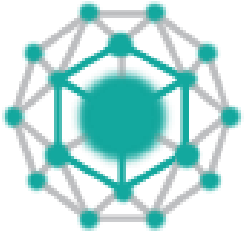


MY HEALTH
MY DATA

Trusted data sharing
enabled by blockchain technology

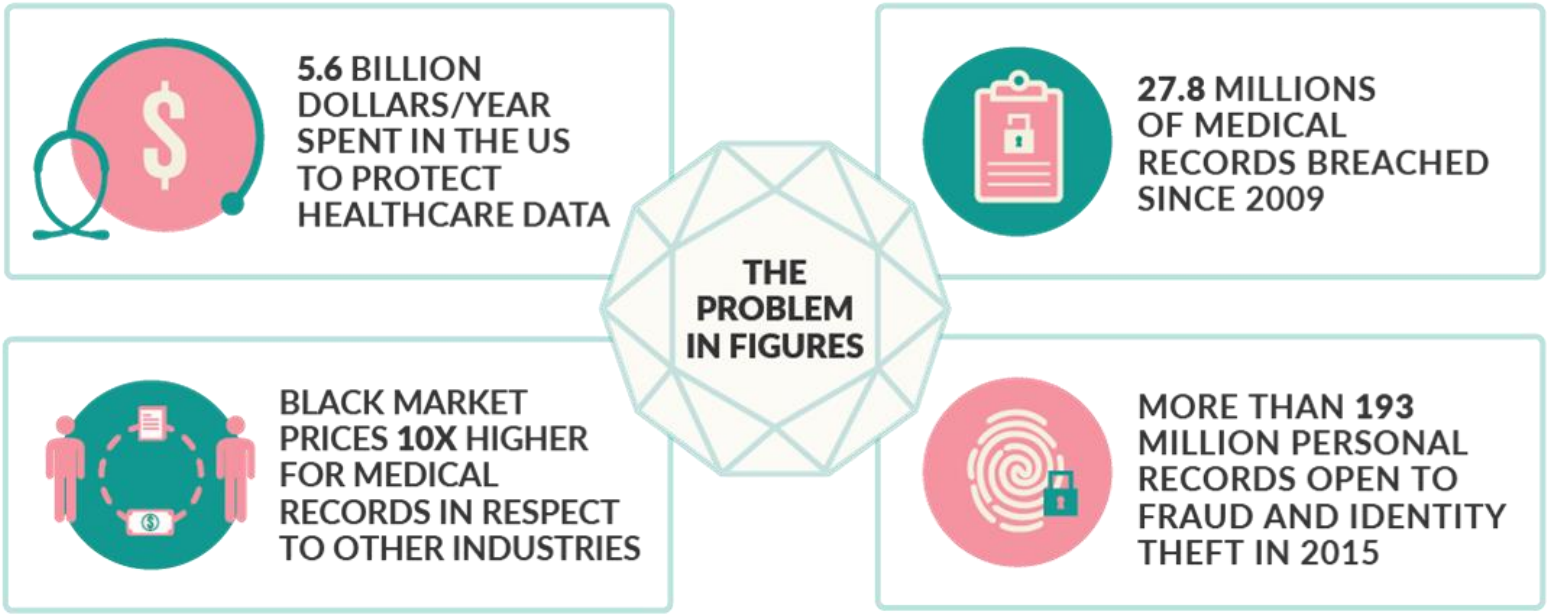
Peter Kieseberg (& Rudolf Mayer)
SBA Research

SBA Research

The big data revolution in healthcare

With its 150 exabytes of stored data worldwide per year, healthcare is a bright example of “data explosion” phenomenon

