MY HEALTH MY DATA

ERRIN ICT Working Group Meeting on Blockchain

Brussels, 13 June 2018

ERRIN European Regions Research and Innovation Network

Anna Rizzo

LYNKEUS

STRATEGY CONSULTING | BLOCKCHAIN & SMART CONTRACTS | DATA ANALYTICS

(Project Coordinator)

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“MY HEALTH, MY DATA”

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

BLOCKCHAIN WALLET

BLOCKCHAIN WALLET

DATA HARMONIZATION

ENCRYPTION SOLUTIONS

Data users

Biomedical and pharma industry

Academia

BLOCKCHAIN WALLET

BLOCKCHAIN WALLET

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

BLOCKCHAIN
WALLET
BLOCKCHAIN
WALLET
DATA
HARMONIZATION
ENCRYPTION
SOLUTIONS
BLOCKCHAIN
WALLET
BLOCKCHAIN
WALLET

WHY MHMD?

Medical data are more threatened than ever….

5.6 BILLION DOLLARS/YEAR SPENT IN THE US TO PROTECT HEALTHCARE DATA

27.8/67.7 MILLIONS OF MEDICAL RECORDS BREACHED SINCE 2009

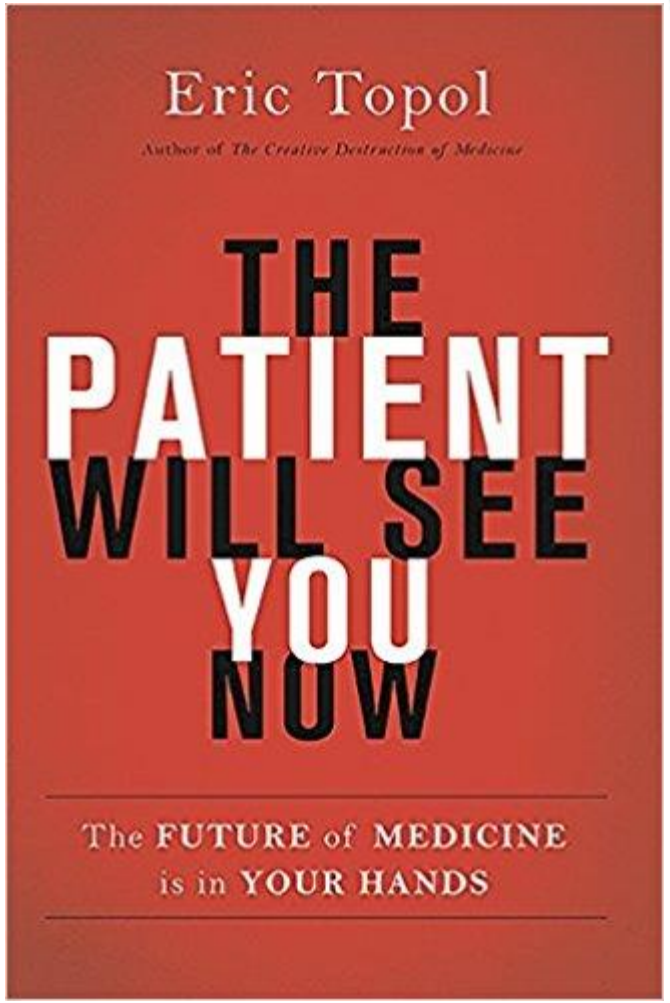
THE PROBLEM IN FIGURES

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…

Patient Power

Patient Empowerment Foundation

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**

MHMD mission

(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

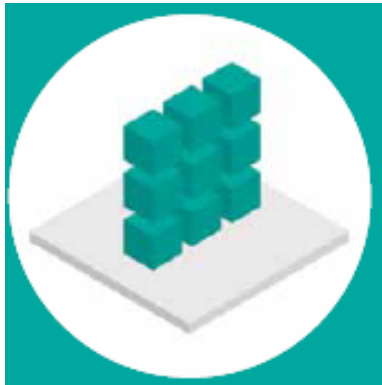
Grant individuals ownership and control of their personal health data

How will MHMD do that?

"Gears" (CC BY-ND 2.0) by Charlie Gross Photography

"Gears" (CC BY-SA 2.0) by AJC1

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.

(1) BLOCKCHAIN

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**

gnúbila

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

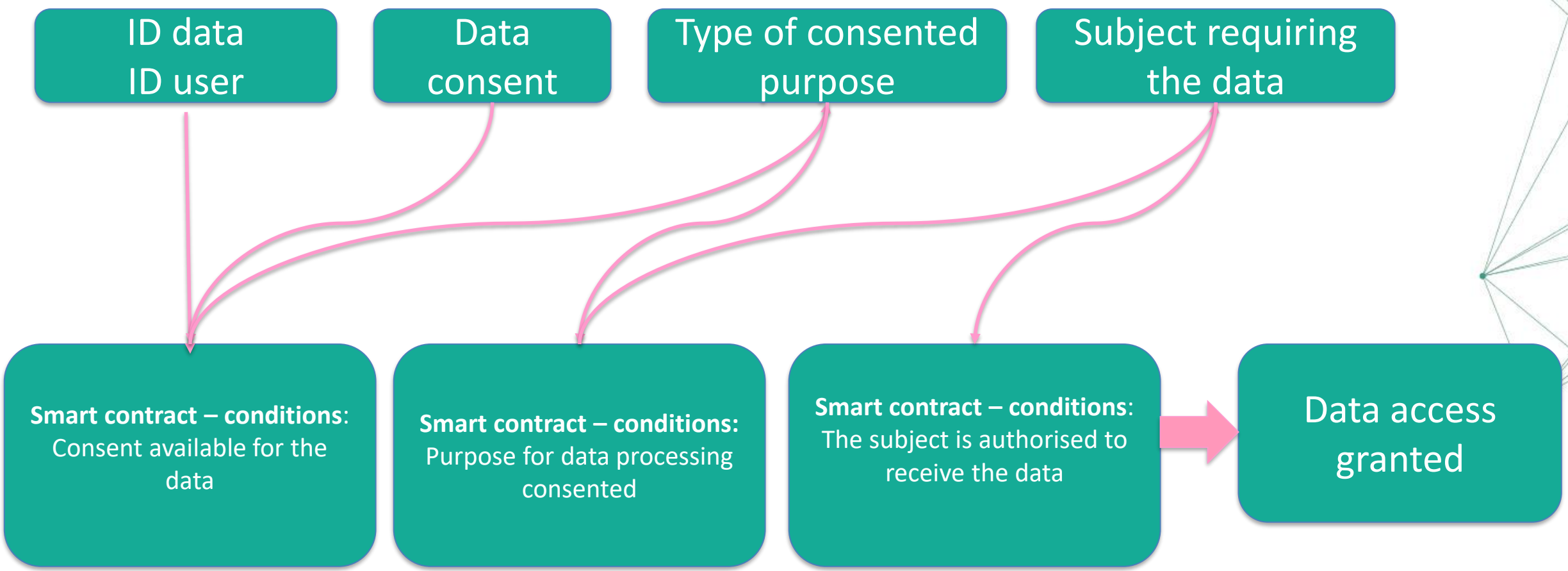
(2) SMART CONTRACTS

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.

LYNKEUS gnúbila

Regulating data access and enforcing consent through a smart contract



MHMD key innovations for patients

PERSONAL DATA ACCOUNTS

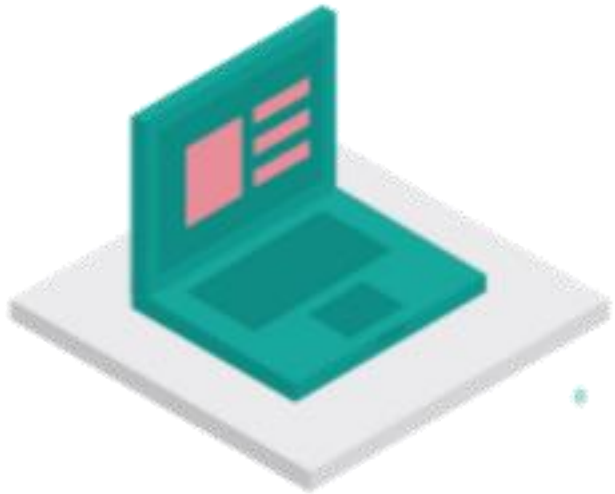
Personal storage clouds will enable individuals to access their data from any techno-logical device through the blockchain and employ them for personal use.

