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Mini Review

Blockchain Technology for Healthcare: Facilitating the Transition to Patient-Driven Interoperability

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ABSTRACT

Interoperability in healthcare has traditionally been focused around data exchange between business entities, for example, different hospital systems. However, there has been a recent push towards patient-driven interoperability, in which health data exchange is patient-mediated and patient-driven. Patient-centered interoperability, however, brings with it new challenges and requirements around security and privacy, technology, incentives, and governance that must be addressed for this type of data sharing to succeed at scale. In this paper, we look at how blockchain technology might facilitate this transition through five mechanisms: (1) digital access rules, (2) data aggregation, (3) data liquidity, (4) patient identity, and (5) data immutability. We then look at barriers to blockchain-enabled patient-driven interoperability, specifically clinical data transaction volume, privacy and security, patient engagement, and incentives. We conclude by noting that while patient-driving interoperability is an exciting trend in healthcare, given these challenges, it remains to be seen whether blockchain can facilitate the transition from institution-centric to patient-centric data sharing.

Contents

1. Introduction

The 2009 Health Information Technology for Economic and Clinical Health Act (HITECH), part of the American Recovery and Reinvestment Act, earmarked almost $30 billion in funds to incentivize Electronic Health Record (EHR) adoption by US healthcare providers, largely through the “Meaningful Use” (MU) program [1]. As a result of this effort, providers and hospital use of EHRs has increased dramatically—while

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only 9% of non-federal acute care hospitals had a basic EHR in 2008, 96% had an EHR by 2015 (with basic EHR defined as a set of 10 core measures including clinician notes, medication lists, and problem lists, among others) [2]. Unfortunately, while the digitization of health records has clearly increased, sharing electronic health data between different hospitals and providers has lagged behind EHR adoption, for numerous reasons, including technical, operational, and privacy-related concerns [1, 3–5].

Interoperability in healthcare is often focused around data exchange between business entities—for example, multiple hospital systems through a state-wide Health Information Exchange (HIE) [6]. However, there has been a recent push towards patient-driven interoperability, in which health data exchange is patient-mediated and patient-driven. Notable recent efforts in this area include the 21st Century Cures Act's (21CCA) emphasis on Application Programming Interfaces (APIs) [7], the API requirement in MU stage 3, and recent announcements supporting open APIs from the Department of Veterans Affairs (VA) [8] and from the Center for Medicare and Medicaid Services (CMS) [9].

The shift towards patient-centered interoperability is an important trend that has the potential to lay new groundwork for data sharing in healthcare. Patient-centered interoperability, however, brings with it new challenges and requirements around security and privacy, technology, incentives, and governance that must be addressed for this type of data sharing to succeed at scale, and many of these challenges are still not solved for traditional interoperability [10]. Thus, it is appropriate to look for novel or disruptive interventions that could be applicable in facilitating the shift to patient-centered interoperability. Such interventions could ease the tension between the advantages of data liquidity—clinical, research, operational—and the substantial barriers to interoperability that define the landscape of health data sharing.

Blockchain is one such novel technology that could have a role in improving interoperability. Blockchain—described in detail elsewhere [11, 12]—has particular appeal to health data given its emphasis on sharing, distribution, and encryption. In particular, newer blockchain efforts—smart contracts, second-layer systems, permissioned blockchains—further the potential health care use-cases, and there has been no shortage of hype surrounding the potential of the technology within healthcare [13]. In this work, we describe the health data interoperability problem, and the shift from institution-driven interoperability to patient-centered interoperability. We look at potential ways blockchain could facilitate this transition and benefit interoperability in general. Finally, we close by noting the often substantial limitations around these approaches, as well as appropriate next steps.

2. Interoperability: Current State

The Health Information and Management Systems Society defines interoperability as "the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged" [14]. For healthcare, interoperability has several potential benefits. First, well-communicating systems can improve operational efficiency, reducing time spent on administrative tasks like manually entering data received from faxes [15]. Interoperability can also reduce duplicate clinical interventions like imaging studies or lab orders, decreasing overall health system cost, decreasing waste, and improving patient safety by reducing the exposure to radiation or invasive procedures [16, 17]. Finally, interoperability may also improve clinical care, by facilitating improved access to relevant, longitudinal clinical data at the point-of-care [18]. While there are mixed results from empirical studies looking at specific interoperable implementations, for example, state-level HIEs [6], the overall goal of interoperability is a necessary component of cost-effective, comprehensive clinical care.

The healthcare interoperability landscape is generally centered around business entities, like hospitals, private clinics, and pharmacies, and data is typically created and siloed within the information system that creates it (for example, a hospital's electronic health record) (Fig. 1A). Exchange is often motivated by financial incentives or regulatory pressure [19], and numerous efforts exist to encourage better health data liquidity. For example, 21CCA places a strong emphasis on data sharing [7], and HITECH laid the groundwork for state-wide health-information exchanges, which have also required significant funding [20]. The result of this structure is that an individual patient's health data is scattered across numerous systems, and no institution has a complete picture. Furthermore, even if the different systems were highly interoperable, there would still be missing data—personal device monitor data, lifestyle behavior, social determinants of health—that is generated by patients. The EHR representation of a patient is often the closest approximation of a complete picture that exists in one place, and there has been recent interest in bringing in additional data to EHRs, in particular the social and behavioral determinants of health, to address this limitation [21–23].

Additionally, there are numerous challenges to interoperability that persist. Exchange between different institutions can be operationally challenging, and requires significant collaboration between the entities involved. Data sharing agreements, complex patient matching algorithms, procedures, and governance rules are just some of the issues that need to be agreed upon before data exchange can take place [24]. There are also numerous technical barriers. For example, transactional and entity authentication must be robust (and repeated for every entity-to-entity relationship.) Activity and threshold monitoring, along with some anomaly detection, should also be in place. Finally, the security of data exchange is paramount, and standards for data exchange (for example, FHIR or CDA [25]) must also be agreed upon.

In this setting, there has been a burst of recent energy towards improving the ability of patients to access their own health data. There is little ambiguity about whether patients should be able to access their health data—HIPAA requires that covered entities provide individuals with access to their health data upon request (with certain exceptions, like psychotherapy notes) [26]. While this has traditionally been handled by organizational Health Information Management offices through photocopies and faxes, electronic data access is now heavily regulated through efforts like Meaningful Use (which requires that has a patient has the ability to view, download, and transmit their health information, as well as access their health information through an API [27]) and 21CCA, which actually legislates an API requirement for EHR system certification [7]. Patient portals continue to provide patients with electronic access to their results and other documentation [28], and taking the API functionality a step further, the CMS and VA recently announced new initiatives to further improve patient access to their electronic health data [8, 9]. Clinical data standards like Fast Healthcare Interoperability Resources (FHIR), as well as practical implementation consortiums like the Argonaut project, will further reduce barriers to data exchange [29].

As data liquidity becomes less of a concern through expanded APIs, and as patients obtain better electronic access to their data, they can increasingly become the digital stewards of their health data. The data may still be largely generated in institutional silos, but, patients will now have the ability to build a comprehensive view of their health, retrieving their data and sharing it as appropriate with other entities (Fig. 1B). The transition to patient-driven interoperability will require new processes around security protocols, privacy configurations, electronic consent, and governance. Next, we look at how blockchain technology could intervene and provide benefit in this transition.

3. Reducing the Cost of Verification and Networking

The key features of blockchain technology are described in detail elsewhere [11–13]. In brief, blockchain technology can allow multiple stakeholders to agree, at regular intervals, about the true state of shared data. Such shared data can represent credentials and attributes of transactions, information about individuals, entities etc. Depending on how

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