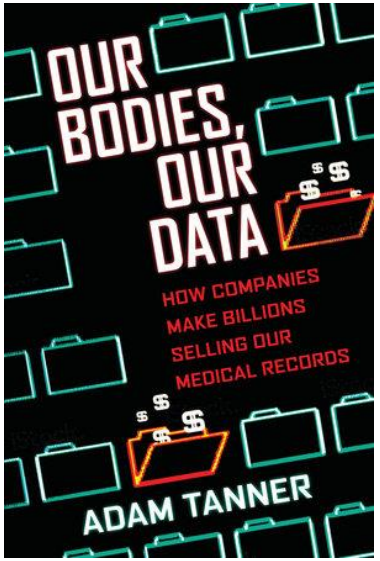
Health data is abundant – and at risk



Patients are skeptical about data sharing

"Soon after you tell your doctor about an intimate medical problem, data about your condition are sold commercially to companies that have nothing to do with your treatment or billing"

Adam Tanner, "Our Bodies, Our Data"



Patients are skeptical about data sharing

Austrian E-Health (“ELGA”) records proposed to be made available for research

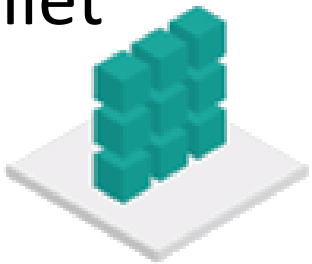
➔ Patients unsubscribe from the service!

Blockchain: new ways for data sharing?

- Need to develop new mechanisms of trust and of direct, value-based relationships between people, hospitals, research centres – and businesses
- Many initiatives (Public and private, in the EU, US,..) currently addressing potential of applying blockchain to health data
- Great general expectations: “what Internet did to transaction costs regarding information, blockchain can do regarding trust”
- Assumption that what is needed for health data is a Distributed Empowerment system
- Leading to an open biomedical information network centred on the connection between organisations and the individual

Blockchain: new ways for data sharing?

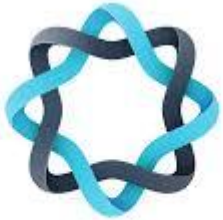
- Blockchain ledger is the secure, non-editable record
- Stakeholders are equipped with a ‘wallet’
  - an encrypted identifier
  - his/her dynamic consent
  - his/her data access policy file



- This could lead to Personal storage clouds for ubiquitous individual data access through blockchain and advanced personal use

Various initiatives

MY HEALTH
MY DATA



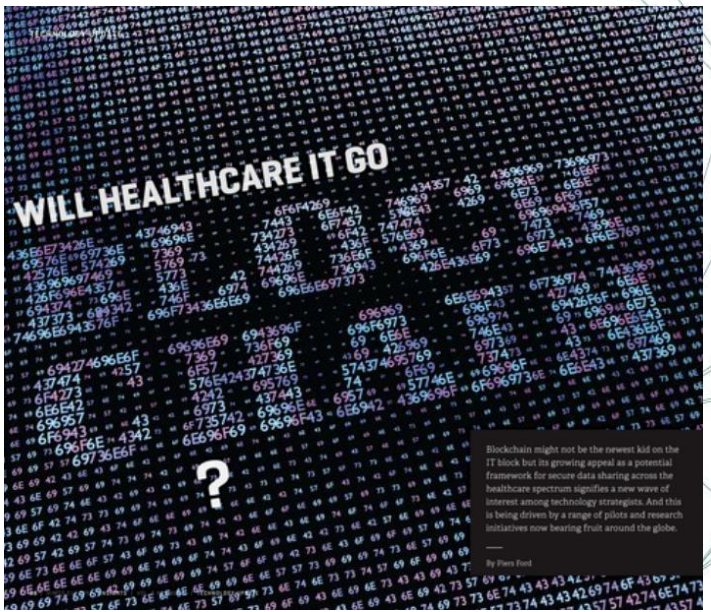
MEDICALCHAIN

MEDREC
Blockchain for EMRs
pubpub.org/pub/medrec

healthcoin

Blockchain hype ?