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.

(3) PERSONAL DATA ACCOUNTS

Individual data ownership and control



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

digi.me
it's your life

HWC
www.hwcomms.com

(4) DYNAMIC CONSENT

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

"Hacked..." (CC BY-NC-ND 2.0) by Christine Krizsa

- **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.

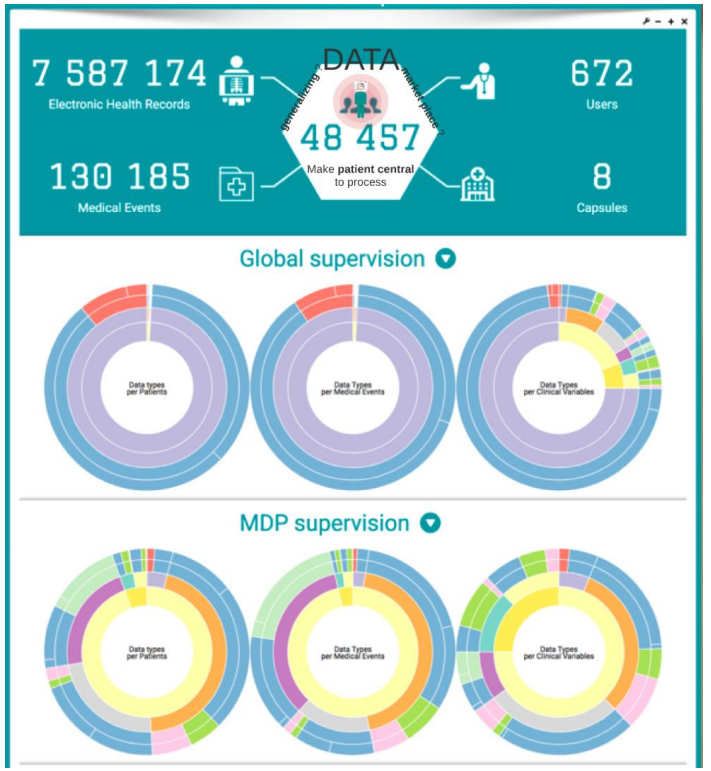
Synthetic data have been preliminary used for *data mapping, profiling and testing privacy-preserving algorithms*.

(7) DATA CATALOGUE

Glancing at the data…

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*



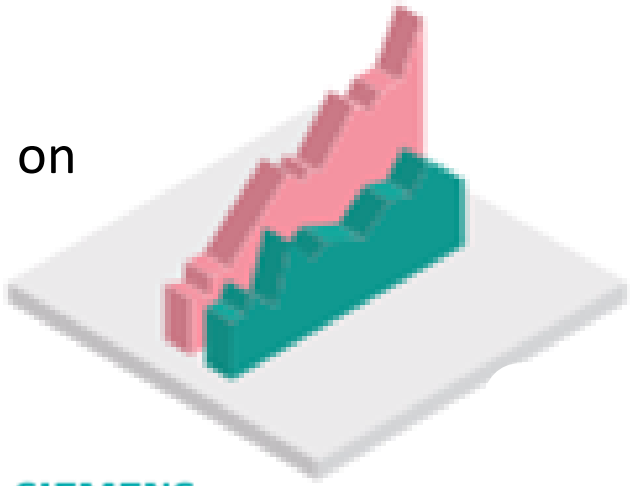
(8) BIG DATA ANALYTICS

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



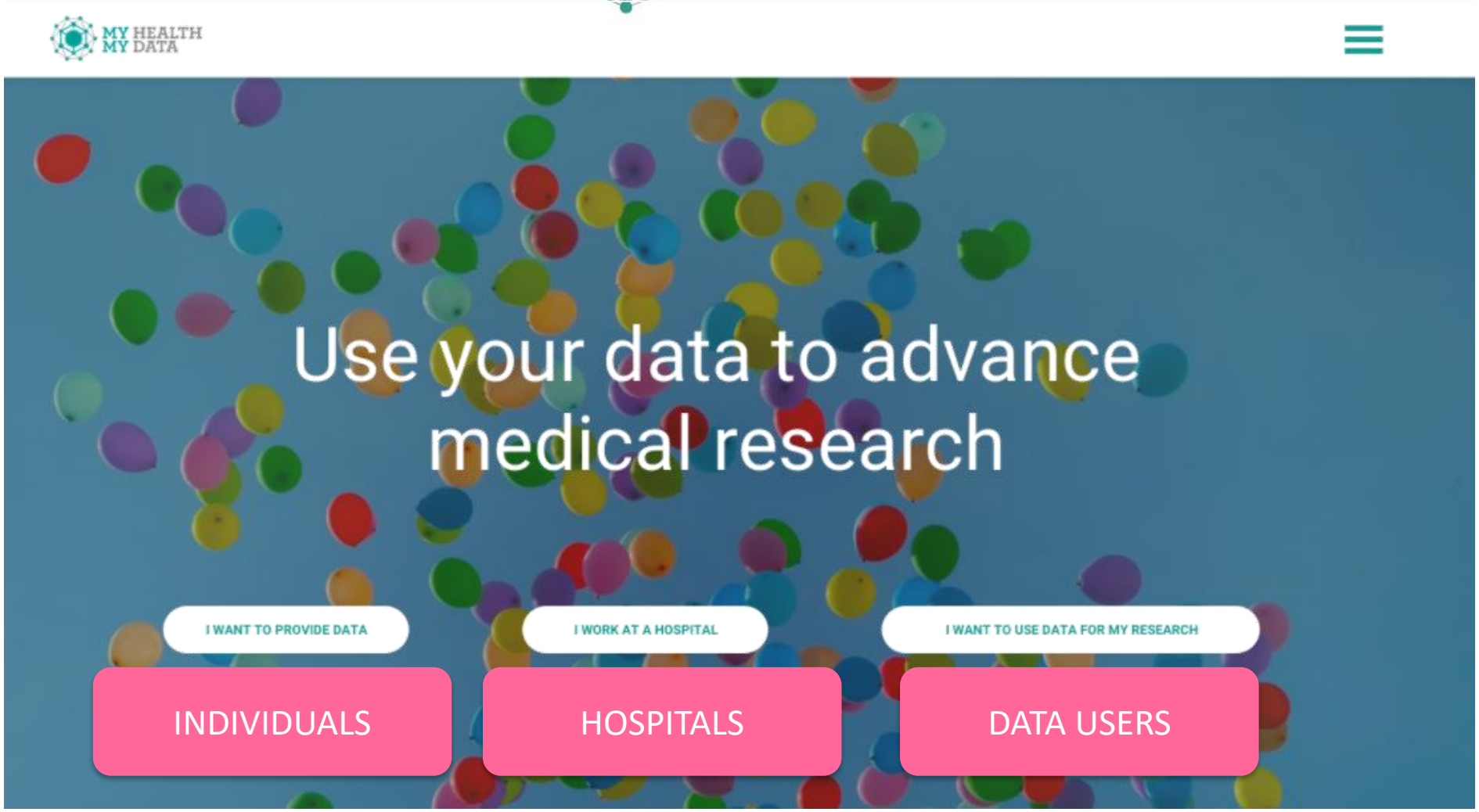
Hes·so GENÈVE
Haute Ecole Spécialisée de Suisse occidentale

