

Research Article

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Older LGBTQ+ and blockchain in healthcare: A value sensitive design perspective

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Abstract: Most algorithms deployed in healthcare do not consider gender and sex despite the effect they have on individuals' health differences. Missing these dimensions in healthcare information systems is a point of concern, as neglecting these aspects will inevitably perpetuate existing biases, produce far from optimal results, and may generate diagnosis errors. An often-overlooked community with distinct care values and needs is LGBTQ+ older adults, who have traditionally been under-surveyed in healthcare and technology design. This article investigates the implications of missing gender and sex considerations in distributed ledger technologies for LGBTQ+ older adults. By using the value sensitive design (VSD) methodology, our contribution shows that many value meanings dear to marginalized communities are not considered in the design of the blockchain, such as LGBTQ+ older adults' interpretations of trust, privacy, and security. By highlighting the LGBTQ+ older population values, our contribution alerts us to the potential discriminatory implications of these technologies, which do not consider the gender and sex differences of marginalized, silent populations. Focusing on one community throughout, we emphasize the need for a holistic, VSD approach for the development of ledger technologies for healthcare, including the values of everyone within the healthcare ecosystem.

Keywords: blockchain, value sensitive design, aged care, LGBTQ+ older adults, diversity

1 Introduction

Blockchain in healthcare, including aged care, is presented as an enabling technology used to create greater interoperability between existing information systems (IS), bringing benefits such as transparency, data accuracy, traceability, and reliability. By adopting blockchain in healthcare, some argue that it will increase the trust (or reliability), security, and privacy of health information [1,2]. Blockchain in care domains is a contentious topic, while much work is being done on realizing blockchain-enabled health information systems (BCHIS), many others doubt the benefits. Indeed, as technology is not value-neutral [3], technologies such as distributed ledger technologies have positive and negative impacts on the values within and arising from the ecosystem where these technologies are implemented [4].

The advent of BCHIS has many positive applications across healthcare, including improved electronic health record (EHR) management, health data analytics, and cross-institution data sharing. However, the distributed invention reduced everything to bits of data, leaving aside other fundamental aspects inherent to technological ecosystems, including human values. Indeed, the introduction of ledger technologies, artificial intelligence (AI), and robotics in healthcare is expected to increase productivity and resource efficiency, as has happened in the industrial and retail sectors [5]. The reality, however, is that these technologies have a significant impact on human values that should be taken into account beforehand, not as an afterthought [3].

The interplay between values, aged care, and distributed ledger technologies has not received much attention, unlike the primary focus has been on cryptocurrencies, smart contracts, or smart properties [6]. The *lex cryptographica* and the legal analysis have also revolved around smart contracts, intellectual property, and data protection [7], working on the impacts of such technologies on the law. There is increasing use of distributed ledger technologies for healthcare, and the number of publications is growing [8]. Although healthcare is a sensitive domain of application with very distinct values, a thorough analysis considering human values and value meanings is lacking.

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We address this gap by investigating the impact of using and developing distributed ledger technologies (or blockchain) in healthcare for vulnerable populations. We focus on a specific community in care with its own set of value meanings: LGBTQ+ older adults.¹ This community suffers from extreme loneliness due to historical discrimination, lack of social acceptance, isolation, and underestimated feelings [9]. Each cultural group has distinct value priorities, meanings, conceptualizations, and definitions [10]. LGBTQ+ older adults are no different [11]. Applying the value sensitive design (VSD) methodology, our contribution shows that many values dear to marginalized communities are not considered by the technical blockchain literature. Moreover, by highlighting this community's under-surveyed values, our contribution shows the potential discriminatory implications of these technologies, which do not consider silent aging populations [12]. By considering the values of a particular group, we emphasize the importance of recognizing the diversity of values among the aging population to avoid system bias and acknowledge the required cultural sensitivity in care [13].

After a brief introduction, in the second section, we describe what distributed ledger technologies are, which healthcare applications exist, and how systems may inadvertently violate privacy, reinforce social prejudices, and discriminate against different users. In the third section, we introduce the lens through which we address this topic, i.e., the VSD method, followed by an introduction to the older LGBTQ+ community case study. We finish the article by conceptualizing the values of this community concerning blockchain to stress the importance of accounting for the diversity of values in healthcare technology.

