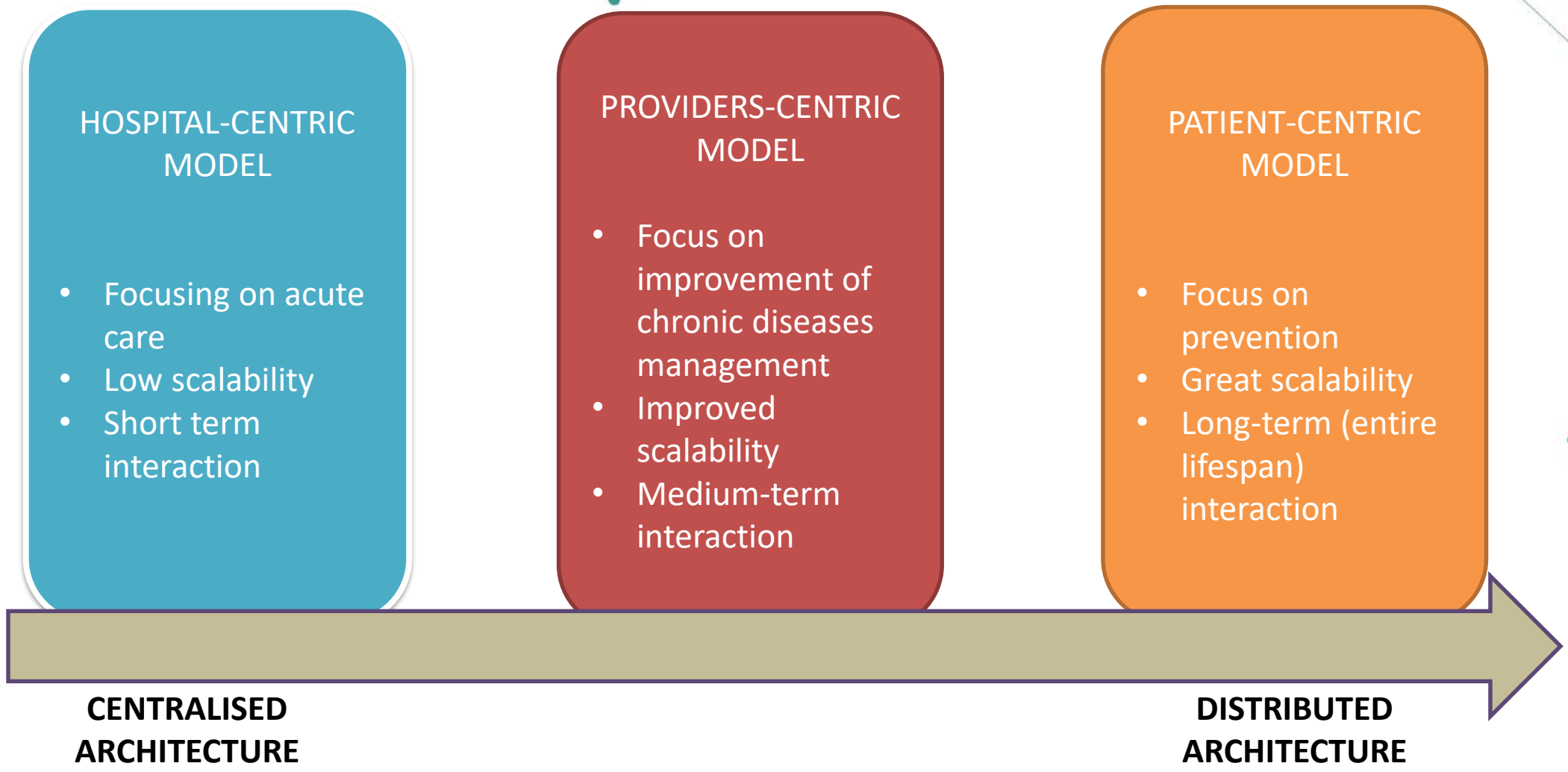
MY HEALTH
MY DATA

Blockchain and Healthcare

Mirko De Maldè – Lynkeus (Project Coordinator)

Frankfurt Blockchain Summit – Frankfurt – 25th March 2019

From the centrality of the hospital to the centrality of the patient



Limits of centralisation and the role of blockchain

Limits of centralization:

Multiple, centralized databases have proven to be:

- Vulnerable
- Expensive
- Unable to provide the integration needed for enabling truly personalized care

Blockchain opportunities

The blockchain/DLTs might be helpful a complex environment such as healthcare where:

a) Multiple actors (professionals, nurses, patients, payors, researchers)…

b) …need to access and exchange data in a secure manner…

c) …while respecting relevant regulations…

d) …ensuring data integrity …

e) …interacting with external stakeholders (research centers, biomedical industries…)

f) …without necessarily trust each others

Blockchain and DLTs can hopefully support such a process addressing the current shortcomings and offering an alternative way to:

- Filling the **«trust gap»**
- **Automating** data exchange, business processes, and relevant policies' enforcement
- Ensure regulatory **compliance**

Why blockchain is relevant for healthcare

- Overcoming issues associated with **centralized healthcare data management**
- Enabling individual **self-sovereignity and patient-centric healthcare** (also through direct control of data by patients)
- Facilitating health data exchange
- Creating new economy and market around patient data
- Improving economic incentive schemes and provide individuals with additional motivations for engaging with their health

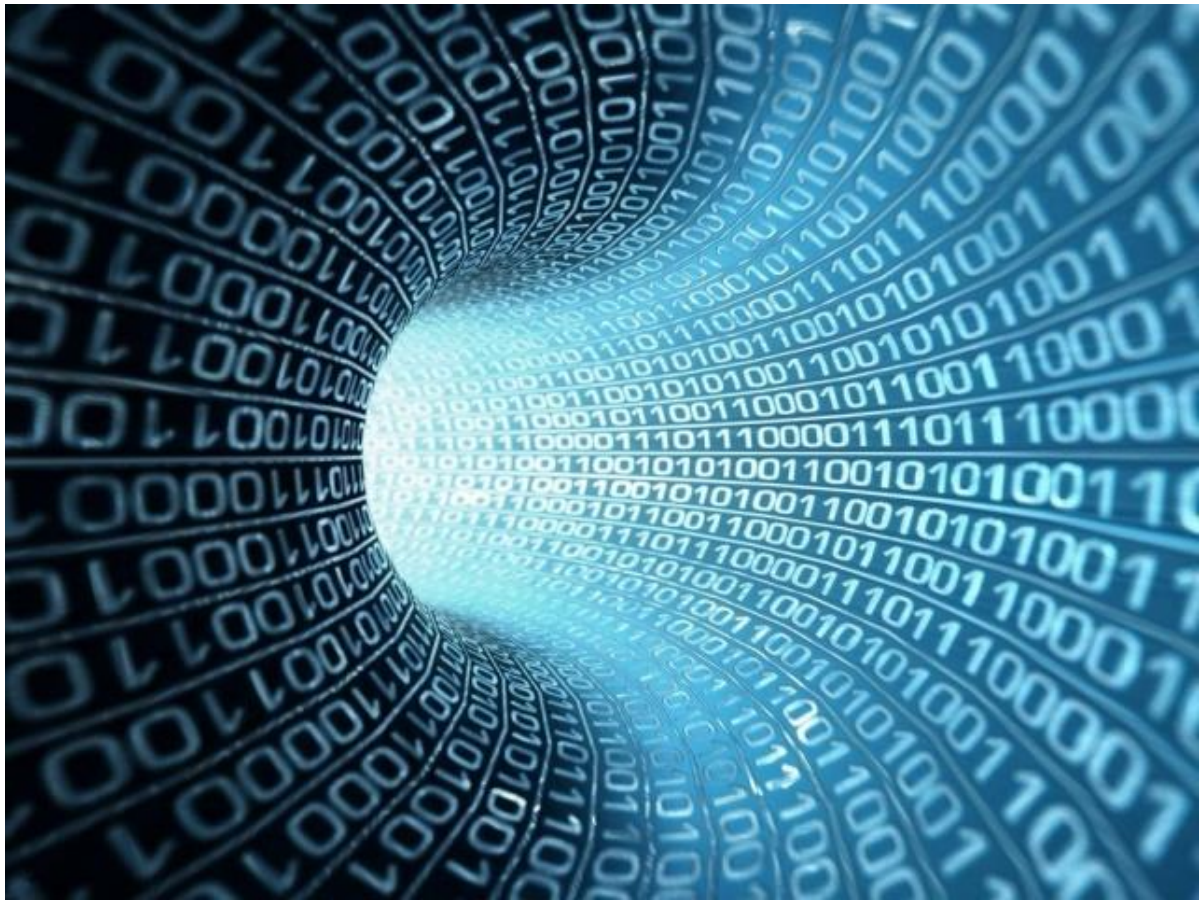
Blockchain can mean different things for different actors:

