other sectors. Most of the empirical research has focused on the use of blockchain to strengthen health information technology (HIT) security or privacy, or to improve HIT interoperability across different health care systems. Only a very small minority of studies looked at whether blockchain technology could actually improve health care outcomes. While applications of blockchain technology have been reportedly used in rural Indonesia, Kenyan slums, and Syrian refugee camps for identity management, we are not aware of any empirical research, other than our own preliminary pilot work, that evaluates blockchain's applicability for identity management with PEH.[11,14,28] Given this lack of empirical evidence for the use of blockchain technology for identity management to improve health equity, we propose a research agenda that can help answer critical questions. We derived this research agenda from three main sources: first, was a rationale, pragmatic set of questions that arose based on our own clinical work caring for this population as well as our own pilot project using blockchain technology; second, was a critical review of the literature described above, noting key research

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gaps; and third, we drew constructs and questions from well-described theoretical frameworks concerning the adoption and uptake of new technologies, including the technology acceptance model (TAM) and the unified theory of acceptance and use of technology (UTAUT).[41,42] Our proposed research agenda poses questions across five key domains: scope and burden of the problem; acceptability and feasibility of the solution; technology and infrastructure requirements; ethical, legal, and regulatory implications; and implementation and effectiveness (Box 1).

Scope and burden of the problem: What is the true scope and burden of the identity management problem among PEH, and what is its quantifiable impact on driving health inequities in this population? Clinicians caring for PEH, and the social workers who often help them track down vital documents, can tell you anecdotally that identity management in this population is a pervasive problem. Our own pilot data show that photo IDs and other vital documents are required to access services at nearly every health care or homeless services agency in our community.[11] We must better quantify this, in larger populations across multiple locales, particularly in terms of the associated costs (both time and money) that lost identity has on PEH and the systems that serve them. The next step will be to quantify the effect this has on access to medical and social services, and how this translates into driving poor health outcomes and/or perpetuating homelessness. This type of research will provide a clear baseline from which to benchmark future progress on blockchain's use in addressing this problem and narrowing health inequities.

Acceptability and feasibility of the solution: What are the perspectives of acceptability and feasibility among PEH, service providers, and policymakers on the use of blockchain technology for identity management? While there is still very much a digital divide between PEH and the general population, there are some preliminary data to suggest that many PEH do have access to mobile phones[43] and that mobile health technology (mHealth) interventions are both acceptable and feasible in this population.[44,45] Our own preliminary work suggests that blockchain technology for identity management among PEH was generally acceptable, although this needs much more thorough vetting at scale.[11] For instance, among passwords, QR codes, and biometrics, we would like to know what is the preferred method of validating identity and what challenges exist with different mobile phone plans and devices. Furthermore, many questions remain about the details of how service providers and policymakers would implement and use such a system. We must determine how much of a technology literacy gap must be overcome by PEH and service providers alike to understand what blockchain technology is, what it can and cannot do, and how it will be applied to solve the identity management problem. Furthermore, the perspective of policymakers and other regulators must be heard and incorporated in order for such a disruptive technology solution to be implemented. This will require both formative research and empirical evaluation of blockchain-based identity management systems.

Technology and Infrastructure Requirements: What technology and technology infrastructure would be needed to implement blockchain solutions for identity management

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Box 1.

USING BLOCKCHAIN TECHNOLOGY TO SOLVE THE PROBLEM OF IDENTITY MANAGEMENT FOR PEOPLE EXPERIENCING HOMELESSNESS: A RESEARCH AGENDA FOR A POTENTIAL "TECHQUITY" SOLUTION

Research Domain	Key Research Question	Examples Of Specific Research Questions
Scope and Burden of the Problem	What is the true scope and burden of the identity management problem among PEH, and what is its quantifiable impact on driving health inequities in this population?	• What is the quantifiable time and financial costs of addressing identity management for both PEH and service providers? • How does lack of identity hinder access to care and contribute to health inequities? • What are current solutions and workarounds to the identity management problem among PEH?
Acceptability and Feasibility of the Solution	What are the perspectives of acceptability and feasibility among PEH, service providers, and policymakers on the use of blockchain technology for identity management?	• Will PEH and service providers alike accept and adopt a blockchain technology solution? • How feas • How do you best explain a new, complex, and disruptive technology to patients, service providers, and policymakers, patients to build trust and facilitate adoption? • How do we establish the initial validity of a user on a blockchain or that they are alive ("liveness test")? Is there a role for biometrics? • How does government oversight work in blockchain systems which are peer to peer networks? • What business and regulatory changes will be needed to fully benefit from the blockchain technology so it is not constrained by outdated and inequitable policies and regulations?

(*continued for p. 269*)

Box 1. (*continued*)

Research Domain	Key Research Question	Examples Of Specific Research Questions
Technology and Infrastructure Requirements	What technology and technology infrastructure would be needed to implement blockchain solutions for identity management among PEH?	• What types of personal mobile devices (i.e., smartphones) are required for the application of this technology and how feasible is it for PEH to have access to this and be able to use it? How will PEH manage passwords and encryption, or will another method like biometrics be used? • What solutions will require public versus private or consortium blockchain networks? • What will be the practical advantages and disadvantages of adopting permissioned versus non-permissioned networks? • What data are stored On-chain versus Off-chain? • How would interoperability and standards established in blockchain be used on different devices and platforms? • Which consensus framework will work best in terms of acceptability, efficiency, and trust—proof of work, proof of stake, proof of capacity, Practical Byzantine Fault Tolerance, or others?

