



# SALUS COOP

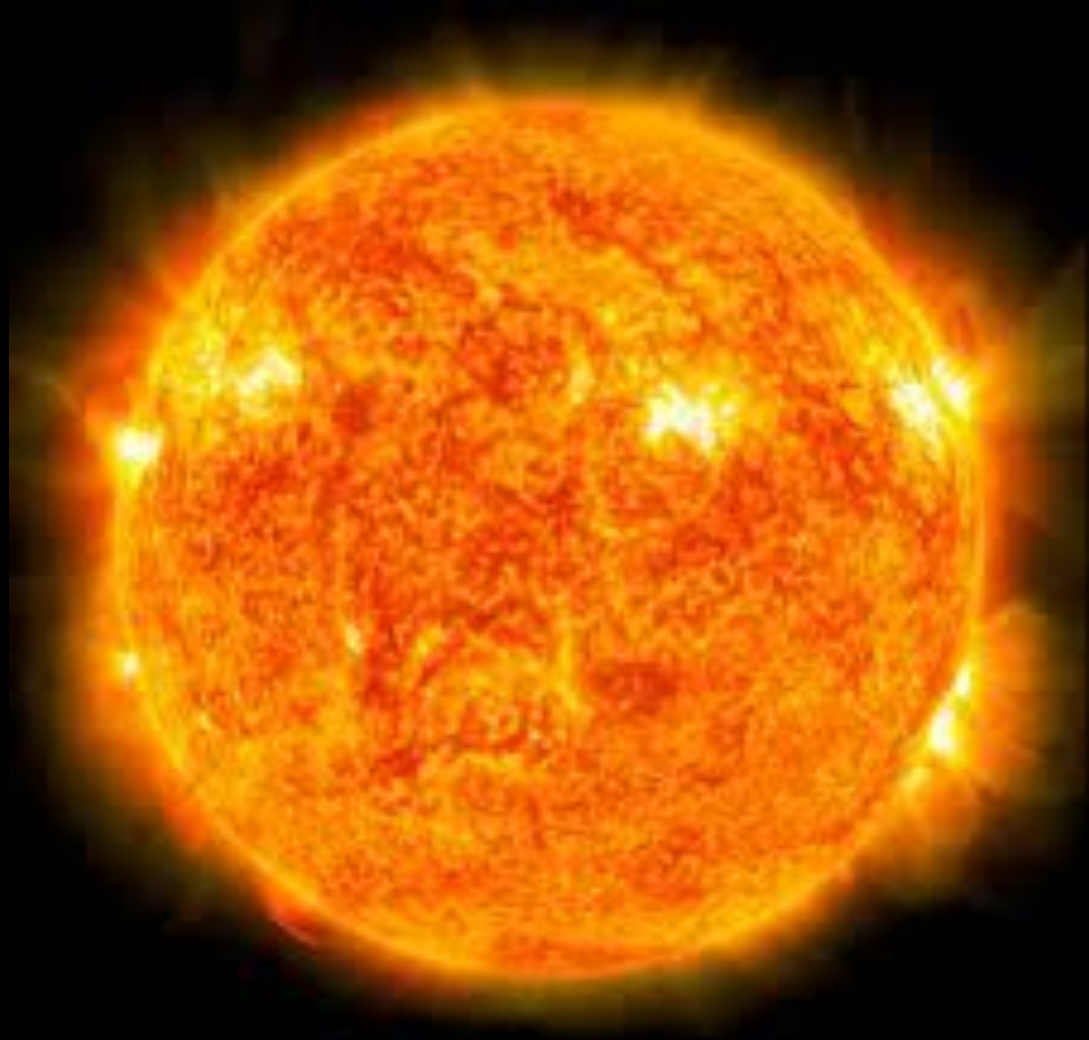
Citizen data cooperative for health research

