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# A Consent Model for Blockchain-Based Health Data Sharing Platforms

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**ABSTRACT** In modern healthcare systems, the ability to share electronic health records is crucial for providing quality care and for enabling a larger spectrum of health services. Health data sharing is dependent on obtaining individual consent which, in turn, is hindered by a lack of resources. To this extent, blockchain-based platforms facilitate data sharing by creating a trusted distributed network of users. These users are enabled to share their data without depending on the time and resources of specific actors (such as the health services). In blockchain-based platforms, data governance mechanisms become very important due to the need to specify and monitor data sharing and data use conditions. In this article, we present a blockchain-based data-sharing consent model for access control over individual health data. We use smart contracts to dynamically represent the individual's consent over health data and to enable data requesters to search and access those data. The dynamic consent model extends to two ontologies: the Data Use Ontology (DUO) which models the individual consent of users and the Automatable Discovery and Access Matrix (ADA-M), which describes queries from data requesters. We deploy the model on Ethereum blockchain and evaluate different data sharing scenarios. The contribution of this article consists of the creation of an individual consent model for health data sharing platforms. Such a model guarantees that individual consent is respected and that all the participants in the data sharing platform are accountable. The evaluation of our solution indicates that such a data sharing model provides a flexible decision-making approach over data usage by data requesters. Our experimental evaluation shows that the proposed model is efficient and adapts to personalized access control policies in different data-sharing scenarios.

**INDEX TERMS** Blockchain, data sharing, distributed ledgers, EHR exchange, individual consent.

## I. INTRODUCTION

With the rapid development of big data technology, enormous amounts of data are currently being generated [1]. Data providers such as companies, organizations, and individuals increasingly choose to share their data for research and other various purposes. As data sharing rapidly steps up, sharing practices are lagging in specifying and protecting individual consent preferences.

### A. CONSENT MATTERS

In this work, we enable individuals to decide how to share their health data with data requesters, such as researchers, organizations, or companies. Although distributed internet-based solutions (such as cloud-based systems) can already connect data providers and data requesters, the difficulty of ensuring compliance from both parties remains. Individual data sharing faces the problem of

unambiguously defining consent while data requesters face the issue of clearly stating their intentions (i.e. a well-known example of this conflict is the Cambridge Analytica case [2]). Furthermore, storing data in internet-based solutions (such as cloud-based systems) creates large pools of data that are handled almost exclusively by a few big corporate actors with business incentives to maintain this status quo [3]. This raises data privacy concerns, especially when the data consist of sensitive health records. For example, cloud-based systems store large data aggregates in data centers. In order to move towards decentralized data sharing models, individual users need to be empowered to steer data sharing practices. In this article, we propose a generic methodology to achieve this by dynamically representing individual consent for data-sharing.

### B. CHALLENGES

The problem with the ownership and privacy of personal health data is exemplified by the issue of data generated by consumer wearables. Even if wearables collect individual

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data, users do not typically own these data. Instead, they are collected and stored by device manufacturers [4] who often charge a monthly fee for the use of their platform [5]. By contrast, in a patient-centered data sharing ecosystem, data is available to the user; it is controlled by the person who generated it; it is privacy-enabled and secure, and maintains data provenance information [6]. Moreover, the General Data Protection Regulation (GDPR) [7], adopted by the European Union, suggests that default entitlements in personal data rest with the data subject, as do individual control rights. Amongst these rights, GDPR gives individuals the right to restrict processing and to request the deletion of data, which is known as the “right to be forgotten” [8]. To this extent, blockchain is a novel technology that enables fine-grained data from each individual to create a global resource where data integrity and immutability of transaction is ensured. Blockchain enables the storage of transactions relating to data exchange in a verifiable and non-reputable way by all the actors in the system. At the core of blockchain systems is the decentralization of control. Decentralization offers a substantial opportunity in a data-sharing scenario because it eliminates centralized control over data and enables individuals to decide how to share their personal records. Although platforms to support data sharing with blockchain-based solutions have been proposed [9]–[12], to date no frameworks model individual consent in relation to the purpose of use. To construct a dynamic consent-based model, we need to address the following questions:

- How to represent individual consent in a machine-readable way?
- How to connect the users over the platform?
- How to dynamically match the purpose of use of data requesters to the individual consent of data providers?
- How to ensure data integrity and maintain a verifiable history of changes over time?
- How to build an efficient framework?

### C. CONTRIBUTIONS

To address the above issues, we introduce a dynamic consent model for health data sharing using blockchain technology. Individuals, as data providers, decide on the data use conditions and access that data requesters must comply with. Such a model guarantees that individual consent is respected and that there is accountability for all the participants in the data-sharing platform. It provides a GDPR-compliant model, whereby all the uses of data are monitored by the decentralized model, and permissions can be modified or removed upon users’ request. The novelty of the solution stands in combining two consent representation models (DUO [13] and ADA-M [14]) to represent and standardize user consent and to dynamically match it to data requester purpose statement queries. By using a blockchain model, we maintain a transaction history of all transactions related to data. Through this, the data provider specifies individual data sharing rules, monitors the use of data, and revokes or updates access to the data at any time.

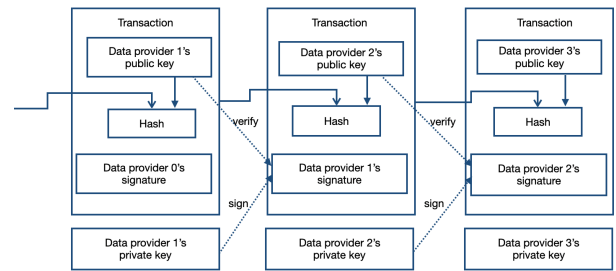


FIGURE 1. Chain of transactions in blockchain [16].

The remainder of this article is structured as follows: Section II discusses the background work related to data-sharing platforms. Section III discusses related work and highlights the limitations of the state-of-the-art. Section IV presents our dynamic consent-based architecture model. Section V presents the implementation of the solution. Next, Section VI evaluates the solution using the LUCE [15] data sharing platform. Section VII discusses the impact of the solution in terms of scalability, privacy, and data heterogeneity. Finally, section VIII presents conclusions and future works.

## II. BACKGROUND

In this section, we briefly review background works on data sharing solutions using blockchain technology, smart contracts, and ontologies for consent representation.

### A. DATA EXCHANGE WITH BLOCKCHAIN TECHNOLOGY

Blockchain was initially proposed by Nakamoto [16] in 2008 as a digital cryptocurrency which is based on a distributed ledger technology as seen in Fig. 1. The model is permissionless, meaning that anyone can join and leave the network. The interaction occurs in the form of transactions that are bundled together in blocks. When a transaction is generated, it propagates in the network. Specific nodes, called miners, verify the validity of transactions, create new blocks, and append new valid blocks to the blockchain. In order to add a new block, typically miners have to solve a cryptographic puzzle, also known more generically as consent models. Depending on the blockchain model, adding new blocks (especially when using cryptographic puzzles) can be computationally expensive. The miner who creates a new candidate block broadcasts it to the network. The consensus among nodes is reached by verifying that the identified block is valid. Finally, the candidate block is added to the chain resulting in all the nodes updating their blockchain data. As seen in Fig. 1, the blocks in the chain are linked to their predecessor block through a unique hash value. Through this, all the network shares the same transaction data with the certainty that the information stored in the chain contains valid transactions that are verified and cannot be tampered. Nowadays, blockchain technology has evolved from crypto-currency solutions into more general-purpose platforms. Ethereum [17] is one of the widely used general-purpose blockchain solutions. It uses an Ethereum virtual machine (EVM) to run programs called

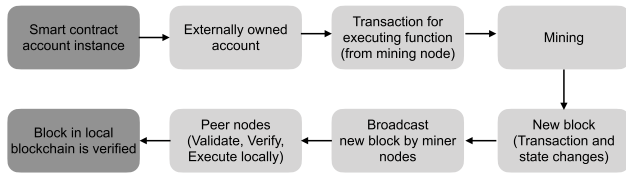


FIGURE 2. Smart contract execution in Ethereum.

