



# Salus.coop

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A citizen-driven community governance model for health data

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*OCTOBER 2017*

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*#saluscoop*

[www.saluscoop.org](http://www.saluscoop.org)

## An emerging context

Social / technological / economic

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Changes in the  
capacity of citizens  
and social demands

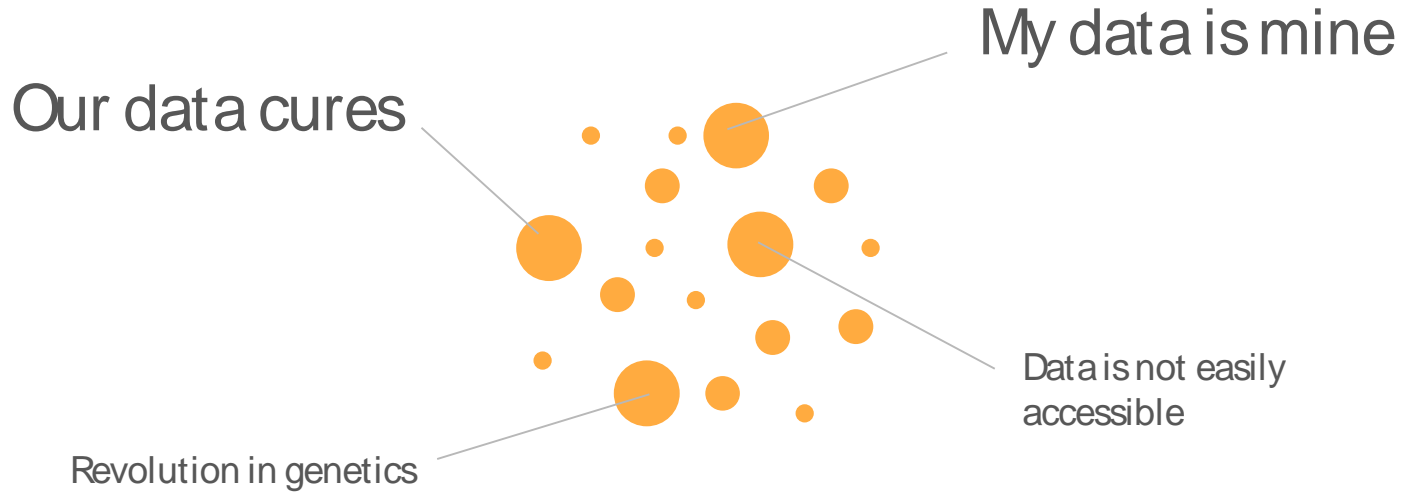
Data-driven  
innovations in  
technological  
developments and  
research

Economic pressure  
on public health  
systems

## Current context

Social / technological / economic

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It's your body

You paid for it

It is worth more than any other type of data

It's being widely sold, stolen and hacked. And you don't know it.

It's full of mistakes, that keep getting copied and pasted, that you can't edit

You are/will be generating more of it, but it's homeless

Your medical privacy is precious

The only way it can be made secure is to be decentralized

It is legally owned by doctors and hospitals

Hospitals won't or can't share your data ("information blocking")

Your doctor (>65%) won't give you a copy of your office notes

You are far more apt to share your data than your doctor

You'd like to share it for medical research, but you can't get it

You have seen many providers in your life; no health system/insurer has all your data

Essentially no one (in the US) has all their medical data from birth throughout their life

Your EHR was designed to maximize billing, not to help your health

You are more engaged and have better outcomes when you have your data

Doctors who have given full access to their patients' data make this their routine