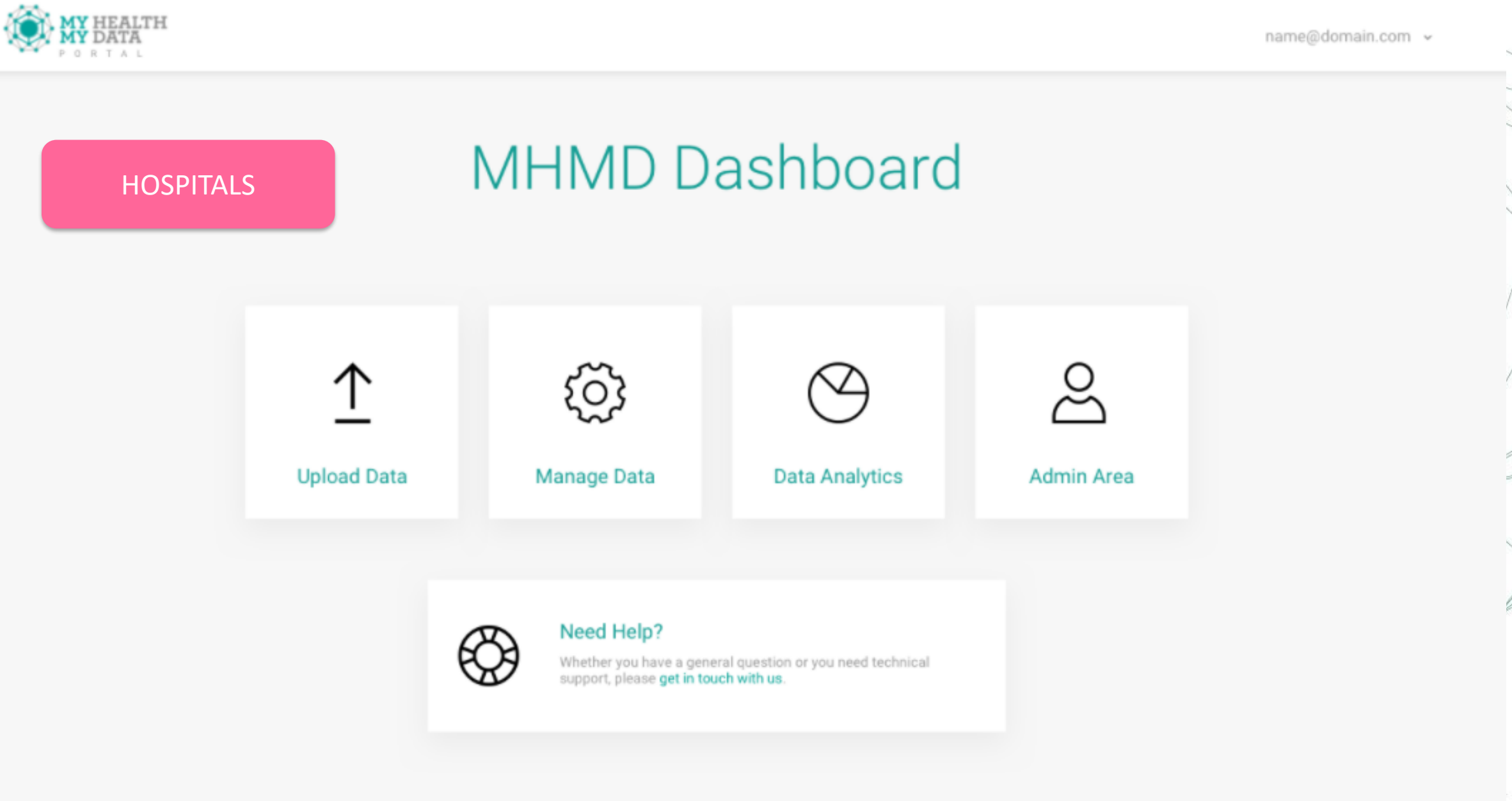
TRANSILVANIA
University of Brasov

ATHENA

SIEMENS
Healthineers

The MHMD user interface




MY HEALTH MY DATA PORTAL
name@domain.com
HOSPITALS
MHMD Dashboard
Upload Data
Manage Data
Data Analytics
Admin Area
Need Help?
Whether you have a general question or you need technical support, please get in touch with us.

HOSPITALS

Upload Data

Search/Filter Data

Data Providers: Select

Data Types: Select

Search by keyword/identifier: Keywords Here

SEARCH DATA

Your Data

Data Category	Data Sub-Category	Data Item
Data Category	Data Sub-Category	Data Item
Data Category	Data Sub-Category	Data Item
Data Category	Data Sub-Category	Data Item
Data Category	Data Sub-Category	Data Item
Data Category	Data Sub-Category	Data Item
Data Category	Data Sub-Category	Data Item
Data Category	Data Sub-Category	Data Item

Data Permissions

- Permissions Setting 1
- Permissions Setting 2
- Permissions Setting 3
- Permissions Setting 4
- Permissions Setting 5