*smart contracts*. Smart contracts incorporate the business logic of transactions, thereby defining when and what constitutes a valid transaction.

Blockchain enables decentralized data sharing with no need for centralizing the data to a particular organization. In this way, information on data transactions between data providers and data requesters are immutable and safeguard ownership of the data. Via blockchain, it is possible to monitor the data exchange and keep a data transaction history across the nodes in a distributed leaderless manner.

### B. FROM DATA SHARING TO SMART CONTRACTS

Smart contracts [18], [19] are self-executable codes that control the data transfer or cryptocurrencies over the blockchain network. Smart contracts translate contractual clauses into a code that enables automated workflows and eliminate the need for a trusted third party.

A smart contract executes independently and automatically based on the data that was entered in the triggering transaction. The most prominent blockchain that supports smart contracts is the Ethereum blockchain. In this article, we use Ethereum smart contracts [20] to model the interaction between individuals, whom we refer to as data providers, and data requesters. The two actors interact with each other via smart contracts. These are configured by data providers to capture the logic for dynamically deciding if the data can be shared with data requesters.

Fig. 2 represents the execution of a smart contract in Ethereum. A smart contract contains functions that can be executed by an *external account*. To execute a function, the decentralized application retrieves an instance of a smart contract by its address and starts a transaction. To take effect, a transaction has to be mined by peer nodes. After successful mining, a new block containing the transaction address is created. The miner node broadcasts the new block to the peer nodes. Afterwards, this new block is validated, verified, and executed by peer nodes and added to the blockchain.

### C. DATA SHARING WITH LUCE

Havelange *et al.* [15] developed LUCE, a blockchain-based data-sharing platform to automatically track compliance with data licensing terms, and to facilitate data sharing concerning the rights of data subjects. To resolve trust issues between the two data sharing parties, LUCE attaches a license to the data. The license clearly states data usage terms. Via the blockchain platform, LUCE automatically tracks compliance with the licensing terms, even after the data has been acquired by the data requester. The use of data from data requesters is recorded by LUCE, and if a data requester acts

in a way that doesn't comply with the data requester terms, the data provider can act on his rights. For example, data subjects can enforce GDPR rights to access, rectify, and erase the data. LUCE distinguishes between three different roles: Data Providers, Data Requesters, and Supervisory Authorities [15]. By building on a blockchain solution LUCE offers the following features:

- **Immutable information:** Transactions relating to data exchange are stored in the platform and can not be destroyed. Therefore, the transactions showing which data provider shared data and which data requester has access to specific data remain available indefinitely in the platform.
- **Ownership:** The smart contract specifies data access and links to the owner, therefore, a data provider can prove the existence and integrity of data processed on the blockchain.
- **Transparency:** A shared distributed ledger of all data usage is created. Due to the fact that the ledger can be changed only by having the consensus of the network, the transactions are known to be consistent, transparent, and accurate. Supervisory authorities are enabled to inspect transactions and intervene accordingly.

In our project, the data provider uploads individually owned data to LUCE and specifies the terms of use. We extend LUCE with a consent model and test our model with data generated through IoT devices. *Data requesters* use LUCE to find datasets based on their needs. The supervisory authority is responsible for intervening on data misuse and for enforcing GDPR rights. In our approach, we introduce the consent representation model and test the model with IoT data that are shared in the LUCE platform.

### D. CONSENT CODES IN DATA SHARING

Ontologies provide a conceptualization of domain knowledge such that the information can be understood and processed by machines and by humans. Ontologies facilitate the interpretation of consent in regards to data use conditions. Two ontologies were considered relevant for modeling individual consent for supporting EHR data sharing:

#### 1) DATA USE ONTOLOGY (DUO)

Dyke *et al.* [13] provide an ontological representation of data use categories by using *consent codes*. The ontology includes terms describing data use conditions for research data in the health/clinical/biomedical domain. Specifically, DUO standardizes data use restrictions into machine-readable consent. DUO is a simple model that data providers can easily use to define data sharing consent. However, from a data requester perspective, DUO lacks the details needed to represent the purpose of use. This is why we use the DUO model only to define individual consent choices of data providers.

#### a: CONSENT STATEMENT

Table 1 shows an abstract view of the DUO model. Initially, a dataset is assigned to a primary category according to the data provider's consent. More restrictions on

**TABLE 1.** The primary categories of DUO. Data providers use them to express data-sharing consent preferences [13].

Main Categories	Meaning/Assumptions
<b>Primary Category (Mandatory)</b>	
No restrictions (NRES)	<ul style="list-style-type: none"> <li>No restrictions on using the data</li> </ul>
General research use and clinical care (GRU-CC)	<ul style="list-style-type: none"> <li>For health, medical or biomedical purposes</li> <li>Includes population origin or ancestry study</li> </ul>
Health, Medical or Biomedical research and clinical care (HMB-CC)	<ul style="list-style-type: none"> <li>Limited to HMB purposes</li> <li>Excludes population origin or ancestry study</li> </ul>
Open the dataset to population and ancestry research (POA)	<ul style="list-style-type: none"> <li>Use of the data limited to study of population origins or ancestry</li> </ul>
Disease specific research and clinical care (DS-XX-CC)	<ul style="list-style-type: none"> <li>Use of the data must be related to a disease</li> </ul>

individual data can be included by specifying more categories. These are classified as secondary categories and can only be selected after choosing one of the primary categories. Examples of such restrictions include non-profit-only, geographical restrictions, time limits, etc.

## 2) AUTOMATABLE DISCOVERY AND ACCESS MATRIC (ADA-M)

Woolley *et al.* [14] define a matrix of categories for expressing data use restrictions. This is a comprehensive information model that provides the basis for producing structured metadata *profiles*. ADA-M is a complementary approach for classifying data use conditions and permissions. In our model, we take advantage of the granularity of the ADA-M model for representing the purpose statements of data providers.

### a: PURPOSE STATEMENT

As shown in Table 2, the ADA-M model [14] uses categories e.g. Research Purpose and sub-categories e.g. use for biomedical research (HMB) as a way to represent consent with more detail.