It requires comprehensive, continuous, seamless updating

Access or "control" of your data is not adequate

~10% of medical scans are unnecessarily duplicated d/t inaccessibility

You can handle the truth

You need to own your data; it should be a civil right

It could save your life



**MORE HEALTH**

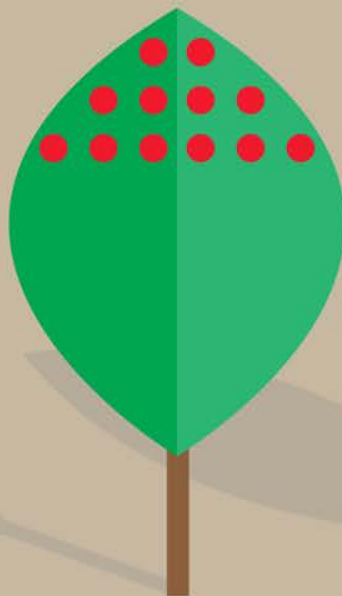
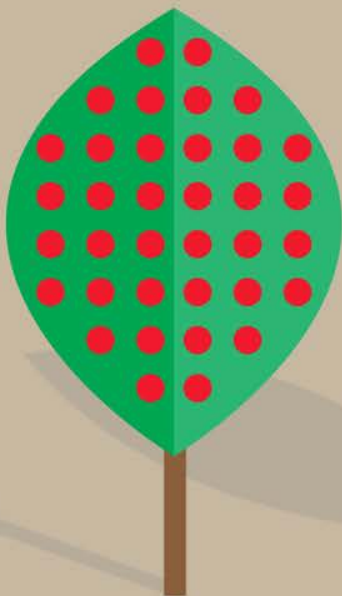
**LESS COST**

Technology modifies

**access:**

**SCARCITY IS RELATIVE**

## Technology / Available elements

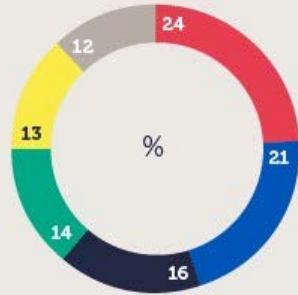


60,000+

people in

60 nations

ranked the following types  
of data as most private:



● NATIONAL ID NUMBER, PASSPORT  
or any other government-issued ID

● CONTENT OF PHONE and ONLINE  
CONVERSATIONS

● WHO I'M RELATED TO  
including children, parents, and relatives

● PHONE NUMBER and EMAIL ADDRESS

● WHAT I READ, WATCH, AND LISTEN TO  
on websites and apps

● JOB AND INCOME HISTORY  
including salary and welfare benefits

### **Omidyar Network**

*A philanthropic investment firm harnessing the power of markets to create opportunity for people to improve their lives. #PositiveReturns*

<https://medium.com/positive-returns/trust-and-privacy-cb27e85fecf5>

### **A Global Crisis of Trust**

Research commissioned by Omidyar Network reveals the extent of the global “Data-Trust gap”, showing how pervasive the **lack of trust** is for individuals who have to share their personal data with either **governments or companies**.





To explore a citizen-driven model of collaborative governance & management of health data.

This model should enable citizens to share their health data to accelerate research and innovation in healthcare, thus maximizing social and collective benefits.

# Envisioned scenario

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Emitter



Citizens as data donors  
and administrators



Receivers

## Data providers

- Public health centres
- Private health centres
- Apps/ wearables/ devices
- Personal



## Data users

For offering personalized services

- Service companies
- Health companies
- Startups
- Medical associations
- Administrations
- Etc.



## Data users

For conducting research

- Research centres
- Universities
- Research units in companies



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# First feasibility study

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July-December 2016, Barcelona

Focus

# BREAST CANCER



Active and  
empowered  
Patients  
Association



World Research  
Health Centers



Disease with high  
Social Impact

# Objective and work done

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## Objective

To explore, define and validate the hypothesis of creating a cooperative of citizens willing to govern the use of their health data, by analyzing the social, technological and legal viability.

## Focus

Breast cancer

## +25 interviews

### Actors interviewed

- Patient associations
- Researchers
- Physicians
- Bioethics experts
- Entrepreneurs in the health sector
- Open data promoters
- Blockchain experts
- Legal experts

### Topics covered during interviews

- Perceived benefits and values
- Perceived risks
- Possible barriers
- Relationship between groups of agents

## 2 validation sessions

### 34 participants

Representatives of the three main actors groups: citizens, providers and users of data

### Main topics covered in the sessions

Benefits and risks of four models of data governance: individual, public, private, collective

## Initial findings

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### PERCEIVED UNIVERSAL BENEFITS

#### Provision

- > Prevention & personalization
- > Management of healthcare services

#### Innovation

- > Research
- > New business models in healthcare



### TERMS

#### Control and Transparency

- > Clear and understandable information
- > Who has access to data? What for?
- > What are the results of data use?