The Economist (2015), “The promise of the blockchain: The trust machine”, October 31st



HIMSS Europe - Health IT Central – May 15th, 2017

Blockchain value propositions for healthcare

	Health Information Exchange (HIE) Pain Points	Blockchain Opportunities
	**Establishing a Trust Network** depends on the HIE as an intermediary to establish point-to-point sharing and "book-keeping" of what data was exchanged.	**Disintermediation of Trust** likely would not require an HIE operator because all participants would have access to the distributed ledger to maintain a secure exchange without complex brokered trust.
	**Cost Per Transaction,** given low transaction volumes, reduces the business case for central systems or new edge networks for participating groups.	**Reduced Transaction Costs** due to disintermediation, as well as near-real time processing, would make the system more efficient.
	**Master Patient Index (MPI)** challenges arise from the need to synchronize multiple patient identifiers between systems while securing patient privacy.	**Distributed framework for patient digital identities,** which uses private and public identifiers secured through cryptography, creates a singular, more secure method of protecting patient identity.
	**Varying Data Standards** reduce interoperability because records are not compatible between systems.	**Shared data** enables near real-time updates across the network to all parties.
	**Limited Access to Population Health Data**, as HIE is one of the few sources of integrated records.	**Distributed, secure access** to patient longitudinal health data across the distributed ledger.
	**Inconsistent Rules and Permissions** inhibit the right health organization from accessing the right patient data at the right time.	**Smart Contracts** create a consistent, rule-based method for accessing patient data that can be permissioned to selected health organizations.

Putting the patients in the loop

*"Patients ownership of their data is an entitlement and **civil right that should be recognized**"*


The New York Times

The Opinion Pages | OP-ED CONTRIBUTORS

The Health Data Conundrum

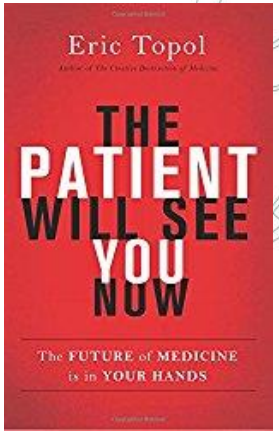
By KATHRYN HAUN and ERIC J. TOPOL JAN. 2, 2017

General Data Protection Regulation

Right to data portability:

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

From patient being "***the single most unused person in health care***" to a new era of **healthcared emocratisation**



MyHealthMyData at a glance

- Duration: November 2016 – October 2019
- 9 Research Partners
- 4 Clinical partners:
- 1 Legal consultancy:
- 1 Industry:

A long story of EU-funded research

Health-e-Child

From FP6…

Sim-e-Child

MD-PAEDIGREE

Passing through FP7…

CARDIOPROOF

To H2020

MY HEALTH MY DATA

- … providing a lot of experience with health data

MHMD mission

CITIZENS' EMPOWERMENT

Grant individuals ownership and control of their personal health data

DATA PRIVACY AND SECURITY

Ensure the strongest privacy protection and health data security

DATA VALUE ENHANCEMENT

Leverage the value of large biomedical datasets for medical care, research and business

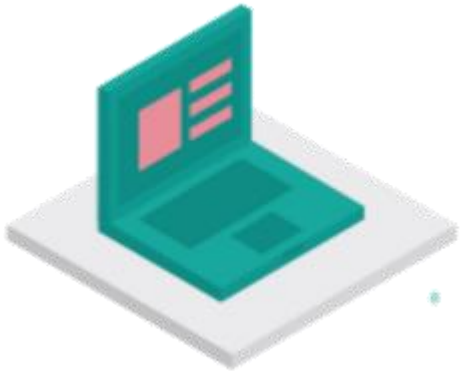
How will MHMD do that?