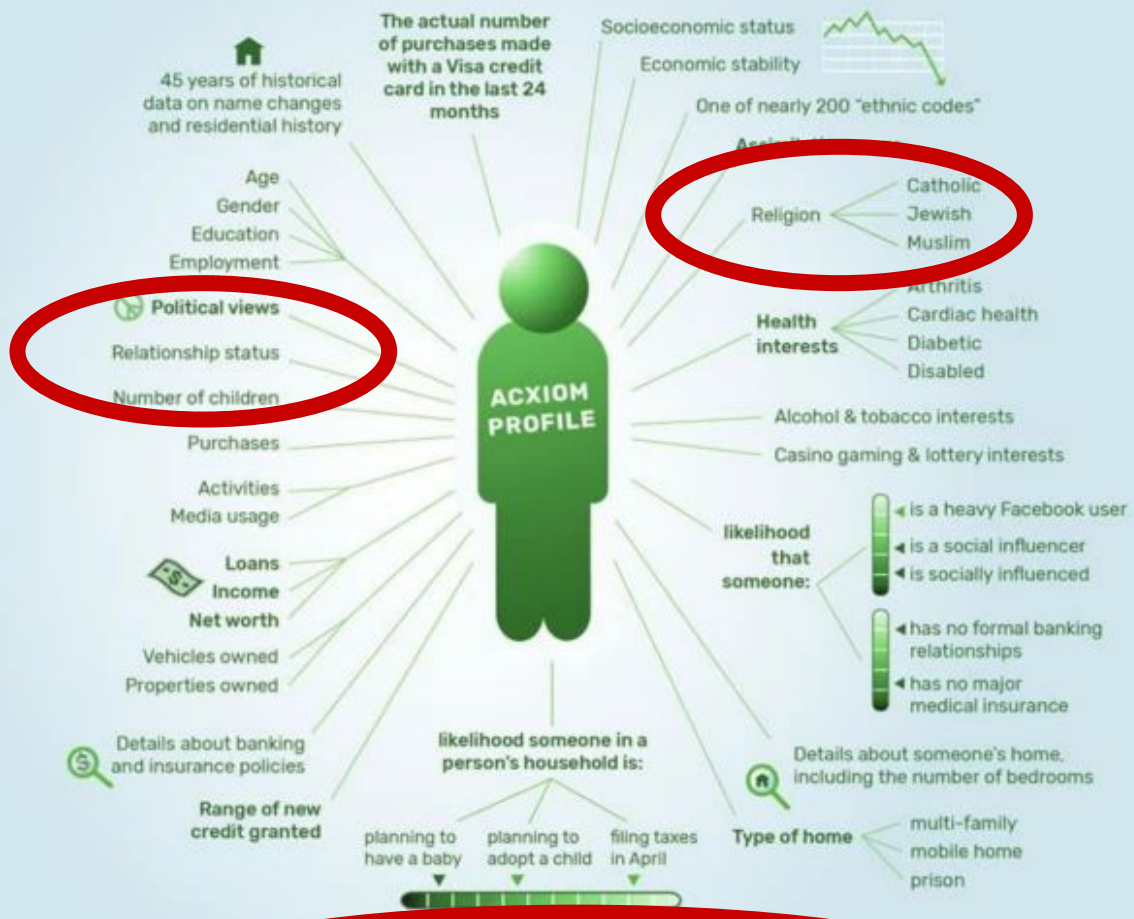


#salusCoop

@saluscoop

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





**Acxiom provides of up 3,000 attributes and scores on 700 million people in the US, Europe, and other regions.**



5.0

3.6

4.9

4.8

Female  
Age : 37

Female  
Age : 37

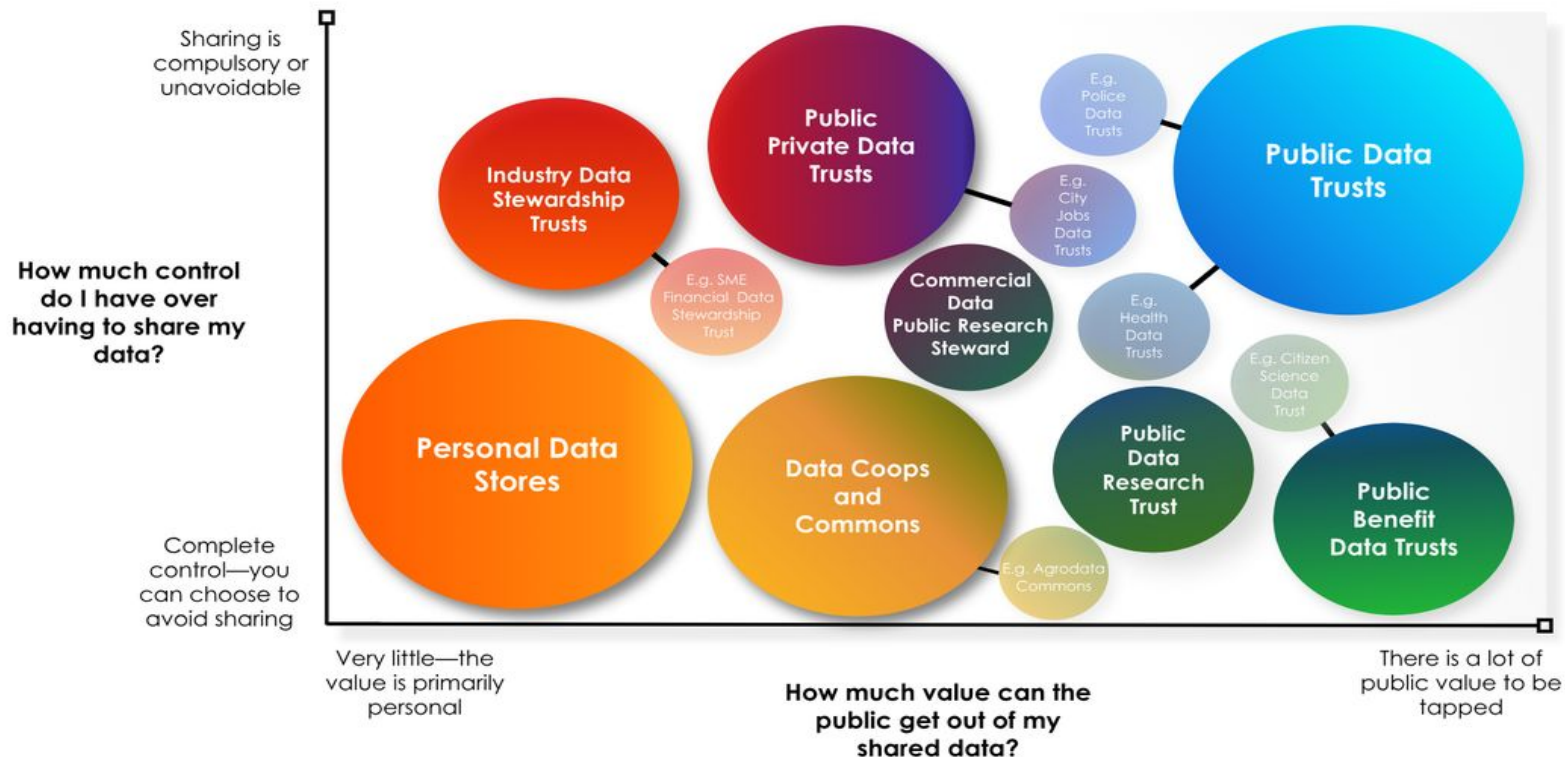
Male

# China's Social Credit System

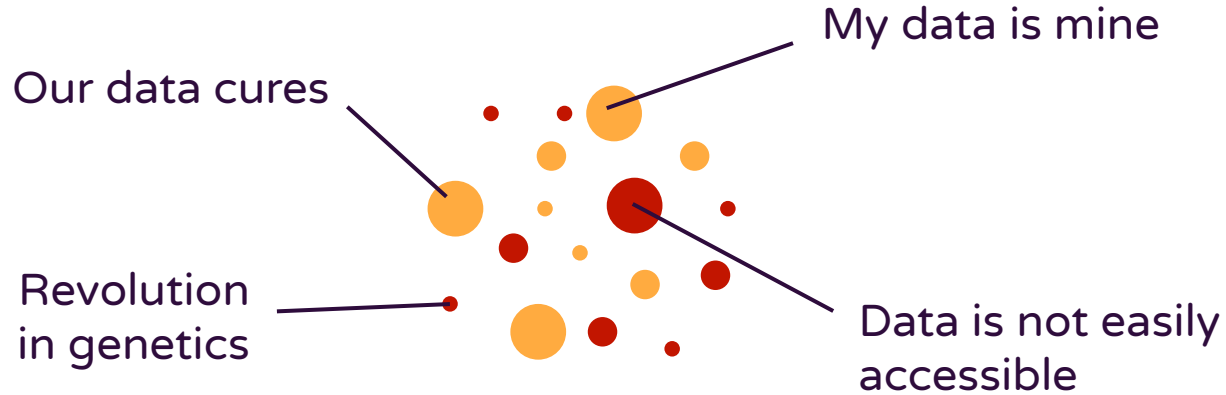


# A new framework for data governance

— Lines point to an example (small bubbles)  
■ Colour indicates institutional overlap  
● Bubble size indicates size of sector