#### Anonymity and Security

- > Prevent re-identification as much as possible
- > Not central repository of data

#### Collective benefits

- > No individual return
- > Citizen-driven research agenda



### BARRIERS

#### Entry barrier to citizens

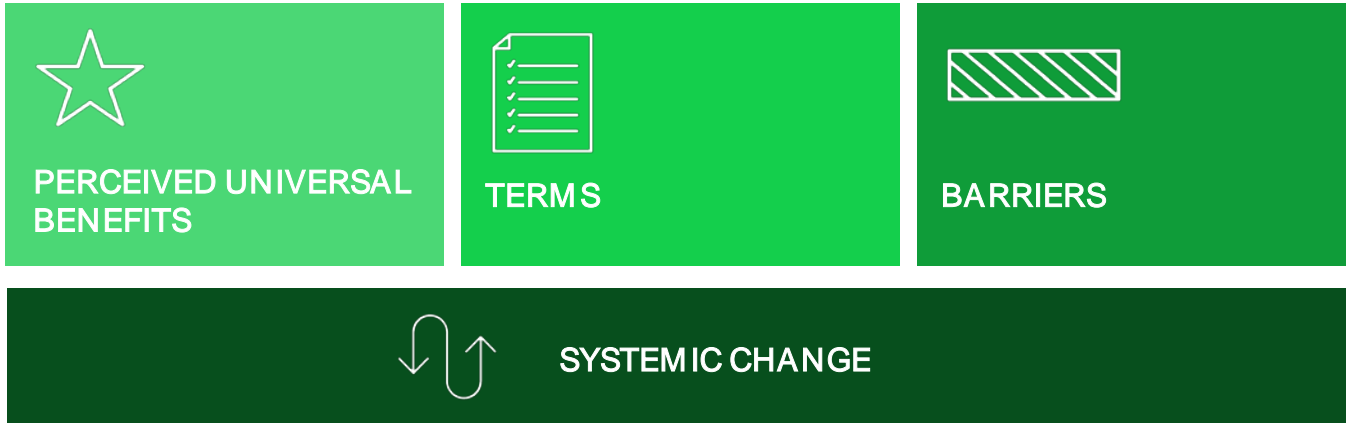
- > Motivate citizens to participate
- > Help citizens understand the health data ecosystem and the value of sharing data
- > Consider possible technological / educational barriers that might prevent access to certain groups

#### Barriers among agents

- > Possible changes in the relationship between patient and physician
- > Possible changes in the practices of physicians
- > Distrust towards business-driven research

## Triggers of systemic change

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# SYSTEMIC CHANGE

**Data:** scarcity → abundance

**Management:** individual → collective

**Channels:** intermediaries → direct

**Knowledge:** asymmetry → symmetry of  
information

**Publications:** selective → integral

**Actors:** a certain number → multiplicity

**Innovation:** on products → on processes



## Our ethical code

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Decisions making between all



Easy and agile participation



Transparency



Social return

## Data governance principles

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### Conditional donation

Citizens have the right to decide under which conditions they want to donate their health data.

### Collective benefits

The use of data by any agents should generate a clear and unequivocal benefit to society.

### Motivational incentives

In order to reach a significant data sample for conducting research, it is key to motivate the greatest number of citizens to donate their data. Incentives to individuals shouldn't be put ahead of the common good. Incentives could be given in form of services.

### Rights management

Mechanisms of collective governance that allow to guarantee the collective benefits from data use, and manage citizens' conditions on data donation

# Health data commons

Ecosystem of actors

## Data keepers



Public health centres

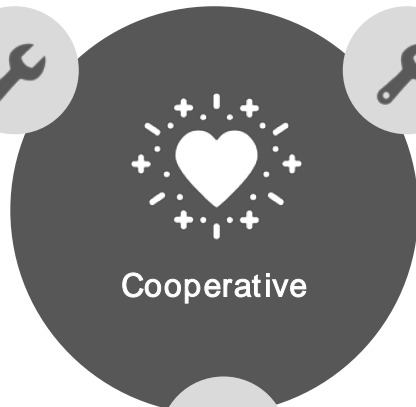


Private health centres



etc...

Providers of services to data keepers  
(aggregation and structuring of the data)



Providers of services to data users  
(analysis, visualization, modelization...)