- For **hospitals** it might be a way to solve data insecurity and interoperability;
- For **doctors** it might help manage professional identity and simplify payments;
- For **pharma** and **medical device companies** distributed ledgers can assist in supply chain, inventory management and frauds detection.
- For **patients** it can provide the opportunity to control and own their data, their insights and their health

Data Access and exchange	• Improved access to data • Identity management tools • Longitudinal health record
Drugs authenticity	• Supply chain transparency • Provenance tracking • Reduce drugs counterfeiting
Clinical trials	• Improve transparency and auditing • Improve relationship management among stakeholders • Facilitate protocol and consent management and updates
Epidemiology and public health	• Improve data flow on the spread of contagious diseases
Medical IoT	• Encrypt and share securely patient generated data • Ensure privacy and security and identity of the medical device
Improved service management	• Improved control and transparency over access to health services by individuals, including visit to GPs, drugs consumption, access to Emergency rooms
Introduce reward systems of service tokenisation	• Improve engagement of individuals, encouraging healthy behaviours or facilitating access to specific services
Blockchain-based claims billing management / health insurance	Improve health insurance services providing , tamper-proof claim management and fraud reduction, reduction of administrative burdens, as well as enabling personalised services, dynamic pricing, improved access

A focus on blockchain for health data management

Medicine: increasingly a data-driven science

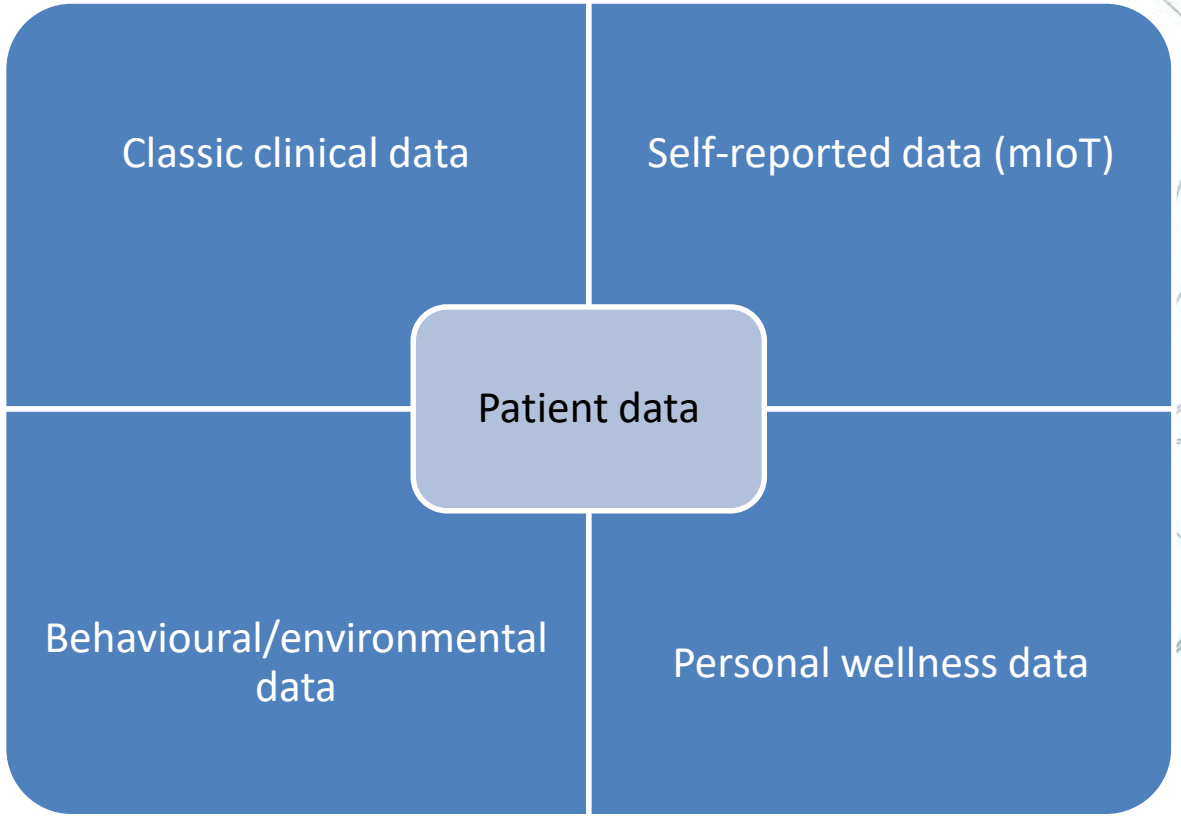


"*big-data_conew1*" (CC BY-SA 2.0) by luckey_sun

- With **its 150 exabytes of stored data worldwide per year**, Healthcare is a bright example of **"data explosion"** phenomenon
- Within 2020 – **40% of IoT technologies will be healthcare-related**
- This will be the basis of hte "Internet of Medical Thing" (IoMT), or **medical Internet of Thing (mIoT)**

Health data megatrends

- Patient datasets are expanding, thanks to genomic data and patient-generated data
  - convergence of medical data about patients generated by healthcare providers with a plethora of non-medical, lifestyle related data, much of which is generated by the patient.
  - Some forecasts see a **300% growth** in healthcare data between 2017 and 2020.
- Improved patient engagement and self-management will occur as a result



Data-related pain points

- We are in a “data-rich but information-poor” paradox, as currently the available is not leveraged enough to help providers help patients.
- It is very difficult to mobilise data, both due technical shortcomings and regulatory constraints
- There are no available solutions for integrating sparse sources of data (data generated in the hospitals, patients-generated data, etc.) in a meaningful way.
- Data usage for research and commercial purpose is limited and difficult

Three key issues

PORTABILITY

- Access to personal health data for patient is not straightforward, not timely, and often patients are not offered with option for easily share their data with other individuals