# Current context



Changes in the  
capacity of citizens  
and social demands

Data-driven innovations  
in technological  
developments & research

Economic pressure on  
public health systems

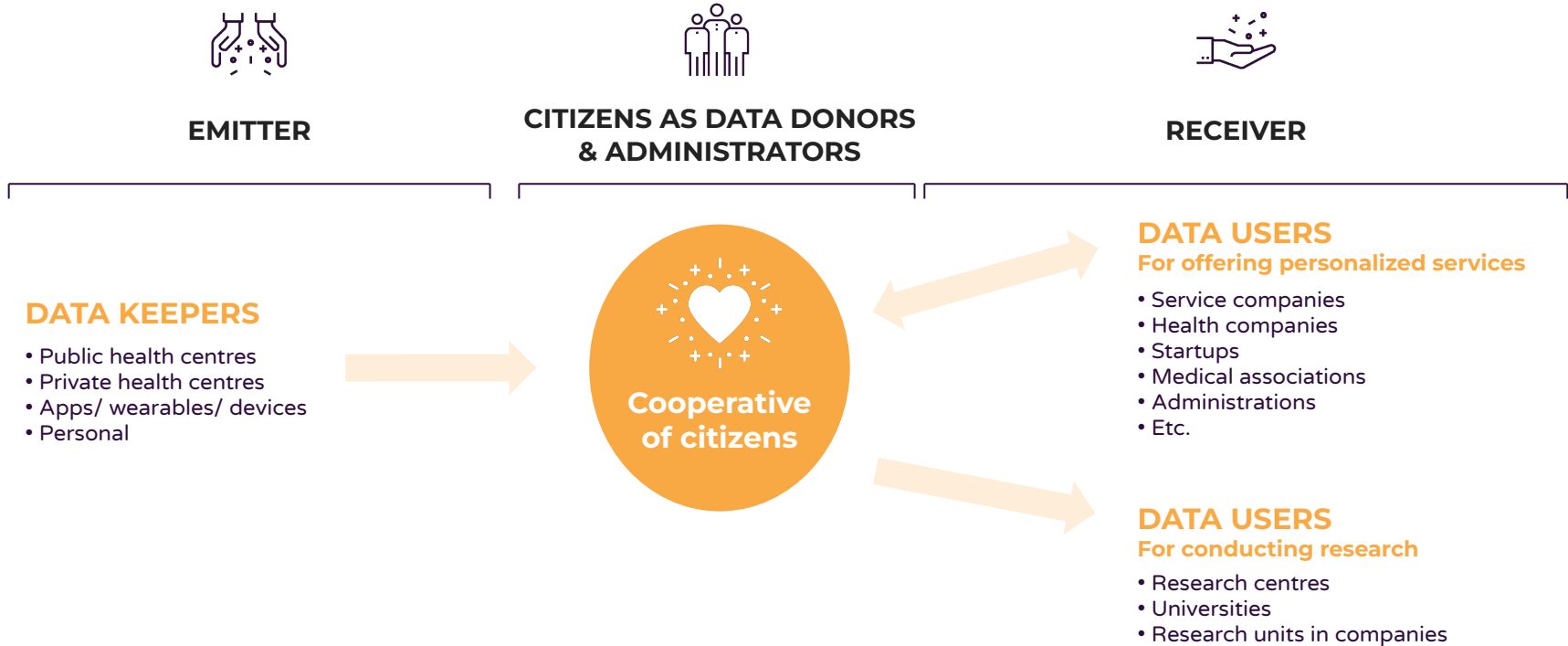
# Objective



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





# 2017 / Barcelona

## 46 Socis/es

### QUI SOM?

- Joan Guanyabens Calvet
- Andrea Barbiero
- Javier Creus Román
- Mara Balestrini
- Valeria Righi
- Gabriela Masfarré Pinto
- Lluís Muns Terrats
- Jose Manuel Picas Vidal
- Genís Roca Verat
- Pere Merino Tarafa
- Gemma Domènech
- Fernando de la Rosa

- Marta Segura Bonet
- Lluís Torrens Mèlich
- Francesc Lopez
- Sandra Walsh
- Carlos Cuffí Estevez
- Miquel Angel Oliva
- Marc de San Pedro
- Juan Antonio de los Cobos
- Felipe Macias Acuña
- Àngels Cobo
- Pere Pascal
- Betsabé Melcon

- Ariadna Esteve
- Sara Mas
- Darina Codina
- Mont Porta
- Vicky Medina
- Tino Martí
- Simona Levi

I 15 socis/sòcies col·laboradors



# First feasibility study



**Barcelona,  
Spain**



**July to December,  
2016**



**Focus: Breast  
cancer**

# First feasibility study



## 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.



## +35 INTERVIEWS

### Actors interviewed:

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

### Topics covered during the 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:

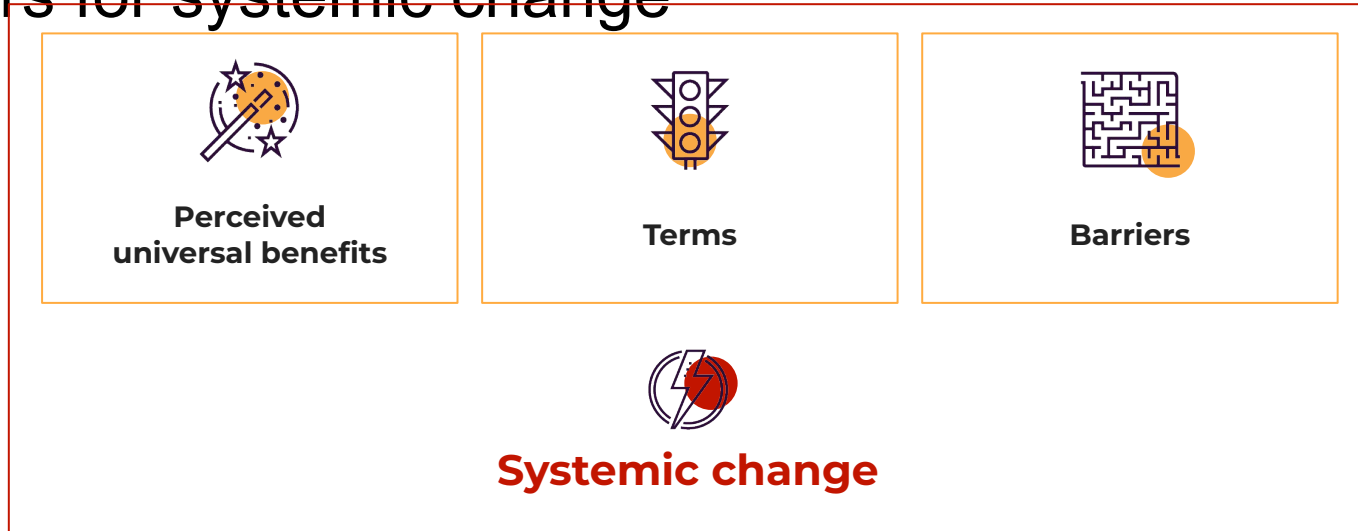
- Citizens
- Data keepers
- Data users

### Main topics covered in the sessions:

Benefits and risks of four models of data governance:

- Individual
- Public
- Private
- Collective

# Triggers for 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

# Initial findings



## PERCEIVED UNIVERSAL BENEFITS

### Provision:

- Prevention & personalization
- Management of healthcare services

### Innovation:

- Research
- New business models in healthcare



## TERMS

### Control & transparency:

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

### Anonymity & Security:

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

### Collective benefits:

- No individual return
- Citizen-driven research agenda



## BARRIERS

### Entry barriers 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

# Data governance principles



## **CONDITIONAL DONATION**

Citizens should 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



**"Data is the raw material of the 21st century, and the question 'Who owns that data?' will decide in the end whether democracy, a participatory social model, and economic prosperity can be combined."**