MANAGE SETTINGS

HOSPITALS

Admin Area

My Account

User Management

Audit Trail

Permissions Defaults

Users

+ Create new user

Show 10 users per page

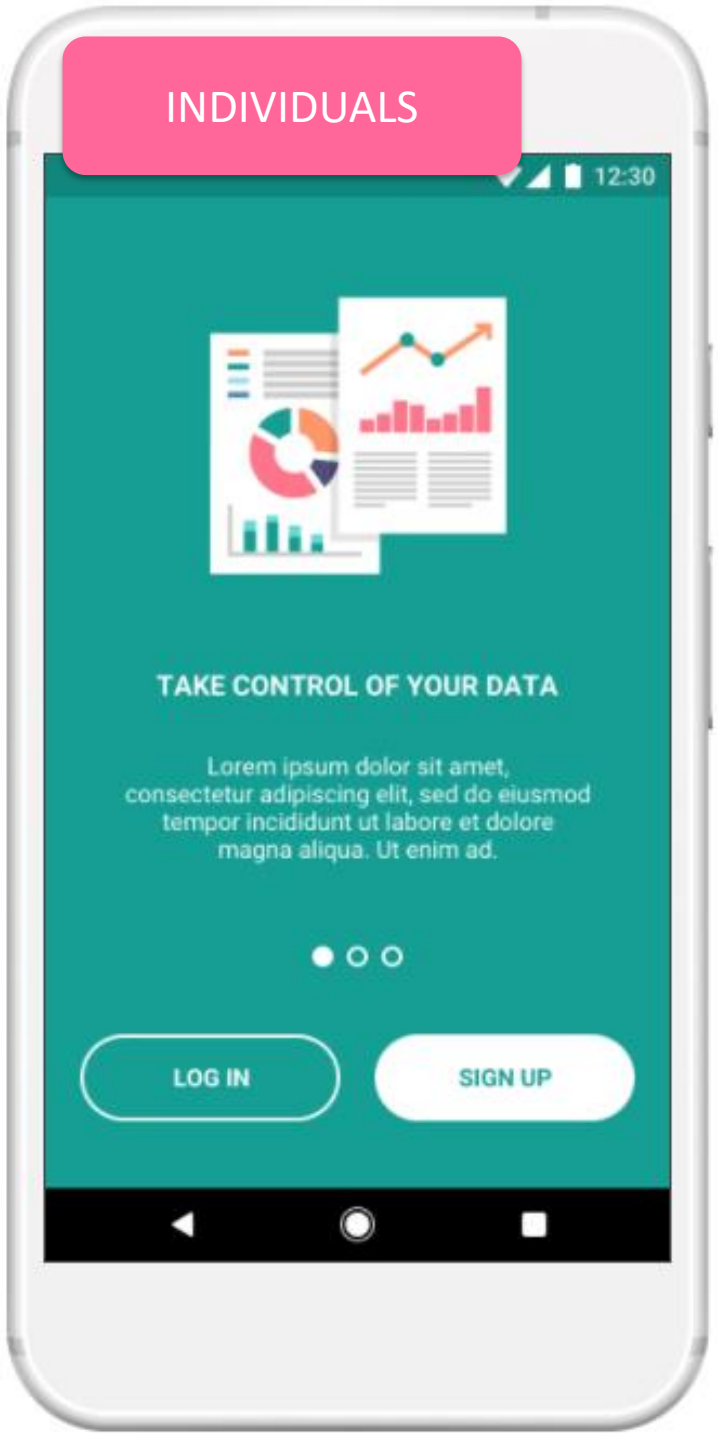
Search Users

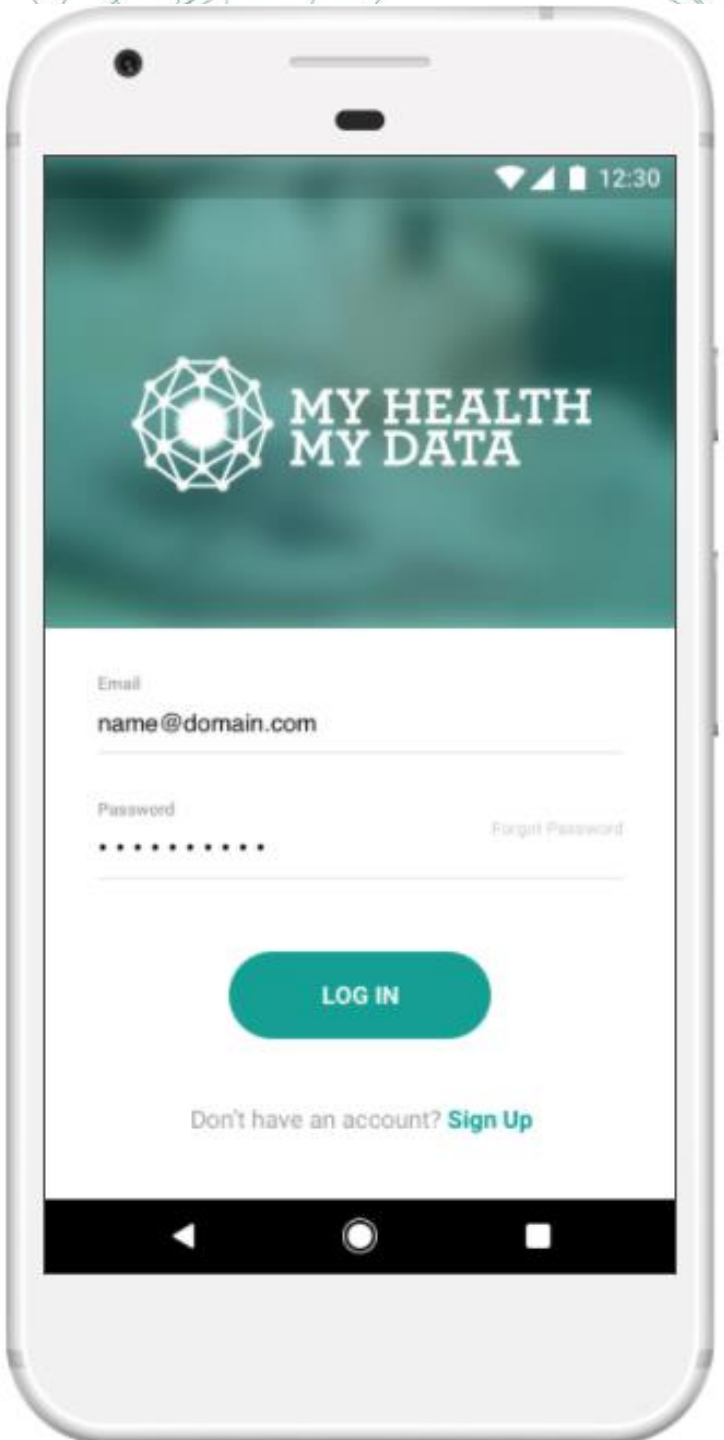
ID	Username	Full Name	User Type	Actions
42	name@domain.com	Jackie Robinson	Admin	
43	name@domain.com	Jon Snow	User	
18	name@domain.com	Eddard Stark	User	
24	name@domain.com	Kobe Bryant	Admin	
6	name@domain.com	LeBron James	User	
33	name@domain.com	Kareem Abdul-Jabbar	User	
66	name@domain.com	Apu Nahasapenapethelhan	User	
23	name@domain.com	Michael Jordan	Admin	
14	name@domain.com	Brandon Ingram	User	
34	name@domain.com	Giannis Antetokounmpo	User	

