ERRIN ICT Working Group Meeting on Blockchain

Brussels, 13 June 2018

Anna Rizzo

(Project Coordinator)
MyHealthMyData (MHMD) is a Horizon 2020 Research and Innovation Action (ICT-18-2016 - Big data PPP: privacy-preserving big data technologies) developing a blockchain-based platform for sharing and exchanging PERSONAL HEALTH DATA for medical care, research and development.
MHMD stakeholders

Data providers

- Individuals
- Hospitals

Data users

- Biomedical and pharma industry
- Academia
MHMD at a glance

- **Duration**  November 1, 2016 – October 31, 2019
- **Funding**  €3,456,190
- **Consortium**

5 SMEs

4 Clinical partners

4 Research centres and Academia

1 Legal consultancy  1 Industry
WHY MHMD?
Medical data are more threatened than ever.

**The Problem in Figures**

- **5.6 Billion Dollars/Year** spent in the US to protect healthcare data.

- **27.8/67.7 Millions** of medical records breached since 2009.

- **Black Market Prices** 10x higher for medical records in respect to other industries.

- **More than 193 Million** personal records open to fraud and identity theft in 2015.
...while patients and citizens are not taking part in the health process

Currently, patient is “the single most unused person in health care”.
Public initiatives are calling for individuals and patient engagement...
ENTERS THE GDPR:
new rights, new opportunities

- **Data access:** “A data subject should have the right of access to personal data which have been collected concerning him or her”

- **Data portability:** receive personal data in a “structured, commonly used, machine-readable and interoperable format”

- **Patient consent:**
  - Freely given, informed, and specific
  - Easily readable, and in plain language
  - Data Controller will have to demonstrate consent
(1) DATA PRIVACY AND SECURITY
Securing and de-identifying sensible data making use of state-of-the-art data security and privacy-preserving technologies

(2) DATA VALUE ENHANCEMENT
Leverage the value of biomedical datasets for medical care, research and business

(3) CITIZENS’ EMPOWERMENT
Grant individuals ownership and control of their personal health data
How will MHMD do that?
Using blockchain and smart contracts

**BLOCKCHAIN**
The data platform will rely on the blockchain system, a digital ledger where data is trimmed in hash-based language code and data transactions are visible to the entire network of stakeholders, minimizing any possibility of fraudulent usage.

**SMART CONTRACTS**
Self-executing contractual states, based on the formalisation of contractual relations in digital form, will automate the execution of peer-to-peer transactions under user-defined conditions.
A secure, non-editable digital ledger where:

- All transactions are confirmed by the network as entries forming blocks of transactions
- The whole network monitors the legitimacy of each transaction, guaranteeing a distributed control system

Applying the blockchain approach to health data will guarantee a distributed control over lawfulness and legitimacy of data transactions
A consortium blockchain

Based on Hyperledger Fabric

- Lightweight (not computationally and energy hungry)
- High transactions throughput (1500 transactions per second)
- Open source but production quality
- Modular and flexible: can be adapted according to the data governance model
- Simple to use and performant

- **Private and permissioned:** collectively defined membership and access rights within the consortium members

No consensus mechanism required (computationally demanding): all consortium members are already trusted parties
Self-executing contractual states, based on the formalisation of contractual relations in digital form, that automate the execution of peer-to-peer transactions under user-defined conditions.

Regulate data transactions on the blockchain, allowing to set use conditions and consent options for different stakeholders and purposes.
Regulating data access and enforcing consent through a smart contract

Smart contract – conditions: Consent available for the data
ID data
ID user

Data consent

Type of consented purpose

Subject requiring the data

Smart contract – conditions: Purpose for data processing consented

Smart contract – conditions: The subject is authorised to receive the data

Data access granted
MHMD key innovations for patients

PERSONAL DATA ACCOUNTS
Personal storage clouds will enable individuals to access their data from any technological device through the blockchain and employ them for personal use.

DYNAMIC CONSENT
A dynamic consent interface will allow users to grant, deny or revoke consent to data access for different uses according to their preferences.
Personal storage clouds enabling individuals to access their data from any technological device through the blockchain and employ them for personal use.

Aggregate personal data from disparate sources (social media accounts, clinical data repositories, personal drives, wearable devices, etc.), in a single, user-owned account.
Dynamic Consent allows to extend traditional consents into a user workflow in which patients may or may not allow access to their data based on a range of key parameters:

- **What will data be used for**
- **What data will be retained**
- **What data will be shared with 3rd parties and for what purpose**
- **How will the right to be forgotten be implemented**
- **Define post-mortem usage or donation of personal data.**
MHMD key innovations for security, privacy, and data usage

MULTILEVEL DE-IDENTIFICATION AND ENCRYPTION TECHNOLOGIES
Multi-party secure computation and homomorphic encryption techniques will be employed for encoding and de-associating sensible data from the owners’ identity, still allowing the application of advanced analytics on pseudonymised or anonymised data.