## III. RELATED WORK

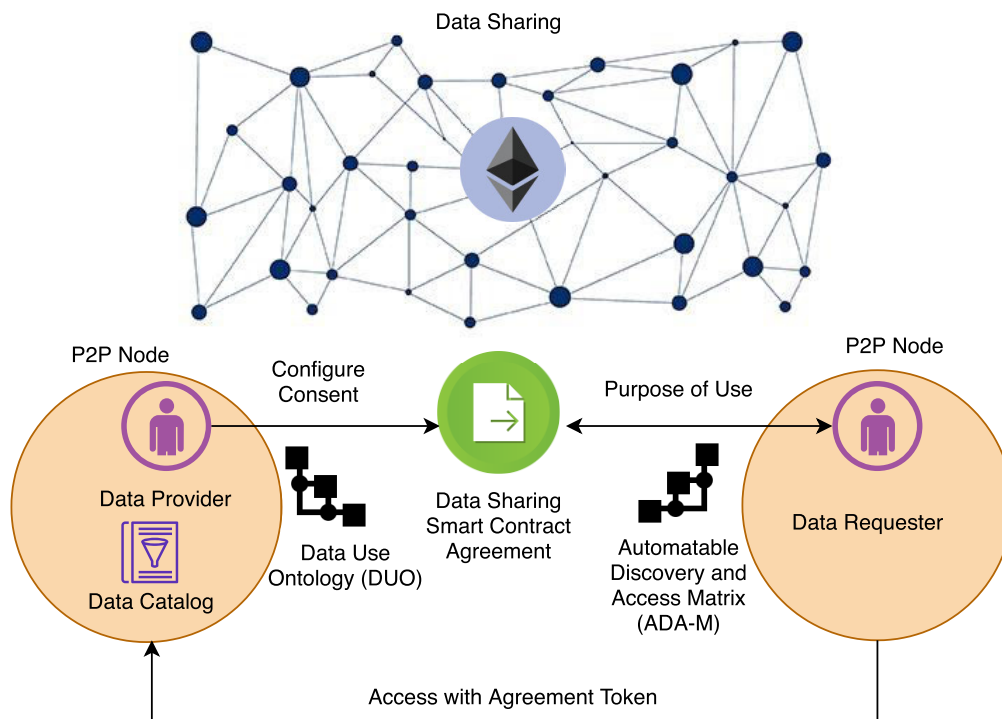
Several research works [21], [22] on consent-based data sharing have been proposed in different domains. Riggs *et al.* [23] address the issue of data sharing with consent in genomic data. They introduce a one-page web-based consent form for genomic data sharing which avoids multi-page consent terms. Via a questionnaire with 5162 respondents, they show improved data access when the simplified consent form is used. In the privacy domain, authors [24] propose a web standard protocol called User-Managed Access (UMA) to enable applications to offer stronger consent management abilities. UMA gives an individual a unified control point for authorizing who and what can get access to his or her online personal data and services (such as creating status updates), no matter where those resources live online. While a generic solution

**TABLE 2.** ADA-M [14] categories for representing purpose statements of data requesters.

Main Categories	Subcategories
Research Purpose (GRU)	<ul style="list-style-type: none"> <li>Use for methods development (NMDS)</li> <li>Use for reference or control material (RS-XX)</li> <li>Use for research concerning populations (PO)</li> <li>Use for research ancestry (ANS)</li> <li>Use for biomedical research (HMB)</li> </ul>
Health, Medical or Biomedical research Purpose (HMB)	<ul style="list-style-type: none"> <li>Use for research concerning fundamental biology (FB)</li> <li>Use for research concerning genetics (GSO)</li> <li>Use for research concerning drug development (DD)</li> <li>Use for research concerning any disease (DS-XX)</li> <li>Use for research concerning age categories (AGE)</li> <li>Use for research concerning gender categories (GEN)</li> </ul>
Clinical Purpose (CC)	<ul style="list-style-type: none"> <li>Use for decision support (DSO)</li> <li>Use disease support (DS)</li> </ul>

and versatile for online data, UMA does not explicitly solve consent requirements from an EHR data-sharing perspective. It also suffers from a lack of auditability over data access. Indeed the intentions of the data requesters, when they gain data access, are not explicit. Through our solution, we categorize the consent according to the terms of use. The auditability of the platform enables the identification of any inappropriate data use, the revocation of access, and the possibility to be forgotten by the data requester at any time. Several blockchain-based solutions [25]–[27] have been recently proposed with a focus on privacy-preserving data sharing, data management of EHRs, or sharing of health data in cloud storage. While these approaches potentially improve data sharing practices, so far only a few address consent and how it could be included in blockchain-based data sharing platforms. In particular, Bhaskaran *et al.* [28] propose a consent based double-blind anonymous data sharing built on Hyperledger Fabric [29]. Their model defines a Know your Customer (KYC) application, which is built on a permissioned blockchain. Differently from our solution, this model is not suitable in a permissionless setting where any user can join and contribute to the platform. Moreover, in contrast with our model which enables both data providers and data requesters to dynamically define the terms of data usage, the purpose of the use is not modeled for data requester queries. Thus, the proposed model of Bhaskaran *et al.* [28] is currently unable to dynamically adapt the consent to different data queries.





**FIGURE 3.** A consent model for blockchain based architecture using smart contracts.

ProvChain [10] and DataProv [11] are blockchain-based approaches to verify data provenance accountability. However, these solutions are not focused on modeling dynamic consent. Neisse *et al.* [30] propose a blockchain-based approach for data accountability and data provenance tracking. Their solution enables data tracking and reuses based on the consent of data providers. The solution includes a smart contract that describes the terms of use as well as data provenance information. In contrast to our model, this solution mainly focuses on data providers and data controllers but does not meaningfully include data processors such as researchers who are reusing the data while maintaining the individual consent rights of the data providers.

#### IV. CONSENT BASED ARCHITECTURE MODEL

In this section, we illustrate the architecture of our framework. Following and extending upon the LUCE architecture [15], we distinguish the following actors and resources.

- **Data provider:** A data provider owns and shares the data. A data provider can specify consent in plain text form by using DUO terms. Data providers can be any individual, researcher, or an organization with data ownership. The key functionality of the data provider is: a) To register in the LUCE platform b) Publish data with the desired consent c) Update data if required d) Remove data entirely if desired.
- **Data requester:** A data requester is looking for data for a specific purpose. A data requester can request the data from a data provider by using the ADA-M matrix form.

The key functionality of data requester is: a) To register on the LUCE platform; b) Search for the data by giving a purpose statement; c) Request access to the data once the desired one is found; and d) Confirm compliance with consent terms of the data provider.

- **EHR data:** EHR data (Electronic health records) contains information about the medical history of a patient, and it is owned by a patient, authorized practitioner or an organization.<sup>1</sup>
- **Datastore node:** A datastore node stores all the information related to the required data. It could be in cloud storage or local organizational storage.

Additionally, we work under the following assumptions:

- Datasets are shared as a whole. Thus, in the current model, a data provider is unable to share only a portion of a dataset.
- Data records are anonymized by data providers prior to enabling data-sharing.

The workflow of a consent model using blockchain is depicted in Fig. 3. The data provider gives consent using the DUO model as specified in Fig. 1. The consent statement of the data provider is recorded into the blockchain using a smart contract. When a data requester queries the data, it uses the ADA-M matrix ontology. The *purpose statements* of data requesters are recorded into the blockchain via the smart contracts. This occurs when a smart contract matches

<sup>1</sup> Although they are currently not formally considered as part of the EHR, we extend the EHR data definition to data collected from wearables as they contain valuable information on the physiological parameters of patients. The proposed model is agnostic to this extended definition of EHR.

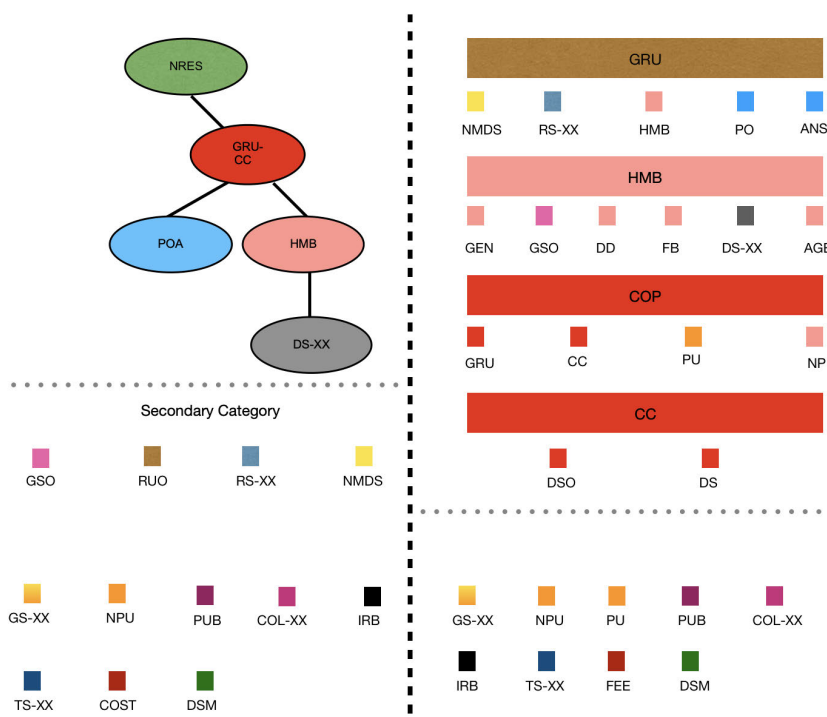


FIGURE 4. Consent codes matching for DUO (left-side) and ADA-M matrix (right-side).

the consent of a data provider (*consent statement*) to a query from the (*purpose statement*) of a data requester.