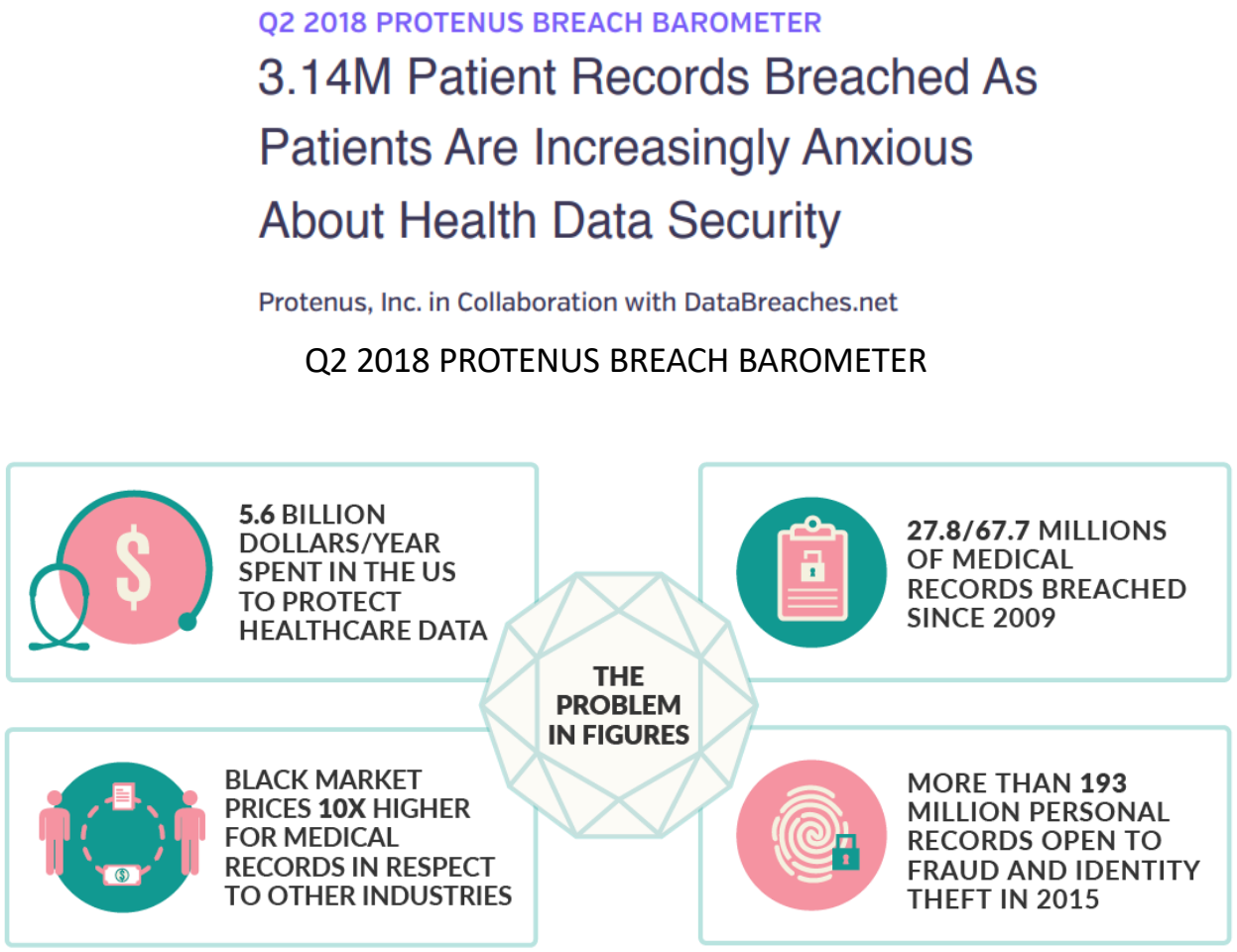
SECURITY

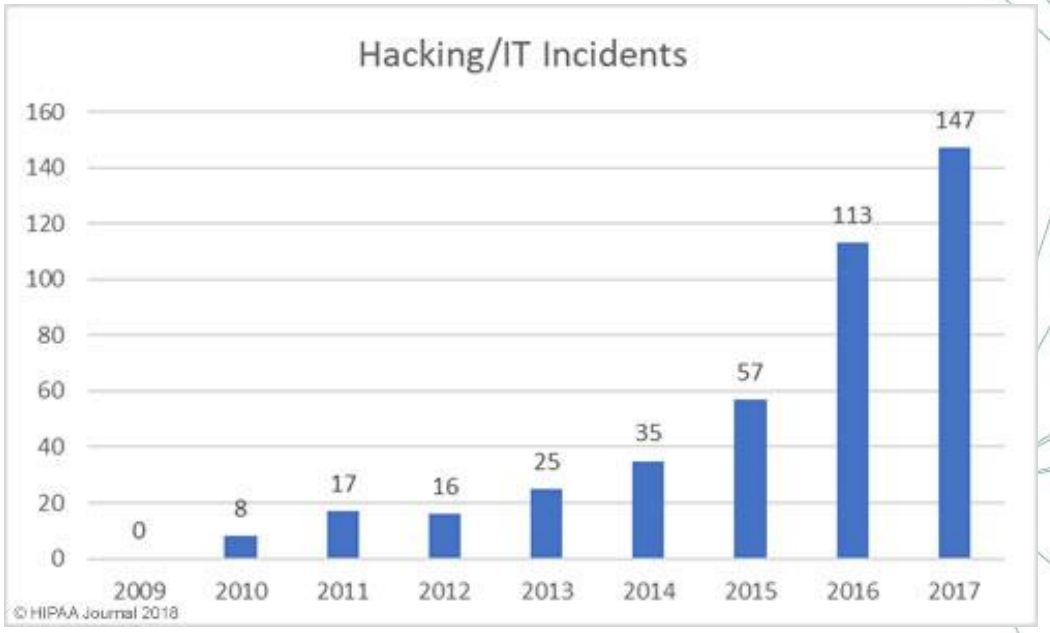
- There is a growing concern regarding data security, given the increase of identity theft and data breaches

DATA VALUE

- Hospitals and other healthcare providers are not able to extract maximum value from their data, allowing processing by third party tools for getting improved diagnosis and therapies.

Security issues are particularly concerning





"Healthcare Data Breach Statistics." *HIPAA Journal*, HIPAA Journal, www.hipaajournal.com/healthcare-data-breach-statistics/. 9/11/2018

The new «civil right» to data ownership

"[We shall overcome] the old, paternalistic model in medicine in which the data is generated and owned by doctors and hospitals"…
"Patients should be the owners of their own medical data. It's an entitlement and civil right that should be recognized".

The New York Times

The Opinion Pages | OP-ED CONTRIBUTORS

The Health Data Conundrum

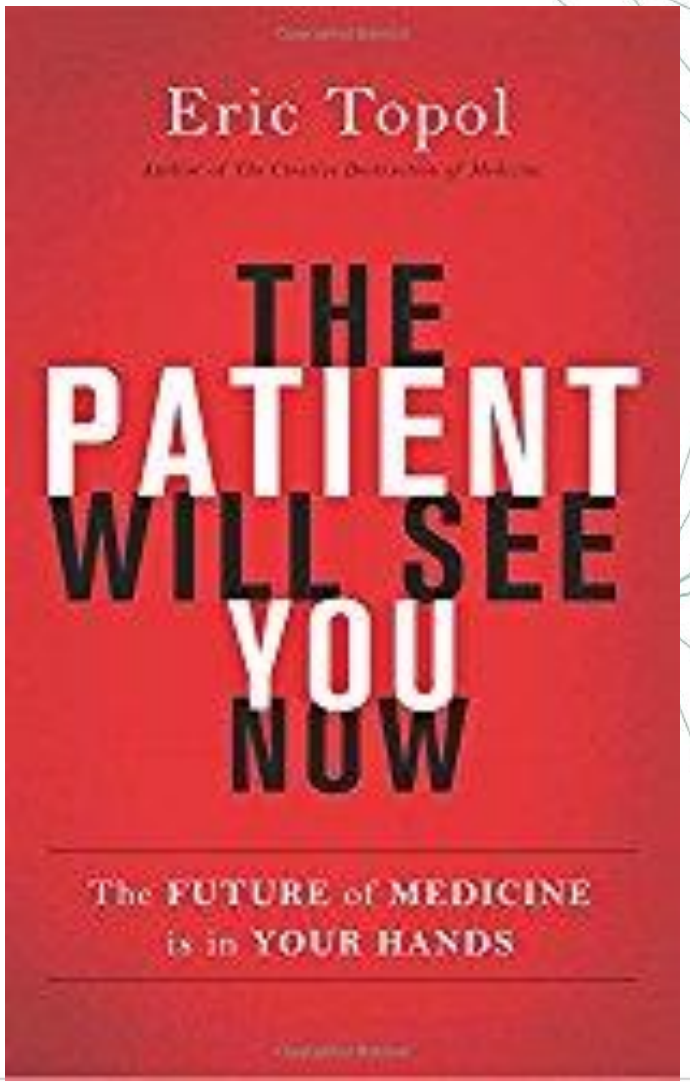
By KATHRYN HAUN and ERIC J. TOPOL JAN. 2, 2017

Is not (just) about ownership…

- The point is having the data at the right moment at the right place
  - Data access
  - Data usage

The patient at the centre

- Currently, patient is “***the single most unused person in health care***”**.**
- Thanks to mIoT, smartphone, and Personal Data Account, a new era of **healthcare democratisation will start**.



