Karlsruhe Institute of Technology

Where did my data go? Evaluation of Distributed Ledger Technologies' Suitability for Personal Data Provenance in Healthcare and Finance

Bachelor's Thesis of

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I declare that I have developed and written the enclosed thesis completely by myself, and have not used sources or means without declaration in the text.

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1 Introduction

With e-health [Eys01], e-finance [AMS02], cloud services, 'Internet of Things', social media, etc. spreading and growing by the day, data exchanged, analysed or produced by intelligent devices become more and more difficult to trace [17]. It is often unknown how information is collected, how it is further processed, by whom, and for what purpose [Zub15]. This kind of information is often referred to as *data provenance* (DP), where "The provenance of a data item includes information about the processes and sources that lead to its creation and current representation" [GD07, p. 3]. The purpose of provenance is to extract relatively simple explanations for the existence of some piece of data from some complex workflow of data manipulation.

With digitalisation, the concern with potential exposure of private and sensitive personal information is rising [TQV21], and with it, the significance of DP [BT19]. Also, information is not only personal and private, but also proprietary. Consumers should know if their data had been manipulated and how, in a network, that provides interoperability and connects actors in a secure, trustworthy, transparent and 'user friendly' way [Sun+14].

An increasing amount of research is being done to utilize DP technologies [BT19] in the fields of *healthcare* [Mar+20; LAC19; Le 18; HK21; Rah+20; Sun+14], *finance* [Sin+20; Liu+21; SAD19; Sir+19], supply-chain [Man+18], cloud services [Xia+17], scientific research [SPG05], storage systems [Mun+06], etc.

A lot of progress has been made recently regarding personal data and its protection [; 18; 19, TRND]. In European data protection law, everybody has the right to know where the organisation accountable got his data from, what the data was used for, where it was transferred to and how long it is stored, regardless of location [, GDPR]. However, laws and regulations alone cannot provide consumers with information about their personal data [CAG02]. The regulations created the need for tools, which can enable consumers to exercise their rights.

Unfortunately, many tools failed to meet the requirements of such technology [Hed08; Nor09; Hu+20]. In order for such tools to work, a combination of not only proper standards and legislation is needed, but also international adoption as well as mature and suitable technologies and architectures for their development [CAG02]. When improperly designed, DP tools can be a severe threat to the consumer and in a networked environment with a lot of actors this can be a complex and costly system to implement and manage [Hed08].

There are tools that partially solve some of the existing problems like owning your data, knowing where it is stored and what's happening to it [, MTM], others provide full access to all personal data along information flows [BKB16] or easy-to-understand visualization techniques [SS17]. However, these tools are still built in a centralised manner. While centralised databases provide advantages in terms of, for instance, maintainability, they have drawbacks in terms of their availability, performance (bottlenecks), and don't necessarily solve the issue with untrustworthiness [Sun20, p. 266-267].

To desire a one-fits-all solution is unrealistic. Recently, however, the *distributed ledger technologies* (DLTs) are on the rise and steadily becoming more versatile in terms of applicable

use cases [Mau+17]. DLT has been developed to keep a distributed immutable ledger of financial transactions [Sun20]. The ledger can be seen as a provenance record of, say, bitcoins; and it is therefore unsurprising that DLT could be used to record provenance in other settings. By leveraging the global-scale computing power of distributed networks, a DLT-based DP can provide integrity, authenticity, transparency, accountability, provenance and trustworthiness through its decentralized architecture, immutable record of transactions, lack of single authority, consensus mechanisms, smart contracts, tamper-proof storage of data, etc. [; Mar+20; Mun+06].