Fig. 4 represents the matching of consent codes between the DUO and ADA-M matrix. It represents the DUO consent codes with abbreviations that match the ADA-M codes. In the figure, a similar color signifies that there is a consent match between two parties. For example, as specified in Table 1, if a data provider gives consent for HMB research (HMB), this is represented in solid pink color in Fig. 4 (left-side). Similarly, if there is a query regarding Fundamental biology (FB) research, we can observe in Fig. 4 (right-side) that *FB* has a solid pink color and that there is a match in the given consent. If there is a match, access is granted to the data and the datastore is accessible to the data requester. In case of no match, the request is denied and the data requester is notified.

## V. CONSENT MODEL IMPLEMENTATION

In this section, we provide the implementation details of the smart contract and the extension of LUCE [15] with the consent model proposed in this article.

### A. EXPERIMENTAL SETUP

We implement the smart contract in Solidity [31], a language for smart contracts provided by the Ethereum blockchain. Our consent model is then deployed into the LUCE [15] platform — a blockchain-based data sharing platform implemented in Python and deployed on the Ganache Ethereum network [32]. To run our experiments, we use a LuceVM virtual machine [15] which is running on a 64 bit Ubuntu 16.04 LTS (Xenial Xerus) Linux operating system.

The virtual machine is equipped with 1024 MB RAM. Our consent model implementation is available as open-source.<sup>2</sup>

LUCE is implemented on top of the Ethereum blockchain. It uses Web3 javascript libraries [33] to interact with the Ethereum blockchain. LUCE uses Django [34] for implementing the user interface. The data providers interact via the Django web framework to share the data and specify the associated consent. LUCE stores the link between the smart contract and the corresponding datastore location.

Every data provider has a smart contract that is used to record the consent and to compare it to the data requester's purpose of use statement. Fig. 5 shows the code snippet of a smart contract for our data sharing platform. The contract stores the data provider consent statement as a *struct* named *DataProvider\_PrimaryCategory*. This describes the consent given by the data provider while publishing the data. Optionally, if more restrictions are needed on the data consent form, data providers can specify *DataProvider\_SecondaryCategory* and *DataProvider\_Requirements*. By calling the *UploadDataPrimaryCategory* function, the consent of the data provider is stored on the blockchain. Similarly, the data provider can call the *UploadDataSecondaryCategory* and *UploadDataRequirements* functions to submit the additional terms for data use. Data requester function *giveHMBpurpose* requests the data by submitting the purpose of use through this function. Similarly, there are other functions defined in the smart contract to query the data while describing the requester's requirement.

<sup>2</sup><https://gitlab.com/vjaiman/consentblockchainluce>

```

pragma solidity ^0.4.25;

contract ConsentCode{
    address public dataProvider;

    mapping (address => DataProvider_PrimaryCategory) objects;
    mapping (address => DataProvider_SecondaryCategory) objects1;
    mapping (address => DataProvider_Requirements) objects2;
    mapping (address => ResearchPurpose) researchpurpose;
    mapping (address => HMBResearchPurpose) hmbresearchpurpose;
    mapping (address => ClinicalPurpose) clinicalpurpose;
    mapping (address => Person) person;
    mapping (address => GeographicSpecificRestriction) geographicrestriction;
    mapping (address => Profit) profit;
    mapping (address => DataRequester_Terms) datarequesterterms;

    function UploadDataPrimaryCategory(address _address1, bool _NoRestrictions, bool _OpenToGeneralResearchAndClinicalCare,
        bool _OpenToHMBResearch, bool _OpenToPopulationAndAncestryResearch, bool _OpenToDiseaseSpecific) public {}

    function UploadDataSecondaryCategory(address _address1, bool _OpenToGeneticStudiesOnly, bool _ResearchSpecificRestrictions,
        bool _OpenToResearchUseOnly, bool _NoGeneralMethodResearch) public {}

    function UploadDataRequirements(address _address1, bool _GeographicSpecificRestriction, bool _OpenToNonProfitUseOnly,
        bool _PublicationRequired, bool _CollaborationRequired, bool _EthicsApprovalrequired, bool _TimeLimitOnUse,
        bool _CostOnUse, bool _DataSecurityMeasuresRequired) public {}

    function giveResearchPurpose(address _address2, bool _UseForMethodsDevelopment, bool _UseForReferenceOrControlMaterial,
        bool _UseForPopulationsResearch, bool _UseForAncestryResearch, bool _UseForHMBResearch) public {}

    function giveHMBPurpose(address _address2, bool _UseForFundamentalBioResearch, bool _UseForGeneticsResearch,
        bool _UseForDrugDevelopmentResearch, bool _UseForAnyDiseaseResearch, bool _UseForAgeCategoriesResearch,
        bool _UseForGenderCategoriesResearch) public {}

    function giveClinicalPurpose(address _address2, bool _UseForDecisionSupport, bool _UseForDiseaseSupport) public {}
    function givePerson(address _address2, bool _UseByAcademicProfessionals, bool _UseByClinicalProfessionals,
        bool _UseByProfitMakingProfessionals, bool _UseByNonProfessionals) public {}

    function giveGeographicSpecificRestriction(address _address2, bool _UseBySpecifiedCountries) public {}
    function giveProfit(address _address2, bool _UseForProfitPurpose, bool _UseForNonProfitPurpose) public {}

    function giveDataRequester_Terms(address _address2, bool _NoTimelineRestrictions, bool _NoFormalApprovalRequired,
        bool _NoCollaborationRequired, bool _NoPublicationRequired, bool _NoDataSecurityMeasures, bool _NoDataDestructionRequired,
        bool _NoLinkingOfAccessedRecords, bool _NoRecontactingDataSubjects, bool _NoIntellectualPropertyClaims,
        bool _NoUseOfAccessedResources, bool _NoFeesForAccess) public {}
    function AccessData (address _address1,address _address2) view public returns (bool) {}

```

FIGURE 5. Smart contract in consent model.

Through the LUCE platform, the model interacts with Ganache [32], a test network that creates a virtual Ethereum blockchain and generates pre-configured accounts that are used for the development and testing. The accounts are pre-funded which enables the deployment of the contracts. Ganache provides the balance in *ether* and notifies the *gas* used for running the transactions.