The General Data Protection Regulation (GDPR)

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

- ***Right* to *data portability*:** receive personal data in a **structured, commonly used, machine-readable and interoperable format**"

- **Consent**
  - **Freely given**, **informed**, and **specific**
  - **Easily readable**, and in **plain language**
  - Data Controller will have to **demonstrate consent**

Blockchain and data access

Facilitate data exchange…

- …relying on peer-to-peer distributed architectures

Enable direct access and control of data by patients…

- …through innovative consent tools, allowing them to decide who can access to data and for what purpose

Easy traceability of data modifications

- …also making forgery or versioning issues more difficult

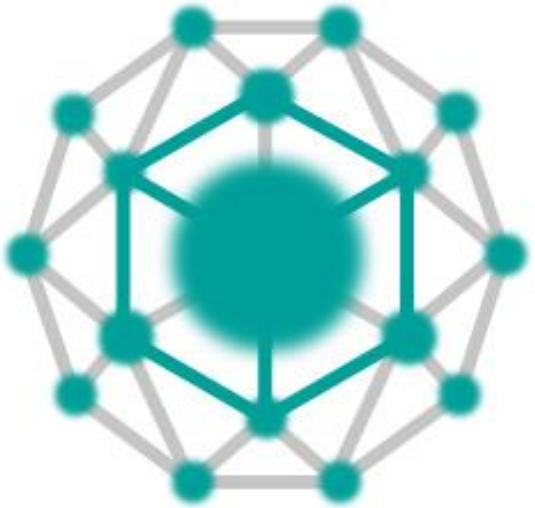
Overcome the current centralised and siloed data storage approach…

- …also enabling interoperability and longitudinality through «personal data wallet»

Creating new economy and market around patient data

Enable the creation of a comprehensive data ecosystem for all stakeholders

- patients, doctors, institutions, public decision makers, researchers, biomedical industries



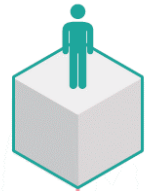
MY HEALTH
MY DATA

MYHEALTHMYDATA APPROACH

MHMD goals

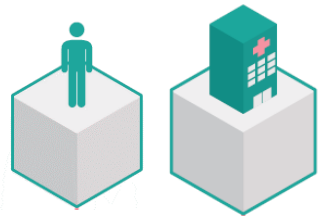
- **CITIZENS' EMPOWERMENT**

(PDA, dynamic consent, smart contracts)



- **DATA PRIVACY AND SECURITY**

(blockchain, de-identification, encryption)



- **DATA VALUE ENHANCEMENT**

(blockchain, big data analytics for pseudo/anonymised data)

A consortium blockchain

- Based on Hyperledger (permissioned)
  - Lightweight / non-intrusive / high performances
  - Nodes forming a consortium
- Shared responsibilities
- Building on a network of trusted partners

What role blockchain plays in MHMD?

- Act as a “traffic light” which manages and authorises data exchange and access, according to user-defined rules, consent, and policies
- Provide full traceability and auditability of data access and exchange
- Automate application of privacy-preserving tools on data
- Facilitate GDPR compliance in particular in regard to right to erasure/correction and relevant reporting obligations