ANGELA MERKEL



# Conditions for data donation



Let's decide  
the future  
of our data

Participate here [www.ideasforchange.com/triem](http://www.ideasforchange.com/triem)

**TRIEM**  
by SalusCoop & IdeasForChange

d-LAB | A programme of  
MOBILE CAPITAL  
BARCELONA

IDEAS  
FOR  
CHANGE

SALUS COOP

Ship2B  
ACCELERATOR FOR A BETTER WORLD

R&J  
A&A

UOC

CDE

# Conditions for data donation

- **Who requests data**
- **Which data is requested**
- **What is research conducted for**
- **How will results be shared**

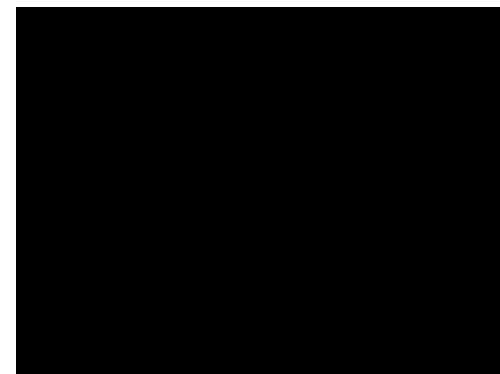
TRIEM

# Conditions for data donation

TRIEM Web



Veure vídeo!



# TRIAM

by SolusCoop & IdeasForChange



## ¡Decidamos el futuro de nuestros datos!

Nuestros datos de salud son uno de los recursos más valiosos para generar conocimiento e innovación. Cómo gestionarlos es una decisión que depende de cada uno de nosotros. A través de esta aplicación, podrás contribuir a crear las primeras licencias de datos para el beneficio de todos. ¿Te sumas?

[Quiero participar](#)

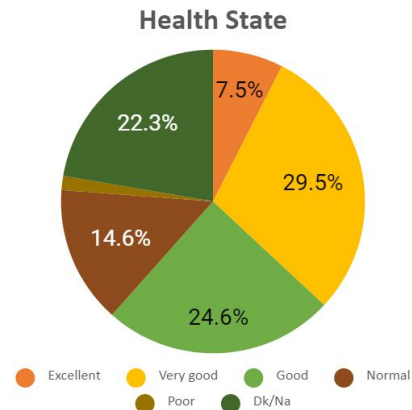
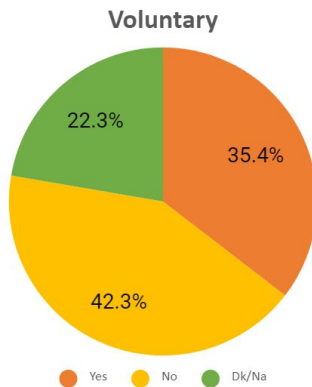
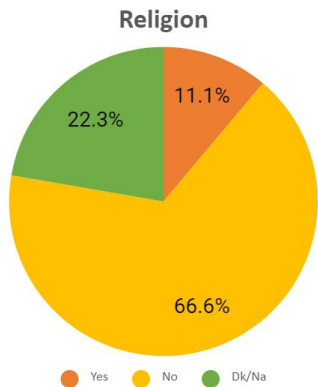
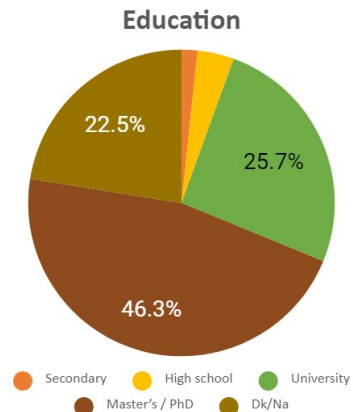
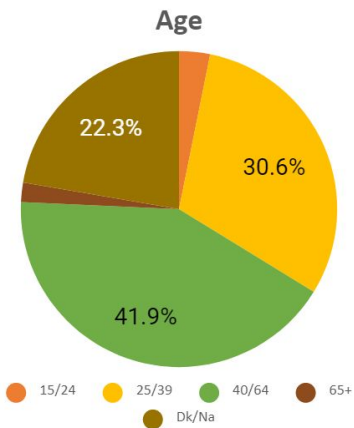
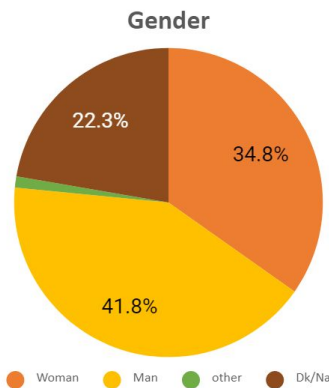
[Quiero saber más](#)