2 Literature review

2.1 The blockchain

In 2008, Satoshi Nakamoto introduced *blockchain*. Blockchain was not a major technological innovation, but incremental development of existing technologies such as private-public key encryption and peer-to-peer networks developed in the 1970s, consensus mechanisms, and decentralized, distributed data storage developed later [14]. Blockchain is an open, public ledger stored on many decentralized nodes to support

intermediary-free transactions called decentralized, trustless peer-to-peer transactions [8]. That is, participants in the network need not trust each other [7]. Iansiti and Lakhani [15] defined blockchain as “an open, distributed ledger that can record transactions between two parties efficiently and in a verifiable and permanent way,” while Bacon et al. [7] referred to the blockchain as “a specific type of database that uses certain cryptographic functions to achieve the requirements of data integrity and identity authentication.” On its side, the National Institute of Standards and Technology defines it as follows:

“Blockchains are distributed digital ledgers of cryptographically signed transactions that are grouped into blocks. Each block is cryptographically linked to the previous one (making it tamper evident) after validation and undergoing a consensus decision. As new blocks are added, older blocks become more difficult to modify (creating tamper resistance). New blocks are replicated across copies of the ledger within the network, and any conflicts are resolved automatically using established rules” [16].

Distributed ledger technologies have several advantages over existing systems, such as traditional distributed database management systems like structured query language-based systems and non-relational systems [17] and traditional ledger-based system architectures which relied on a central or trusted third-party ledger [18]. It allows data integrity by creating persistent records of relevant transactions and identity authentication without involving intermediaries, i.e., it eliminates the middleman [7]. Before blockchain, it was impossible to organize individual activities over the Internet without a centralized body and ensure no interference. It is considered a tamper-proof system unless the controlling parties decide to alter the history of the blockchain [19], supported by an append-only data structure and a data verification feature via consensus protocols. These protocols remove the risk of duplicate entry or fraud [8]. It also heavily relies on cryptography to secure the data ledgers with both the current and its adjacent completed block involved in the cryptography process [8]. Registered transactions cannot be altered unless the whole chain of actual recorded transactions is changed with mutual consensus, ensuring that the data stored on the blockchain are reliable and not edited without traceability. In this way, blockchain “provides a way for people to agree on a particular state of affairs and record that agreement in a secure and verifiable manner” [14].

Additionally, with blockchain, all transactions are recorded in chronological order, time-stamped, and visible to everyone on the blockchain, making it transparent. Users can remain anonymous as transactions occur between encrypted alphanumeric addresses. Users can programmatically set up algorithms

¹ Lesbian-Gay-Bisexual-Transgender-Intersex-Queer+others, aged 65 years and above.

to trigger transactions [20]. The origin of any ledger can be backtracked along the chain. The ledger is distributed across every single node in the blockchain, making it highly distributed. All transactions stored in the blocks are contained in the chain, making it decentralized and guaranteeing data recovery. These features make blockchain technology extremely useful, with salient advantages of transparency, decentralization, and security in many sectors, including government [21] and business [22]. Companies have been using blockchain to track items through complex supply chains for a while [15], and its adoption has been critical for meeting the citizens' demands. Schuetz and Venkatesh [23] showed, for instance, that by increasing financial inclusion in rural areas, blockchain technology has the potential to connect rural populations to supply chains. In the energy sector, distributed ledger technologies may advance energy practices and processes' efficiency, advance decentralized generation, and allow peer-to-peer energy trading [24].

Although the recent hype of blockchain and its transition to AI, the research on blockchain adoption is still in its infancy. Until now, the adoption of such complex technology research highlighted professionals' expectations [25], but it still lacks a greater understanding of how particular populations, such as older adults, would see the benefits of applying such a technology. Furthermore, there is a lack of literature on the challenges these technologies pose to users and with which remedies they are empowered to mitigate those risks.

2.2 Healthcare and blockchain

Medicine falls behind other sectors in embracing new technologies, as it is a highly complex, sensitive, and regulated sector [26]. Together with the continuous shortage in healthcare budgets, the difficult choice in expenditure allocation, and the potential adverse effects on users, the adoption of healthcare technologies is not straightforward. Thus, there are no significant surveys investigating distributed ledger technology applications in healthcare. However, the literature stresses that they could address urging issues in healthcare, such as fragmented records and hard access to patient health information, thanks to fundamental features like immutability, decentralization, and transparency [27]. There are numerous systems applying blockchain in healthcare found in the literature. Some examples include mobile healthcare applications with cloud storage [2]; blockchain-enabled diagnosis and treatment systems [28]; cloud-based health resource sharing for diagnosis [29]; EHR management [30]; drug supply chain governance [31]; and monitoring of data across multisite clinical trials [32]. The literature also

reports various possible benefits provided by introducing blockchain in healthcare, including convenient data sharing [29], increased data security and privacy [2,32], greater privacy [30], more transparency [31], data ownership and control [33], interoperability [28], and advanced data traceability [34]. Table 1 illustrates some of the most common applications of blockchain in healthcare and their benefits.