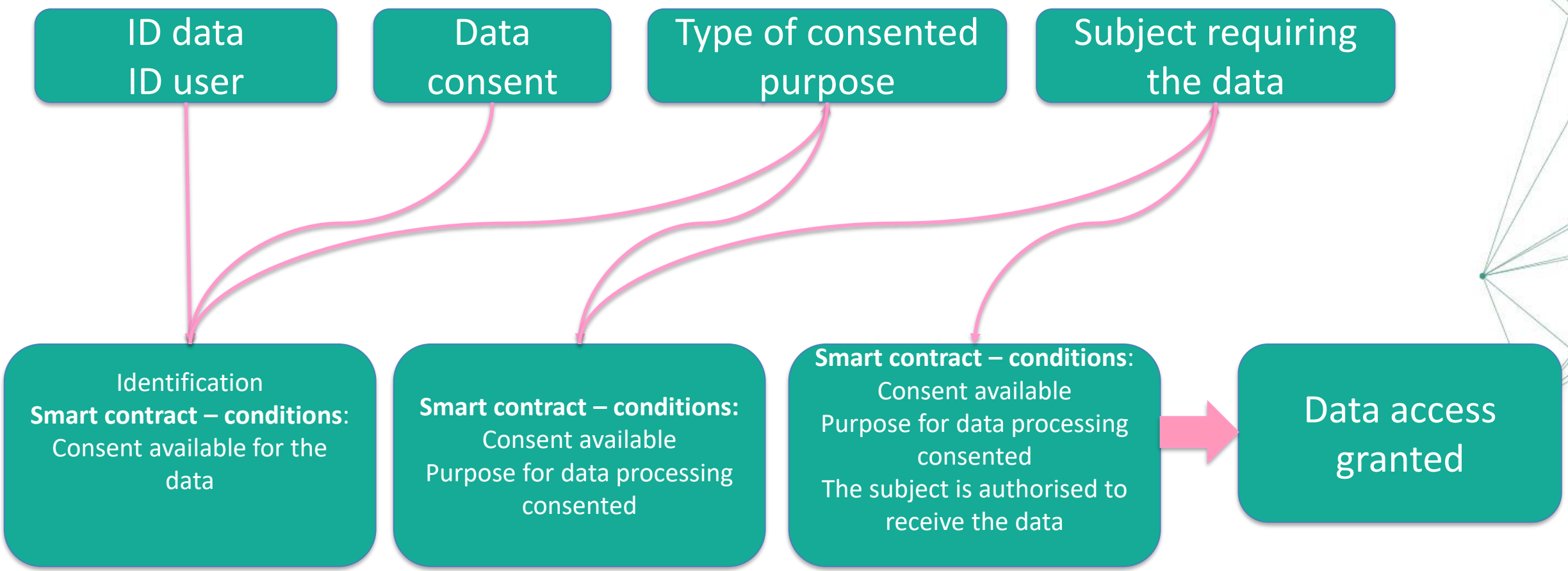
Getting patients in the loop

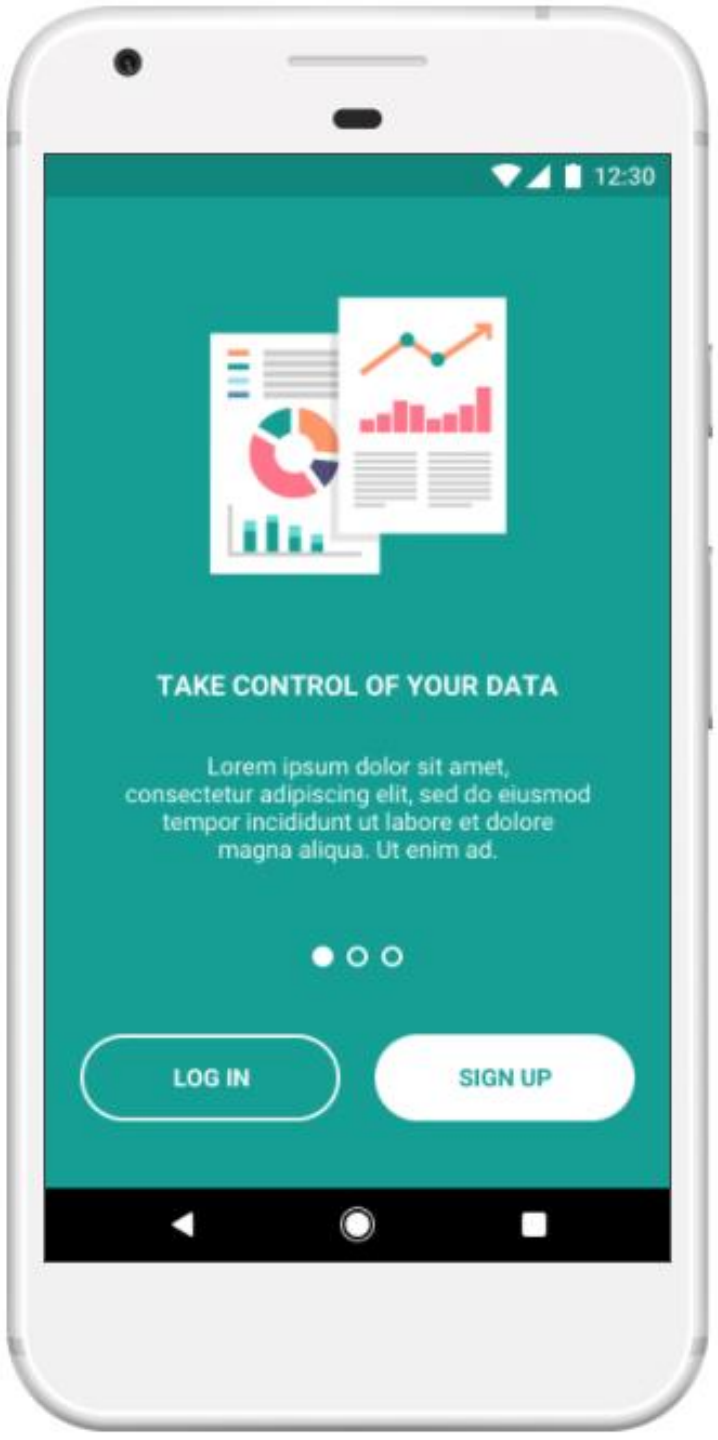
- Patients can be provided with a **mobile application** for:
  - Managing consent and data access rights
  - Have full visibility on data access and receive data access requests
  - Advanced personal use and sharing
  - More efficient communication with care providers
  - **Extract maximum value from their data**

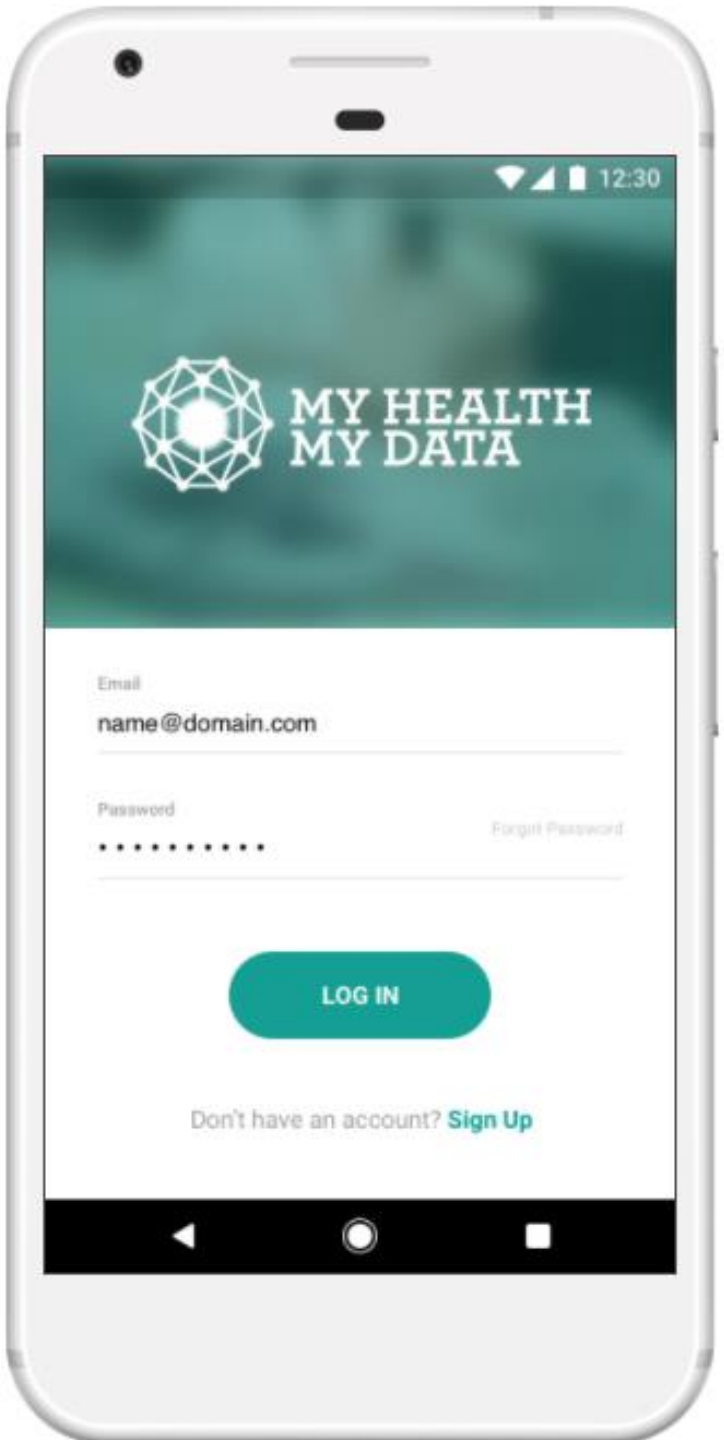
Dynamic consent key features

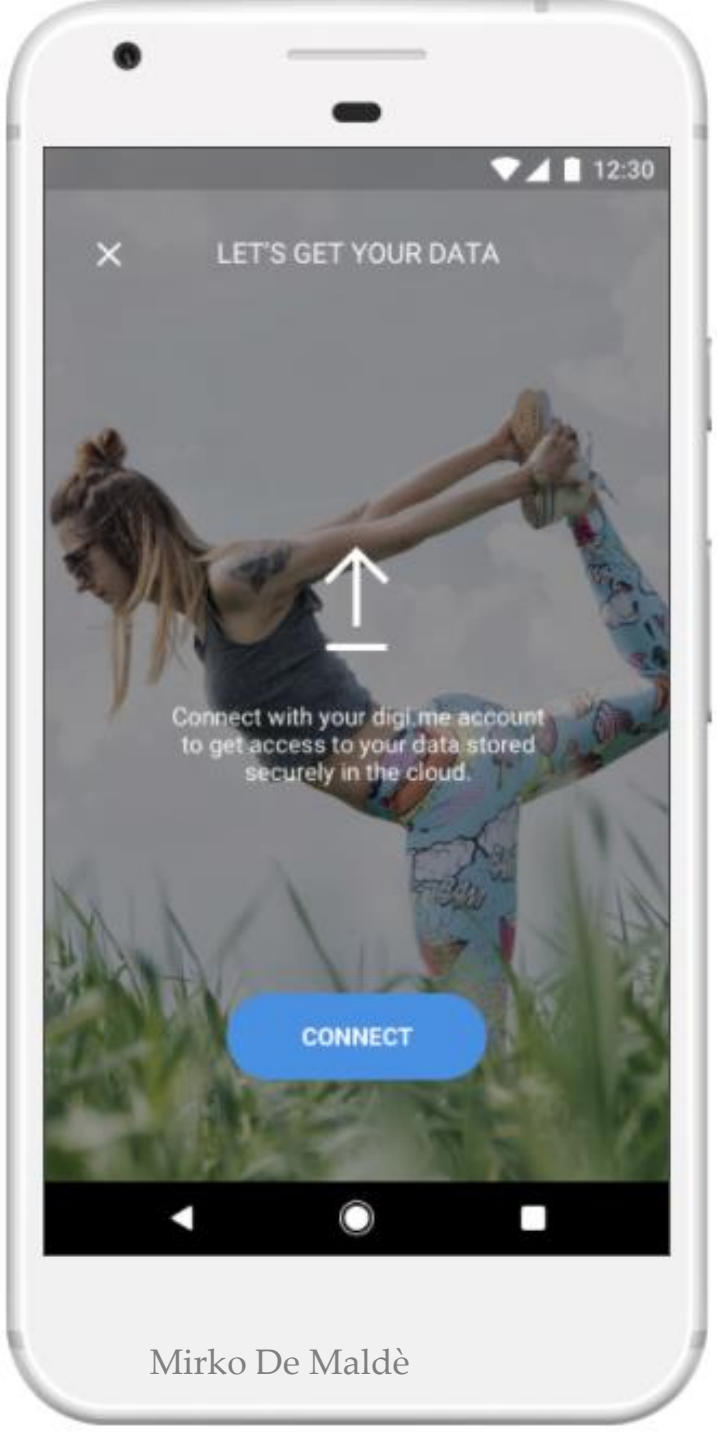
- **Assign data access rights, deciding**
  - Kind of third parties authorised to access data
  - Purpose of data processing
  - Other terms for data access
- **Stay informed of, and enquiry on, relevant data transactions after access has been granted**
- **Be able to revoke data access rights, or extend them**
- **Be able to receive requests from stakeholders for data access permissions**.
  Requests may also include incentives offered by stakeholders in exchange for data
- **Define post-mortem usage or donation of personal data**