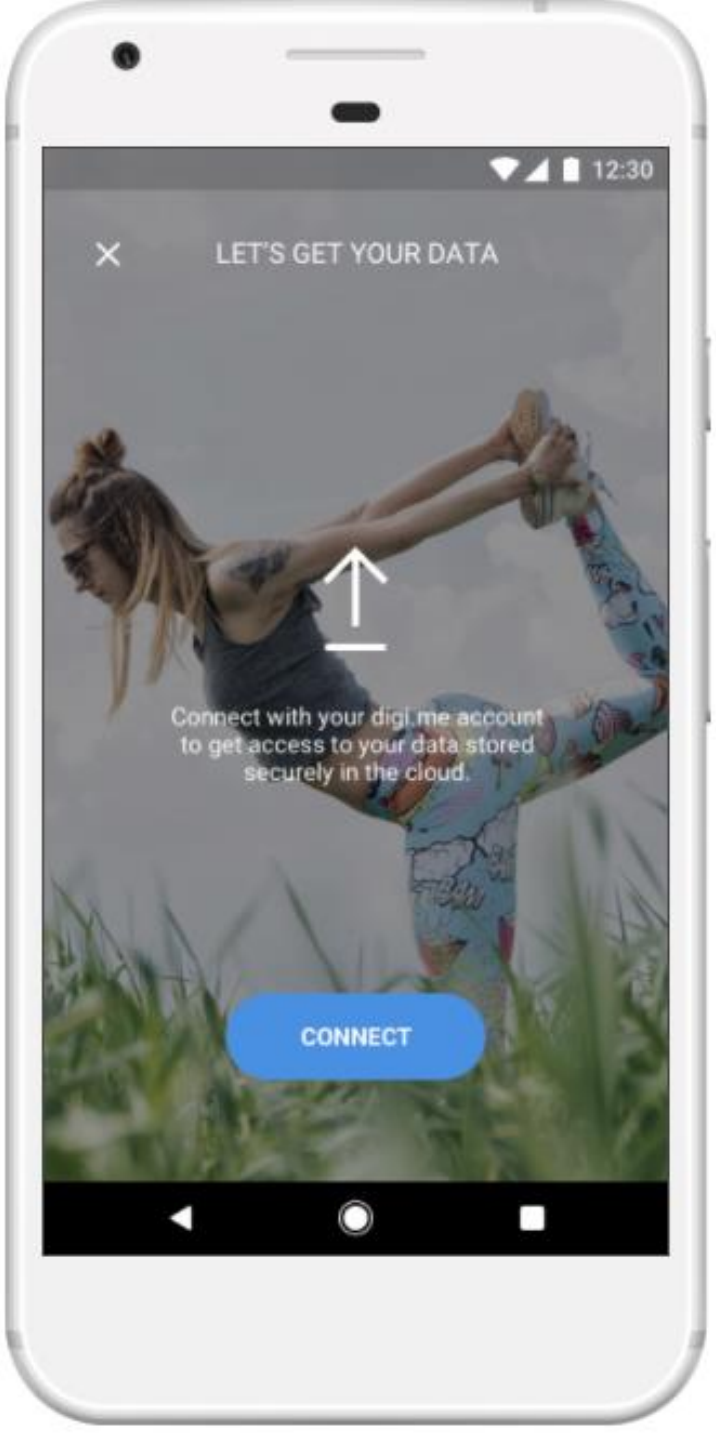
INDIVIDUALS

Harness your data to
participate in medical research

INDIVIDUALS







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