There are, however, different DLTs and they vary from each other in many ways such as their design, purpose, way of access, way of governance and so on [Cho+19]. So it is important to understand the characteristics, capabilities and trade-offs of individual DLTs [Kan+20] in order to select the most suitable approach for personal DP in the field of *healthcare* and *finance*. This leads us to the research question: *What are the properties of Distributed Ledger Technologies that make them beneficial/suitable for personal data provenance in healthcare and finance?*

In the next section, take a closer look at data provenance, the requirements of such approaches and the use cases selected in our work. In section three we describe distributed ledger technologies, their different designs, characteristics and properties, as well as DLTs' suitability for DP. Section four presents an evaluated mapping of our selected DLT approaches to the financial and healthcare DP requirements. This is followed by discussion in section five, consisting of principle findings, implications for practice, implications for research, limitations and future work. Then we end the work with a brief conclusion in section six.

2 Data Provenance

2.1 Definition

In this work we define *data provenance* (DP) as an approach/technology that can be used to record not only metadata, data origin and/or data operation, but also processes that act on data and agents that are responsible for those processes. Most importantly, this should be achieved in a secure, trustworthy and transparent way, that ensures accountability and is in accordance to international laws and regulation, with the well-being of the consumer in mind.

2.2 Requirements

DP approaches/technologies, suitable for tracing the origin and source of personal data and the processes that led to its current state, have to fulfil a number of requirements. Using the available literature, we derived and formulated the following requirements, which we then presented through the lens of the two use cases investigated in our work.

We combined the requirements into suitable groups: "User" contains requirements associated with the data of the individual user; "Data" contains the features that the data is required to posses in such approaches/technologies; "System" consists of requirements about the concrete DP approach/technology as an usable system; "Security" and "Other" include the fundamental security requirements and requirements that are necessary in almost every system.

Group	Requirement	Description
User	Identification	An unique identifier allows identification and lays the ground for accountability [Lee+13], but also anonymity, pseudonymity and unlinkability should be possible [HPH11; Sen].
	Ownership	Allows Data Subjects to get an overview, request or perform changes and deletion of the data that they own. [ZN+15]
	Accessibility	Allows Data Subjects with access to view, store, retrieve, move or manipulate data, based on their access rights [ZN+15; BKB16].
Data	Traceability	Give information on what transmitting principle was used, what type of data, for what purpose and to whom the information was sent. How data is collected; how, when, where it is stored [Fre+08; ZN+15, p. 13].
	Completeness	Collecting complete provenance information can fully take the advance to track data and actions for identity management, error detection, etc. Incomplete provenance data may lead to detection missing and suppression of abnormal behaviors [GGM12; HPH11].
	Granularity	Not only the process derivation of a data file, but also the components of files such as paragraphs, shapes and images should be traced with regard to their origins. Fine-grained provenance information helps achieve highly precise anomaly detection and auditing [HWA10].
⋮	⋮	⋮

⋮	⋮	⋮
System	Scalability	With the increase of the data volume and the number of operations, it should be possible to store and process provenance information efficiently and without risk of information loss [TBA16; Fre+08, p. 16].
	Interoperability	By definition - the capability to communicate, execute programs or transfer data between various systems in a manner that requires Data Subjects to have little or no knowledge of the unique characteristics of those systems [, IntOp].
	Trust	If the Data Subject trusts the system, they seem to be willing to share personal information [BHS02]. The willingness to share data can also increase if the Data Subject finds the advantages of engaging in such a transaction more valuable than the loss of privacy [BGS05; AG05].
Security	Confidentiality	Ensures non-disclosure of data traveling over the network to unauthorised Data Subjects [Asg+12].
	Integrity	Ensures that the Data Receiver may detect unauthorised changes made to the data [Tsa+07].
	Availability	Ensuring that data and is provenance is available to Data Subjects,when and where they need it [Lia+17].
Other	Policies	Enforce laws [] and regulations such as purpose limitation [FHS17], data minimisation [ASS17], etc.
	Usability	Provides clear interfaces and structures that display provenance information in an understandable way (usage of icons, graphs, etc.). Managing security (and privacy) is not the primary task of the user [Fre+08].
	Logging	Provides mechanisms to log and timestamp the transfer of the data between Data Subjects [HPH11; MZX16; Wan+16; Sue+13].