Providers of services to cooperative members  
(PHR, wearables...)



## Data users



Universities



Research centres



Clinical research companies

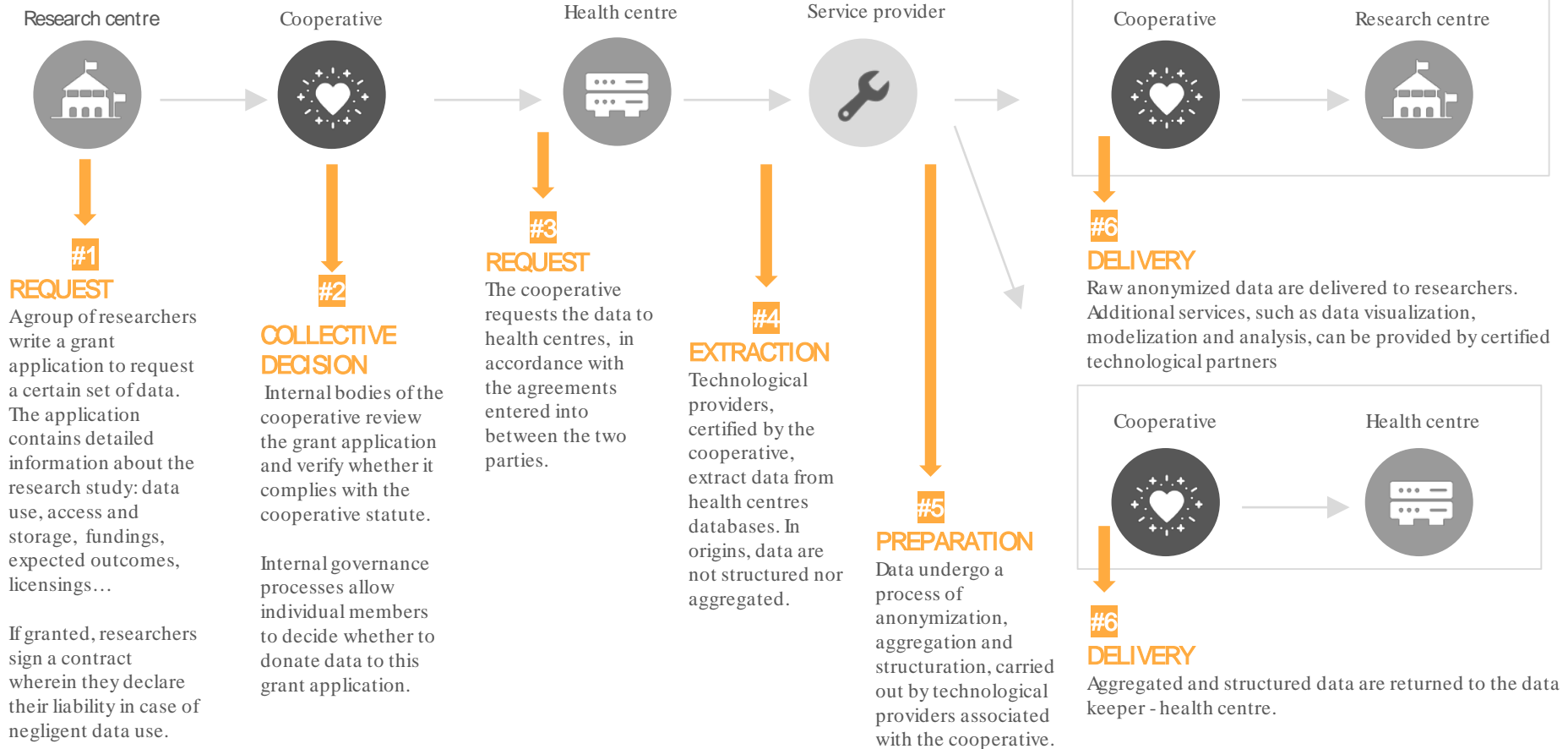


etc...

