(1) Title

Patient Perceptions of Blockchain-Based Personal Health Records: Qualitative Insights on Security, Trust, and Data Control

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(3) Abstract

Blockchain technology is increasingly proposed as a foundation for next-generation personal health record (PHR) systems, yet little is known about how patients themselves perceive its value. This qualitative phenomenological study explored patient perspectives on blockchain-based PHRs, with a focus on perceived security, efficiency, and patient-centeredness. Drawing on the Technology Acceptance Model (TAM), the Theory of Planned Behavior (TPB), and Diffusion of Innovations (DoI), semi-structured interviews were conducted with patients who had experience using PHRs and familiarity with blockchain concepts. Data were analyzed using interpretative phenomenological analysis and supported by QDA Miner Lite for systematic coding and theme development. Participants viewed blockchain as a promising approach to improving data security, integrity, and trusted access to health information, while also enabling more timely, interoperable data sharing across providers. At the same time, concerns surfaced around technical complexity, private key management, and digital literacy, particularly for non-technical users. Interviews were conducted with 13 participants, and data were analyzed. The findings highlight the need to design blockchain-enabled PHR systems that balance strong security with usability, accessibility, and clear patient control.

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(4) Keywords

Blockchain; PHR; Data Security; Patient-Centered Care; Web3; Healthcare Informatics; Blockchain Adoption

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(5) Section Headings

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1. Introduction

The rapid digitalization of healthcare has amplified the need for secure, interoperable, and patient-centered systems for managing personal health information. Personal Health Records (PHRs) play a meaningful role in this transformation by enabling individuals to store, access, and share their health information across different healthcare settings. Unlike Electronic Health Records (EHRs), which are controlled by providers, PHRs position patients as the primary custodians of their health data. However, traditional PHR systems continue to face persistent challenges related to data security, transparency, interoperability, and user trust.

Blockchain technology has emerged as a promising foundation for addressing these limitations. Its core features—decentralization, immutability, and cryptographically enforced access control—offer opportunities to enhance the integrity, auditability, and reliability of health information exchange. Blockchain-enabled PHR solutions may allow patients to retain granular control over who accesses their data, while promoting interoperability and reducing the risks associated with centralized storage.

Despite these theoretical advantages, limited research has explored how patients themselves perceive the value of blockchain within PHR systems. As the ultimate end users of PHR technology, their perceptions influence adoption, trust, and long-term sustainability. Understanding patient experiences and expectations is hence essential for designing blockchain-enabled PHRs that are both technically robust and user-centered.

This study addresses this gap by examining patient perceptions of blockchain-based PHRs using a qualitative phenomenological approach. Grounded in the Technology Acceptance Model (TAM), the Theory of Planned Behavior (TPB), and the Diffusion of Innovations (DoI) framework, the study draws on semi-structured interviews to explore three central themes: (1) perceived security and trust, (2) perceived efficiency and interoperability, and (3) patient empowerment, usability, and data control. The findings contribute patient-centered insights to ongoing discussions on the future of decentralized health information systems and offer design considerations for organizations seeking to deploy blockchain-based PHR technologies.

2. Theoretical Framework

Blockchain adoption within healthcare is influenced not only by technical capabilities but also by behavioral, perceptual, and social factors that shape how patients evaluate the usefulness and trustworthiness of new technologies. Three theoretical models guided this study: the Technology Acceptance Model (TAM), the Theory of Planned Behavior (TPB), and the Diffusion of Innovations (DoI). These frameworks support the exploration of patient perspectives by connecting perceived system qualities with behavioral intentions and real-world adoption challenges. Together, TAM, TPB, and DoI provided a comprehensive lens for interpreting patient perceptions in this study.

2.1 Technology Acceptance Model (TAM)

The Technology Acceptance Model posits that two primary determinants—*perceived usefulness* and *perceived ease of use*—shape an individual's intention to adopt a technology. In the context of blockchain-based PHRs, perceived usefulness relates to whether patients believe the system enhances data security, provides trustworthy access control, or simplifies communication with providers. Perceived ease of use pertains to navigation simplicity, reduced technical burden, and intuitive interaction with blockchain features such as private keys or permission settings. TAM is valuable for examining how patients balance the benefits of enhanced security with the potential complexity of decentralized systems.