BIG DATA ANALYTICS
The project will explore the feasibility of applications leveraging the value of large clinical datasets, particularly advanced data analytics, medical annotation retrieval engines and patient-specific models for physiological prediction.
(5) MULTILEVEL DE-IDENTIFICATION AND ENCRYPTION TECHNOLOGIES

- Multi-party secure computation
- Homomorphic encryption

- Encode and de-associate sensible data from the owners’ identity, still allowing the application of advanced analytics

- Allow computation on encrypted data
(6) PENETRATION AND RE-IDENTIFICATION CHALLENGE
Checking the ability of avoiding privacy & security breaches

- Penetration testing and vulnerability assessment on the project federated Infostructure

- Active self-hacking and public hacking simulations

- Testing external re-identification possibilities on
  1) synthetic datasets attributed to virtual patients
  2) patients consenting to being used as test-basis
Synthetic datasets: machine learning to enable machine learning

• Fully artificial data automatically generated by recursive conditional parameter aggregation with global statistical models through machine learning algorithms.

• According to MIT Institute for Data, Systems and Society: “artificial data give the same results as real data, without compromising privacy”

In MHMD, synthetic cardiology data sets have been obtained at Barts’ Hospital (QMUL) based on aggregate statistics of a population of 100,000 patients. The datasets contain fake names, addresses, DOB, DOD, episode visits, anthropometry (e.g. weights, heights, BMI, BSA, etc.) and cardiac function parameters, etc.

Synthetic data have been preliminary used for data mapping, profiling and testing privacy-preserving algorithms.
The **MHMD DATA CATALOGUE** will allow potential data users:

- To have a **preliminary look** at the type of **datasets available** on the platform
- Perform some **high-level descriptive statistics** on the data through the use of **multi-part computation**
BI Big Data Analytics

Leveraging the value of large biomedical datasets

The project will explore the feasibility of

1. advanced data analytics
2. medical annotation retrieval engines
3. patient-specific models for physiological prediction on de-identified and encrypted data
The MHMD user interface

Use your data to advance medical research

INDIVIDUALS
HOSPITALS
DATA USERS
## Upload Data

### Search/Filter Data

<table>
<thead>
<tr>
<th>Data Providers</th>
<th>Data Types</th>
<th>Search by keyword/identifier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Select</td>
<td>Select</td>
<td>Keywords Here</td>
</tr>
</tbody>
</table>

### Your Data

<table>
<thead>
<tr>
<th>Data Permissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permissions Setting 1</td>
</tr>
<tr>
<td>Permissions Setting 2</td>
</tr>
<tr>
<td>Permissions Setting 3</td>
</tr>
<tr>
<td>Permissions Setting 4</td>
</tr>
<tr>
<td>Permissions Setting 5</td>
</tr>
</tbody>
</table>

### Data Categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-Category</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
<tr>
<td>Data</td>
<td>Data Sub-Category</td>
<td>Data Item</td>
</tr>
</tbody>
</table>
Use the data that powers your digital life to help others.

Harness your data to participate in medical research.
INDIVIDUALS

TAKE CONTROL OF YOUR DATA

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim.

Email
name@domain.com

Password

Don't have an account? Sign Up

LOG IN

LET'S GET YOUR DATA

Connect with your digital account to get access to your data stored securely in the cloud.
INDIVIDUALS
INDIVIDUALS
DATA USERS

Search the Data Catalogue

Keywords
Data Provider Type
Data Modality
Data Sensitivity

What’s inside our data catalogue?

Data Providers
- Unit 1
- Unit 2
- Unit 3

Data Types
- Unit 1
- Unit 2
- Unit 3
- Unit 4

Diseases
- Unit 1
- Unit 2
- Unit 3
- Unit 4

Drugs & Chemicals
- Unit 1
- Unit 2
- Unit 3
- Unit 4
**Data Users**

**Search the Data Catalogue**

- **Data Providers:**
  - Variable
  - Variable

- **Data Types:**
  - Variable

- **Keywords:**
  - Variable
  - Variable

**Search Results**

Page 1/1 (2 individuals / 5 records found)

<table>
<thead>
<tr>
<th>PID</th>
<th>Title</th>
<th>Description</th>
<th>Data Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.15785/MHMD/982</td>
<td>Title Goes Here Like This</td>
<td>Description goes here like this and can be about this long</td>
<td>Data Provider Name Here</td>
</tr>
<tr>
<td>10.15785/MHMD/983</td>
<td>Title Goes Here Like This</td>
<td>Description goes here like this and can be about this long</td>
<td>Data Provider Name Here</td>
</tr>
</tbody>
</table>
Thank You!

Contacts:
info@myhealthmydata.eu

Website:
http://www.myhealthmydata.eu/

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 732907