Reclaiming your healthcare data

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The amount of global healthcare data is increasing dramatically. Whereas back in 2013, we only generated around 153 exabytes of healthcare data, this number is projected to rise to as much as 2,314 exabytes in 2020 – a 15-fold increase in 7 years. IBM suggests that by 2020, global healthcare data will double every 73 days. Of course, this brings a lot of benefits such as enhanced research opportunities and more precise, effective, and efficient diagnostics. Conversely, this raises further concern over fundamental issues regarding the data security in the current system and the entities involved in administering our healthcare data.

Although virtually all participants within the healthcare ecosystem – especially pharmaceutical companies – would benefit profoundly from being able to access more data, all participants in the healthcare ecosystem are hesitant to share such data. This reluctance is partly due to uncertainty as to how this data is handled, which parties are accessing it and to what end.

Who owns our healthcare data?

While the answer to that question varies from country to country, unawareness regarding access rights to healthcare data is seemingly a ubiquitous problem. In the U.S., for instance, the healthcare data is legally owned by the patient but entrusted to physicians (more details). Despite the efforts that some countries are currently undergoing to resolve prevailing issues – for instance the electronic health record in Germany – currently, healthcare data is often rather fragmented. Physicians, for example, can only access the data that they gathered themselves (either through examinations or records provided by their patients).

This medical data cannot be shared with a patient's other doctors for both regulatory reasons as well as a lack in interoperability of prevalent systems. Consequently, there is hardly any possibility to access essential patient data in the event of a medical emergency. Data security is another issue in the present system. Data manipulation (for instance in context with the NHS) as well as significant data breaches elicit concern: between 2009 and 2017, more than 176,709,300 healthcare records were either exposed or stolen; nowadays, new healthcare breaches are reported daily (more details).

We consider this to be disconcerting for two reasons: Firstly, healthcare data is highly sensitive. It is therefore highly relevant to know not only who can see but also who can alter this data. Secondly, there is a lot of disruptive and monetary potential in our health

information. While a lot of companies are looking into ways to gather and harness this data, the patient providing the data is hardly ever part of the equation and compensated accordingly. Indeed, patient data is seen by companies as one of the most valuable assets. Surprisingly it is tech companies which run first approaches to give healthcare data ownership back to the patients.

Big Tech is establishing healthcare data marketplaces

Apple, for example, is working with start-up Health Gorilla to add diagnostic data i.e. from blood work to the iPhone by cooperating with, inter alia, hospitals and lab-testing companies (more details). The goal is to create a healthcare data marketplace for iPhone users. Alphabet is entering the healthcare and insurance sector with its unit Verily. And with its Connected Care Solutions, Philips provides an intelligent healthcare service. At the core, all of these initiatives aim close the interoperability gap between different parties within the healthcare ecosystem – especially patients and hospitals.

The significant benefits of such initiatives notwithstanding, one key issue remains: using those systems, patients are giving their data away to third parties and hence out of their control. While there may be significant benefits to digital health solutions, we can only imagine what – besides patient treatment – this data will be used for. We believe that what we need is a system that engenders trust between all parties; a system that allows patients to share their healthcare data without discomfort by creating transparency.

A decentralized perspective by DLT solutions

Let's imagine a world in which patients are in full control of their medical data. Although there would no longer be an intermediary in charge of administering this data, it is unlikely that patients would store it locally, e.g. on a hard drive. After all, we may want our doctors to be able to access our health record without having to physically stop by or send it via an insecure connection. What is more, we want this data to be accessible in the event of an emergency. So, let's imagine a decentralized, accessible system for our healthcare data. Distributed ledger technologies (DLTs) could play a vital role in allowing for such a system by providing a secure transaction layer that all parties involved could trust in. This doesn't necessarily mean that all data is stored directly on the blockchain. In fact, we distinguish two types of information:

- "on-chain" data is stored directly on the chain, thus blockchain being the single source of truth, whereas
- "off-chain" information has links on the blockchain that allow for the identification of information stored in a traditional database and that help encrypt the data.
  Whereas off-chain solutions facilitate more expansive medical details and the storage of any format and size of data but also comes with further requirements such as additional

integration layers. Which solution is the most viable depends on the exact use case and its goal.