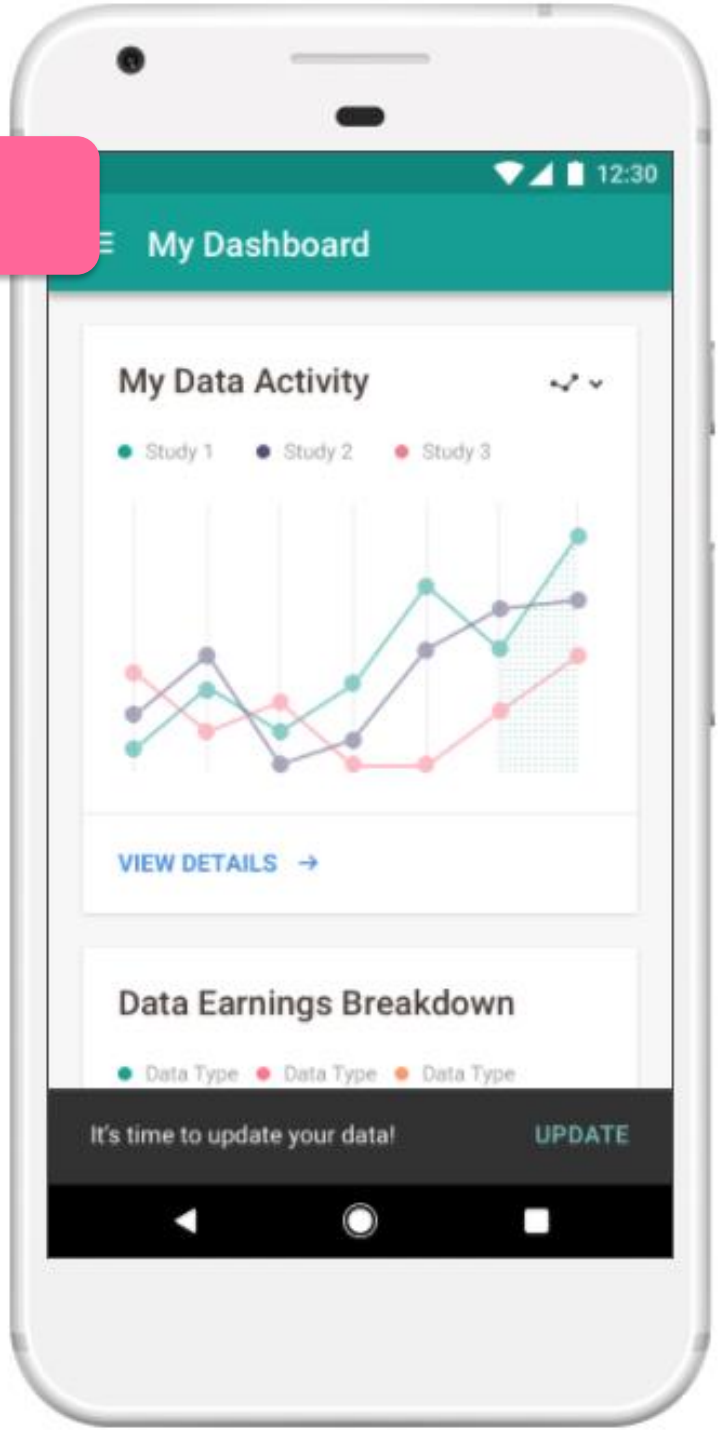
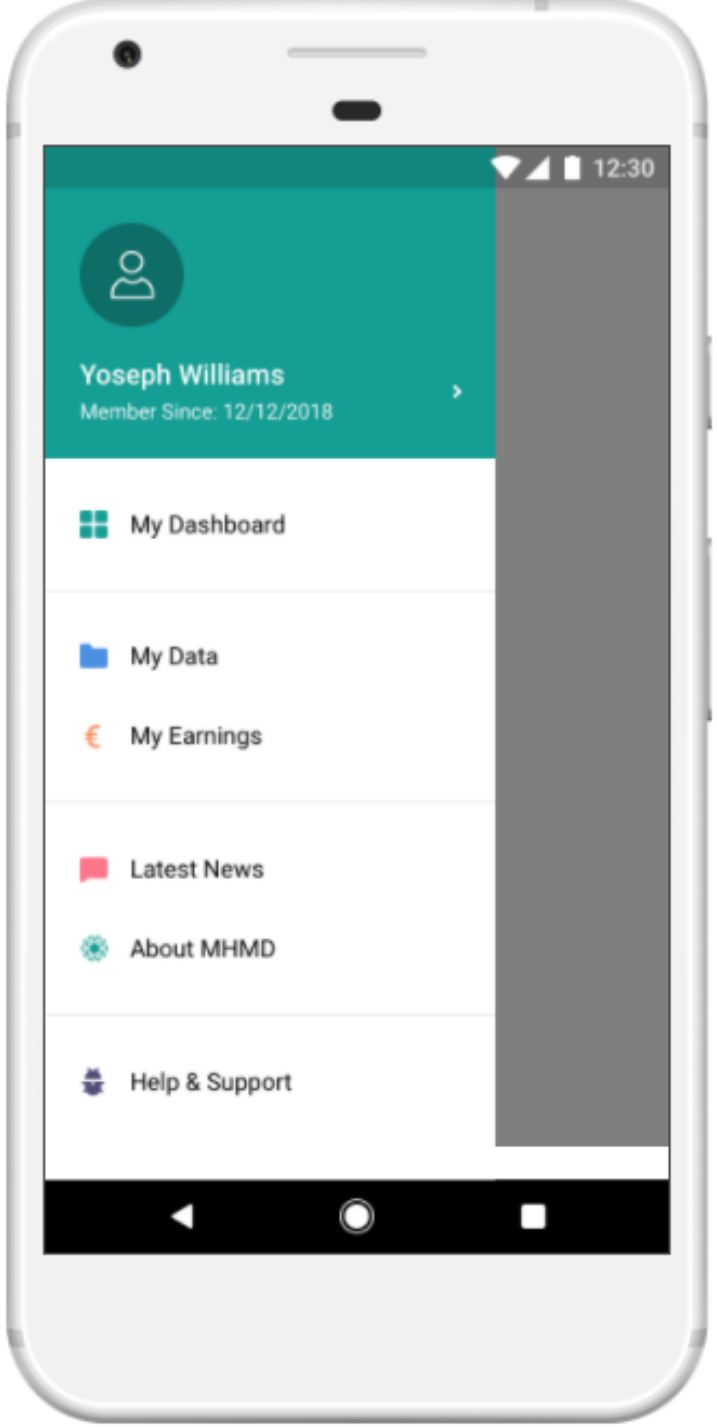
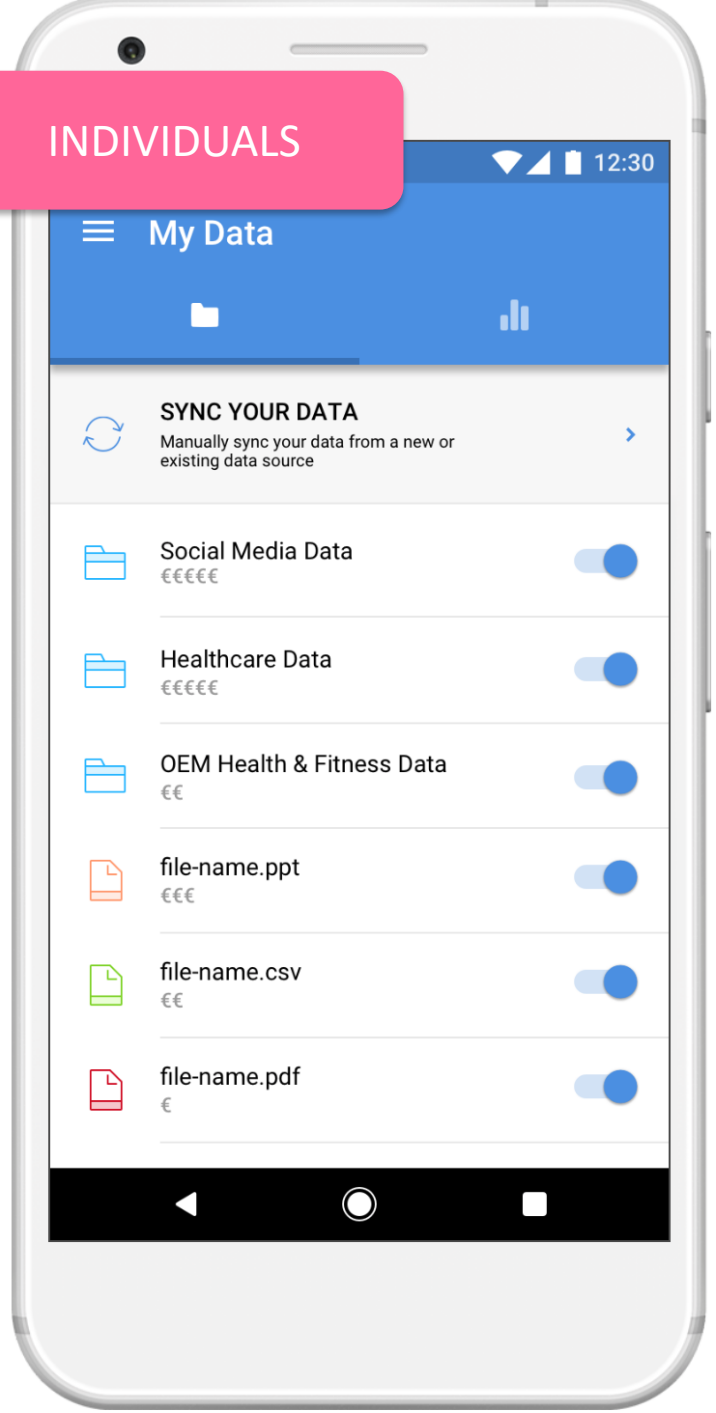
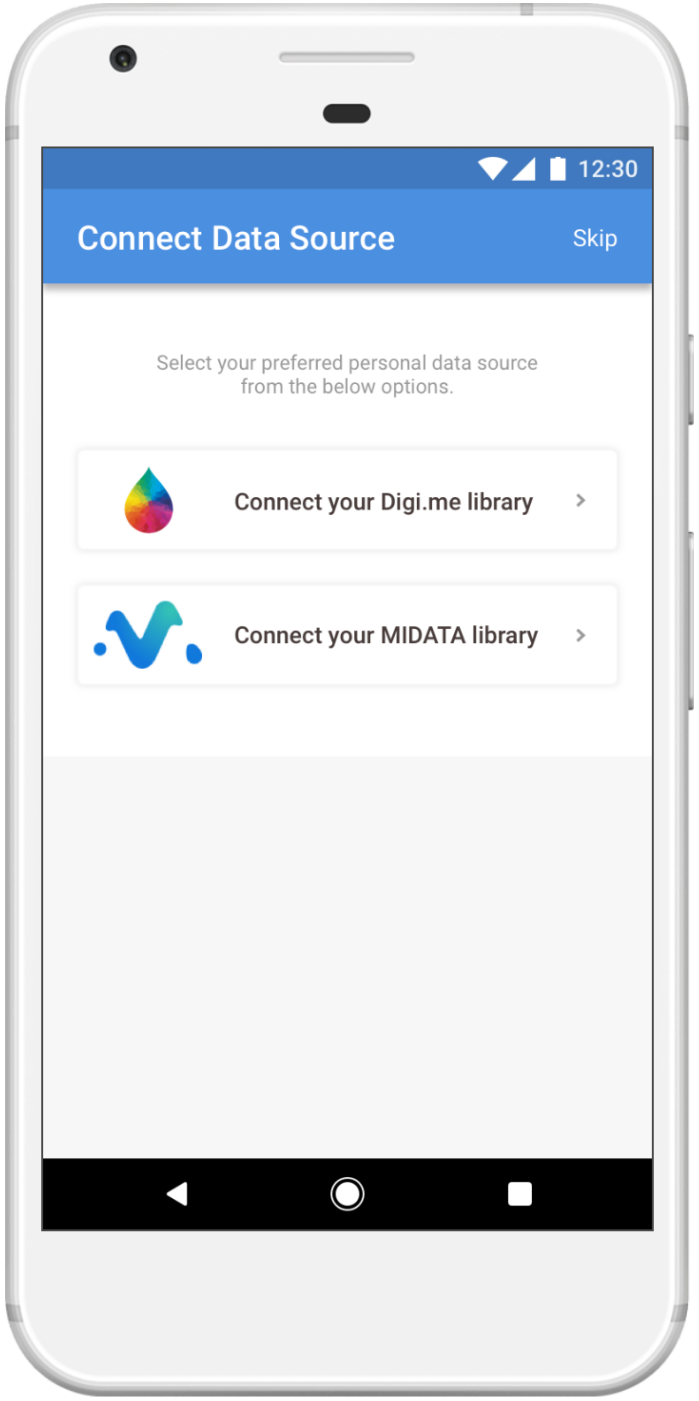