2.3 Use Cases

In this work we investigate DP approaches for both *healthcare* and *finance*. While such approaches need to fulfil all of the above mentioned requirements, each requirement can have different level of importance or meaning in the specific use case. In this section, we will discuss these differences between *healthcare* and *finance* requirements.

The marked fields in the following table show which requirements are more nuanced than the general DP requirements and, consequently, where the requirements differ in meaning and importance (empty means that the requirement is similar to the general description in table 2.2).

Group	Requirement	*Healthcare*	*Finance*
User	Identification	x	x
	Ownership	x	
	Accessibility	x	x
Data	Traceability	x	x
	Completeness		
	Granularity		
System	Scalability		x
	Interoperability		
	Trust	x	x
Security	Confidentiality	x	x
	Integrity		
	Availability	x	
Other	Policies	x	
	Usability		
	Logging		

2.3.1 Healthcare

Actors: *Patient, Physician, Institution*

In regard to medical treatment and *patient* safety, the importance of data, its origins and quality have long been recognised in clinical research [Cur+17] [Muh14]. Creating trust relationships among the various actors is vital - e.g., evidence-based medicine and healthcare-related decisions using third-party data are essential to patient safety [Mar+20]. DP is also crucial for solving confidentiality issues with healthcare information like accidental disclosures, insider curiosity and insider subornation [Rin97b]. In the following we discuss the important aspects of each of the specific healthcare DP requirements pointed out in table 2.3.

Identification: There are important trade-offs between indentifiability and unlinkability/anonymity. For example, a patient feels that their physician misrepresented a test and wants to share this information, but is reluctant to do so, since casting the physician in a negative light can have repercussions in their care at a later time []. Another example is the perceived stigma of having a mental disorder acts as a barrier to help seeking. It is possible that patients may be reluctant to admit to symptoms suggestive of poor mental health when such data can be linked to them, even if their personal information is only used to help them access further care. There is a significant effect on reporting sub-threshold and non common mental disorders when using an anonymous compared to identifiable questionnaire [Fea+12]. Studies suggest that anonymity is strategically used and fosters self-disclosure among individuals who are embarrassed by their illness [Rai14].

On the other hand most people believe that, when a physician makes an error, an incident report should be written and the individual should be identified on the report. People are reluctant to accept physician anonymity, even though this may encourage reporting [Eva+04]. Also, Data Protection Act insists that patients must consent directly to participate in research or that patients' data must be completely anonymised. However, this causes particular problems for epidemiological research [War+04] which often requires access to routinely collected identifiable personal data, or requires identification of research participants from such data. Obtaining individual consent from large numbers of patients may be onerous or simply impossible, for example if patients have died or moved away, and participation bias may undermine the data. Anonymising data is difficult and expensive and greatly limits their future value [Wal06].

Ownership: A relevant issue is the ongoing debate about the ownership of patient data among various stakeholders in the healthcare system including providers, patients, insurance companies and software vendors. In general, the current model is such that the patient owns his/her data, and the provider stores the data with proprietary software systems. The business models of most traditional EHR (electronic health record) companies are based on building proprietary software systems to manage the data for insurance compensation and care delivery purposes. Such approach does not encourage or makes it difficult for individual patients to share data for scientific research, nor does it encourage patients to obtain their own health records that may help better manage their health and improve patient engagement [Adi+17].

Accessibility: It is important that the different actors can view, store, retrieve, move, request changes/deletion or manipulate medical data based on their access rights [Ber17]. For example, patients should be able to see what prescriptions they have so they know what medicine to

take; physicians should be able to alter the prescriptions of their patients and also to see what prescription a patient has gotten from other physicians so that they can correctly treat them and avoid medication errors; an institution should be able to verify a patient's prescription to make sure that they are not trying to purchase unintended pharmaceuticals [, Priv].