# TRIEM

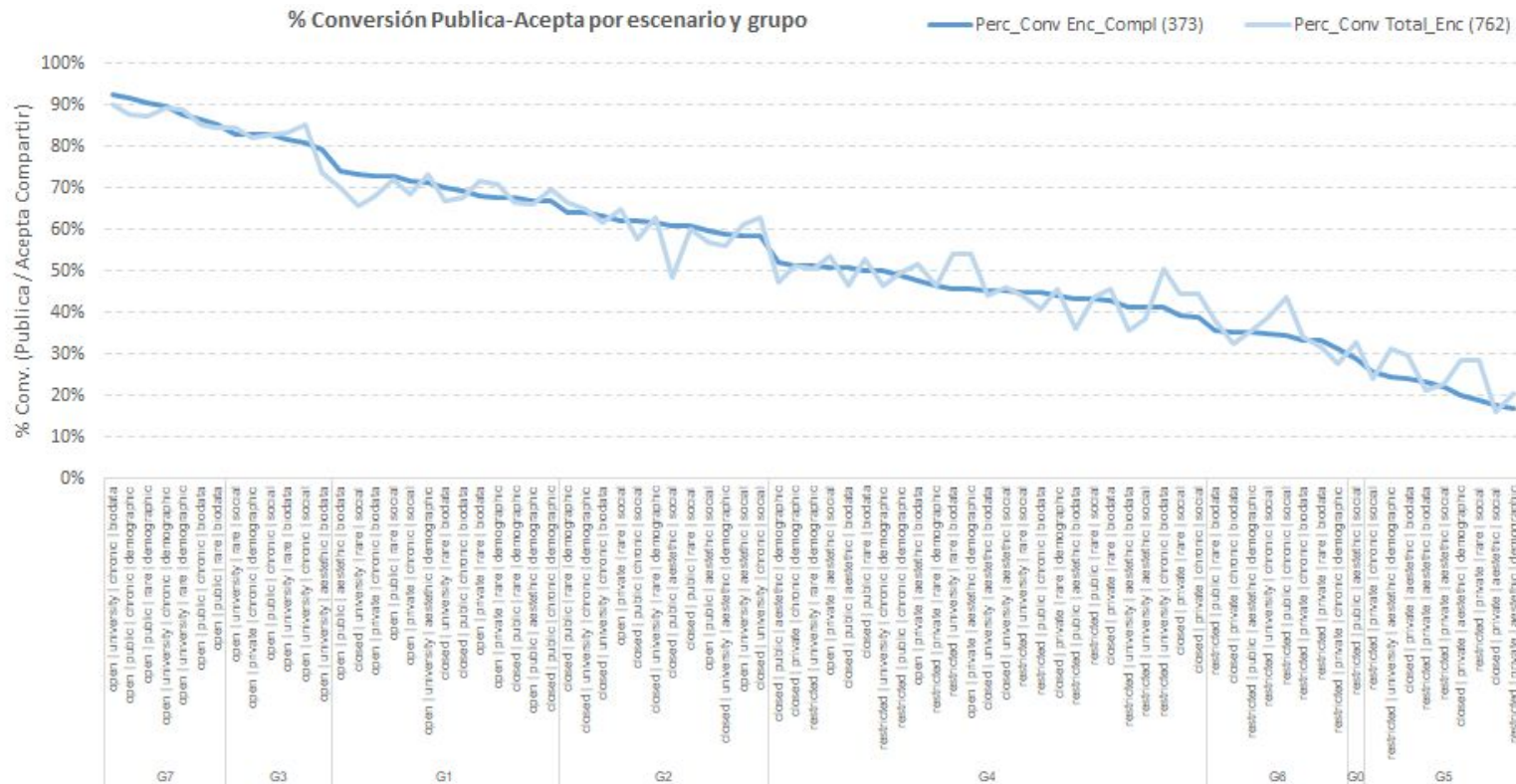




# 600 identified respondents to more than 8.000 scenarios



# Results after 8.000 scenarios valuated by citizens



TRIAM

% Donation = “yes”..

8.000 scenarios. TRIAM 2018. SalusCoop

SEGMENTO	PUBLICACIÓN	ENTIDAD	ENTIDAD	% DONACIÓN
Salus	Open	Pública & University	Chronic & rare	87%

+Private	Open	Private	Chronic & rare	72%
+Aesthetics	Open	Publica & university	Aesthetic	71%
+Closed	Closed	Public & university	Chronic & rare	64%

Rest of others	otras combinaciones	otras combinaciones	otras combinaciones	38%
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## Main conclusions

### % Donation drivers:

1st. Shared Results

2nd. Non-profit entities

3rd. Only critical diseases

- No risks allowed

- No incentive changes  
donation (money included)



# SALUS CG LICENSE

Salus Common Good Data License for Health Research

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100%

Chronic &  
Rare diseases

100%

Non Commercial  
entities

100%

Shared free results

100%

Privacy protection

100%

Change preferences  
any time

When you apply ***Salus Data License for Health Research*** to any data you are contributing to public interest, relevant issues, open knowledge discoveries to improve our collective health.

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Supporting entities: SALUS CG license has been developed by SalusCoop a citizen cooperative of data for health research created in Barcelona, 2017. Learn more & join at: [www.saluscoop.org](http://www.saluscoop.org)

If you already  
give away your  
data in every  
tweet, like or  
post, why not do  
it for a purpose?