These systems and their potential benefits could be classified in several categories, including (1) data management applications to unify and more effectively handle patient details (e.g., integration and encryption of digital assets to ensure data reliability and protection, as well as patient identity and confidentiality, patients' health records, and cloud healthcare data storage) and to facilitate data sharing between healthcare institutions, (2) supply chain management, including drugs, vaccine, and pharmaceutical supply chain, (3) internet of medical things, (4) biomedical research and education, i.e., to merge data for research purposes and minimize academic fraud, (5) health data analytics, including remote patient monitoring, supervision of drug intake, (6) health insurance claims, reporting, and fraudulent billing protection, and (7) health clinical trial analytics [1,8,34,45,47,48].

One of the most promising applications of distributed ledger technologies in healthcare is EHR. An EHR is a collection of patient data "designed to allow patient medical history to move with the patient or be made available to multiple healthcare providers" [47]. EHRs allow the electronic exchange of health information with different providers to improve patients' quality of care in a meaningful way. EHRs improve clinical decision-making, reduce duplication of diagnostic testing, better medication management, increase the adoption of screening programs, and improve coordination among medical professionals [33]. More broadly, other potential benefits of blockchain healthcare technology could also be seen in patient monitoring [35]. For example, Rupasinghe et al. [49] present a conceptual BCHIS that manages and analyzes EHRs to identify older adults in care who are at higher risk of falling. As another example, Uddin et al. [50] designed an end-to-end eHealthcare framework to facilitate professional data sharing and safeguarding EHR privacy via blockchain. An example in the plain language of blockchain-enabled EHRs is as follows:

"When new healthcare data for an aged care patient is created, that data is first encrypted and then a new block containing that data is instantiated and distributed to all peers in the patient network. If a majority of the peers have approved the new block, then the IS will append it to the chain; otherwise, the block will be rejected from the main chain. Once in the chain, the block cannot be modified without modifying all subsequent blocks and thus data modification is easily detected. Aged care patients can link their

Table 1: Examples of blockchain applications and related benefits in healthcare

Benefit	System	Literature	Explanation
Convenient health data sharing	Mobile healthcare applications with cloud storage	[2]	Health data can be uploaded to the blockchain and shared with healthcare providers from a mobile device
	Cloud health resource sharing for breast tumour diagnosis	[29]	Comfortable and convenient health data sharing using smart contracts
	Automated remote patient monitoring	[35]	
	User interaction data gathering via smartphones during dyslexia testing	[36]	
	Blockchain-enabled parallel healthcare systems for gout diagnosis and treatment	[28]	
	Medical image sharing	[37]	Using the blockchain to store medical images and user access permissions
Data security	Mobile healthcare applications with cloud storage	[2]	Decentralized, private cloud storage and sharing for health data
	Cloud health resource sharing for breast tumor diagnosis	[29]	Trusted entities on the blockchain allow secure access to external data
	EHR management	[30]	Anti-tampering of medical records with smart contracts
		[38]	Blind signatures to reinforce tampering protection
		[39]	The unforgeability of data on the blockchain for security
		[40]	Advanced cryptographic techniques within the blockchain
	Mobile medical record management	[41]	Utilizing the secure multi-party computation cryptography enables secure data sharing
	Blockchain-enabled parallel healthcare systems for gout diagnosis and treatment	[28]	Secure health data sharing on the blockchain
	Automated remote patient monitoring	[35]	
	Clinical trial consent collection and storage	[34]	
	Healthcare predictive modeling and machine learning	[42]	Security enhanced by avoiding single-point-of-failure on the blockchain
Data privacy	Health monitoring with Internet-of-Things	[43]	Avoiding bottleneck attacks and data security risks common on centralized systems
	Drug supply chain governance	[31]	Using blockchain in drug supply governance provides a secure and transparent supply chain
	Mobile healthcare applications with cloud storage	[2]	The reliance on pseudoanonymity and public key infrastructure keeps user privacy
	EHR management	[30,39,40,44]	User control over health data access and exchange ensures privacy
	Mobile medical record management	[41]	
	Managing and monitoring data in multi-site clinical trials	[32]	Ensuring data privacy across multiple clinical trial sites without affecting transaction efficiency
	Blockchain-enabled parallel healthcare systems for gout diagnosis and treatment	[28]	Sharing patient health information and maintaining privacy through a permissioned, private blockchain
	Healthcare predictive modelling and machine learning	[42]	Only permissioned institutions may access patient health information on a private blockchain network
	Mobile healthcare applications with cloud storage	[2]	Permanently retrievable proof of data integrity and validation from the blockchain network
	EHR management	[30]	A cryptographic hash of stored medical records
		[38]	Blind signatures confirm the identities of parties
Trust or data reliability integrity		[39]	Using multiple authorities to produce blind signatures for confirming the identities of parties
	Clinical trial data sharing	[45]	Smart contracts improve scientific credibility of findings from clinical trials by ensuring data integrity

(Continued)