## VI. EVALUATION

To evaluate our solution, we used the D1NAMO dataset [35], a publicly available dataset of 29 patients who collected data using wearables and smartphone technology. The dataset contains data from 20 healthy (H#001-020) patients and 9 with diabetes (D#001-009). Every participant in the dataset collected data for 3 to 4 days. Among others, these data include heart rate, activity, and breathing collected via a wearable sensor. The 29 participants signed an informed consent form during the collection of the data. The data is now open to everyone, but the given consent remains unchanged and within the organization that collected the data. Currently, there is no way to meaningfully follow up on the study with the same data providers. Research clearly suggests that as the needs of future researchers studying data change, the individual consent of the participants

also evolves [36]–[39]. For this reason, we assume that the 29 individuals in the dataset might have different wishes regarding their data use now and therefore would provide different consent terms. For example, a diabetic patient might opt to open the data for the research community by expressing a consent statement in the primary category of the DUO model, while other patients are not open to sharing their data with a broad consent. In this case, they could opt for a *disease-specific* category of consent and share the data only for research on a particular disease. In order to evaluate our consent model, we consider different data provider profiles and data requesters with different data request statements.

### 1) DATA PROVIDER PROFILES

Table 3 represents three data provider profiles. They are classified as *open*, *restrictive*, and *very-restrictive* in relation to their consent statement. A data provider consent statement is classified as *open* if it shares the data for general research use and profit-making purpose. In the *restrictive* data provider category, a data provider refuses to share data for general research. Instead, s/he makes the data available for health research and profit-making purposes only. This means that a data requester who requests the data for general research use is unable to access the data.

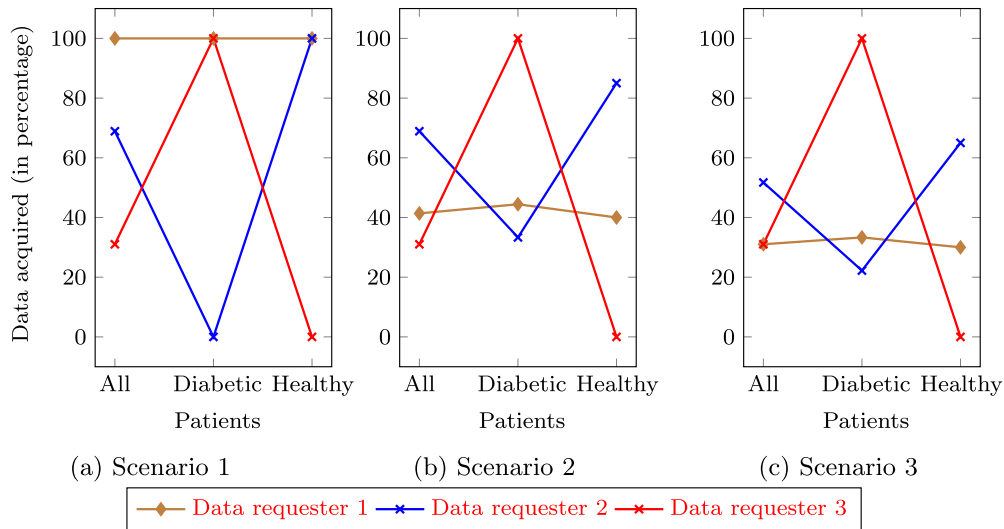


FIGURE 6. Access control evaluation over D1NAMO dataset.

TABLE 3. Data provider profiles for consent representation.

	Open	Restrictive	Very restrictive
General research	✓	✗	✗
HMB research	✗	✓	✗
DS research	✗	✗	✓
Profit-use	✓	✓	✗

DS= Disease-specific

TABLE 4. Data requester's profiles for purpose of use statement representation.

	Data req. 1	Data req. 2	Data req. 3
General research	✓	✗	✗
HMB research	✗	✓	✗
DS research	✗	✗	✓
Profit-use	✓	✓	✗

DS= Disease-specific

In the *very-restrictive* category, data providers share the data only for disease-specific research use such as diabetes, cancer, etc. It also opts out from sharing the data for profit-use purposes. Therefore, if a data requester has a profit-making intention, it will be denied access to the data. These are the three major categories where we categorized the data provider consent statements.

## 2) DATA REQUESTER PROFILES

Table 4 represents the data requester profiles divided into three categories. *Data requester 1* is requesting data access for general research use and profit-making intention i.e. it is requesting the data for *method development* or any other research use. *Data requester 2* is requesting data access for HMB research and profit-making intention i.e. it is requesting the data access for *fundamental biology data* or any other data category described in ADA-M matrix form. Similarly, *Data requester 3* is requesting data access for disease-specific

research and non-profit use. In the following, we randomly assign a profile to every user. Based on the profile, we define their individual consent and measure what portion of the dataset the data requesters will be able to access given the different individual consent forms in the platform.

Based on the different data provider profiles defined earlier, we simulate the following scenarios:

- 1) Scenario 1: 100% open
- 2) Scenario 2: 40% open, 40% restrictive, 20% very-restrictive
- 3) Scenario 3: 30% open, 30% restrictive, 40% very-restrictive

Scenario 1 creates consent statements where all the data providers are open to share their data. Thereby, all the patients open their data for general research and profit making purposes. Scenario 2 simulates consent statements where 40% of data providers are *open*, while 40% are *restrictive* and rest 20% are *very-restrictive*. Similarly, in the case of scenario 3, data providers submit consent statements where 30% are *open*, while 30% are *restrictive* and the rest 40% are *very-restrictive*. This represents the data providers who are more restrictive compared to the previous scenarios but they are open to share more for disease-specific purposes. In this evaluation, we expect that individual consent introduces more individual data sharing control and that the individual dynamics will reflect on which purpose of use statement will be more successful in obtaining the data.

*Scenario 1:* In *scenario 1*, everyone is willing to share their data, that means all the healthy and unhealthy subjects are open to share the data with others. Therefore, as seen in Fig. 6, data requester 1 can access the whole data shared by data providers. Data requester 2 is requesting data for HMB research, therefore it will access only the data from healthy patients, which is the portion of the data needed for this research. Overall, data requester 2 will get the 68.9% of the dataset. Similarly, data requester 3 is requesting the data for disease-specific research and non-profit use, therefore,



**TABLE 5. Consent matching in Scenario 1.**

	No. of data provider's	Data req. 1	Data req. 2	Data req. 3
D#002	9	✓	✗	✓
H#002	20	✓	✓	✗

DS= Disease-specific

**TABLE 6. Consent matching in Scenario 2.**

	No. of data provider's	Data req. 1	Data req. 2	Data req. 3
D#002	4	✓	✗	✓
H#002	8	✓	✓	✗
D#004	3	✗	✓	✓
H#004	9	✗	✓	✗
D#005	2	✗	✗	✓
H#005	3	✗	✗	✗

DS= Disease-specific

s/he will be able to access the data from diabetic patients as requested by the research purpose statement. This is because all the data providers open their data for profit use and therefore, non-profit data requesters will also get access to the data. We observe a detailed view of consent matching for Scenario 1 in Table 5.

*Scenario 2:* In *scenario 2*, as seen in Fig. 6, we observe a drop in the percentage of data shared with the data requester 1. It means, based on the consent specified by data providers, there is more access control by the consent model. This is explained by the fact that only 40% of the data providers are open. All the other data providers in this scenario are now restrictive or very-restrictive. We observe that data requester 1 only accesses 41.37% of the dataset, a considerably lower percentage compared to the previous scenario. However, we observe an increase in percentage for data requester 2 that access 68.96% of the dataset. This happens because data requester 2 is requesting data with a more specific purpose of use (HMB research). Moreover, 40% of data providers who are restrictive will grant access to more specific research statements (such as HMB research). Similarly, for data requester 3, we don't see any changes in the dataset access percentage. Since data requester 3 is seeking data for disease-specific and non-profit use, therefore, it will always match the consent, even from the restrictive user profiles. We observe a detailed view of consent matching results for Scenario 2 in Table 6.