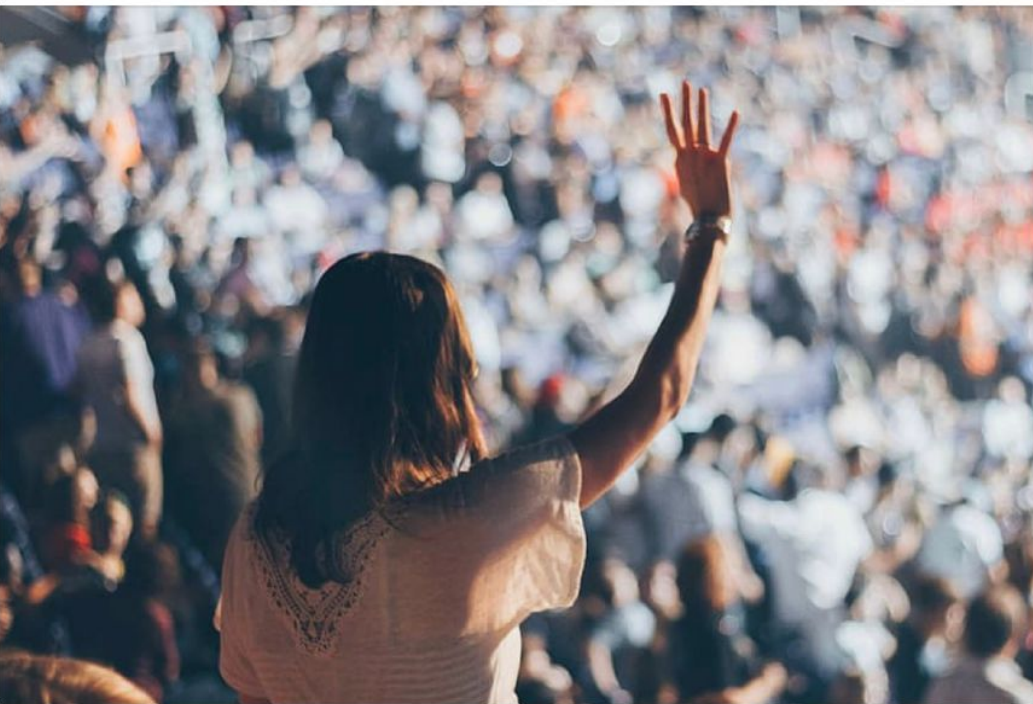
Portrait young woman

**#YourDataAreVital**  
**TO CHANGE THE GAME**



**SALUS.COOP** Activar Windows  
Ve a Configuración para activar  
Data Donors for Common Good





**SALUS.COOP**

Data Donors for Common Good

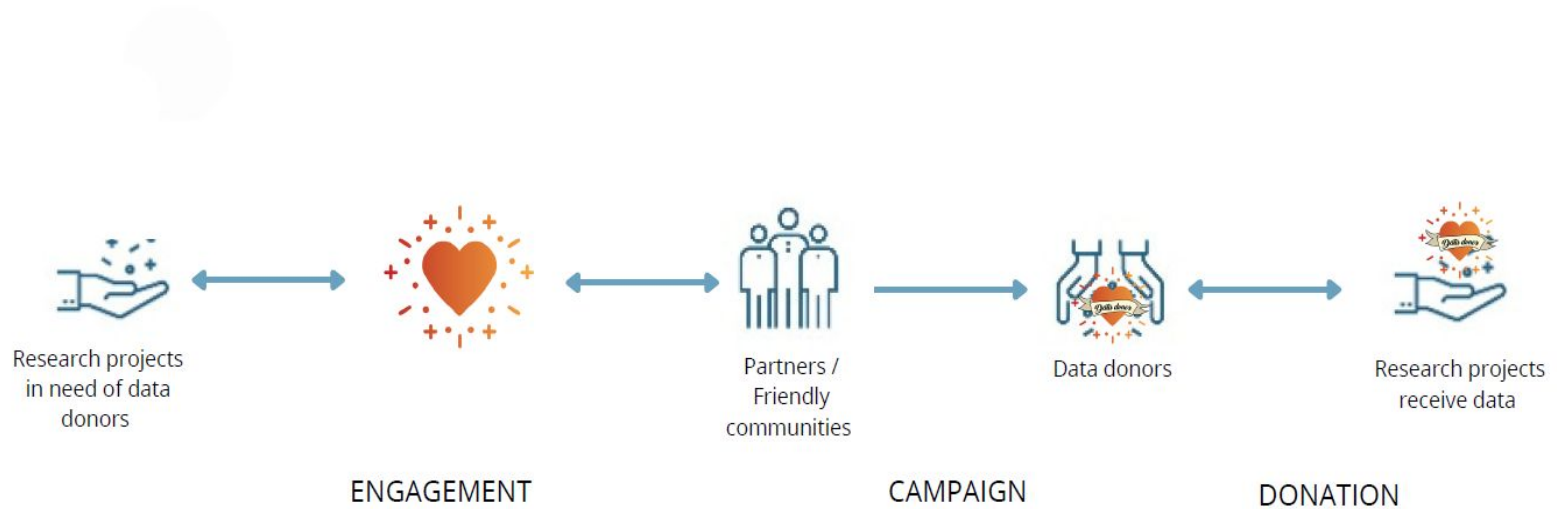
The **non-profit cooperative** from  
**Citizens to Citizenship.**

**THE GAME CHANGER TO ACHIEVE  
ACTUAL HEALTH & SOCIAL IMPACT  
IN THE NEXT 5 YEARS.**

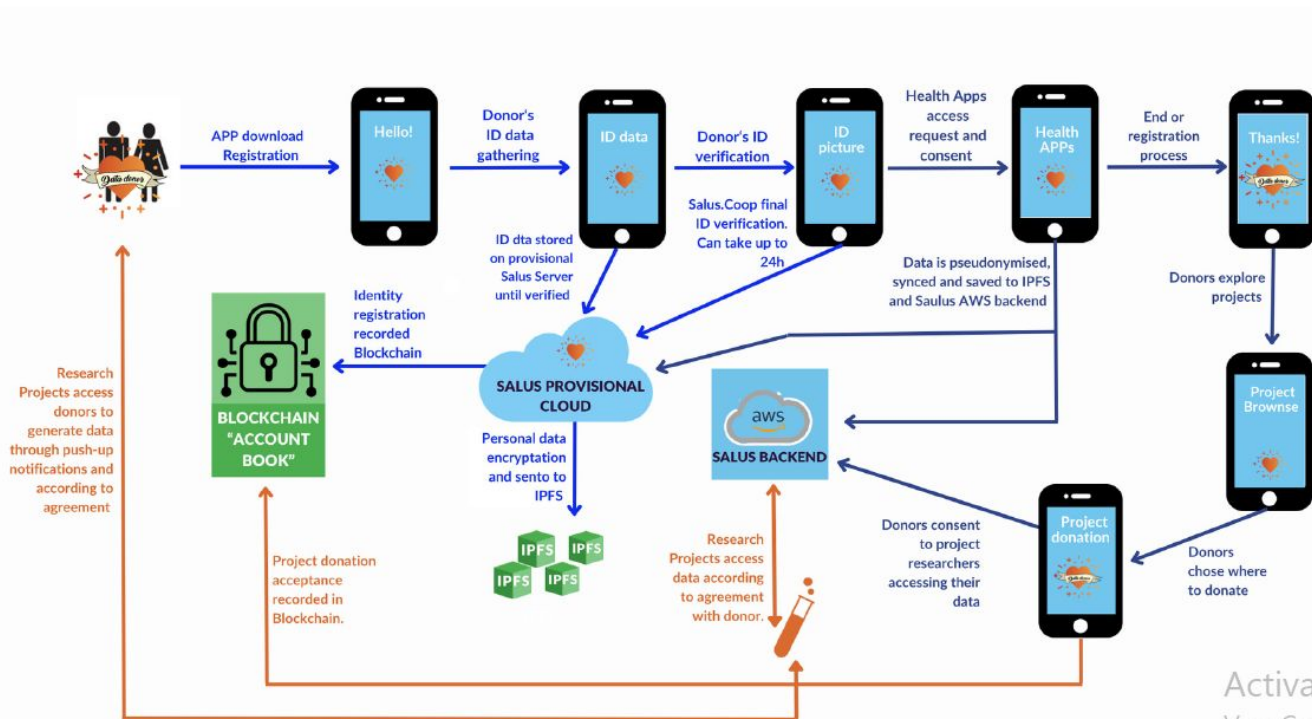
Activar Windows

Ve a Configuración para activar

# REAL WORLD BIG DATA. CITIZEN TRUST FOR COLLECTIVE BENEFIT.



# REAL WORLD BIG DATA. CITIZEN TRUST FOR COLLECTIVE BENEFIT.



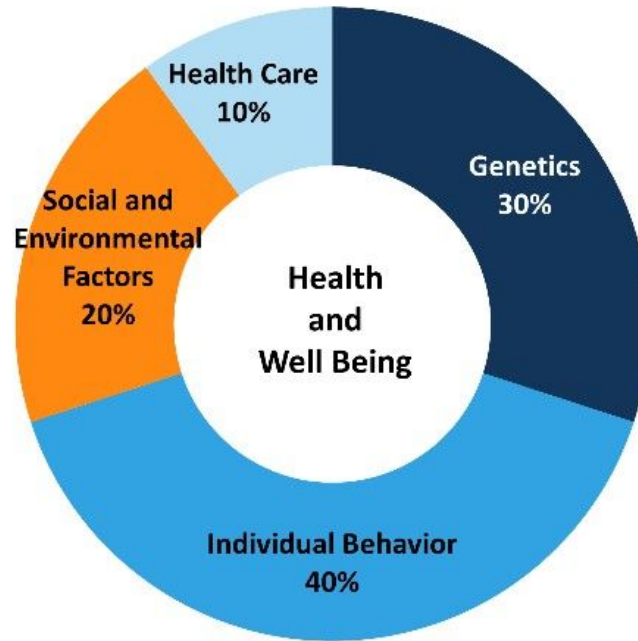
# Data altruism as defined in the DGA



- Data altruism is **voluntary sharing of data** for objectives of general interest on the basis of consent or permission without seeking or receiving a reward.
- **Objectives of general interests (set by national law)** may include
  - healthcare,
  - combating climate change,
  - improving mobility,
  - facilitating the development,
  - production and dissemination of official statistics,
  - improving the provision of public services, public policy making
  - or scientific research purposes in the general interest