Table 1: Continued

Benefit	System	Literature	Explanation
Data ownership and control	Blockchain-enabled parallel healthcare systems for gout diagnosis and treatment	[28]	User-controlled personal medical records and traceable record changes on the blockchain ensures data integrity
	Clinical trial consent collection and storage	[34]	Transparent and immutable consent protocols viewable by patients inspires trust in clinical trials
	Mobile healthcare applications with cloud storage	[2]	Users retain ownership and control of health data, they can grant, deny, or revoke access from other parties
	EHR management	[30,33,40,44,46]	As interoperability becomes more patient-centric, blockchain technology may give patients greater control over their data and facilitate information exchange
Data traceability	Mobile medical record management	[41]	Users control their medical records on a blockchain storage system accessible by a smartphone
	Mobile healthcare applications with cloud storage	[2]	Data access is accountable and traceable. Malicious entities can be identified if a leak occurs
	EHR management	[30]	State transitions can be tracked with smart contracts (e.g. a change in viewing rights)
	Blockchain-enabled parallel healthcare systems for gout diagnosis and treatment	[28]	Traceable personal medical record changes on the blockchain
Greater transparency	Healthcare predictive modeling and machine learning	[42]	Immutable audit trails
	Health monitoring with Internet-of-Things	[43]	All transactions stored on a ledger and time stamped
	Drug supply chain governance	[31]	
	Clinical trial consent collection and storage	[34]	
	Health monitoring with Internet-of-Things	[43]	Cross-institutional transparent data sharing and security
	Clinical trial consent collection and storage	[34]	Consent protocols and revisions for clinical trials are transparent for patients
	Drug supply chain governance	[31]	Transparent drug transaction data on the blockchain to show the flow of drugs
Interoperability in healthcare	EHR management	[33,40]	Facilitating the exchange of health-related information throughout different parties and different systems
	Blockchain-enabled parallel healthcare systems for gout diagnosis and treatment	[28]	Unfragmented, yet shareable, patient health information using blockchain systems

identity to blockchain data through a private key and share it with other care organizations. This tamper-proof care data is immediately visible and retrievable to all connected organizations, making blockchain the single source of accurate, trustworthy information” [47].

The current state of aged care EHRs is disjointed due to a lack of greater interoperability between providers and hospital IS, especially concerning unified data, common architectures, and privacy and transparency concerns [51]. The adoption of EHRs by healthcare entities is varied worldwide. Factors affecting adoption include an institution’s technological infrastructure [52]. Moreover, the push for personal EHRs, for which patients are more involved in health data collection (e.g., through smartphones or wearable devices)

and data management, introduces further security and privacy challenges [33]. As a solution to the current problems with EHRs and similar challenges with other healthcare IS, blockchain technology seeks to offer a transparent and tamper-proof platform to support the integration of care-related information across a range of care and cure applications and stakeholders. The integration of blockchain technology into healthcare may improve the reliability of health data, making it resistant to tampering and revision while also enabling better accessibility and data transparency [48].

Although BCHIS may bring about incredible progress in healthcare delivery, more research and co-design are needed to ensure these systems account for the diversity of values found in healthcare and avoid bias. Gender and

sex considerations in healthcare are crucial because they affect individuals' health differences, yet most algorithms deployed in the healthcare context do not consider these aspects. Missing these kinds of dimensions in healthcare IS raises concern, as neglecting these aspects risks potential discrimination [53]. Questions about the consequences of missing the gender and sex dimensions in algorithms that support decision-making processes are nevertheless particularly poorly understood and often underestimated [54,55]. Still, technology is not value-neutral and can have adverse consequences if values are not considered. This is particularly salient in healthcare because it is a sensitive domain of application with very distinct values that, if missed, can have disastrous consequences for the safety of the patients.

3 Methods

3.1 VSD

We contribute to the literature by reflecting on the interplay between values, aged care, and distributed ledger technologies through a VSD approach. VSD is a methodology used to investigate values relating to the technological ecosystem and design systems that account for user values [3]. In VSD, values refer to “what is important to people in their lives, with a focus on ethics and morality” [3]. VSD seeks to empower human values in the design of technology. Today, we can see blockchain as a technology that supports human beings in a highly connected digital world as moral and prosocial persons to give and involve reliable signals of trustworthiness. In the design of new BCHIS, there is a strong need for a comprehensive theoretical and methodological framework to deal with the value dimensions of its design.

VSD considers human values during the design of new IS, or the evaluation of an old one, to resolve value conflicts and promote positive value impacts. Friedman and Hendry [3] explain the three iterative investigations used in VSD as follows.