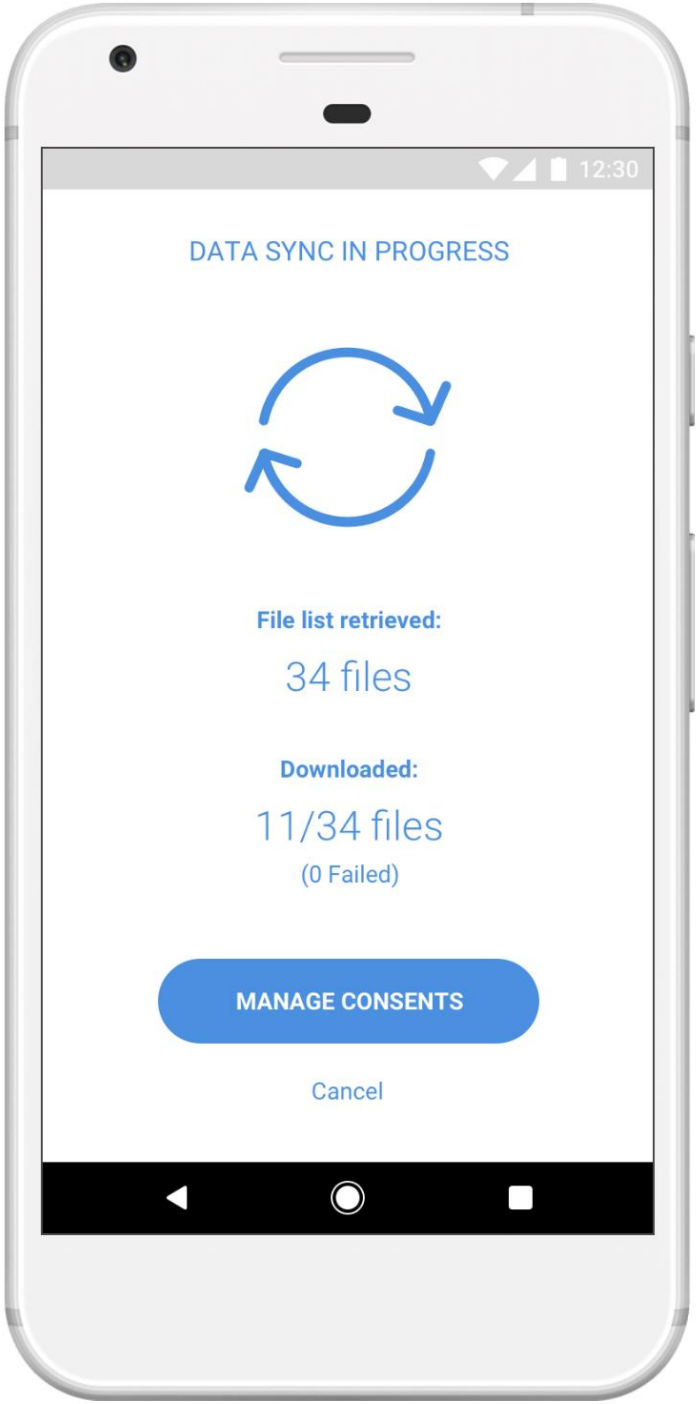


MY HEALTH MY DATA

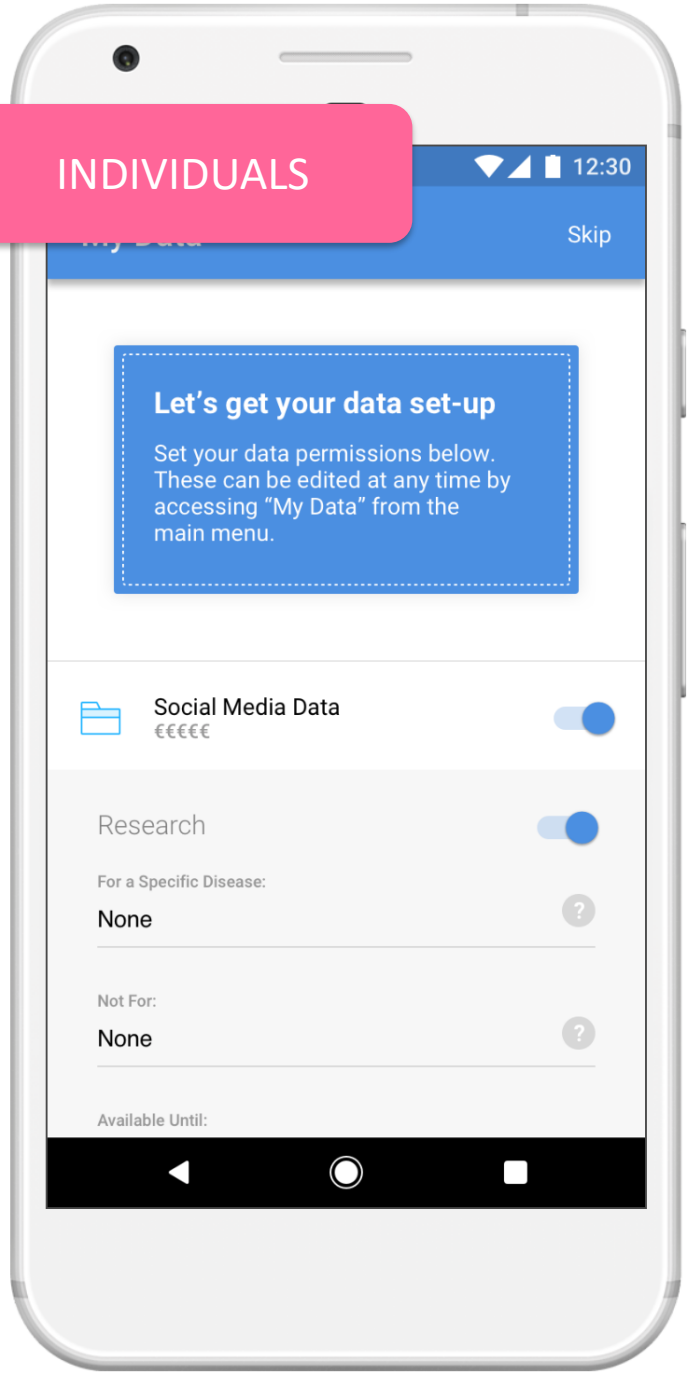
INDIVIDUALS

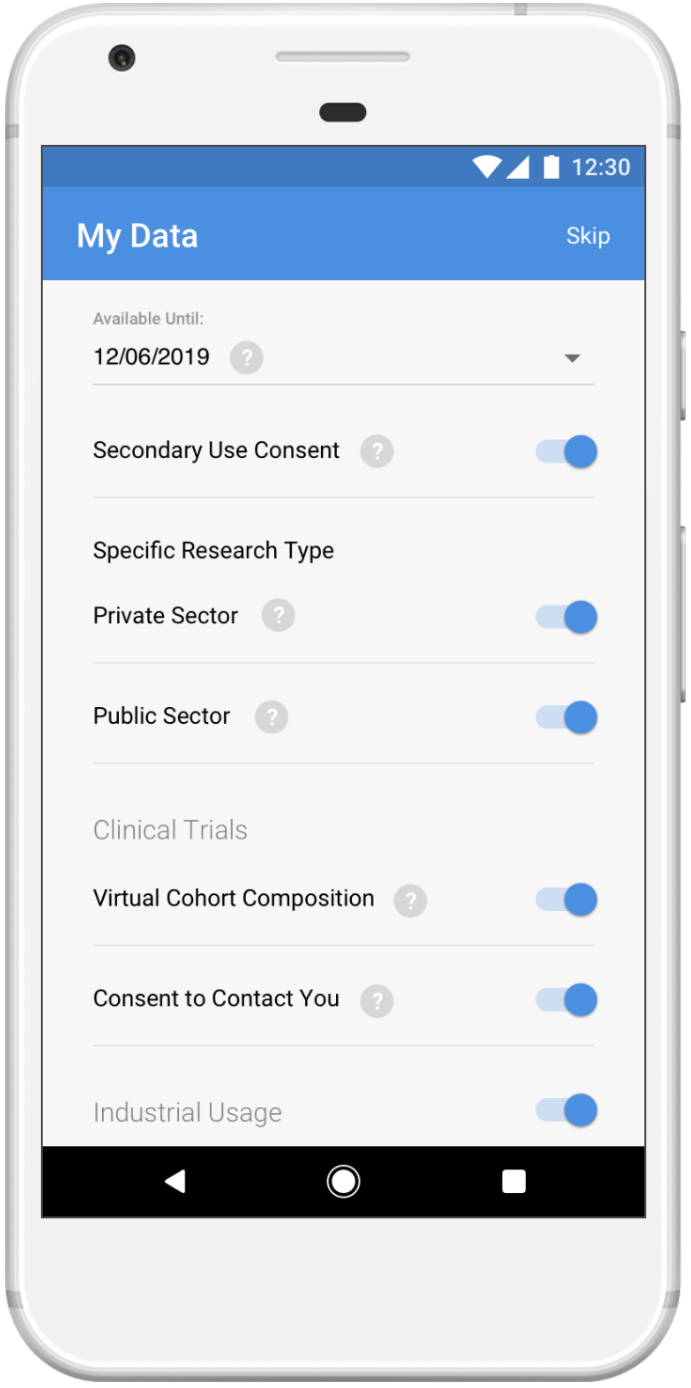


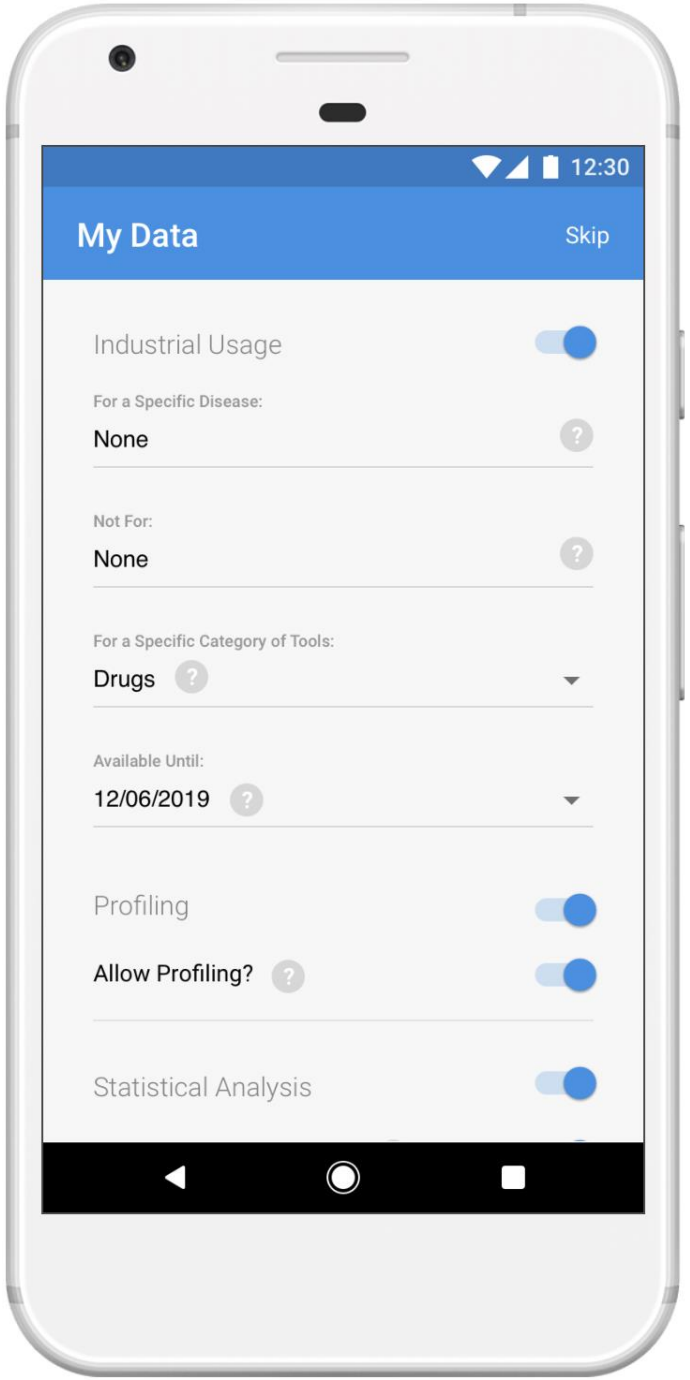




INDIVIDUALS







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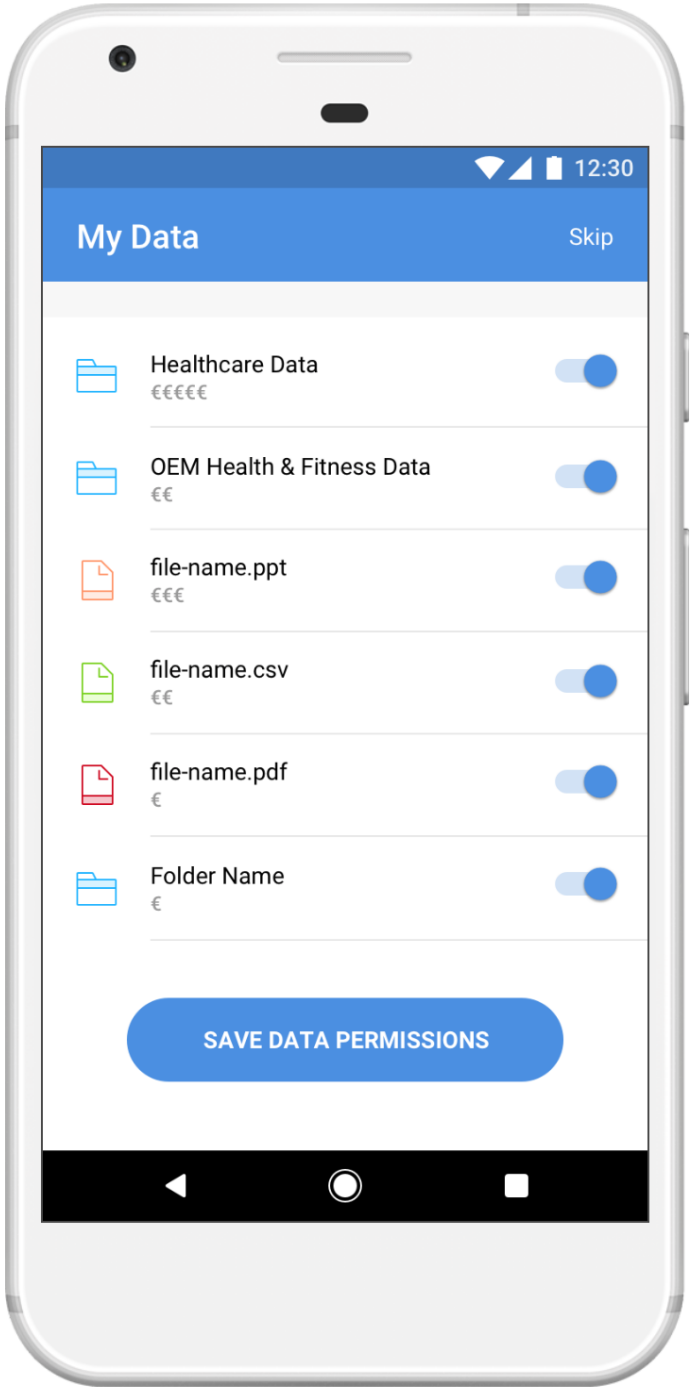


MY HEALTH MY DATA DATA CATALOGUE

name@domain.com

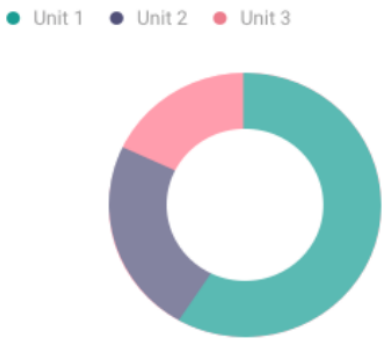
DATA USERS

Search the Data Catalogue

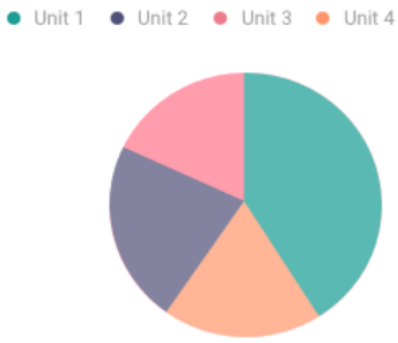
Keywords | Data Provider Type | Data Modality | Data Sensitivity | SEARCH DATA