*Scenario 3:* In *scenario 3*, as seen in Fig. 6, we observe a sharing percentage drop for data requester 1 and 2 compared to the previous scenarios. Since only 30% data providers are open while the majority of data providers are very-restrictive, there is a strict access control by the consent model. We observe that data requester 1 can only access 31.03% of the dataset while data requester 2 can only access 51.72% of the dataset. We observe no changes in percentage for data requester 3 which is explained by the profile of

**TABLE 7. Consent matching in Scenario 3.**

	No. of data provider's	Data req. 1	Data req. 2	Data req. 3
D#002	3	✓	✗	✓
H#002	6	✓	✓	✗
D#004	2	✗	✓	✓
H#004	7	✗	✓	✗
D#005	4	✗	✗	✓
H#005	7	✗	✗	✗

DS= Disease-specific

data requester 3 which is requesting data for disease-specific research. We observe a detailed view of consent matching results for Scenario 3 in Table 7.

Fig. 6, shows the evaluation results in the three different scenarios. The results show that i) our consent model for data sharing gives users greater data control and ii) different user consents will reflect the specificity of purpose of use statements.

### 3) COST ANALYSIS

To understand the applicability of the consent model, we perform a cost analysis to evaluate the applicability of our smart contract model. In performing the cost analysis, we considered several parameters:

- 1) Total amount of gas spent during contract deployment.
- 2) Amount of gas consumed on executing the data provider consent.
- 3) Amount of gas consumed on executing the data requester queries.
- 4) Amount of gas spent while matching the consent.

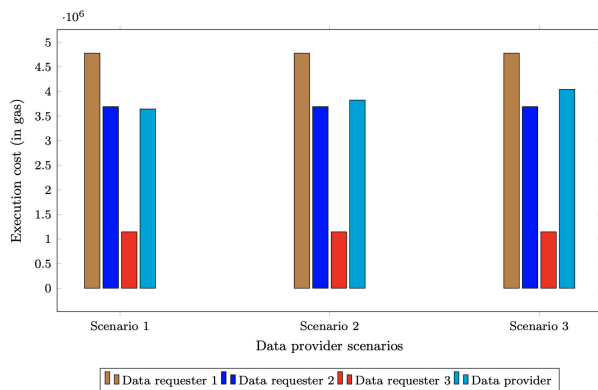
In the Ethereum environment, every operation in the smart contract consumes some amount of gas (a measure of the computational effort required to perform an operation). Some operations require more computational effort than others, therefore the gas consumption can vary. We evaluate gas consumption of the smart contract based on the relevant operations and based on who is performing them (the data provider or the data requester). Table 8 shows the total gas consumption to execute the contract is 1765926. We considered the average gas price of 8 Gwei according to the current date and time of ETH gas station [40]. Therefore, the relevant cost of contract deployment is 0.0141274 ETH with a corresponding price of \$ 2.92.

To better understand the involved costs, we calculate the total cost of contract deployment and the cost of interactions between the data providers and data requesters. Therefore, the total cost for sharing the data is measured by the accumulative cost of contract deployment, the cost for submitting the consent, and the data requesters' cost for querying the data. Fig. 7 shows the amount of gas consumption for different scenarios. From the results, we can observe that most data requesters consume more gas than data providers. This is explained by the number of interactions that they have with the smart contracts of data providers. The broader the

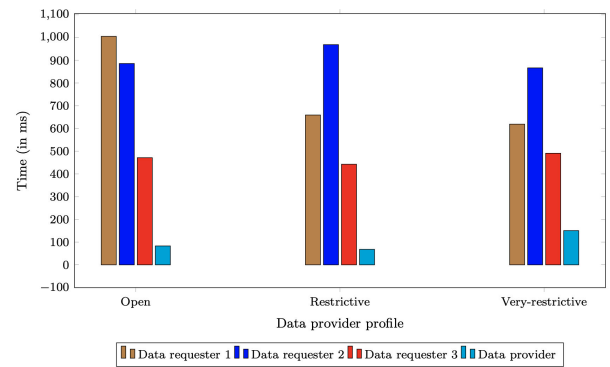
**TABLE 8. Gas consumption of smart contract.**

Actions	Transaction cost	Execution cost	Ether cost	Cost*
Deployment	2372326	1765926	0.0141274	\$ 2.92437
UploadData				
PrimaryCategory	88129	64745	0.000518	\$ 0.10567
UploadData				
SecondaryCategory	26814	3622	0.000029	\$ 0.00592
UploadData				
Requirements	60053	36285	0.0002903	\$ 0.05922
giveResearch				
Purpose	87280	63896	0.0005112	\$ 0.10428
giveHMBPurpose	45902	22198	0.0001776	\$ 0.03623
giveClinical				
Purpose	44699	21635	0.0001731	\$ 0.03531
giveGeographic				
SpecificRestriction	25182	2374	0.000019	\$ 0.00388
giveProfit	44723	21723	0.0001738	\$ 0.03546
givePerson	45357	22101	0.0001768	\$ 0.03606
giveData				
RequesterTerms	46265	22177	0.0001774	\$ 0.03619
AccessData (Max)	84341	60253	0.000482	\$ 0.09833
AccessData (Min)	32543	8455	0.0000676	\$ 0.01379

\*= Ether conversion with present date price (Average (8 Gwei))

**FIGURE 7. Gas consumption in different scenarios for the whole dataset.**

expressed purpose of the use is, the more data providers may be contacted to ask for data access. This is also reflected in the fact that the data requester 3, who is looking only for diabetes data, will be requesting the data only of 9 of the 29 participants as opposed to data provider 1 and 2 who will contact all 29. Furthermore, data providers who are more restrictive would have to evoke additional functions in the smart contract than the more open data requesters, which is reflected in a slight increase in costs for data providers by approximately 6 percent, amounting to \$ 0.006. A detailed table of costs is shown in 8. It is possible to fund the data provider costs by requesting a small fee to be paid by the data

**FIGURE 8. Latencies of data providers and data requesters.**

requesters when the data is accessed. The overall costs in the system will remain the same, however, the incentives between data requesters and data providers could be better balanced if data requesters did not occur costs to share their data. The deployment cost for one smart contract is  $\approx$  \$ 3, which is covered once by the data provider. The total deployment cost of the whole D1NAMO dataset amounts to \$87. To place this into perspective, the costs of the D1NAMO dataset project are approximately several thousand more. While these studies are important, the data collection could be achieved by our model with minor efforts and with more flexibility for secondary uses of the same data.

#### *a: LATENCY MEASUREMENTS*

With an increasing willingness to share data, we believe that individual data could be collected in much shorter time frames. While platforms like LUCE are not available to the public yet, we show that it would be possible to efficiently reconstruct databases even in scenarios where users would not be always fully open to data sharing. For example, if we want to develop the same dataset of 29 patients, each patient can easily share data on the LUCE platform by submitting their consent. As seen in Fig. 8, the latency of a data requester is higher due to the interaction with multiple contracts. The single interaction with one smart contract is in the order of 50 ms. This means that for interacting with 1000 potential data providers, it would take about 50 seconds. The interaction with all the 29 patients in the dataset, it takes 1.5 seconds. Fig. 8 shows the average interaction by each data requester which is  $\approx$  1 sec. Moreover, it takes an average of 220 ms to submit queries by each data requester. The latency for data providers might vary. For example, a very-restrictive data provider uses the *UploadDataRequirements* function, which takes  $\approx$  150.6 ms to execute.

## **VII. DISCUSSION**

In this section, we discuss several issues related to data sharing using a blockchain-based consent model.