Traceability: Traceability in healthcare is at the crossroads of numerous needs. It is therefore of particular complexity and raises many new challenges. Identification management and entity tracking, from serialization of pharmaceuticals, to the identification of patients, physicians, locations and processes is a huge effort, tackling economical, political, ethical and technical challenges. There are growing needs to increase traceability for drug products, related to drug safety and counterfeited drugs [KS18]. Technical problems around reliability, robustness and efficiency of carriers are still to be resolved. Traceability is a major aspect of the future in healthcare and requires the attention of the community of medical informatics [Lov08].

Trust: Trust is, of course, essential to both physician and patient. Without trust, it is difficult for a physician to expect patients to reveal the full extent of their medically relevant history, expose themselves to the physical exam, or act on recommendations for tests or treatments [Saf+98; Mos+98]. Trust promotes efficient use of both the patient's and the physician's time. Without trust, the process of informed consent for the most minor of interventions, even a prescribed antibiotic, would become as time consuming as that needed for major surgery [Goo02]. Furthermore, physician-to-patient relationship is jeopardised when people do not trust that their personal health information will be kept confidential, and that these data will not be utilised for purposes other than medical [KLG03].

It is also suggested that it is morally important for doctors to trust patients. Doctors' trust of patients lays the foundation for medical relationships which support the exercise of patient autonomy, and which lead to an enriched understanding of patients' interests. It may not be possible to trust at will, the conscious adoption of a trusting stance is necessary as the burdens of misplaced trust fall more heavily upon patients than physicians [Rog02].

In terms of medical research, one of the three key factors to the patients willingness to share data is contingent upon trust who is accessing the data [KMR19].

Confidentiality: Trust and confidentiality between a physician and patient is not new: it is central to the practice of healthcare and has been focused on since Hippocrates. Whilst the concept of patient confidentiality has endured as an ideal throughout history. In the digital age, patient confidentiality is often framed within the context of electronic patient records and the potential involvement of third parties. While the involvement of institutions and other research organisations can resolve many practical issues for healthcare providers, it often involves the transfer of sensitive patient information to these institutions [Rin97b]. Therefore, it is important that there isn't any disclosure of medical data traveling over the network to unauthorised actors [Rin97a, p. 96]. Sometimes, however, difficulties with keeping the confidentiality of personal health information may arise, because of the often unclear position of family members and friends, in patient's health and medical treatment [Pet+04].

Availability: Medical data and its provenance should be available and ready for immediate use, especially in cases of emergency [KLG03]. The immediate availability of patient and resource oriented information is of great importance, in order for physicians and institutions to, for example, identify the most appropriate ambulance and healthcare setting; provide guidance to physicians as to the most appropriate management of the emergency case at hand;

prioritize/classify the emergency case and overall improve the quality of the emergency care [PMV12].

Policies: Unfortunately, legal controls over data collection in European countries have badly affected the work of epidemiologists [WN94a]. While data protection laws, policies and regulations aim to protect the patients information, rights and health, they might cause harm to the patients well-being in the long run, by damaging the ability of institutions to conduct unbiased and reliable medical research [War+04; WN94b].

Logging; system **Usability, Scalability** and **Interoperability**; data **Integrity, Completeness** and **Granularity** are, of course, of great importance and are requirements that should be fulfilled in every DP approach. However, these requirements don't seem to have any specific aspects that differ from the financial DP requirements or our general description in table 2.2. Therefore, we concluded that they don't require that much of our attention or detailed investigation.

2.3.2 Finance

Actors: *Consumer, Institution*

In online banking, digital money and digital financial services, the importance of information about transactions, money flow, money origin, credit scores and financial decisions is becoming bigger and bigger since the emergence of e-finance [AHS02]. DP is of great use not only in investigating money laundering [Ung+06], tracing donations [Sir+19], charities [Sin+20] or illegal funding [Tei18], but also loans and financing, mortgages, trading of currencies, insurance policies and others [But20]. However, 'big tech' are also venturing into financial services [Boi+21]. While being accused for abuse of market power and anti-competitive behaviour, they are also famous for not giving extensive information on how personal data is analysed, processed or interacted with by third parties and international or government organisations [, RV19], which has a negative impact on the consumers' ability to trace their personal data.