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

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

(1) PERSONAL DATA ACCOUNTS

Individual data ownership and control

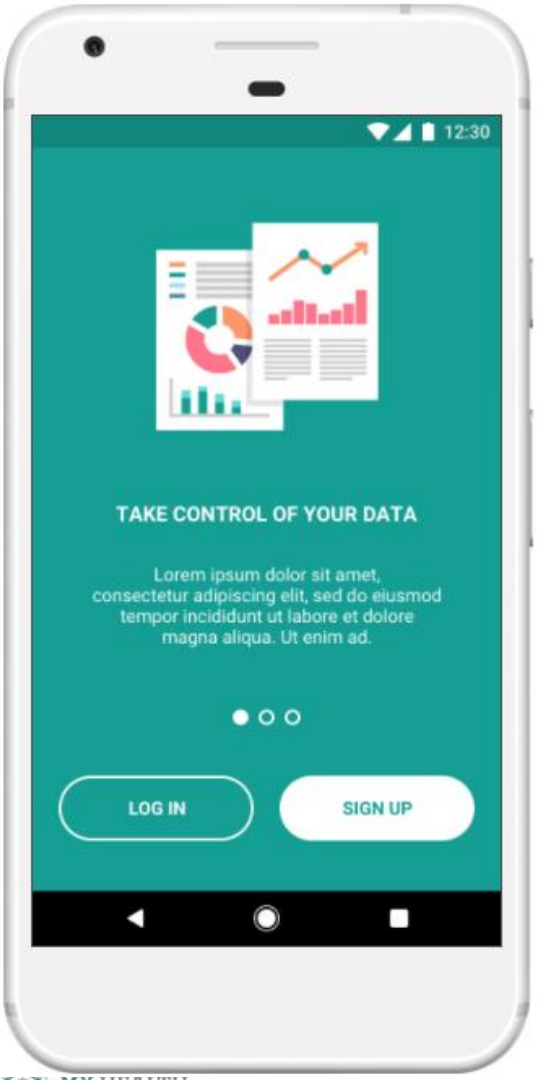


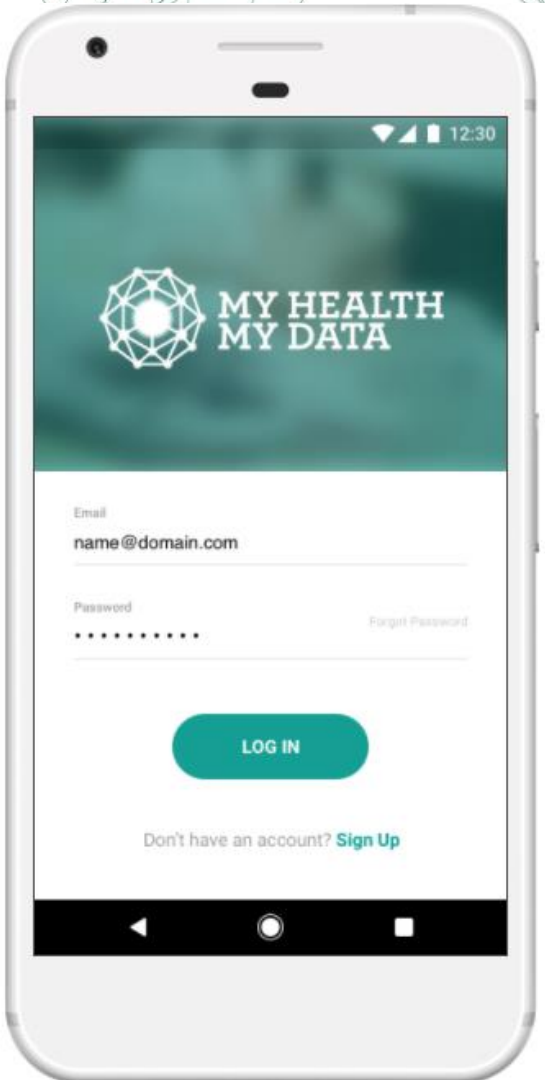
Personal storage clouds enabling individuals to access their data from any technological device through the blockchain and employ them for personal use.