2.2 Theory of Planned Behavior (TPB)

The Theory of Planned Behavior emphasizes how *attitudes*, *subjective norms*, and *perceived behavioral control* influence technology adoption. Applied to blockchain-enabled PHRs, TPB helps explain how patient attitudes toward privacy protection, trust in technology, social influence (including healthcare providers), and self-efficacy shape adoption decisions. Perceived behavioral control—patients' confidence in managing technical tasks—has direct relevance due to blockchain's unique requirements such as managing digital identities, secure keys, or approving access permissions.

2.3 Diffusion of Innovations (DoI)

The Diffusion of Innovations framework outlines how individuals adopt new technologies based on characteristics such as *relative advantage*, *compatibility*, *complexity*, *trialability*, and *observability*. For blockchain-based PHRs, relative advantage includes improved transparency and data integrity; compatibility relates to how blockchain integrates with existing healthcare practices; and complexity often emerges from the technical nature of blockchain interfaces. Trialability and observability also influence awareness and trust as patients attempt to evaluate benefits before full adoption. DoI provides an interpretive foundation for understanding how blockchain innovations spread through patient populations and healthcare environments.

3. Methods

3.1 Research Design

A qualitative phenomenological research design was used to explore how patients perceive blockchain-enabled Personal Health Record (PHR) systems. Phenomenology was appropriate because the study sought to capture the lived experiences, attitudes, and meanings that patients assign to security, trust, usability, and data control in PHR environments. This approach aligns with the goal of understanding perceptions rather than measuring predefined variables. The design also allowed the researcher to examine how patient beliefs intersect with broader constructs from the Technology Acceptance Model (TAM), Theory of Planned Behavior (TPB), and Diffusion of Innovations (DoI).

3.2 Participants and Sampling

Participants were adults with prior experience using Personal Health Records and at least a basic familiarity with digital technologies. Purposive sampling was used to identify individuals who could offer meaningful insights into PHR use and concerns related to data privacy, security, and system usability. A total of **13 participants** were recruited, and **data saturation was reached after the 12th interview**, with the 13th confirming stability in emerging themes. This sample size aligns with recommendations for phenomenological studies aiming to develop rich, in-depth thematic insights.

3.3 Data Collection

Data were collected through **semi-structured interviews** conducted via Zoom. Interview durations ranged from **40 to 60 minutes**, allowing participants to freely describe their experiences with PHRs and their expectations from a blockchain-enabled system. The interview protocol included open-ended questions related to perceived security, privacy, efficiency, data access, usability, and concerns about emerging technologies. All interviews were audio-recorded with participant consent and transcribed for analysis. The researcher took field notes to capture nuances in tone, emphasis, and context.

3.4 Data Analysis

Data were analyzed using **Interpretative Phenomenological Analysis (IPA)**, which emphasizes understanding how individuals make sense of their lived experiences. Transcripts were carefully reviewed, coded, and categorized into themes. **QDA Miner Lite** software supported the systematic coding process, enabling efficient organization of text segments and facilitating the identification of repeated patterns. The analysis followed a structured progression: initial coding, clustering into meaning units, theme development, and cross-case comparison. This iterative method resulted in the emergence of three core themes: (1) perceived security and trust, (2) efficiency and interoperability, and (3) patient empowerment, usability, and digital literacy challenges.

4. Findings

Analysis of the interview transcripts revealed three interconnected themes that reflect how patients perceive blockchain-enabled PHR systems: (1) perceived security and trust, (2) efficiency and interoperability, and (3) patient empowerment, usability, and digital literacy. These themes represent the core dimensions shaping patient expectations and willingness to adopt a blockchain-based PHR.

4.1 Perceived Security and Trust

Participants consistently expressed concern about the security of current PHR systems, particularly in relation to data breaches, unauthorized access, and lack of transparency in how hospitals or third parties handle health information. Blockchain was frequently described as “more secure,” “tamper-proof,” or “trustworthy” because of its immutability and decentralized nature.

Several participants believed that blockchain could offer stronger protection against data manipulation or unauthorized sharing, especially compared to centralized systems vulnerable to single-point attacks. However, participants also noted that the perceived trustworthiness of blockchain depends on their ability to understand how the technology works. The idea of managing cryptographic keys or accessing data through a decentralized interface raised concerns among non-technical participants. For some, the technology felt "too technical" or "intimidating," potentially limiting adoption despite its security advantages.

Overall, blockchain was perceived as enhancing trust—*if* designed in a way that minimizes technical burden on the user.

