



## *MyHealthMyData*

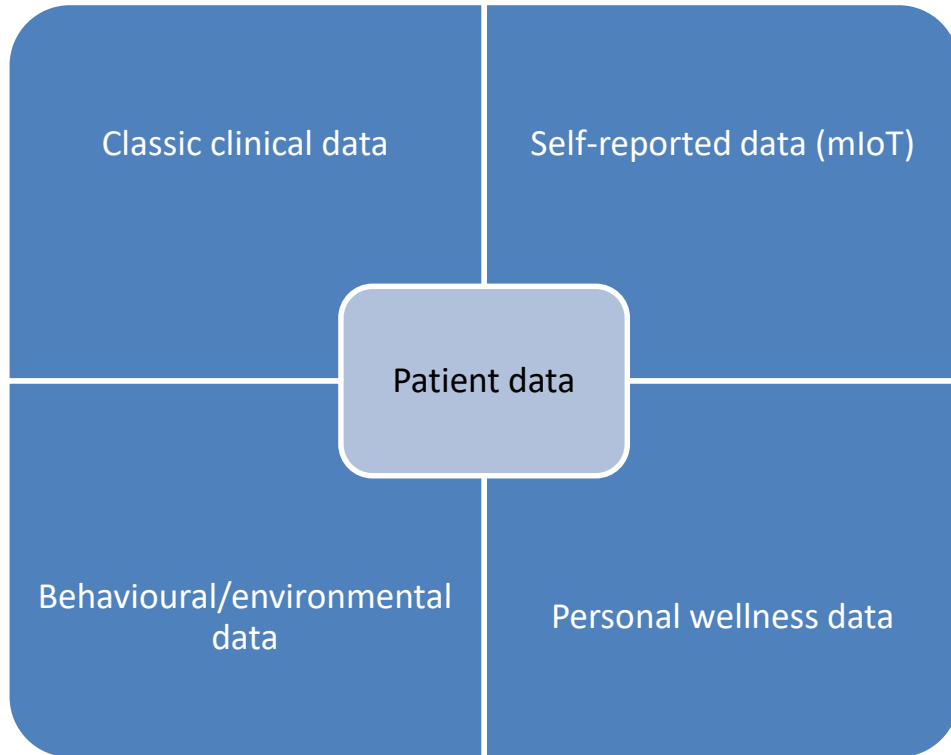
*Novel ways for secure health data exchange combining blockchain  
and privacy-preserving and security technologies*

*Mirko De Maldè – Lynkeus (Project Coordinator)*

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Horizon 2020 – Grant # 740129



## Medicine: increasingly a data-driven science



- Healthcare is a bright example of “**data explosion**” phenomenon
- Within 2020 – **40% of IoT technologies will be healthcare-related (medical Internet of Thing (mIoT))**
- Patient datasets are expanding, thanks to genomic data and patient-generated data
  - Some forecasts see a **300% growth** in healthcare data between 2017 and 2020.

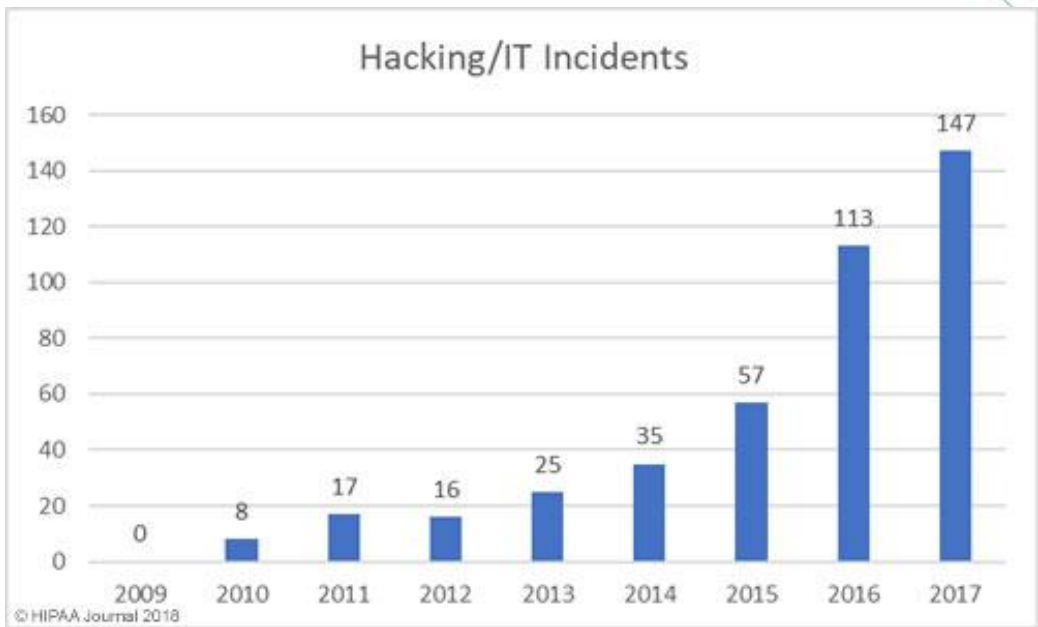
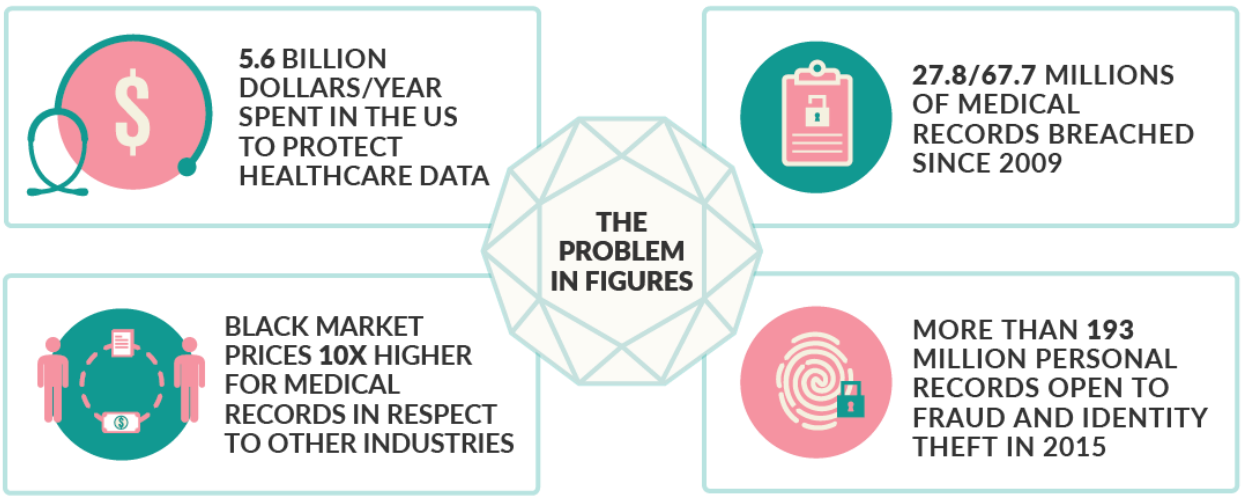
# Security issues are particularly concerning