exchange rate

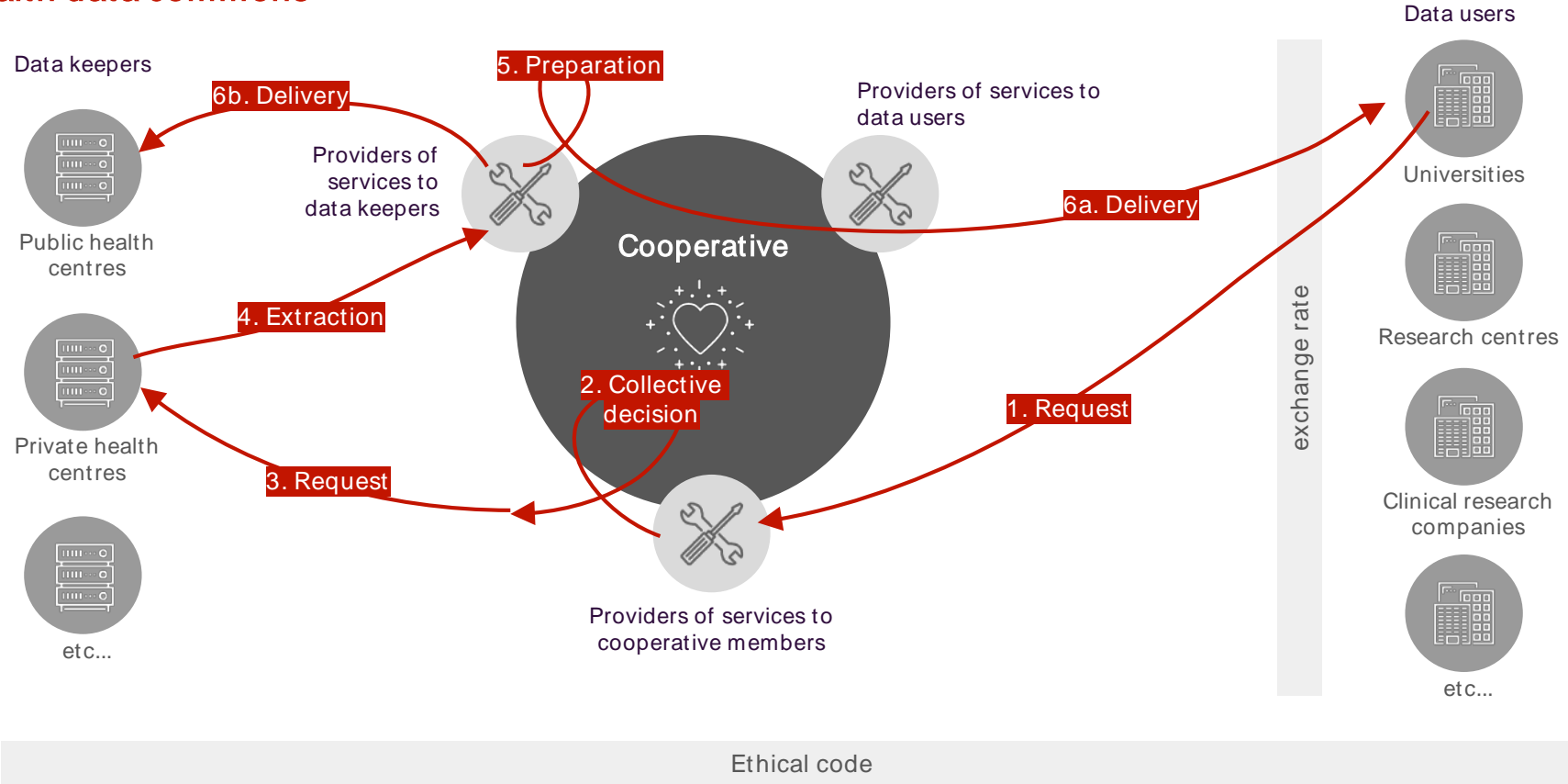
Ethical code

# Data flow narrative



# Data flow

## Health data commons



## Pilot 1



Gracia, Barcelona  
Spain



Focus: Noise pollution

How noise pollution in cities is affecting  
citizens' health?

## Pilot 2



VHIO Hospital Vall d'Hebron,  
Barcelona, Spain



Focus: Breast cancer

What clinical and psychosocial factors  
can trigger relapse processes in breast  
cancer patients?



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A CITIZEN COOPERATIVE FOR GOVERNANCE & MANAGEMENT OF HEALTH DATA

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