Regulating data access through a smart contract









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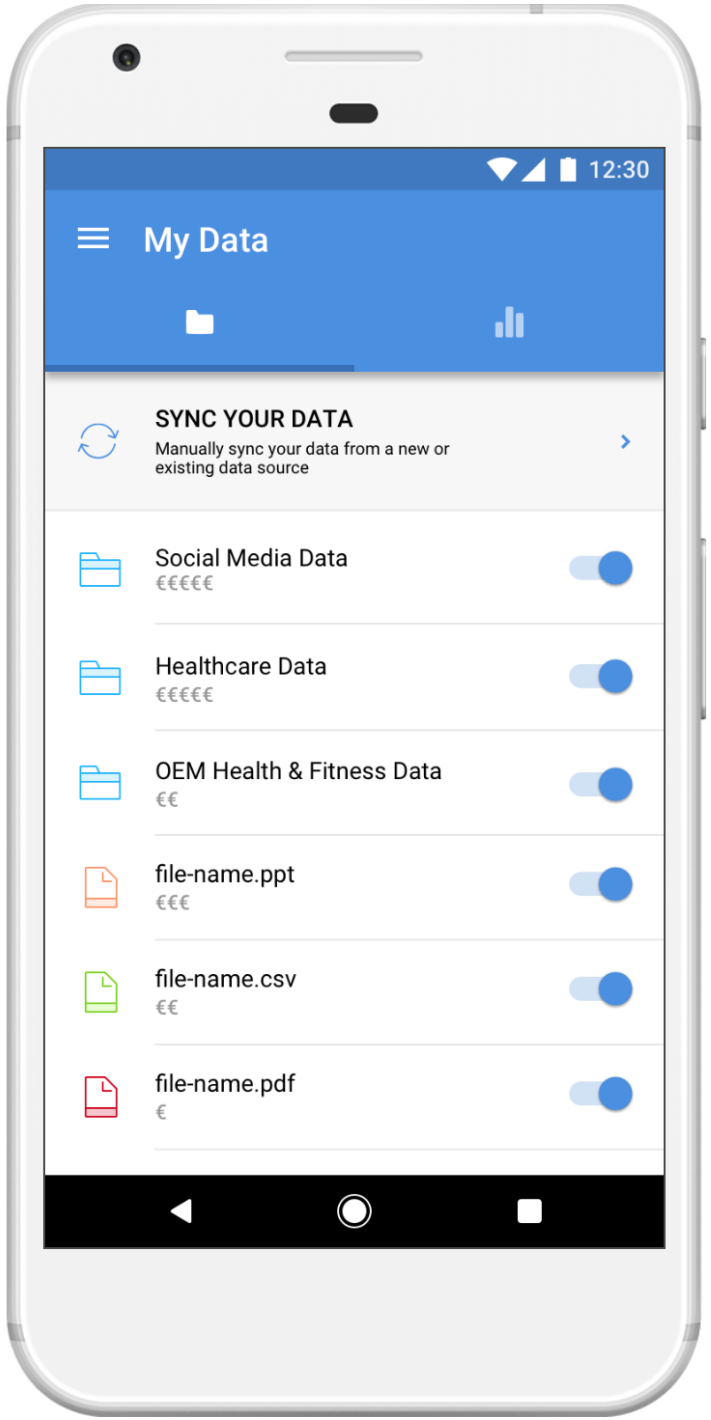