Group	Use Case Requirements
User	Without ownership or access to their own information, *consumers* cannot be certain if their data is inaccurate, obsolete, or otherwise inappropriate. [Cha85] The fear of abuse alters *consumer* behaviour and anonymity can be misused by criminals [CPS96]. A balance between identification and unlinkability must be achieved. *Consumers* should be able to perform operations in an pseudonymous way, that ensure ownership (pseudonyms are not improperly used by others) and ensure individuals are held accountable for abuses created under any of their pseudonyms. [Cha85]
Data	Tracing leads to transparency among actors. It should be possible to trace messages, transactions, what information and how it has been collected, analysed or processed (e.g. if donation funds are utilized properly or not). (aid) Data must be complete, accurate and fine-grained, in order to achieve precise anomaly and fraud detection and not negatively impact decision making or put *consumers*, *institutions* and their money or financial data at risk [Rua+19].
System	*Institutions* generally have an interest in maintaining good relations with *consumers* and share many of the same interests and concerns [Cha85]. To ensure trust, *institutions* need efficient, interlinked and, in a way, pervasive record-keeping system (fingerprint), while still providing *consumers* with monitoribility and control. Such systems may also have to handle a large amount of transactions [Cha85]. Easily scalable system can bring efficiency gains and lower entry barriers for *consumers*, however, there should be ways to prevent discrimination, abuse of market power, anti-competitive and monopolistic use of data [Boi+21].
Security	Where there is money related information, the actors involved are a potential subject to numerous types of crime. Non-disclosure, accuracy and availability of data, as well as state-of-the art security measures are, therefore, of great importance, in order to prevent theft, fraud, money laundering [Ung+06] or terrorist related activity [Tei18].

3 Distributed Ledger Technologies

A distributed ledger (also called a shared ledger or distributed ledger technology or DLT) is a consensus of replicated, shared, and synchronized digital data geographically spread across multiple sites, countries, or institutions [Sun20]. Unlike with a centralized database, there is no central administrator [Sca16].

The distributed ledger database is spread across several devices (nodes) on a peer-to-peer network, where each replicates and saves an identical copy of the ledger and updates itself independently. The primary advantage is the lack of central authority. When a ledger update happens, each node constructs a new transaction, and then the nodes vote by consensus algorithm on which copy is correct. Once a consensus has been determined, all the other nodes update themselves with the new, correct copy of the ledger [Mau+17]. Security is accomplished through cryptographic keys and signatures [Sun20]. We differentiate between:

DLT *concepts* - describe the basic structure and functioning of DLT designs on a high level of abstraction. For instance, blockchain is a DLT concept describing the use of blocks that form a linked list. Each block contains multiple transactions that have been added into the block by nodes [Kan+20].

DLT *designs* - specify an abstract description of DLT concepts by adding concrete values and processes for inherent DLT characteristics. There are important differences between DLT designs, which make them suitable for some applications and unsuitable for others [Kan+20].

DLT *characteristics* - represent features of DLT designs, which are of technical or administrative nature. The technical characteristics constrain future changes of the administrative characteristics(e.g., lack of scalability regarding network size of a distributed ledger) [Kan+20].

DLT *properties* - groups of DLT characteristics and shared by each DLT design. For instance, "throughput" and "scalability" are both associated with the DLT property "performance" [Kan+20].

The emergence of DLT, with strong support for data integrity, authenticity and provenance, has opened up the door of opportunities in different domains [; Mar+20; Mun+06; Lia+17; Wor+20]. With the increase in DLT application domains, the number of DLT designs has also increased steadily. These DLT designs vary from each other in many ways such as implementation, purpose, way of access, way of governance and so on [Cho+19]. Therefore, it is important to understand the characteristics of DLT designs and their properties, in order to determine which are more advantageous and most importantly, which properties make them suitable (or not) for a particular use case and its specific requirements.