4.2 Perceived Efficiency and Interoperability

Participants highlighted persistent inefficiencies in traditional PHR systems, such as difficulty accessing records across different providers, redundant tests due to fragmented data, and delays in information exchange. Many expressed frustration that PHRs "do not talk to each other" and require manual effort to retrieve or share data.

Blockchain was perceived as offering potential improvements in efficiency by enabling interoperability, real-time updates, and provider-to-provider continuity of information. Participants believed that blockchain could reduce administrative friction, prevent duplication, and allow data to follow the patient rather than remain locked within institutional boundaries. One participant noted, "I worry that my data can be accessed without my knowledge," highlighting concerns about current PHR transparency.

However, participants also emphasized that efficiency gains would matter only if blockchain-based PHRs integrate seamlessly into existing healthcare workflows. If blockchain introduces additional interfaces, extra steps, or parallel systems, participants feared it could undermine efficiency rather than improve it.

4.3 Patient Empowerment, Data Control, and Usability Challenges

Patients strongly valued the idea of having direct control over who accesses their data, under what conditions, and for how long. Many felt that current PHR systems restrict patient autonomy by limiting access permissions or failing to show who has viewed their information. Blockchain's ability to provide transparent, auditable access logs was seen as a major advantage in promoting patient empowerment.

At the same time, usability concerns emerged as major barriers to adoption. Participants worried about managing private keys, understanding blockchain terminology, or navigating interfaces designed for technically skilled users. Digital literacy varied widely across participants, and several noted that older adults or non-technical individuals may struggle with decentralized systems unless the interface is simplified.

Participants stressed that blockchain-based PHR systems must be designed with intuitive interfaces, clear permissions, and minimal complexity. Without this, the benefits of data control could be overshadowed by user frustration or fear of making irreversible mistakes.

5. Discussion

This study examined patient perceptions of blockchain-enabled Personal Health Record (PHR) systems, with a focus on security, efficiency, data control, usability, and real-world adoption barriers. The findings reinforce and extend existing literature by providing patient-centered insights that connect technical capabilities of blockchain with lived experiences and expectations of end users. Three major themes emerged—perceived security and trust, efficiency and interoperability, and patient empowerment and usability—and each aligns meaningfully with the theoretical frameworks guiding this research.

Security and Trust:
Consistent with the Technology Acceptance Model (TAM), perceived usefulness of blockchain was strongly tied to expectations of improved security, data integrity, and protection from unauthorized access. Participants believed blockchain could reduce vulnerabilities present in centralized PHR systems, echoing prior studies that highlight immutability and decentralization as key benefits. However, ease of use remained a critical concern. Many participants lacked comfort navigating blockchain interfaces or managing private keys, which directly influenced perceived ease of use and willingness to adopt the system. This finding reinforces the importance of designing blockchain PHRs that maintain high security while abstracting technical complexity from the user.

Efficiency and Interoperability:
Participants expressed strong frustration with fragmented PHR systems that fail to share information across providers. Their expectations for blockchain-centered interoperability reflect findings in existing research emphasizing blockchain's role in enabling secure, real-time data exchange. Through the lens of the Theory of Planned Behavior (TPB), patient attitudes toward blockchain's efficiency benefits were positive; however, perceived behavioral control—confidence in navigating new systems—remained a limiting factor. The theme also aligns with Diffusion of Innovations (DoI), particularly relative advantage and compatibility. Patients saw blockchain as advantageous *only if* it integrates smoothly into existing healthcare workflows and does not add extra burden.

Patient Empowerment, Data Control, and Usability:
The strongest theme centered on patient empowerment and transparency. Participants valued the idea of controlling who can access their health data and being able to view audit trails. This finding aligns with the growing push toward patient-centered digital health systems and matches DoI attributes related to perceived compatibility with patients' expectations of autonomy. At the same time, concerns about usability and digital literacy echo broad literature on the digital divide in healthcare. Participants feared making mistakes when using key-based authentication or navigating unfamiliar interfaces. These findings emphasize the need for thoughtful interface design, simplified blockchain interactions, and support for diverse literacy levels.

Collectively, these themes illustrate that blockchain is perceived as promising but not inherently intuitive. Patients appreciate its security and transparency benefits but remain cautious about its complexity. The study extends current research by providing a nuanced understanding of how patients weigh perceived benefits against usability concerns. For

blockchain-based PHR systems to achieve meaningful adoption, developers and healthcare organizations must balance robust technical features with human-centered design and ongoing user support.

6. Implications

The findings of this study offer several important implications for healthcare developers, policymakers, and organizations considering blockchain-enabled Personal Health Record (PHR) systems.