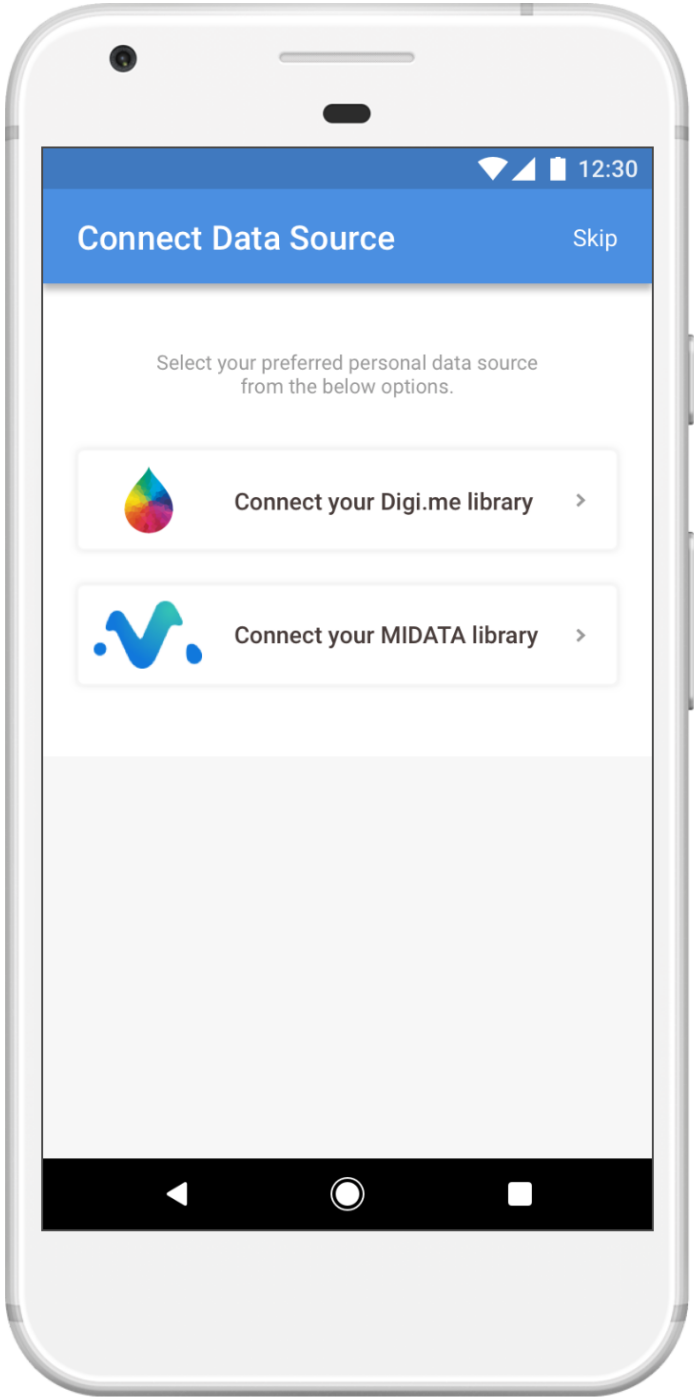

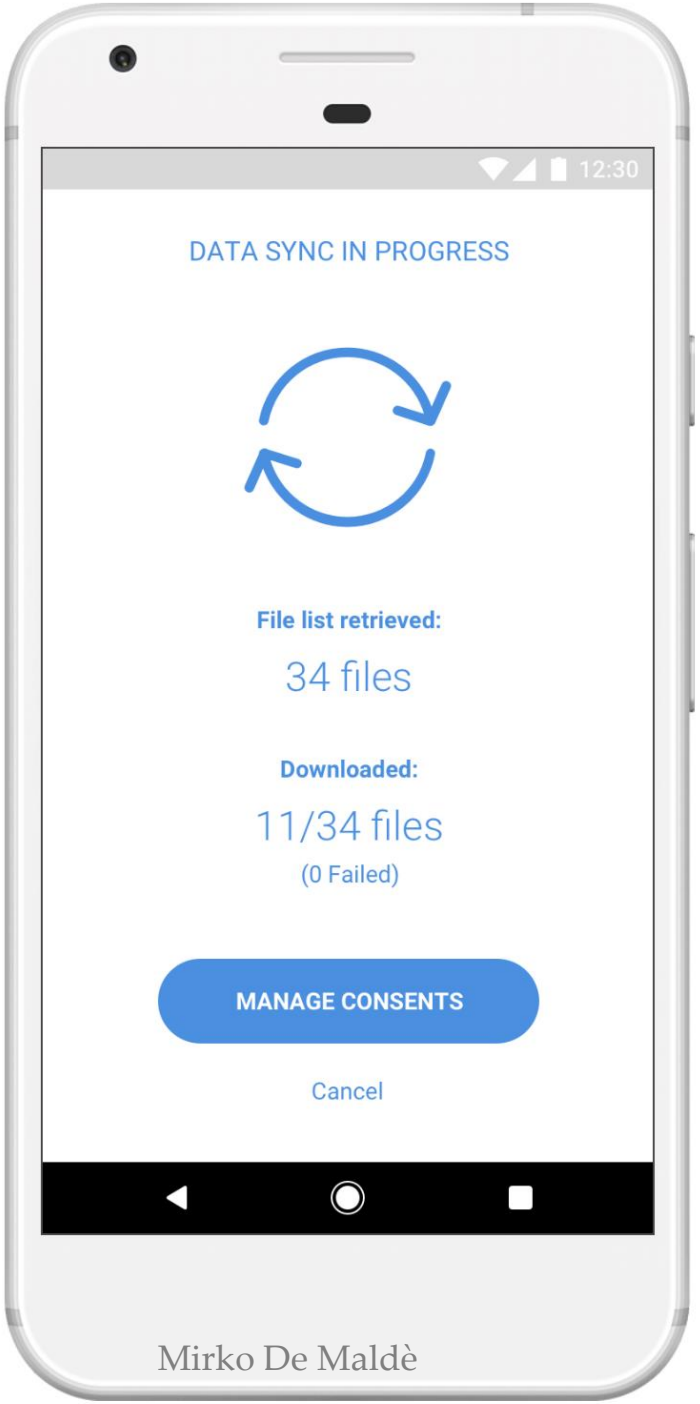

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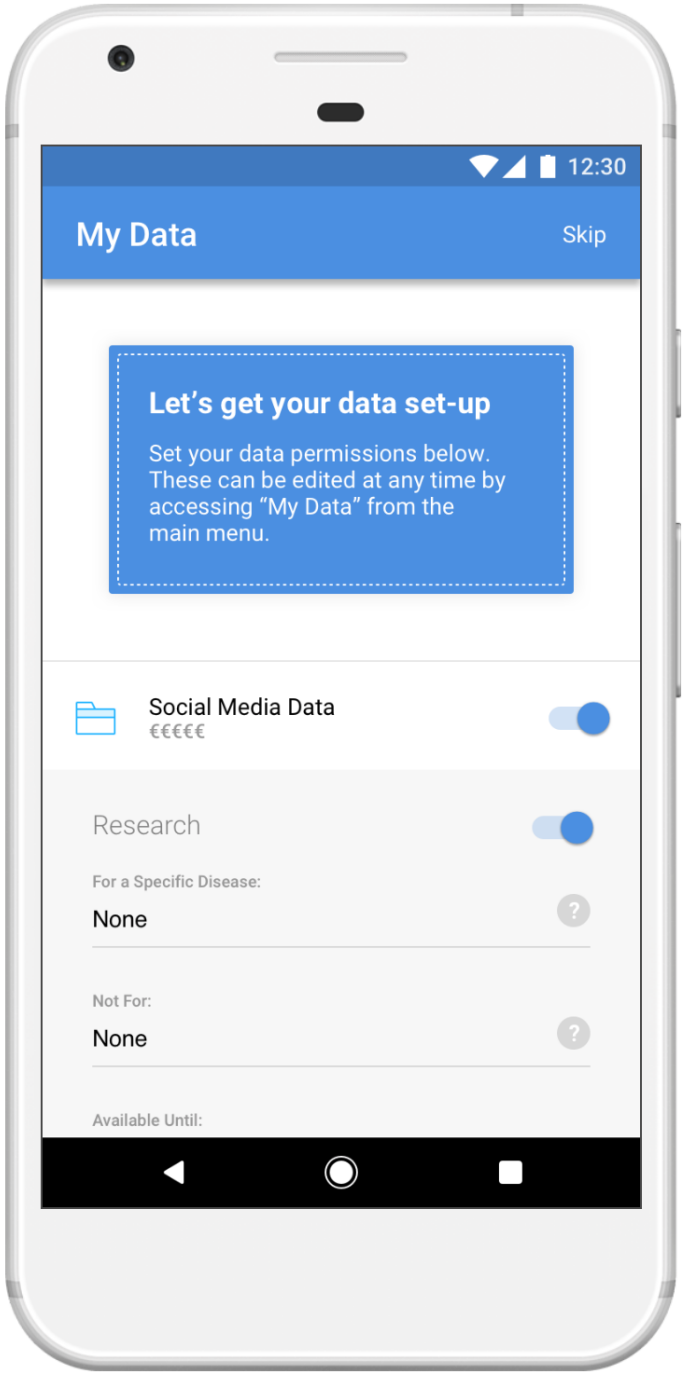