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Box 1. (*continued*)

Research Domain	Key Research Question	Examples Of Specific Research Questions
Ethical, Legal, and Regulatory Implications	What are the legal, regulatory, compliance, and ethical considerations in using blockchain technology for identity management among PEH?	• How would covered entities under HIPAA regulations ensure state and federal law compliance for protected health information of patients? • What will be the legal implications of failure to change information on a blockchain under court orders or to correct medical errors? • What business process changes in organizations will be needed to operate blockchain networks? • Who bears the cost of maintaining blockchain networks for public services and public benefit?
Implementation and Effectiveness	How do we best implement, test, and scale a blockchain technology solution for identity management among PEH and evaluate whether it enhances health equity?	• Can simulated patient data generate evidence to build trust in the system and test it adequately? • How do we integrate blockchain systems with existing health care and social service IT systems? • What will incentivize healthcare providers and other service providers to participate in blockchain research? • What are the best study designs to test the implementation and effectiveness of blockchain technology solutions for identity management among PEH? • Do blockchain-based technology solutions truly advance health equity for PEH, or are there unintended consequences that may perpetuate structural inequities? How do we evaluate this?

among PEH? Blockchain technology is neither homogeneous nor monolithic, and is rapidly evolving. As the number of use cases and industries testing this technology increase, more innovative blockchains are being developed. Concerns about the speed of transactions per second,[46] high energy consumption for achieving consensus in a distributed network,[47] and incentives for operators of the network, have been addressed with variations in the design and consensus mechanisms. The introduction of permissioned blockchains which usually allow a consortium of trusted entities to process transactions may provide some early adoption for businesses, such as health care organizations, that hesitate to put their data on a public ledger. In health care, where providers still resist openly sharing patient information, these technical innovations are important in the adoption of blockchain technology. Hyperledger Indy, for instance, has been developed as an open source permissioned platform by a consortium of some of the large tech companies to help manage distributed identities securely and can facilitate the creation of a potential identity management system.[48,49] For a blockchain technology solution to be effective for identity management among PEH, it must be adopted and implemented by multiple health care and social services providers, interfacing with their own respective information management systems. We must map all the nodes, stakeholders, and technological requirements in a system involved in creating, procuring, reissuing, verifying, and using someone's identity. Fundamentally, we need to understand what technology infrastructure and capabilities must be in place, at both the individual level and the system level, in order for a blockchain-based identity management solution to be adopted and implemented. This may require solving unusual technological infrastructure problems, and uncovering and testing various interoperability issues.

Ethical, legal, and regulatory implications: What are the legal, regulatory, compliance, and ethical considerations in using blockchain technology for identity management among PEH?

Blockchain technology purports to be able to create a secure, private, accessible, portable, and immutable transaction ledger for disparate systems to share protected health information.[50] However, what information is available on the chain and what is linked to off-chain databases will determine the regulatory and legal compliance with existing health information privacy and security requirements.[51] Due to the limited number of studies to evaluate the legal and ethical issues on this topic, there are significant research questions that still remain unanswered for widespread adoption of this technology.[32] Several states have started developing blockchain legislation but they are mostly focused on financial sector applications rather than health care.[52] Multidisciplinary teams must work together to thoroughly vet and address the legal, regulatory, and ethical issues at system, organizational, and individual levels to ensure that the blockchain can meet the security needs of organizations and the privacy needs of PEH.

Implementation and effectiveness: How do we best implement, test, and scale a blockchain technology solution for identity management among PEH and evaluate whether it enhances health equity? Much of the research to answer the four questions above will be formative in nature, from characterizing the baseline scope and burden of the problem, to answering questions of acceptability and feasibility, to understanding the technological

infrastructure required as well as the legal and ethical considerations of implementing such a solution. However, two fundamental questions remain. First, does blockchain technology actually solve the problem of identity management for PEH? Second, does this promote health equity for PEH, by increasing access to services, improving health, and reducing homelessness? Answering these questions will require both efficacy and effectiveness research, using progressively more rigorous study designs including pre-/post-intervention studies and individual or cluster randomized trials.

Conclusion

People experiencing homelessness experience grave health inequities. The identity management problem faced by this population is a major driver of these inequities by fundamentally cutting off their access to necessary health care and social services. Urgent and innovative solutions are needed to address health inequities in this and other vulnerable populations. We propose that blockchain technology has the potential to be an innovative and effective techQuity solution that can solve the identity management problem for PEH and ultimately help reduce the health inequities that disproportionately affect this population.

However, blockchain is still an emerging and relatively untested technology. While it is seeing increased applications across the health care and social sectors, this is still largely uncharted territory, and a myriad of questions remain unanswered. In the case of using blockchain technology for identity management and improving health equity among PEH, we propose a research agenda consisting of five key questions that span defining the baseline problem, addressing acceptability and feasibility, mapping technology infrastructure requirements, understanding legal and ethical considerations, and rigorously testing the effectiveness of such a solution. Without addressing the first four research questions, interventions may be implemented that are not acceptable to PEH or service providers, that do not account for the requisite technology considerations, or that have untoward legal or ethical ramifications. Without rigorously testing the fifth question, we may risk implementing yet another trendy technology that at best falls short of addressing inequities, and at worst continues to perpetuate the systems and structures driving the inequities in the first place. If the research community does not rigorously explore the legal, ethical, operational, and equity implications of this technology, the tech industry may start implementing these solutions independently in an attempt to solve problems that traditional systems have been unable to solve. Therefore, there is urgency to the imperative that researchers get involved early to ensure that the implementation of this technology does not further isolate, stigmatize, and disempower those who are already experiencing inequities in our society. In partnership with PEH and other key stakeholders, we believe this research agenda has the potential to chart the path for blockchain technology to truly become a techQuity solution by solving the identity management problem for PEH.

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