## Q2 2018 PROTENUS BREACH BAROMETER

3.14M Patient Records Breached As Patients Are Increasingly Anxious About Health Data Security

Protenus, Inc. in Collaboration with DataBreaches.net

## Q2 2018 PROTENUS BREACH BAROMETER



“Healthcare Data Breach Statistics.” *HIPAA Journal*, HIPAA Journal, [www.hipaajournal.com/healthcare-data-breach-statistics/](http://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



# 01.

## Human Right #31

Human right #31 is a decentralized human right declared as “Everyone has the right to legal ownership of their inherent human data as property” and an addition to the existing 30 human rights adopted by the United Nations in 1948 and bestowed to every human.

#31 to assure  
organizations  
use it without  
as to where, h  
used.



# 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**





## 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.

## 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

# Why blockchain is relevant for health data management

- Overcoming issues associated with **centralized healthcare data management**
- Enabling individual **self-sovereignty 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





**MY HEALTH  
MY DATA**

## **MYHEALTHMYDATA APPROACH**

# Consortium

## 5 SMEs:

LYNKEUS.



gnúbila



## 4 Clinical partners:



## 4 Research centres and Academia:



## 1 Legal consultancy:



## 1 Industry:

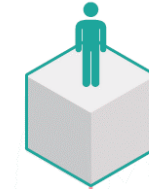


# MHMD goals



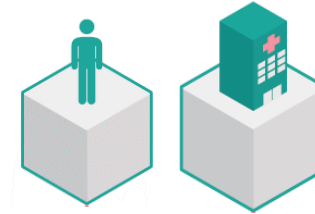
- **CITIZENS' EMPOWERMENT**

(PDA, dynamic consent, smart contracts)



- **DATA PRIVACY AND SECURITY**

(blockchain, de-identification, encryption)

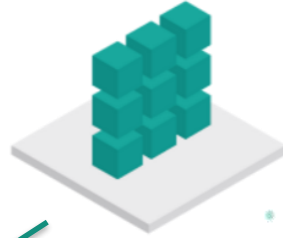


- **DATA VALUE ENHANCEMENT**

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

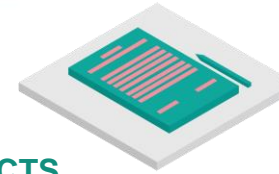


# OBJECTIVES and INNOVATIONS



## BLOCKCHAIN and SMART CONTRACTS

A private/permissioned blockchain architecture that **manages and authorizes the access and exchange of data** according to user-defined conditions

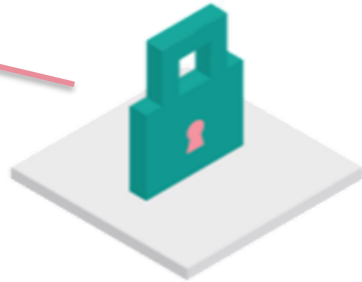
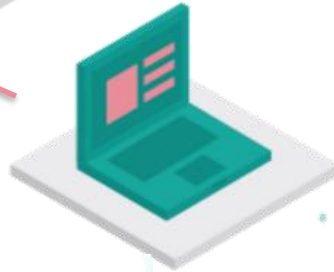