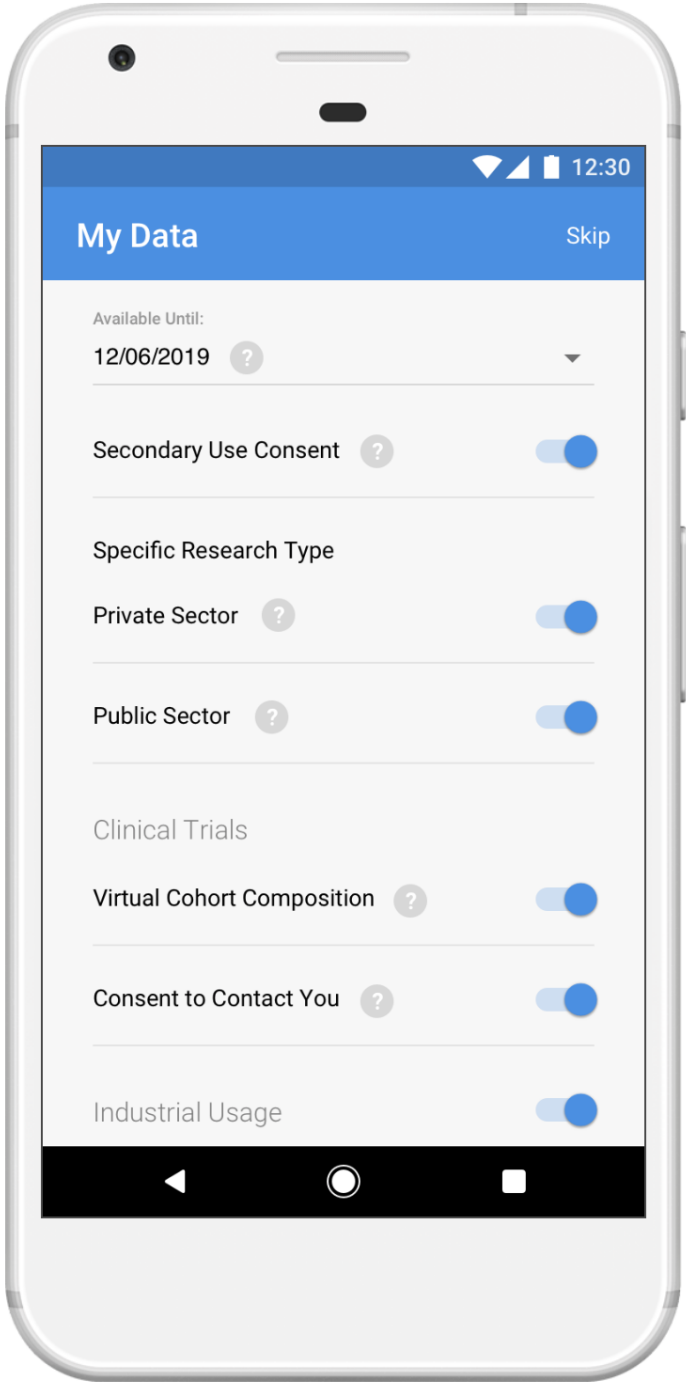

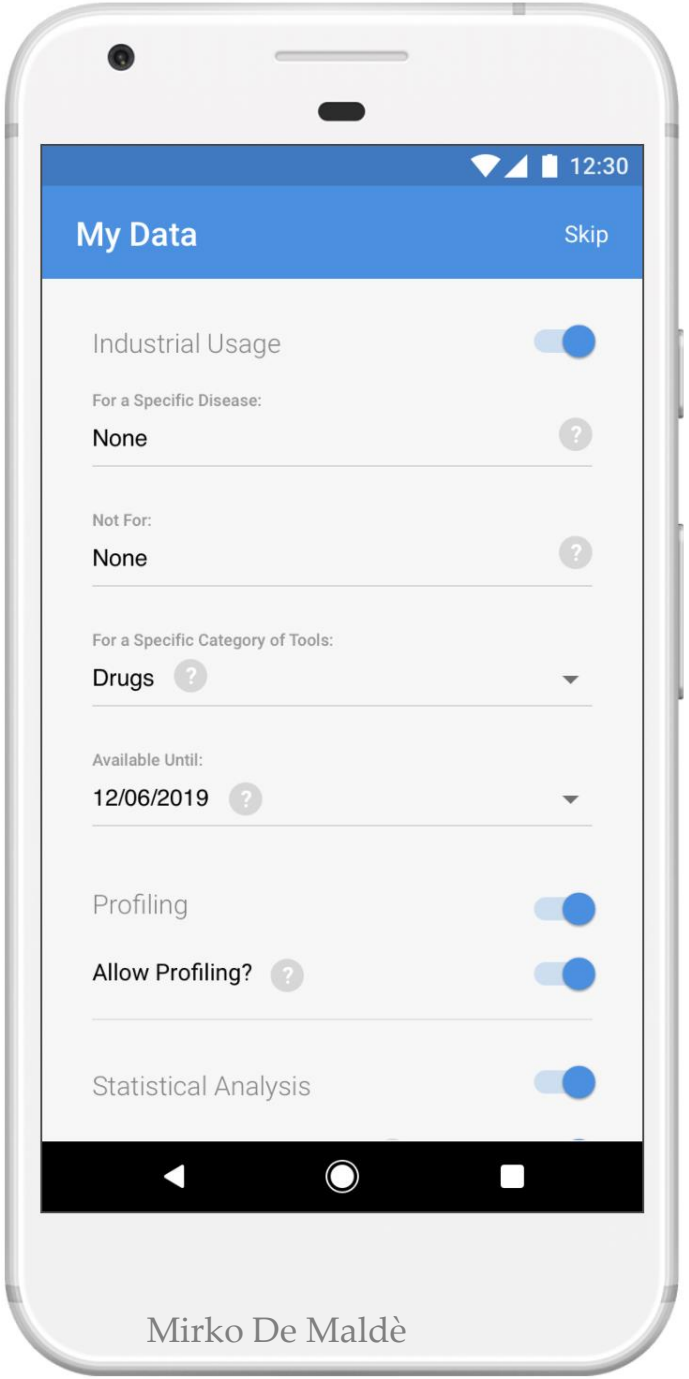

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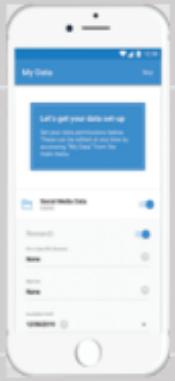
MULTILAYER, PRIVACY PPRESERVING BACK-END

Blockchain records

citizen



Signs up

Sets permissions

Monitors transaction

hospital

Registers institution

Registers data

Sets permissions and privacy settings

business/researcher

Browses data

Requests access

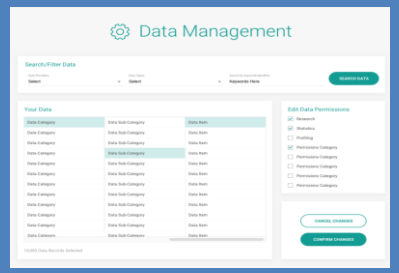
Download and uses data

Blockchain

Data source

Hospital

Data mapping
Access preferences definition



Local Driver (Local DB)

Matching

New transaction: “Data registered in the platform” (**hash** of the new dataset recorded in the blockchain)

Smart contract’s Function “Create study” invoked (includes study definition/data request)

Smart contract informs the network of the data request

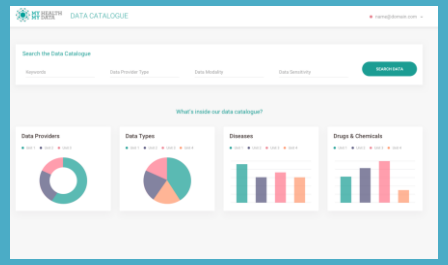
Local drivers at hospitals match data request with their available data and control consent

Smart contract’s Function “Study Response” invoked
(Data available at the hospital – access granted)

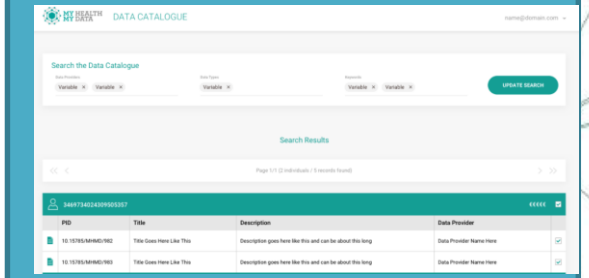
When enough responses are received the smart contract change the status of the study to “Ready” and provide link for off-chain data download

Study Definition

Researcher/ Business



Data catalogue query and data request



Data download

Consortium

5 SMEs:

4 Clinical partners:

4 Research centres and Academia:

1 Legal consultancy:

1 Industry:

For more info:

Contact

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Website

http://www.myhealthmydata.eu/

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