1. *Conceptual investigations* define the IS users and other stakeholders, identify the values of all stakeholders who interact with the IS and conceptually examine how the IS design will positively and negatively impact those values.
2. An *empirical investigation* aims to create further knowledge about those values concerning the IS through empirical means.
3. The *technical investigation* involves designing a new IS to support values as they have been understood empirically, or analyzing how users interact with an existing IS.

Like other healthcare technologies, BCHIS ought to be designed for stakeholders' values, promote positive value impacts, and mitigate adverse effects. To highlight the required value and cultural sensitivity of BCHIS to avoid the replication of bias, considering the values of a specific community, in this case, the older LGBTQ+ community is crucial. In the following sections, we conduct a conceptual investigation of the values that LGBTQ+ older adults have at stake within BCHIS.

3.2 Case study: LGBTQ+ older adults

Each community has a value framework of value priorities, meanings, and orientations [10], and LGBTQ+ older adults are no different [11]. Tenenbaum [56] describes the older LGBTQ+ community as having distinct values, concerns, needs, and critical and experiential interests in aged care. In the search for cultural sensitivity, many LGBTQ+ persons seek out LGBTQ-friendly health services and professionals who are sensitive to their needs and values [57]. The difficulty of finding an LGBTQ-friendly doctor leads to this group being “more likely to delay or avoid necessary medical care compared with heterosexuals” (29% versus 17%, respectively) [58].

The older LGBTQ+ community's values are under-surveyed [59], let alone their values concerning technology generally and distributed ledger healthcare technologies specifically. This lack of understanding challenges the recognition of the effects and impacts on this community, hindering these systems' potential benefits. This community's values are worthwhile investigating in BCHIS design and development to ensure they avoid discrimination and the exacerbation of existing bias against the queer community [12,60]. The modicum of the literature suggests that LGBTQ+ older adults prioritize values of acceptance, privacy, and personhood [56]; inclusive language and disclosing gender identity or sexual orientation [61]; and autonomy and empowerment [62]. LGBTQ+ older adults also have different value meanings. For example, the value of family is often interpreted as a “chosen family” consisting of close friends, rather than relatives [63], and intersex older adults define the value of “non-judgmental care” concerning their intersex status, as it impacts their physical, hormonal, or genetic differences [64].

4 A VSD look at blockchain in healthcare

Following VSD, evaluating whether a technology meets the values of a certain group requires looking at value

meanings and who values them. This article examines the use of blockchain in healthcare with the values of LGBTQ+ older adults in mind. The following sections draw focus to three values in particular: trust, security, and privacy. First, the emergence of these and other values in the use of blockchain in healthcare is presented. Then, the salience of those values and meanings is expanded upon. Last, focusing on the value of trust, security, and privacy, the meanings that LGBTQ+ older adults give to these values are explored concerning blockchain in healthcare. This last section shows how BCHIS could bring about value impacts for this community if BCHIS are not realized to account for the diversity of values found in healthcare.

4.1 Key values in blockchain for healthcare

In the literature, blockchain is primarily promoted as supporting the trustworthiness, integrity, and reliability of data (hereafter referred to collectively as trust), security, privacy, transparency, interoperability, and user control [1,2]. In addition to these being potential benefits of blockchain, several are also human values. That is, blockchain in healthcare evokes several values, including (1) patient trust in the integrity and reliability of her health data, (2) security of patient health data, and (3) privacy of patient health data.

In a survey measuring trust in health information sources, Hesse et al. [65] found that respondents expressed a high level of trust for information provided by physicians, higher than that offered by the Internet, television, radio, family or friends, and other media. As such, the value of *trust* might relate to health information sources. Alternatively, it could relate to trust in care professionals. According to the care ethics tradition, mutual trust between patients and their caregivers is essential to good care [66]. In care ethics, values such as trust exist within the caring relationship between patient and caregiver, not necessarily in the health information they provide, as this is implicit in the trusted relationship. Moreover, implied in the trusted relationship is the assurance of security and privacy.

Security in healthcare can also be defined in different ways. Haas et al. [67] draw a connection between security and access to information, suggesting that enabling “access to an increased number of users poses threats to security and privacy.” In this sense, security restricts unnecessary access to information and guarantees trustworthiness. Security also relates to privacy. Without protecting health information, a patient’s privacy is vulnerable [68]. In Europe, the General Data Protection Regulation establishes binding legal requirements to enforce the protection of these values.

In a review of the state of information security and privacy in healthcare, privacy is described as “a key governing principle of the patient-physician relationship” [69]. Akin to security, privacy also refers to protecting personal data, which is governed by legislation and is geared toward giving back control to users and the possibility to rectify, oppose, and cancel the processing of such data. In their proposed framework for ensuring the privacy of EHRs, Haas et al. [67] present privacy as a driving need to securely guarantee the “controlled disclosure of personal data to third parties.”

