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Research Article

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Role of Blockchain to enable Patient-driven Interoperability

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Abstract The objective of patient-driven interoperability is to enable the individuals to have complete control of their health information and engage in decision-making in terms of information sharing and use. The patient-driven interoperability model therefore aims to improve care coordination and promote better health outcomes by ensuring that the patients are in the center of the data exchange in the healthcare ecosystem

The collaboration among different players of healthcare is important in achieving the following goals: Access to an individual's health information, stored in electronic health records (EHRs), containing information from various sources, and providing a complete picture of their health. Providers have unified access to secure health information from disparate sources with a goal to learn about health systems where care is the focus and help public health agencies and researchers quickly learn, develop, and deliver innovative treatments. By ensuring patients to be in the realm of this information sharing would enable easy access to the right information at the right time. The goal of this paper is to explain how blockchain as a technology can be leveraged to attain these goals and promote patient-driven interoperability

Keywords Blockchain, Application Program Interface (API), FHIR, HITECH, Distributed Ledger, Consensus Protocol, Health Information Exchange, Interoperability, Client-server, Electronic Health records, Hash, nodes, HIPPA

1. Introduction

The healthcare interoperability ecosystem is currently largely driven by the incentives both federal and state and involve business entities to the most part-like hospitals, pharmacies, and private clinics.

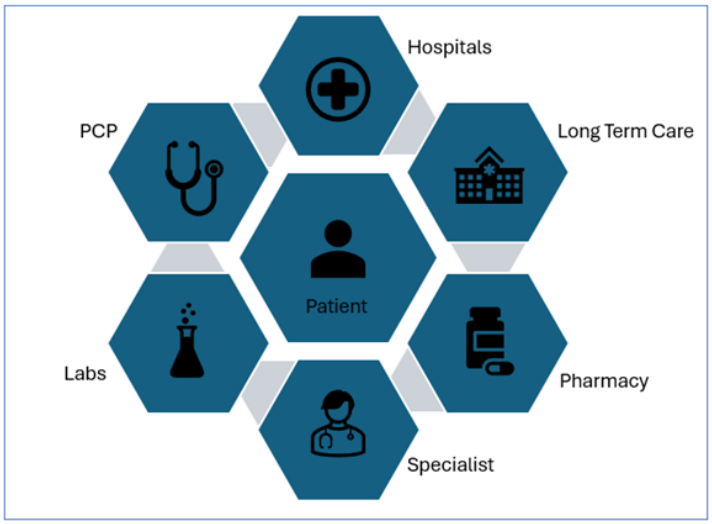

Figure 1: Patient in the center of health care ecosystem

The HITECH act encouraging data sharing among all the entities resulted in a structure where the patient data is scattered among many systems with no central ownership. The second challenge with this arrangement was that patient-centric data such as social and behavioral determinants were missing. Thirdly, in the institution-driven interoperability is a significant amount of collaboration needed between the entities requesting data transfer. The data-sharing rules and governance requirements are a few things to be agreed upon by both parties before the data transfer can happen. The next biggest challenge is to ensure there are no technical limitations and a robust authentication process is established to monitor the activity. And lastly ensuring all the security standards are followed is particularly important [1].

Despite the importance of patient's medical records, currently, the systems are not efficient to ensure easy access and retrieval of data. This data would not be of any use if there were disparate systems in different organizations without an option of secure data exchange. Hence, there is a great shift towards patient-driven interoperability where the ownership of the information lies with the patients. The HIPAA mandates the covered entities to provide the patient with their information upon request. The efforts like Meaningful Use helped a great deal in patients able to access their electronic health records. While there are some more avenues such as patient portals allowing access to personal health records, the API functionality would further improve data exchange. Moreover, the patients would have control over the data and the parties they want to share their records with, they would be able to do so without the need to reveal their identity, in turn helping with the research activities.

2. Role of Blockchain to enable Patient-driven Interoperability

Blockchain is a platform for digital exchange and can be leveraged for a patient-driven interoperability where the patient has more control over their data. On a very high-level blockchain can be described using three important concepts or parameters. a distributed ledger, consensus protocols, and cryptography [2].

- A Distributed Ledger (DL) – Blockchain is based on the peer-to-peer network, where each network node would contain a copy of the ledger. If a node fails, the original data can still be retrieved from the other nodes improving the fault tolerance. A distributed ledger therefore is used to reduce the risk of a single point of failure by eliminating the need for trusted third-party entities.
- Consensus Protocols (CPs) - Blockchain makes use of consensus protocol to ensure the integrity of the blocks by performing validations on the transactions, creating a new block, and appending the created block onto the chain. These protocols ensure that the participants on the network agree on the rules when updating the ledger. Since more nodes will be performing verifying the state change in the network would be much more secure.
- Cryptography - The cryptography technology is used to validate transactions on the blockchain network. A secure digital identity using a pair of public and private keys is assigned to each participant on the network.

Some of the block chain features to enable patient driven interoperability are:

Digital access rules- The authentication and authorization rules are stored in a central location on the blockchain to which the owner in this case the patient would have access. The patient would then be able to assign permissions for their data thus enabling data share. The patient would be able to see the block chain properties like smart contracts when authorizing the release of their data for a given period [1]

Data availability – This would require the patients to consolidate their data together. Using the blockchain's API, the patient will be able to download the records from various systems into a central location. This can be done along with the Blockchain's digital access rules. Thus, all the content can be securely transmitted and linked to the patient's digital key. A patient will be able to connect to various organization's systems using their login and share their blockchain public key, requesting a secure transfer of their data. Since this can be done with multiple institutions the patient's clinical data can be aggregated using the technology. The patient would then be able to publish their data to a blockchain network which can be a great tool to monitor a patient's health information that is collected outside the hospital setting.