### **A. SCALABILITY**

Our blockchain-based consent model gives more flexibility than current methods where organizations must ask for consent using physical forms. Also, smart contracts reduce or

eliminate the need for a trusted third party to process the data. As a result, the cost of data sharing between organizations or individuals is reduced. This model enables large data collection with fast processing and in limited time. Currently, there is a lot of data that is unused because of unfair data sharing practices. With our model, we expect more individual adherence to data sharing. Scalability in blockchain platforms can become a challenge when the number of users increases [41], and in our future work, we will seek to measure how well the platform scales with a large number of users.

### B. DATA HETEROGENEITY FOR DATA SHARING

Shared data are heterogeneous in nature. When sharing data in our platform, there is a need for common ontological representation models where data providers can describe their contents related to their consent. Solutions such as OHDSI [42] and other health data ontological solutions can help to better represent the contents of the shared data.

### C. DATA PRIVACY AND ACCESS CONTROL

In our consent model, individuals are enabled to express consent over their data use and change, modify or request to delete all data if desired. This ensures compliance with privacy protection laws such as the GDPR. Moreover, the transaction data stored in the blockchain do not reveal patient identities nor contain the records of patients. They are rather transactions containing the information about who accessed what records for which purpose. However, there is a need for detailed studies on how these models can be enrolled in a secure and privacy-preserving manner [43]–[46]. The security and privacy aspects were not the focus of this work, but we believe that they are imperative for users' acceptance of such solutions. In future work, we will investigate the use of cryptographic protocols, such as multi-party computation [47], and token-generation [48] for further securing the data-sharing platform.

## VIII. CONCLUSION AND FUTURE WORK

Data privacy is an important issue for most data providers. In the data sharing context, data requesters must comply with GDPR and the consent of data providers. We found that work on facilitating data sharing with user consent is in an early stage. In this article, we proposed a framework for sharing data with explicit consent from data providers. We use the DUO and ADA-M model to embed a standardized ontological consent and data request model. We developed a smart contract to automate a generic consent model, and deployed and tested the solution in LUCE, our data sharing platform. The evaluation shows that data providers achieve data control while sharing the data using our blockchain-based consent model.

As future work, we plan to investigate the scalability of our model where we will measure the impact of the model in real-life scenarios where the number of data providers or data requesters is very large. This could impact the performance of data sharing which is a current working issue in any

blockchain platform. Furthermore, we plan to simulate large tests to ensure that the consent mechanism maintains privacy for data providers.

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## REFERENCES

- [1] B. Marr, *How Much Data do we Create Every Day? The Mind-Blowing Stats Everyone Should Read*. Accessed: Dec. 15, 2019. [Online]. Available: <https://www.forbes.com/sites/bernardmarr/2018/05/21/how-much-data-do-we-create-every-day-the-mind-blowing-stats-everyone-should-read/#4508696a60ba/>
- [2] *Cambridge Analytica Facebook*. Accessed: Dec. 15, 2019. [Online]. Available: <https://www.theguardian.com/news/2018/mar/17/cambridge-analytica-facebook-influence-us-election>
- [3] J. van Dijck, D. Nieborg, and T. Poell, "Reframing platform power," *Internet Policy Rev.*, vol. 8, no. 2, pp. 1–10, Jun. 2019.
- [4] L. Piwek, D. A. Ellis, S. Andrews, and A. Joinson, "The rise of consumer health wearables: Promises and barriers," *PLOS Med.*, vol. 13, no. 2, Feb. 2016, Art. no. e1001953.
- [5] M. Venkataramanan, "My identity for sale," in *Proc. WIRED*, Nov. 2014, pp. 1–4.
- [6] L. J. Kish and E. J. Topol, "Unpatients, why patients should own their medical data," *Nature Biotechnol.*, vol. 33, no. 9, p. 921, 2015.
- [7] *General Data Protection Regulation*. Accessed: Dec. 15, 2019. [Online]. Available: <https://gdpr-info.eu>
- [8] N. Purtova, "The illusion of personal data as no one's property," *Law, Innov. Technol.*, vol. 7, no. 1, pp. 83–111, Jan. 2015.
- [9] O. P. Foundation, "Ocean protocol: A decentralized substrate for ai data & services technical whitepaper," Ocean Protocol Found., Singapore, Tech. Whitepaper Version 2019-APR-15, 2019.
- [10] X. Liang, S. Shetty, D. Tosh, C. Kamhoua, K. Kwiat, and L. Njilla, "ProvChain: A blockchain-based data provenance architecture in cloud environment with enhanced privacy and availability," in *Proc. 17th IEEE/ACM Int. Symp. Cluster, Cloud Grid Comput. (CCGRID)*, May 2017, pp. 468–477.
- [11] A. Ramachandran and D. Murat Kantarcioglu, "Using blockchain and smart contracts for secure data provenance management," 2017, *arXiv:1709.10000*. [Online]. Available: <http://arxiv.org/abs/1709.10000>
- [12] A. Azaria, A. Ekblaw, T. Vieira, and A. Lippman, "MedRec: Using blockchain for medical data access and permission management," in *Proc. 2nd Int. Conf. Open Big Data (OBD)*, Aug. 2016, pp. 25–30.
- [13] S. O. M. Dyke, A. A. Philippakis, J. Rambla De Argila, D. N. Paltoo, E. S. Luetkemeier, B. M. Knoppers, A. J. Brookes, J. D. Spalding, M. Thompson, M. Roos, K. M. Boycott, M. Brudno, M. Hurler, H. L. Rehm, A. Matern, M. Fiume, and S. T. Sherry, "Consent codes: Upholding standard data use conditions," *PLOS Genet.*, vol. 12, no. 1, pp. 1–9, 01 2016, doi: [10.1371/journal.pgen.1005772](https://doi.org/10.1371/journal.pgen.1005772).
- [14] J. P. Woolley, E. Kirby, J. Leslie, F. Jeanson, M. N. Cabili, G. Rushton, J. G. Hazard, V. Ladas, C. D. Veal, S. J. Gibson, A.-M. Tassé, S. O. M. Dyke, C. Gaff, A. Thorogood, B. M. Knoppers, J. Wilbanks, and A. J. Brookes, "Responsible sharing of biomedical data and biospecimens via the automatable discovery and access Matrix (ADA-M)," *NPJ Genomic Med.*, vol. 3, no. 1, p. 7, Dec. 2018.
- [15] N. Havelange, M. Dumontier, B. Wouters, J. Linde, D. Townsend, A. Riedl, and V. Urovi, "LUCE: A blockchain solution for monitoring data license accountability and Compliance," 2019, *arXiv:1908.02287*. [Online]. Available: <https://arxiv.org/abs/1908.02287>
- [16] S. Nakamoto, "Bitcoin: A peer-to-peer electronic cash system," Bitcoin Tech. White Paper, Oct. 2008. [Online]. Available: <https://bitcoin.org/bitcoin.pdf>
- [17] *Ethereum White-Paper*. Accessed: Dec. 15, 2019. [Online]. Available: <https://github.com/ethereum/wiki/wiki/White-Paper>
- [18] N. Szabo, "The idea of smart contracts," Nick Szabo's Papers Concise Tuts., Tech. White Paper, 1997.