Figure 1

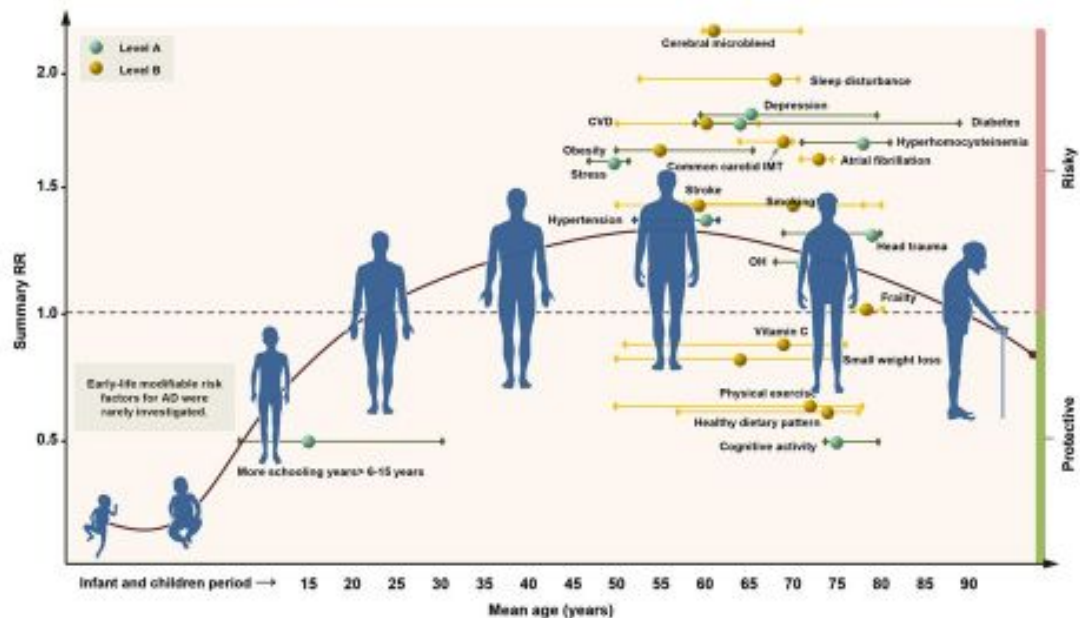
## Impact of Different Factors on Risk of Premature Death



SOURCE: Schroeder, SA. (2007). We Can Do Better — Improving the Health of the American People. *NEJM*. 357:1221-8.

# Evidence-based prevention of Alzheimer's disease

Distribution of modifiable factors with Class I recommendation throughout the course of life.