Rapid Access - Rapid access to clinical information is another way for patient interoperability. The data exchange can begin once the ledger approves the permissions on the chain. Just having the meta-data about the primary data is sufficient to retrieve the actual record even if the primary data is not stored on the blockchain thus making it easy for patients to share their information by enabling data availability.

Patient Identity – Patient identity is another way blockchain would promote the transition to patient-driven interoperability. One of the challenges in the health industry and electronic data exchange is not having a universal identifier for every patient. In the event where a patient could have records with multiple organizations with different clinical systems, it becomes challenging to resolve the patient's identity in the first place. In the case of Blockchain the public-key infrastructure (PKI) can be used to link that patient's records as it serves as a centralized identification method using the individual's public key. Once the organizations know the details of the public key of the patient, they can associate it to their internal key or patient identifier, and any future data exchanges or clinical events can be broadcasted to the blockchain using the patient's public key as a reference [1].

Immutability – In the traditional institution-driven interoperability the ownership of securing and storing data is on the entities collecting the data. With blockchain the clinical data (or metadata) is distributed across multiple entities, thereby reducing the risk of data loss, and ensuring data integrity. As the blockchain is mostly immutable, it will ensure all parties involved would have complete access to the same information once appropriate controls are set in place.

3. Challenges to Blockchain-enabled Patient-driven Interoperability

Despite all the benefits that blockchain provides for patient-driven interoperability there are multiple barriers that are hindering widespread adoption.

1. High volume of clinical data – With the advancements of technology there has been an exponential growth in terms of healthcare clinical data. Every simple transaction can require megabytes of storage. Given the distributed nature of blockchains and the current technology limitations, it is not feasible to store every transaction on [1].
2. Privacy of data - The second challenge in adoption of blockchain is due to privacy and security limitations. In the implementation of the blockchain technology while the primary identity is masked using a public key, the other attributes of transactions are shared. This would be a big deterrent for the healthcare domain. If the user can get hold of the public key using the publicly available data, they would be able to retrieve all the transactions matching that key. While this is a big problem on a public blockchain, this is also a challenge on a private blockchain as it is not possible to restrict the data availability or revoke the authorization to the data once it is linked to a public key [2].
3. Patient engagement – In a patient-driven interoperability model patient participation is more important than an institution-driven construct. In the case of institution-driven interoperability, the onus lied with the providers in procuring and safeguarding the patient data. However, if the ownership falls with patients in managing and safeguarding their electronic data which can result in another challenge in the form of lost or forgotten passwords [1].
4. Security Vulnerabilities – Though blockchain is considered immutable it by no means is not prone to attacks. Since the technology is based on algorithms and code it is susceptible to technical issues. Another big challenge of blockchain technology is social engineering as it is primarily accessed and controlled by people. Hence there is a greater need for scrutiny towards information security just like any other data in the network [1].
5. Incentives - This is one of the biggest barriers in implementing patient-centered interoperability. Despite a law to provide patient-facing APIs for the EHRs it is not applicable for all healthcare data and without financial incentives, the organization would not have the motivation to build patient-facing APIs for data access.

There are some technical limitations around blockchain adoption in healthcare and can be a challenge for already existing integrations. At the same time, lack of education and training is a big barrier to adoption.

4. Alternatives/recommendations to address Patient-driven interoperability.

Given the challenges in adopting the blockchain and at the same time the drive to enable patient-driven interoperability there is a growth of alternate solutions and technologies. In recent years there is increased traction

for the digitization and access to records by the patients both in the technology and from the regulatory perse. One such concept is Personal health records or PHR using HL7 Fast Healthcare Interoperability Resources (FHIR) [3]. A Personal Health Record (PHR) will allow patients to record and manage their health data enabling two-way communication between PHR and EHR. more effective and valuable tools for both the providers and patients. This bi-directional communication between providers and patients in real-time will allow patients to get up to date information about their diagnosis or treatment plans. Patient Health Record (PHR) is defined as "an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment'' [3]. While a patient can have multiple EHRs, there would be only one PHR. There are three types of PHRs.

- Individual – a standalone application allows patients to record their data and does not communicate with EHR.
- Tethered – In this type the PHR is synchronized from a single EHR based on the permission from the patient.
- Integrated – a tethered PHR, synchronized with multiple EHRs.

The tethered PHRs are one way to achieve patient-driven interoperability and it benefits both the patients and the providers equally. Patients will not only have access to their health data they will be able to manage the data and access who would be able to use it. The HL7 Fast Health Interoperability Resources (FHIR) makes use of a modular approach and represents the healthcare data as independent modular entities called Resources. These FHIR resources are managed using APIs and RESTful web services, technologies such as the lightweight HTTP-based REST protocol, JSON, RDF, etc. However, PHRs have some challenges for wide adaptation. The major challenges are the use of technology, accuracy of data, healthcare policies, interoperability, security, and privacy [3].

Thus, a tethered PHR achieves interoperability by using open-source standards and their implementation and allows data exchange with EHR by reducing data integration issues and improving data quality.

5. Conclusion

Despite the limitations and the resistance from large healthcare organizations in adopting blockchain, the technology offers significant promise in ensuring the data is made available securely among the healthcare care system. The technology makes it easier to transition from the institution driven interoperability to patient-centric interoperability as the patients would have complete ownership of their data which would in turn enable them to make meaningful decisions on the care programs.

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