4.2 Additional values in healthcare and technology design

Examining blockchain in healthcare through a VSD lens, there exist other values that current blockchain technology does not make justice, although it may impact them. According to Friedman et al. [70], there are some core values involved in any system design. Table 2 lists and defines those values.

The initial conceptual investigation above shows the emergence of the most salient values implicated in blockchain in healthcare – trust, security, and privacy – however, it lacks a practical examination of the diversity of values in this environment. Whereas *security* is interpreted by the technical community as an essential value, from the user’s perspective and the healthcare system’s goals, other values are also deemed necessary. Ensuring values are of paramount importance in healthcare. To follow is a non-comprehensive exploration of the aforementioned core values in relation to healthcare technology, including blockchain.

1. *Discrimination and bias*: Different cultures have distinct value sets, comprising different value priorities, meanings, conceptualizations, and definitions [10]. Culture shapes a person’s value system; one of the most significant influences on an individual’s values is each person’s cultural background [71,72]. Cultural knowledge, i.e., understanding cultural values, is key to cultural competence in care, including technology-driven care [73].
2. *Consent and autonomy*: Although distributed ledger technologies provide a “shared, immutable, and transparent audit trail for accessing data” [49], this data is used on many occasions as a basis for predictive analysis, which has several associated ethical, legal, and societal concerns [74]. Predictive analytics refers to the use of statistical models to determine future performance based on current and historical data and raise questions in the context

Table 2: List of human values often implicated in system design [70]

Human value	Definition
Human welfare	People's physical, material, and psychological well-being
Ownership and property	The right to possess an object (or information), use it, manage it, derive income from it, and bequeath it
Privacy	A claim, an entitlement, or a right of an individual to determine what information about himself or herself can be communicated to others
Freedom from bias	Systematic unfairness perpetrated on individuals or groups, including preexisting social bias, technical bias, and emergent social bias
Universal usability	Making all people successful users of information technology
Trust	Expectations that exist between people who can experience goodwill, extend goodwill toward others, feel vulnerable, and experience betrayal
Autonomy	People's ability to decide, plan, and act in ways that they believe will help them to achieve their goals
Informed consent	Garnering people's agreement, encompassing criteria of disclosure and comprehension (for "informed") and voluntariness, competence, and agreement (for "consent")
Accountability	Refers to the properties that ensure that the actions of a person, people, or institution may be traced uniquely to the person, people, or institution
Courtesy	Refers to treating people with politeness and consideration
Identity	Refers to people's understanding of who they are over time, embracing both continuity and discontinuity over time
Calmness	Refers to a peaceful and composed psychological state
Environmental sustainability	Refers to sustaining ecosystems such that they meet the needs of the present without compromising future generations

of healthcare. These questions range from how patients gave meaningful consent. What if harm could have been averted if physicians would study their patients more carefully instead of relying on predictive models [75]? The legal research is also rich in pointing out the risks to privacy and data protection in this regard, even in connection to the fairness, accountability, and transparency of the models, for inferences and decisions made upon predictive algorithmic decision-making [76]. Making information open and transparent requires the affected individuals to understand and assess the risks of predictive analytics and automated decision-making systems, allowing them to challenge decisions concerning them [77].

3. The fact that distributed ledgers eradicate the middleman also blurs the *accountability* linked to them. The implementation of blockchain must ensure that a group of persons, institutions, or legal entities are accountable for their actions and assume responsibility.
4. *Courtesy*: In healthcare, good care practice requires cultural competence, value sensitivity, and person-centeredness [13,78]. Since technology is not value-neutral [3], healthcare technologies also need to demonstrate value sensitivity and cultural competence. Good cultural competence in the provision of care is value-based [79], and thus, cultural competence in healthcare technologies could be achieved with a VSD approach [80,81].
5. *Identity*: The value of identity is complicated. One's identity is respected in that the person retains personal data

ownership using blockchain. However, at the same time, parties are pseudonymous, so one's identity is partially lost on the blockchain.

5 LGBTQ+ older adult values and blockchain in healthcare: Overlooked interpretations of trust, security, and privacy

In this section, we reflect on how blockchain in healthcare conceptually impacts the values of the older LGBTQ+ community. Here, we focus on the values of trust, security, and privacy.

In an LGBTQ+ aged care study, Willis et al. [82] identified several critical interpretations of privacy, finding that this community values private time with partners and friends, having partners and friends feel welcome, and acknowledging younger–older LGBTQ+ partnerships. These interpretations of privacy are particularly important given the prevalence of chosen families and the lack of education among health professionals on the importance of nonrelatives as a source of support for the older LGBTQ+ community [63], which could result in breaches of privacy with their partners and friends in a secure, safe space. The lack

of education on these topics raises the additional concern of trust in health professionals; without LGBTQ-friendly service provision, a level of trust is lost.