Jin-Tai Yu et al. J Neurol Neurosurg Psychiatry  
2020;91:1201-1209



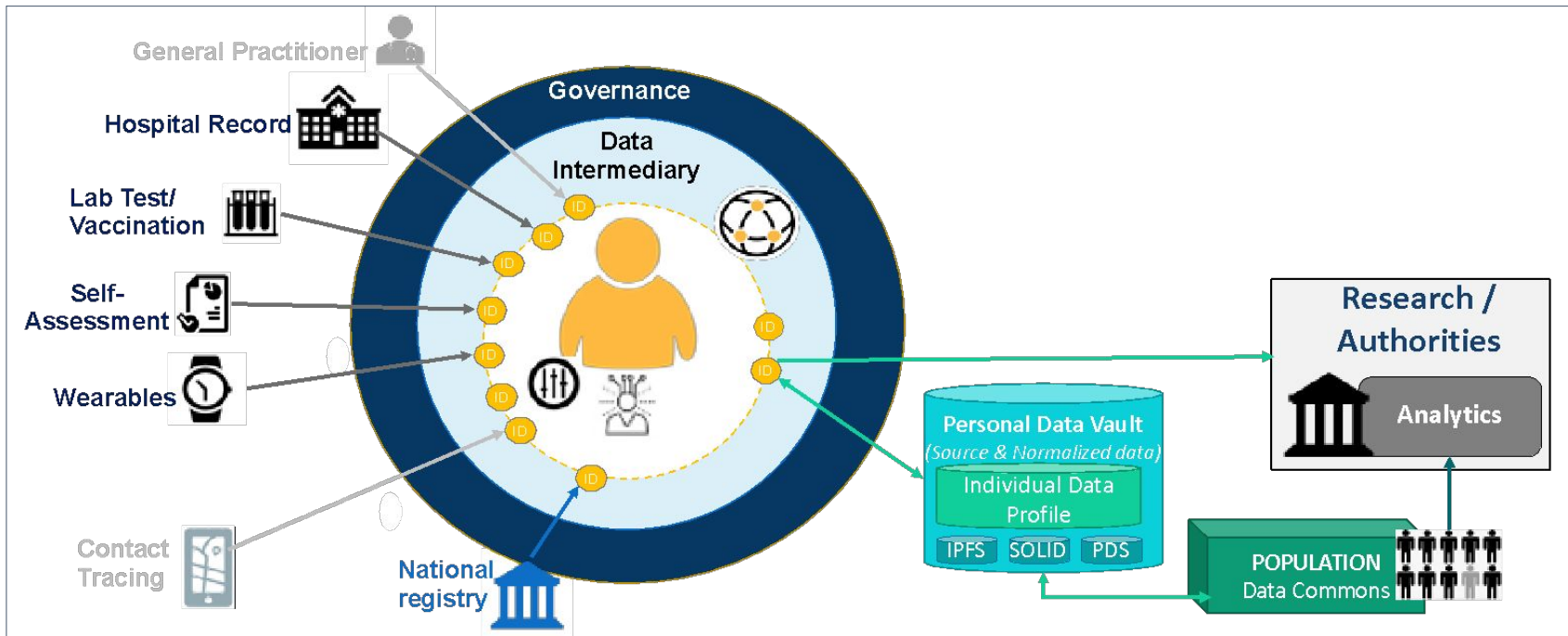
La Marató



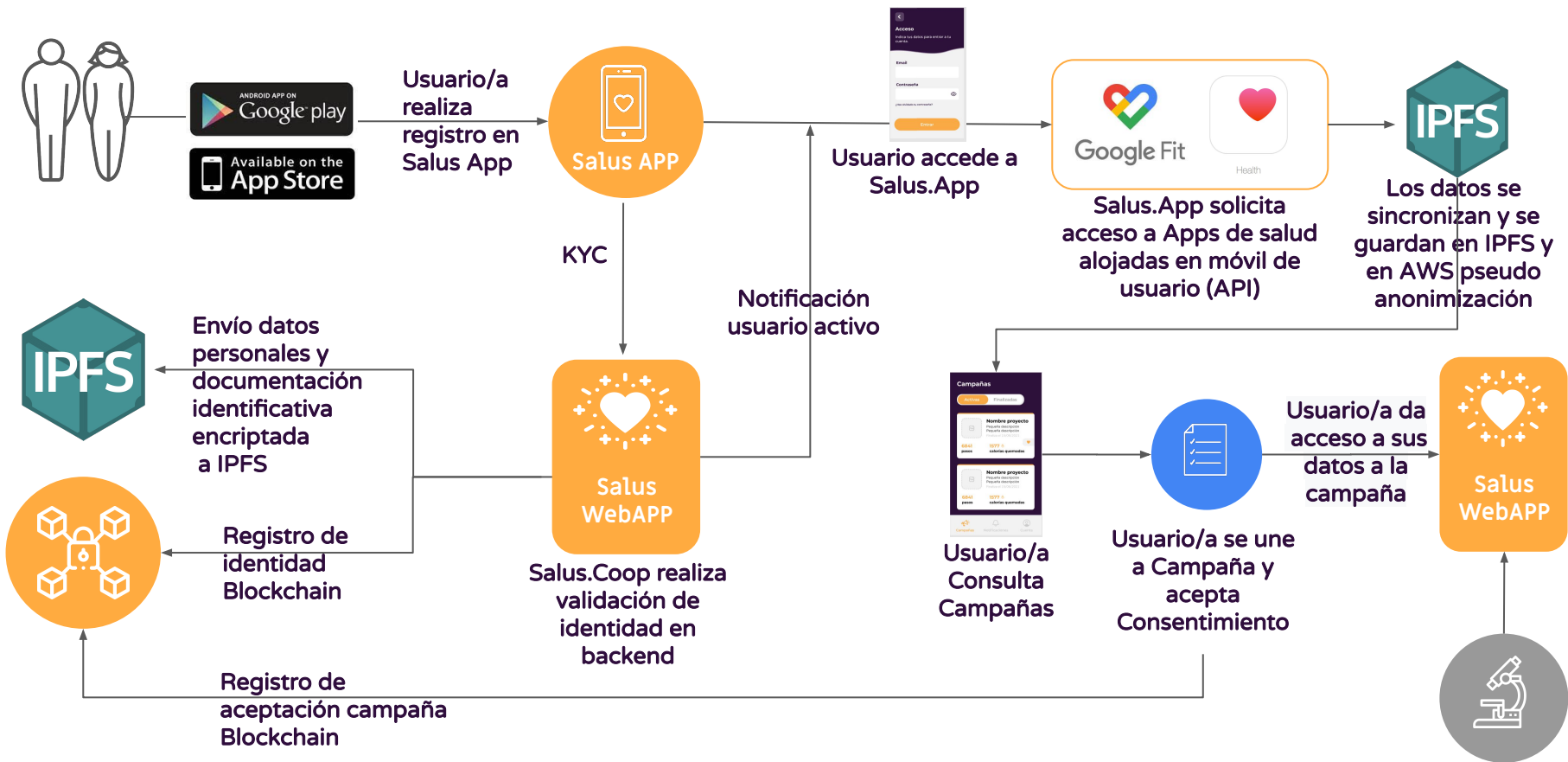
10.715.430€



BANC DE SANG  
I TEIXITS



# Flujo Funcional Salus APP



# Reingenieria de la confianza

Research



**ISGlobal**

Public



Private



Social



# #LesTevesDadesSónVitals PER A LA CIUTAT

## Comparteix-les!

Es gratis, és fàcil i viurem  
millor!



App Salus.Coop  
[www.salus.coop](http://www.salus.coop)

Un projecte de:

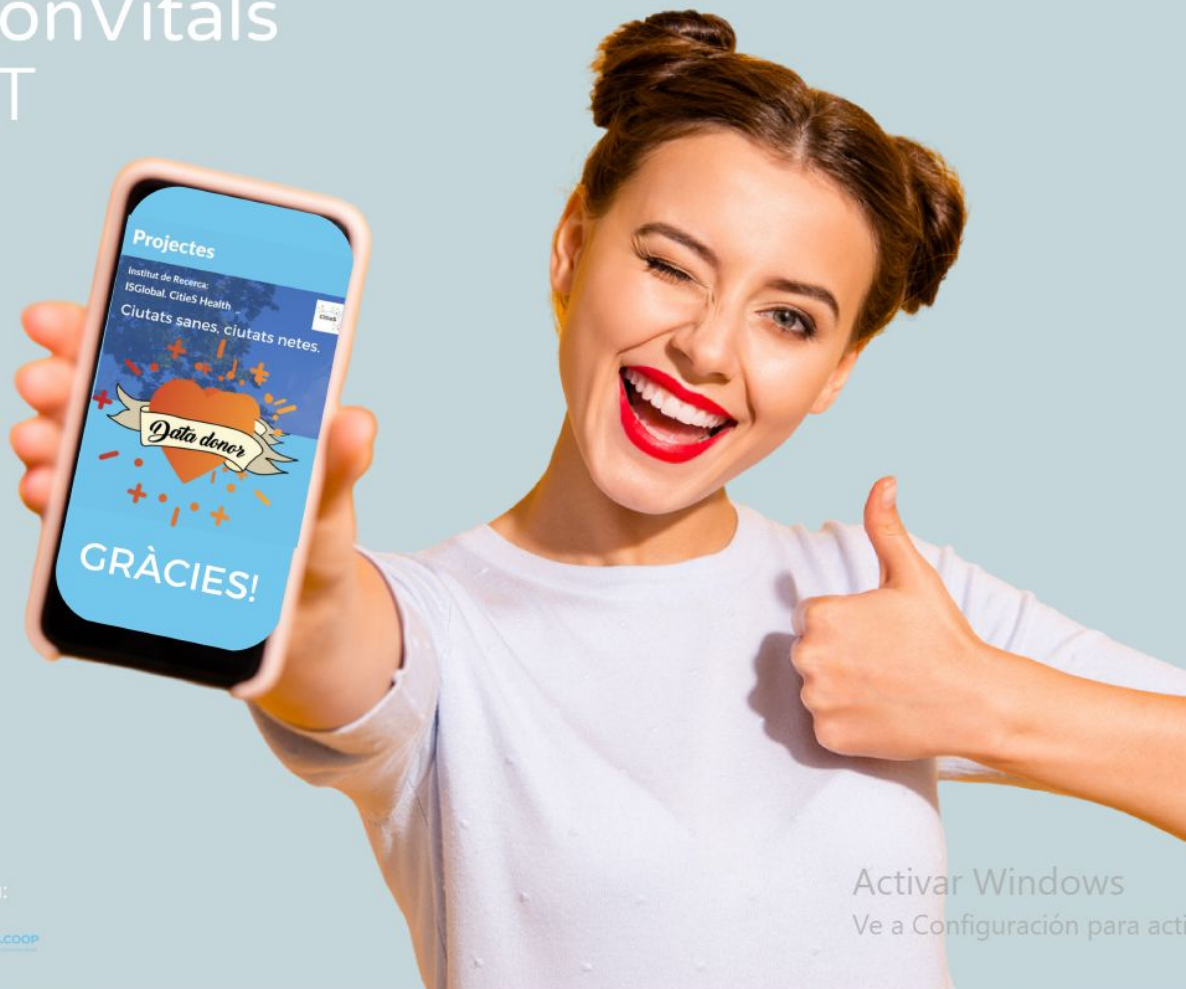


**ISGlobal** Barcelona  
Institute for  
Global Health

Participa:



Promou:



Activar Windows  
Ve a Configuración para acti



# THANK YOU!



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