Implications for System Designers and Developers

The results highlight a critical balance between security and usability. While blockchain's decentralization and immutability appeal strongly to patients concerned about data breaches, many participants expressed hesitation about interacting with blockchain interfaces or managing private keys. Designers must therefore abstract technical complexity through intuitive user interfaces, guided workflows, and simplified identity management. Features such as key recovery options, biometrics, or custodial key management may help bridge the gap between strong security and real-world accessibility.

Implications for Healthcare Organizations

Participants viewed blockchain as a potential solution to long-standing interoperability issues, including fragmented records and redundant testing. Healthcare institutions adopting blockchain-enabled PHRs should prioritize systems that seamlessly integrate with existing clinical workflows and EHR platforms. Doing so can reduce administrative burden, improve continuity of care, and enhance patient–provider communication. Organizations should also invest in educating both clinicians and patients about blockchain's functions and limitations to encourage trust, awareness, and collaborative use.

Implications for Policymakers and Regulators

Given the heightened public concern around privacy and data rights, blockchain-enabled PHRs may support policy initiatives aimed at strengthening patient control and transparency. Policymakers can encourage adoption by establishing clear standards for blockchain governance, interoperability, and consent management. Regulatory frameworks must address key issues such as data ownership, responsibility for key recovery, and compliance with HIPAA or equivalent data protection regulations. Ensuring that blockchain-based health systems adhere to consistent national or international standards will support broader trust and adoption.

Implications for Future Digital Health Innovation

The findings demonstrate that blockchain's value extends beyond privacy and security—it can enable a more patient-centered model of health information management. However, innovation must be paired with digital literacy support, especially for populations with limited technological experience. Training resources, in-app guidance, and support channels can

help mitigate usability barriers and empower a broader demographic to benefit from decentralized PHR systems.

Overall, the study underscores that blockchain alone does not guarantee user adoption. Its success depends on thoughtful implementation that respects patient needs, minimizes cognitive load, and aligns with existing clinical ecosystems. Collectively, these implications highlight the need for human-centered blockchain design that prioritizes both security and usability.

7. Limitations

While this study provides meaningful insights into patient perceptions of blockchain-enabled Personal Health Record (PHR) systems, several limitations should be acknowledged. First, the sample size of 13 participants, although appropriate for phenomenological research, may limit the generalizability of the findings to broader populations. Participants were purposively selected and may have had greater familiarity with digital technologies than the general public, potentially influencing their perceptions of blockchain.

Second, all interviews were conducted via Zoom, which may have affected the level of comfort or depth of expression among some participants due to environmental distractions, privacy concerns, or technology barriers. Additionally, self-reported experiences and perspectives may introduce bias, as participants may have presented their attitudes more favorably or unfavorably depending on personal beliefs about technology.

Third, the study focused specifically on patient perceptions rather than healthcare providers, developers, or administrative stakeholders. These groups may hold different perspectives on the implementation challenges, workflow integration, and technical requirements of blockchain-based PHR systems.

Finally, blockchain technology continues to evolve, and participants' views may shift as new applications, user-friendly interfaces, or regulatory frameworks emerge. Future research should incorporate diverse stakeholder groups and examine real-world prototypes to validate and extend these findings.

8. Conclusion

This study explored how patients perceive blockchain-enabled Personal Health Record (PHR) systems, revealing that blockchain's value is closely tied to its ability to address longstanding concerns in digital health—particularly around security, transparency, and control. Participants recognized blockchain's potential to strengthen data integrity, improve trust, and enable more efficient information exchange across healthcare providers. At the same time, they emphasized that the benefits of decentralization are meaningful only if the system remains intuitive, accessible, and compatible with the diverse digital literacy levels of its users.

The findings demonstrate that blockchain alone is not a complete solution. Successful adoption depends on thoughtful design choices that simplify user interactions, support

patients in managing digital identities, and integrate seamlessly with existing healthcare workflows. The study contributes patient-centered insights to an emerging area of digital health research and highlights the importance of balancing technical innovation with usability and inclusiveness.

As healthcare continues to evolve toward more transparent, interoperable, and patient-centered systems, blockchain-enabled PHRs offer a promising path forward. Further research involving healthcare providers, developers, and real-world prototypes can deepen understanding of how blockchain can be implemented ethically, effectively, and at scale to support the future of digital health. These insights contribute to evolving digital health strategies seeking secure, transparent, and patient-centered PHR solutions.