What's inside our data catalogue?

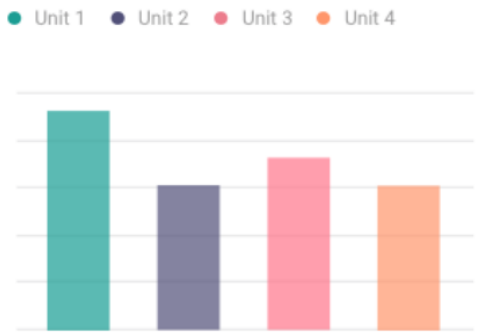
Data Providers



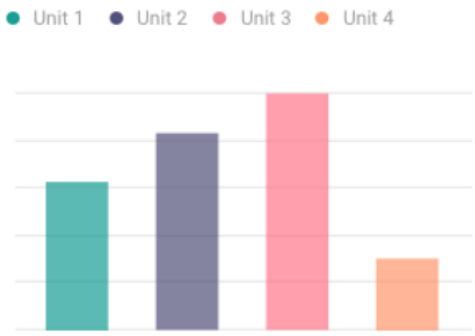
Data Types



Diseases



Drugs & Chemicals



MY HEALTH MY DATA

DATA CATALOGUE

name@domain.com

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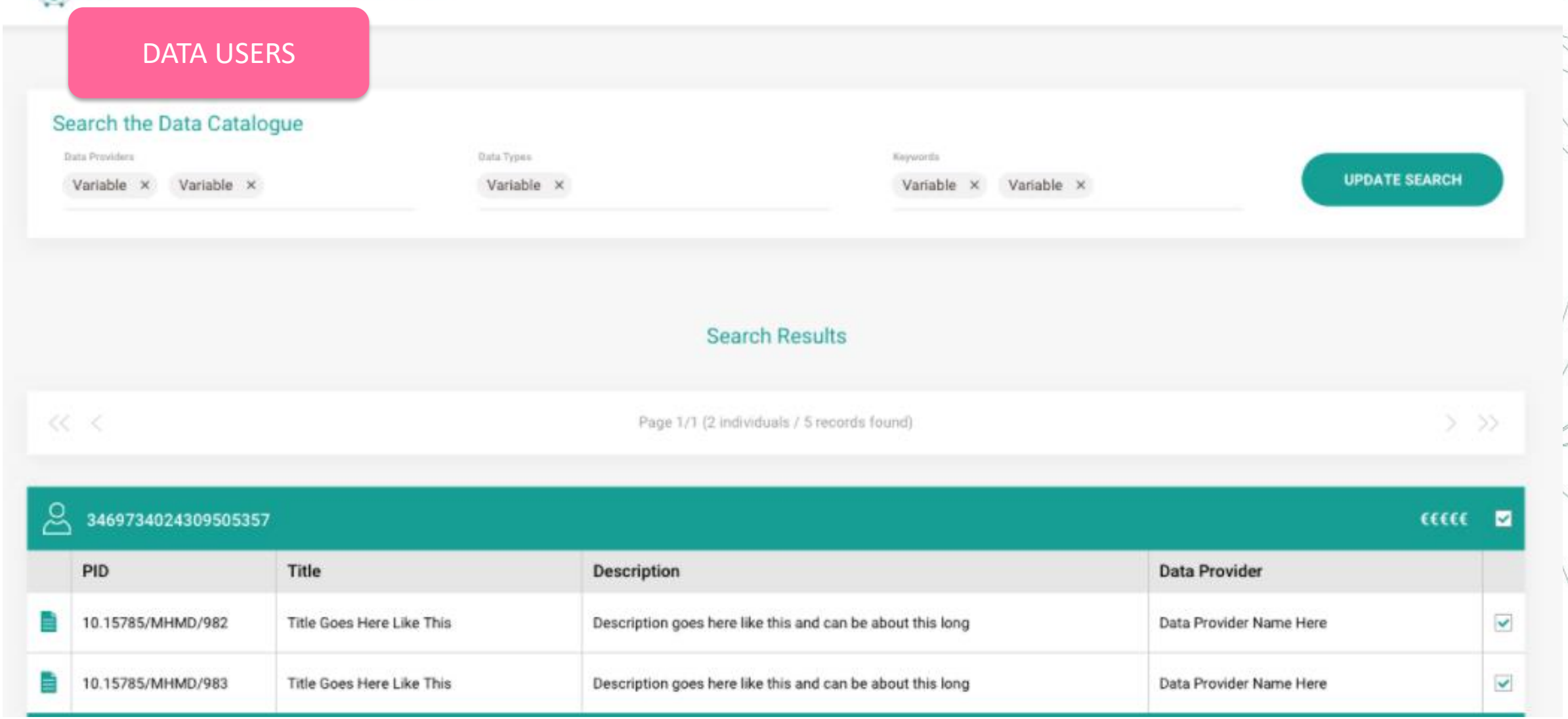

Thank You!

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info@myhealthmydata.eu

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http://www.myhealthmydata.eu/

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