The Estonian approach

Estonia's e-health system is probably the lighthouse project in context of blockchain-based healthcare records. Their electronic healthcare system enables interoperability and data access for patients, doctors, hospitals as well as the government, while ensuring data integrity and risk mitigation in which the blockchain acts as a transaction layer. With this system, Estonia has digitized 99 % of health data nationwide and is handling all healthcare billing electronically (more details). By not saving all healthcare data on-chain but using a mixed approach of on- and off-chain data, a safe, timestamped and tamperproof register of data access and alteration is created. Thus, Estonia has built a system that is cost-effective, sustainable and highly efficient (curious? Click here).

The benefits of DLT for healthcare data

Whatever the exact architecture of such a blockchain-backed solution may look like, we see a few general benefits of the technology for healthcare data:

- Empowering patients: A decentralized approach would allow patients to make decisions regarding the access to their data. This not only encompasses hospitals and payers but may also include clinical research and pharmaceutical companies. Patients could then decide whether to provide the data for free or sell it for specific purposes such as research. This not only creates new incentives within the healthcare ecosystem, but also enables broader access to data, e.g. for research and control groups. Thus, a marketplace for healthcare is created in which the patient is not the product, but an equal market participant. We believe that this newly found power and trust are likely to increase the patient's willingness to share further healthcare data, e.g. from ever-improving health and fitness trackers.
- Creating interoperability: Estonia's e-health system shows how increased interoperability between different participants within the healthcare ecosystem can lead to a faster, more efficient and cost-effective system (click here for more information). What is more, physicians get a more complete view of the patient, hence potentially enhancing the treatment. While in Estonia, there is one collective system, corporate initiatives in this field may lead to a variety of DLT-based systems on the market. Thus, it is important to also ensure interoperability of different DLT-based systems.
- Outcome-based payment: An interoperable system also allows for comparative assessments of treatment outcomes. Accordingly, healthcare reimbursements could be linked to actual patient outcomes, thus building the foundation for value-based care. Consequently, fraudulent practices could be detected more easily. Deloitte estimates global fraud in healthcare at over $ 270bn.

- Enhancing clinical research: Currently, there is still a lack in knowledge about clinical trial opportunities and hardly any incentives for patients to share their medical information other than for sick patients wanting to be treated with and cured by the drug in question (click). Besides giving researches access to data for medical research purposes, they could also find crucial historical, anonymized data sets more easily (more details).

Pharma's first steps in decentralized healthcare data trading

Even outside Estonia, there are projects which have such a decentralized system in mind: Roche Diagnostics, for example, has teamed up with Ocean Protocol to enable secure, real-time transmission of private medical data. In a pilot involving 150 patients, they want to automate the exchange of critical blood levels from patients' self-monitoring device CoaguChek INRange with their hospitals. Thereby, the blockchain guarantees the integrity and provenance of the data and ensures auditability and trust. With their project, Roche and Ocean Protocol take a step towards a decentralized healthcare data marketplace.

DLT is not a panacea for healthcare system integration and data standardization. While it holds high potential for addressing the system's current pain points, neither are the regulatory requirements for this new model sufficiently clear in most countries, nor have all of the distributed ledger technologies available reached a state in which they are ready to be deployed at scale. This notwithstanding, we are currently dealing with an increasingly complex – some may even say broken – market, which demands exploring new, more collaborative models.

DLT, especially blockchain, may allow us to create a system that is defined by trust and mutual benefit. For pharmaceutical companies, this may appear to be a big effort and mindset change initially but being able to access such great amounts of diverse data sets would also entail enormous opportunities for clinical research and, finally, patient outcome.