3.1 Designs

DLT designs can be instantiated as a *public* or *private* [Xu+17; Yeo+17].

public	***private***
Ethereum [, ETH]	Hyperledger [DMH17]

Public: In public DLT designs, the underlying network allows arbitrary nodes to join and participate in the distributed ledger's maintenance. For example, consumers can execute financial transaction without registration or verification of the nodes' identities being required. Public DLT designs are usually maintained by a large number of nodes, for example, Ethereum. Owing to the large number of nodes in the network, each of which stores a replication of the ledger, public DLT designs achieve a high level of availability. To allow many (arbitrary) nodes to find consensus, public DLT designs should be well scalable to not deter performance when the number of nodes increases [Sun20].

Private: In contrast, private DLT designs engage a defined set of nodes, with each node identifiable and known to the other network nodes. Consequently, private DLT designs require verification of the nodes that join the distributed ledger. Private DLT designs are often used if the public should not be able to access the stored data [BM16]. For example, physicians can use a common ledger in Healthcare to collaborate, but do not want to disclose the data to other colleagues or institutions not involved in the collaboration [Sun20].

Public DLT designs bring trust, security and transparency. Everything is recorded, public, and cannot be changed; also the more decentralized and active a public DLT design is, the more secure it becomes; and in terms of transparency - all data related to transactions is open to the public for verification.

Public DLT designs, however, lack speed, face concerns over scalability and energy consumption. The bigger the public network, the slower it is, as more transactions take place and clog the network. For example, Ethereum can handle 13 transactions per second, compared to 3000 by Hyperledger Fabric. In private networks, fewer participants means less time for the network to reach a consensus and as a result, more transactions can take place.

However, the biggest disadvantages of private DLT designs is centralization. Private distributed ledgers inherently become centralized due to their private network. The credibility of a private network relies on the credibility of the authorized nodes, which means they need to be trustworthy as they are verifying and validating transactions.

Besides the choice of going with *public* or *private*, we differentiate between *permissioned* and *permissionless* DLT designs [Yeo+17; Xu+17].

	public	***private***
permissioned	-	Hyperledger [DMH17]
permissionless	Ethereum [, ETH]	-

Permissioned - when consensus finding is delegated to a subset of nodes (which is usually small). Since only selected nodes can validate new transactions or participate in consensus finding, fast consensus finding can be applied, which enables a throughput of multiple thousands of transactions per second [CL+99]. Owing to the small number of nodes involved in consensus finding, they can reach finality, which means that all of a distributed ledger's permitted nodes come to an agreement regarding the distributed ledger's current state [Sun20].

Permissionless - when the nodes' identity does not have to be known [Yeo+17], because all of them have the same permissions. In permissionless DLT designs with a large number of nodes (e.g. Ethereum), consensus finding is usually probabilistic and does not provide total finality, because it is impossible to reach finality in networks that allow nodes to arbitrarily join or leave. Consequently, the consistency between all the nodes of a public, permissionless distributed ledger can, at a certain point in time, only be assumed with a certain probability. Furthermore, a transaction appended to a distributed ledger is only assumed to be immutably stored to a certain probability. In blockchains, this probability of a particular transaction's immutability increases when new blocks are added to the blockchain [DL] [Sun20].

3.2 Characteristics

3.3 Properties

3.4 DLT and Data Provenance

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3.5 DLT in Healthcare

3.5.1 Current State

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3.5.2 HyperLedger Fabric

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3.6 DLT in Finance

3.6.1 Current State

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3.6.2 Ethereum

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4 Evaluated Mapping

5 Discussion

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5.1 Principle Findings

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5.2 Implications for Practice

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5.3 Implications for Research

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5.4 Limitations and Future Work

6 Conclusion

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