- [19] Z. Zheng, S. Xie, H.-N. Dai, W. Chen, X. Chen, J. Weng, and M. Imran, "An overview on smart contracts: Challenges, advances and platforms," *Future Gener. Comput. Syst.*, vol. 105, pp. 475–491, Apr. 2020.
- [20] V. Buterin, "A next generation smart contract & decentralized application platform," Ethereum Tech. White Paper, 2014.
- [21] D. T. Stein and S. F. Terry, "Reforming biobank consent policy: A necessary move away from broad consent toward dynamic consent," *Genetic Test. Mol. Biomarkers*, vol. 17, no. 12, pp. 855–856, Dec. 2013, doi: [10.1089/gtmb.2013.1550](https://doi.org/10.1089/gtmb.2013.1550).
- [22] B. Genge, K. Rantos, G. Drosatos, A. Kritsas, C. Ilioudis, A. Papanikolaou, and A. P. Filippidis, "A blockchain-based platform for consent management of personal data processing in the iot ecosystem," *Secur. Commun. Netw.*, vol. 2019, Oct. 2019, Art. no. 1431578, doi: [10.1155/2019/1431578](https://doi.org/10.1155/2019/1431578).
- [23] E. R. Riggs, on behalf of the Clinical Genome Resource Education Working Group, D. R. Azzariti, A. Niehaus, S. R. Goehringer, E. M. Ramos, L. L. Rodriguez, B. Knoppers, H. L. Rehm, and C. L. Martin, "Development of a consent resource for genomic data sharing in the clinical setting," *Genet. Med.*, vol. 21, no. 1, pp. 81–88, Jan. 2019.
- [24] E. Maler, "Extending the power of consent with user-managed access: A standard architecture for asynchronous, centralizable, Internet-scalable consent," in *Proc. IEEE Secur. Privacy Workshops*, May 2015, pp. 175–179.
- [25] T. T. Thwin and S. Vasupongayya, "Blockchain based secret-data sharing model for personal health record system," in *Proc. 5th Int. Conf. Adv. Inform., Concept Theory Appl. (ICAICTA)*, Aug. 2018, pp. 196–201.
- [26] A. Dubovitskaya, Z. Xu, S. Ryu, M. Schumacher, and F. Wang, "Secure and trustable electronic medical records sharing using blockchain," in *Proc. AMIA*, 2017, pp. 650–659.
- [27] X. Zheng, R. R. Mukkamala, R. Vatrappu, and J. Ordieres-Mere, "Blockchain-based personal health data sharing system using cloud storage," in *Proc. IEEE 20th Int. Conf. e-Health Netw., Appl. Services (Health-com)*, Sep. 2018, pp. 1–6.
- [28] K. Bhaskaran, P. Ilfrich, D. Liffman, C. Vecchiola, P. Jayachandran, A. Kumar, F. Lim, K. Nandakumar, Z. Qin, V. Ramakrishna, E. G. Teo, and C. H. Suen, "Double-blind consent-driven data sharing on blockchain," in *Proc. IEEE Int. Conf. Cloud Eng. (IC2E)*, Apr. 2018, pp. 385–391.
- [29] E. Androulaki, "Hyperledger fabric: A distributed operating system for permissioned blockchains," in *Proc. 13th EuroSys Conf.*, Apr. 2018, pp. 1–15, doi: [10.1145/3190508.3190538](https://doi.org/10.1145/3190508.3190538).
- [30] R. Neisse, G. Steri, and I. Nai-Fovino, "A blockchain-based approach for data accountability and provenance tracking," in *Proc. 12th Int. Conf. Availability, Rel. Secur.*, Aug. 2017, pp. 1–10, doi: [10.1145/3098954.3098958](https://doi.org/10.1145/3098954.3098958).
- [31] Solidity. Accessed: Jan. 15, 2019. [Online]. Available: <https://solidity.readthedocs.io/en/v0.6.4/>
- [32] Ganache. Accessed: Jan. 15, 2019. [Online]. Available: <https://www.trufflesuite.com/docs/ganache/overview>
- [33] Ethereum Javascript Api. Accessed: Jan. 15, 2019. [Online]. Available: <https://web3js.readthedocs.io/en/v1.2.6/>
- [34] Django. Accessed: Jan. 15, 2019. [Online]. Available: <https://docs.djangoproject.com/en/3.0/>
- [35] F. Dubosson, J.-E. Ranvier, S. Bromuri, J.-P. Calbimonte, J. Ruiz, and M. Schumacher, "The open D1NAMO dataset: A multi-modal dataset for research on non-invasive type 1 diabetes management," *Informat. Med. Unlocked*, vol. 13, pp. 92–100, Oct. 2018.
- [36] J. Kaye, E. A. Whitley, D. Lund, M. Morrison, H. Teare, and K. Melham, "Dynamic consent: A patient interface for twenty-first century research networks," *Eur. J. Human Genet.*, vol. 23, no. 2, pp. 141–146, 2015.
- [37] J. Kaye, L. Curren, N. Anderson, K. Edwards, S. M. Fullerton, N. Kanellopoulou, D. Lund, D. G. MacArthur, D. Mascalzoni, J. Shepherd, P. L. Taylor, S. F. Terry, and S. F. Winter, "From patients to partners: Participant-centric initiatives in biomedical research," *Nature Rev. Genet.*, vol. 13, no. 5, pp. 371–376, May 2012.
- [38] I. Chalmers, "People are 'participants' in research: Further suggestions for other terms to describe 'participants' are needed," *BMJ, Brit. Med. J.*, vol. 318, no. 7191, p. 1141, 1999.
- [39] E. M. Meslin and M. K. Cho, "Research ethics in the era of personalized medicine: Updating Science's contract with society," *Public Health Genomics*, vol. 13, no. 6, pp. 378–384, 2010.
- [40] Eth Gas Station. Accessed: Mar. 20, 2020. [Online]. Available: <https://ethgasstation.info/>
- [41] M. Vukolić, "The quest for scalable blockchain fabric: Proof-of-work vs. bft replication," in *Open Problems in Network Security*, J. Camenisch and D. Kesdoğan, Eds. Cham, Switzerland: Springer, 2016, pp. 112–125.
- [42] Observational Health Data Sciences and Informatics. Accessed: Mar. 20, 2020. [Online]. Available: <https://www.ohdsi.org>
- [43] F. Wang, J. Mickens, N. Zeldovich, and V. Vaikuntanathan, "Sieve: Cryptographically enforced access control for user data in untrusted clouds," in *Proc. 13th USENIX Symp. Netw. Syst. Des. Implement.*, Santa Clara, CA, USA, Mar. 2016, pp. 611–626. [Online]. Available: <https://www.usenix.org/conference/nsdi16/technical-sessions/presentation/wang-frank>
- [44] L. Sweeney, "K-anonymity: A model for protecting privacy," *Int. J. Uncertain. Fuzziness Knowl.-Based Syst.*, vol. 10, no. 5, p. 557–570, Oct. 2002, doi: [10.1142/S0218488502001648](https://doi.org/10.1142/S0218488502001648).
- [45] A. Narayanan and V. Shmatikov, "Robust de-anonymization of large sparse datasets," in *Proc. IEEE Symp. Secur. Privacy*, 2008, pp. 111–125, doi: [10.1109/SP.2008.33](https://doi.org/10.1109/SP.2008.33).
- [46] B. Huang, R. Zhang, Z. Lu, Y. Zhang, J. Wu, L. Zhan, and P. C. K. Hung, "BPS: A reliable and efficient pub/sub communication model with blockchain-enhanced paradigm in multi-tenant edge cloud," *J. Parallel Distrib. Comput.*, vol. 143, pp. 167–178, Sep. 2020. [Online]. Available: <http://www.sciencedirect.com/science/article/pii/S0743731520302847>
- [47] A. C.-C. Yao, "How to generate and exchange secrets," in *Proc. 27th Annu. Symp. Found. Comput. Sci.*, Oct. 1986, pp. 162–167.
- [48] P. K. Sharma, M.-Y. Chen, and J. H. Park, "A software defined fog node based distributed blockchain cloud architecture for IoT," *IEEE Access*, vol. 6, pp. 115–124, 2018.



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