LGBTQ+ older adults may interpret the value of security as that supported by safe spaces. These environments enable LGBTQ+ older adults to safely disclose their status to like-minded people [83]. Healthcare environments that display symbols of LGBTQ+ acceptance, such as rainbow flags and pictures of same-sex couples, help provide a sense of feeling safe [82]. More on the value of security for the older LGBTQ+ community, Crameri et al. [84] highlight the importance of being aware of the histories of older LGBTQ+ people and being educated in this area to provide security for those in care.

Reflecting on the older LGBTQ+ community's interpretation of security as safe spaces, examine the following potential negative value impact if this conceptualization is not understood in the realization of BCHIS. Consider a gay man living with dementia who has challenges remembering he is in a same-sex partnership. When this person is made aware that he has a partner, he gets confused and feels uncomfortable being reminded of persisting sexual identity issues emerging from historical discrimination. Now consider this person's partner who takes them to doctor visits. They prefer that health professionals do not greet them as partners because it will make their partner living with dementia upset. The value of security for these LGBTQ+ older adults is interpreted as the safe space that their regular doctor's office creates in this way. Concerning the effective interoperability of blockchain data, if this same-sex couple visits a new healthcare facility made aware that a gay couple is visiting due to the shared health information and, thus, they greet them as such, their value of security is negatively impacted.

On the other hand, consider the positive value impact of accounting the security as conceptualized as "safely disclosing LGBTQ+ status and feeling safe." Regarding the blockchain-enabled management of EHRs, LGBTQ+ older adults need only disclose their gender or sexuality once, if it is relevant to their health assessment. EHRs will be retained and not misplaced on the decentralized blockchain, satisfying the value of security, whereas health records kept on paper can be lost and an LGBTQ+ older adult may need to disclose their status again, potentially making them feel unsafe.

Reflecting on historical discrimination and the importance of ensuring that LGBTQ+ status remains private for those who value it [84], consider the negative value impact of failing to interpret privacy as "private LGBTQ+ status" in BCHIS design. Due to historical discrimination, the LGBTQ+ community highly values privacy related to gender or

sexuality for fear of social stigma. Health information stored with blockchain is irreversible without consensus. This irreversibility creates a problem for those LGBTQ+ older adults who do not want their gender or sexuality to be shared with care services. Moreover, this problem might be exacerbated if an LGBTQ+ older adult changes their sexuality or gender as they age and wants to erase previous identifiers on EHRs.

A systematic review of the perceptions of older LGBTQ+ people regarding sexuality in residential healthcare by Mahieu et al. [85] identified that a lack of privacy is of significant concern. Mahieu et al. [85] raise the issue that a perceived lack of privacy in residential care facilities would prevent socialization and sexual expression. Similar problems with trust are raised here. Without appropriate LGBTQ-friendly measures being put in place by health services, a lack of trust arises. Villar et al. [86] similarly affirm the value of private time with partners and friends and safe spaces to enable a level of security for LGBTQ+ older adults, stating that "measures designed to increase residents' opportunities for privacy and intimacy, in terms of both time and space, seem necessary." The authors highlight that private spaces, control, trust, personal LGBTQ+ relationships, and safe spaces are essential values for the older LGBTQ+ community. Consider the potential positive value impact of ensuring that the value of privacy is conceptualized as "private LGBTQ+ relationships" in creating BCHIS. For some LGBTQ+ older adults, intimate relationships are valuable. If BCHIS provide a more reliable private communication network than existing IS, then LGBTQ+ older adults wishing to hide their relationship out of fear of stigma might be put at ease by higher levels of security and privacy of health information.

Much of the literature about what privacy and trust mean to the older LGBTQ+ community concerns relationships, intimacy, and sexual expression. Yet, there are other needs relating to trust and privacy that are distinct for LGBTQ older adults. Ansara [87] notes that service providers ought to inspire trust in service provision by creating "a privacy policy for people who have previously received services in another gender." That is, the value of preferred gender affirmation is an essential interpretation for both privacy and trust in this community. Reflecting on a potentially negative value impact, consider the failure to understand that the older LGBTQ+ community interprets trust as "confidence in LGBTQ-friendly physicians and preferred gender affirmation." Trust in an LGBTQ-friendly physician is essential for LGBTQ+ older adults to ensure that one's gender or sexuality is respected when a health assessment is made. For instance, an older transman might interpret trust as that which exists in the private, unspoken

agreement with their doctor that they will acknowledge their biological gender in their health assessments but will always address them by their preferred gender. This trust extends to the assurance that the doctor will not share this information with others, including other health professionals or care providers. Using blockchain to efficiently share health information might negatively impact this LGBTQ+ older adult's value of trust as all networked care services will know their transgender status even though they might not need to know.