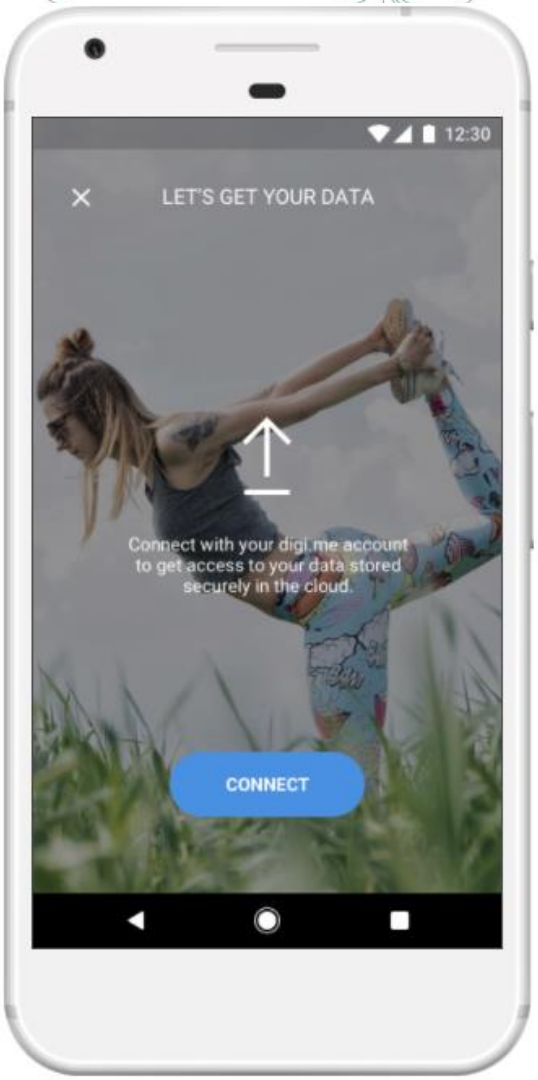
Aggregate personal data from disparate sources
(social media accounts, clinical data repositories, personal drives, wearable devices, etc.), in a single, user-owned account

- *MHMD Mobile App*
- *Data providers like digi.me*

digi.me
it's your life


12:30
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 ad.
LOG IN
SIGN UP


12:30
MY HEALTH MY DATA
Email
name@domain.com
Password
Forgot Password
LOG IN
Don't have an account? Sign Up


12:30
LET'S GET YOUR DATA
Connect with your digi.me account to get access to your data stored securely in the cloud.
CONNECT

(2) MULTILEVEL DE-IDENTIFICATION AND ENCRYPTION TECHNOLOGIES

- **Profile and classify** sensitive data
- **Identify** most suitable de-identification and encryption techniques

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

(3) DATA CATALOGUE

Finding specific data of interest

- Organise datasets so to provide a **database overview**
- Allow researchers to find **what kind of data most suits their needs**

http://maxpixel.freegreatpicture.com/photo-29398

Hes·so GENÈVE
Haute Ecole Spécialisée de Suisse occidentale

ATHENA

TRANSILVANIA
University of Brasov

MY HEALTH MY DATA DATA CATALOGUE

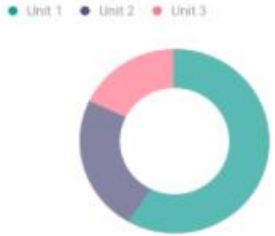
name@domain.com

Search the Data Catalogue

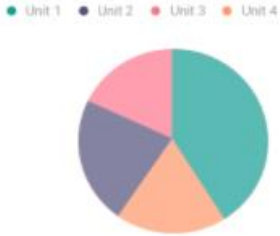
Data Providers | Data Types | Keywords | SEARCH DATA

What's inside our data catalogue?

Data Providers



Data Types



Diseases

Drugs & Chemicals

(4) BLOCKCHAIN

Providing certified information

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 guarantees secure access from anywhere on any device

(5) SMART CONTRACTS

Encoding regulation and implementing it at the speed of light

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

- ***in compliance with the incoming GDPR regulation***
- *allowing to set* ***use conditions and consent options for different stakeholders and purposes.***

(6) SECURITY: PENETRATION AND RE-IDENTIFICATION CHALLENGE

Checking the ability of avoiding privacy & security breaches

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

- **Active self-hacking (1) and public hacking (2)** simulations

- **Testing external re-identification possibilities** on
  1) *synthetic datasets attributed to virtual patients*
  2) *patients consenting to being used as test-basis*

Questions?

http://www.myhealthmydata.eu/

 @myhealthmydata

rmayer@sba-research.org

SBA Research