## PERSONAL DATA ACCOUNTS and DYNAMIC CONSENT

Personal storage clouds to **aggregate personal data from disparate sources** (medical records, mobile apps, IoTs), access it for personal use or share it under conditions defined by a dynamic consent module implemented through a dedicated smart contract



DATA PRIVACY AND SECURITY

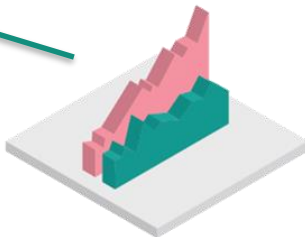


## DATA PRIVACY AND SECURITY TECHNOLOGIES

- **PRIVACY-PRESERVING DATA PUBLISHING (Data anonymisation)**: exposing de-identified data
- **SYNTHETIC DATA GENERATION**: generation of synthetic datasets through machine learning
- **SECURE COMPUTATION (Privacy-preserving data flow execution)**: calculating algorithms on encrypted data



DATA VALUE ENHANCEMENT



## BIG DATA ANALYTICS

Exploring the feasibility on **de-identified** and **encrypted data** of

1. **DeepExplorer/DeepReasoner**: deep learning for AI configuration, data exploration, case-based reasoning, patient stratification
2. **Personalized physiological models for clinical decision support** (blood circulation model)
3. **Machine learning algorithms for knowledge discovery**
4. **Models for estimating the value of 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**



# DATA PRIVACY AND SECURITY TECHNOLOGIES

## PRIVACY-PRESERVING DATA PUBLISHING (*Data anonymisation*)

Expose **de-identified data**

- removing identifying information (*identifiers, quasi identifiers*)
- adding statistical noise



*K-anonymisation (generalisation)*

ID	AGE	ZIPCODE	DIAGNOSIS	ID	AGE	ZIPCODE	DIAGNOSIS
1	28	13053	Heart Disease	1	[20-30]	130**	Heart Disease
2	29	13068	Heart Disease	2	[20-30]	130**	Heart Disease
3	21	13068	Viral Infection	3	[20-30]	130**	Viral Infection
4	23	13053	Viral Infection	4	[20-30]	130**	Viral Infection
5	50	14853	Cancer	5	[40-60]	148**	Cancer
6	55	14853	Heart Disease	6	[40-60]	148**	Heart Disease
7	47	14850	Viral Infection	7	[40-60]	148**	Viral Infection
8	49	14850	Viral Infection	8	[40-60]	148**	Viral Infection
9	31	13053	Cancer	9	[30-40]	13***	Cancer
10	37	13053	Cancer	10	[30-40]	13***	Cancer
11	36	13222	Cancer	11	[30-40]	13***	Cancer
12	35	13068	Cancer	12	[30-40]	13***	Cancer

# DATA PRIVACY AND SECURITY TECHNOLOGIES

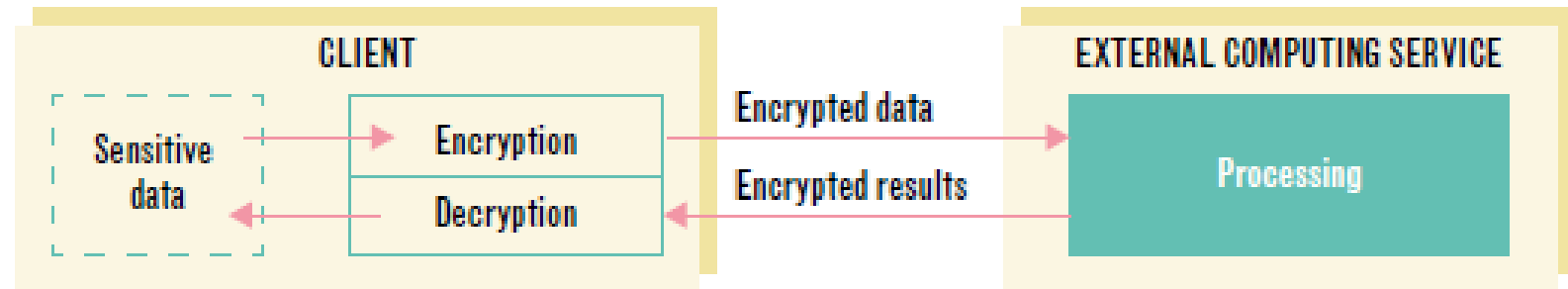


Transilvania  
University  
of Brasov

## SECURE COMPUTATION (*Privacy-preserving data flow execution*)

Calculate algorithms on encrypted data – revealing RESULTS only

- **Secure multi-party computation:** parties jointly compute a function on entries in a distributed manner, keeping the inputs private
- **Homomorphic encryption:** data is encrypted before being sent to the computing service, and calculations are made on encrypted data



'Industrial & Enabling Tech'  
prize category  
(2018 and 2019 finalist)