Furthermore, LGBTQ+ persons value a level of trust in LGBTQ-friendly healthcare professionals who can accurately report on LGBTQ-related health information [57,58], such as one's preferred gender. Consider the positive value impacts for LGBTQ+ older adults by ensuring that trust is effectively interpreted as "confidence in the accuracy of LGBTQ-related health information" in BCHIS design. Consider an LGBTQ+ older adult with a history of having doctors who fail to account for their distinct LGBTQ+ needs when making medical assessments. If blockchain does provide a platform for maintaining more accurate health information than alternate IS, then this person's value of trust will be promoted.

Current blockchain technology does not consider these values and value meanings. Presented often as value-neutral, blockchain is usually praised for enabling a more transparent, open, and power-distributed internet. Still, it has the potential to replicate existing biases against specific communities.

6 Discussion

The purpose of this study is to address the implications of the use and development of blockchain, for specific vulnerable populations, such as older adults, persons with disabilities, or children, in healthcare settings without integrating human values, ethical considerations, or legal aspects. Here, we focus on the older LGBTQ+ community to emphasize the need to account for the diversity of values implicated in the design of BCHIS, which include different sets of value meanings. Accounting for diversity may avoid replicating biases into systems, increasing trust in the system, and ensuring that other values connected to privacy and security are ensured. Applying VSD, this article shows the different values that need to be taken into account for the deployment of ledger technologies for healthcare, as these can have positive and negative impacts on the values of aging populations. Mainly, trust, security, and privacy layers are crucial at the personal and community levels.

Accounting for the diversity of values found in care should translate into technology, including distributed ledger technologies. However, this change, although particularly salient in sensitive sectors such as healthcare, the introduction of blockchain in this space requires a "radical rethink and significant investment in the entire ecosystem" [47]. Moreover, from the same blockchain, new values arise, and further impacts will need to be identified, explored, and resolved [4]. Resolved, in this sense, means that positive impacts should be encouraged, whereas negative impacts should be reconciled.

Discrimination and bias are inherent problems in many systems, including blockchain, AI, and robots [88]. Many biases in the offline world may propagate to systems that heavily rely on human input if not addressed. For example, gender classification systems, often used by social media platforms to infer the gender of users for advertising and personalization purposes, are trained on real-world datasets and are often biased because the data used to train them is biased, containing namely racial and gender stereotypes [54,89–91]. Zhao et al. [92] found that the datasets *imSitu* and *MS-COCO* used to train gender classification systems are significantly gender-biased and that "models trained to perform prediction on these datasets amplify the existing gender bias when evaluated on development data." For example, the verb "cooking" is heavily biased toward females in a system trained using the *imSitu* dataset, amplifying existing gender biases [92]. The same gender biases have been shown in natural language processing [93], another method used to support gender classification systems [94].

Another example of system bias replication is "statistical discrimination," which refers to making (un)educated guesses about an unobservable candidate characteristic, such as which applicants perform well as employees. This has been proven quite problematic from the Amazon-hiring algorithm failure, where women candidates were more often devalued than men, as the company traditionally had hired few women [95]. The algorithm concluded that being a woman was an undesirable characteristic for recruitment purposes. Thus, having a curriculum vitae with the entry of being president of the "women's chess club" was seen as a red flag, giving the candidate more negative scores, while just generally being a member of a "chess club" was seen as positive.

Understanding the impact that algorithms have on different communities and values is challenging, as they may appear much later, usually after being widely used [96], but undoubtedly necessary to make a fairer society. It is often the case that those communities mostly remain invisible, silent, powerless, and unable to understand how these technologies may affect them [12].

7 Conclusions

Our contribution shows that while blockchain developers usually consider the values of trust, security, and privacy when designing blockchain, they do not usually acknowledge and integrate other human values such as human welfare, ownership and property, privacy, freedom from bias, universal usability, trust, autonomy, informed consent, accountability, courtesy, identity, calmness, and environmental sustainability. In this article, we also stress that these are not *mere* values to be integrated into the design of a system. Values need to be juxtaposed to the meaning specific communities ascribe to those values. In the article, we refer to the LGBTQ+ literature to reflect on how LGBTQ+ older adults interpret these values distinctly.

By highlighting the under-surveyed values of LGBTQ+ older adults, our contribution alerts us to the potential discriminatory implications of these technologies, which do not consider vulnerable, silent populations. As such, distributed ledger technology developers should reflect on the effects of their work on efficiency, privacy, and security and user values and the importance of acting upon and integrating those reflections timely and adequately in the development of a new technology that aligns with *Responsible Innovation* [97]. Focusing on one community throughout, the older LGBTQ+ community, we emphasize the need for a holistic, VSD approach for the development of ledger technologies for healthcare, which include the values of everyone within the healthcare ecosystem.

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