

Dades al servei de les persones i el bé comú

Una nova arquitectura tecnològica, social i legal



Javi Creus
@javicreus



M4Social, BCN 2019

**IDEAS
FOR
CHANGE**

"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





**Polémica en la UE
con los datos
generados por los
coches autónomos:
*serán del fabricante,
del dueño o de nadie***

Google recolectó sin permiso datos médicos de millones de personas

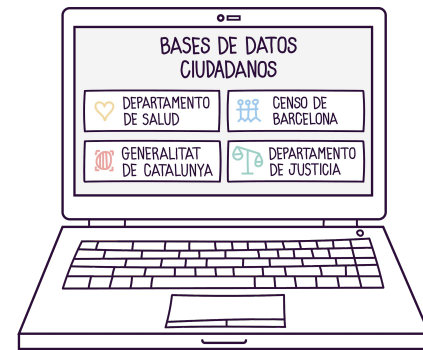
El gigante tecnológico disponía de los datos de los pacientes de la compañía médica Ascension, la mayor firma católica de ese tipo.

Fuente: [La Vanguardia](#)



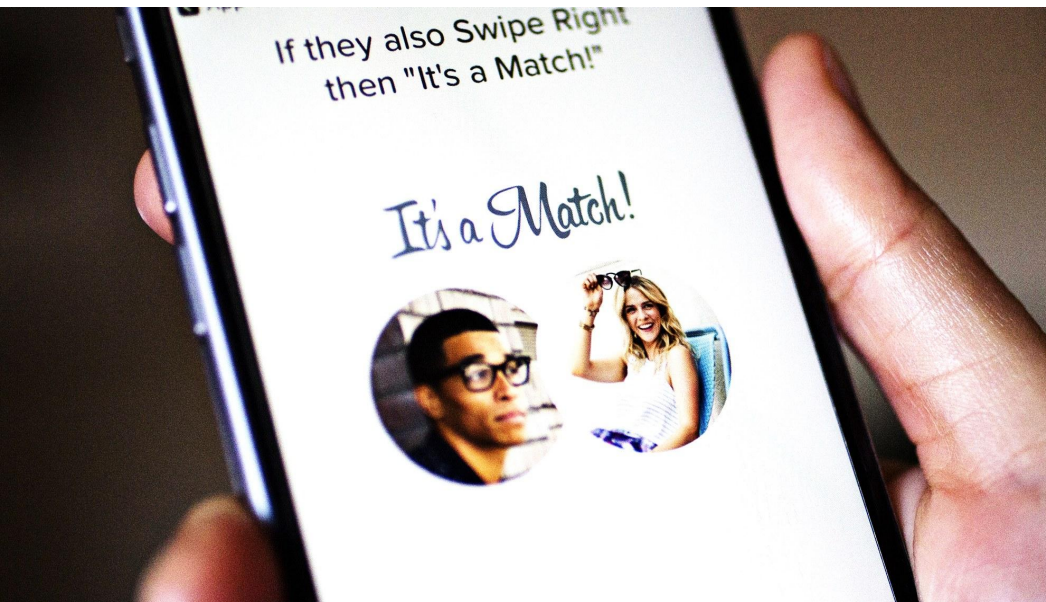


Maria té les seves dades en diferents repositoris centralitzats de diferents organitzacions. No pot accedir-hi.



Les empreses i les administracions públiques tenen les dades de Maria en diferents repositoris. Maria no pot accedir-hi.

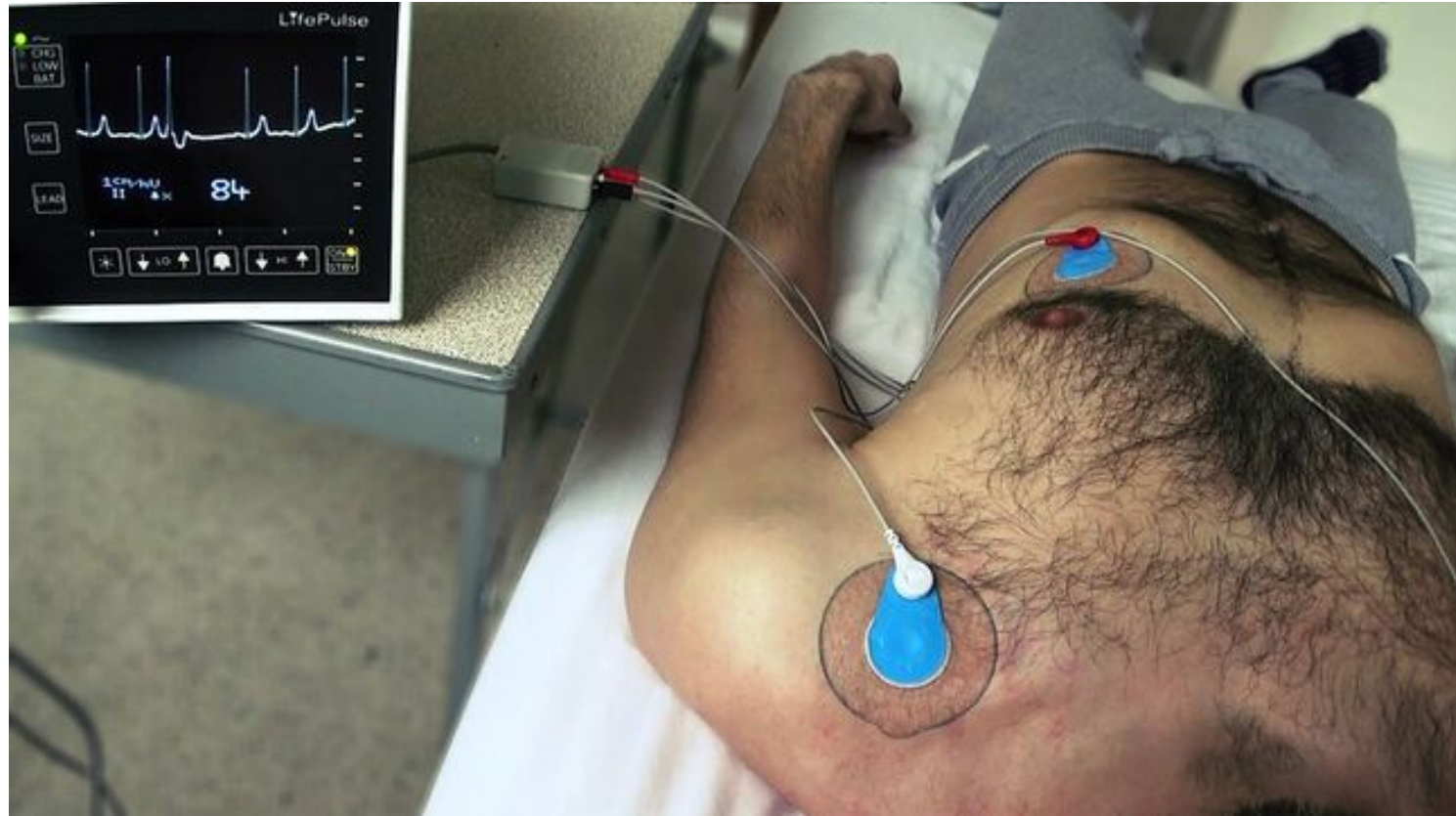
En busca del ranking secreto de Tinder:
la investigación que destapó que los 'match' no los decides tú

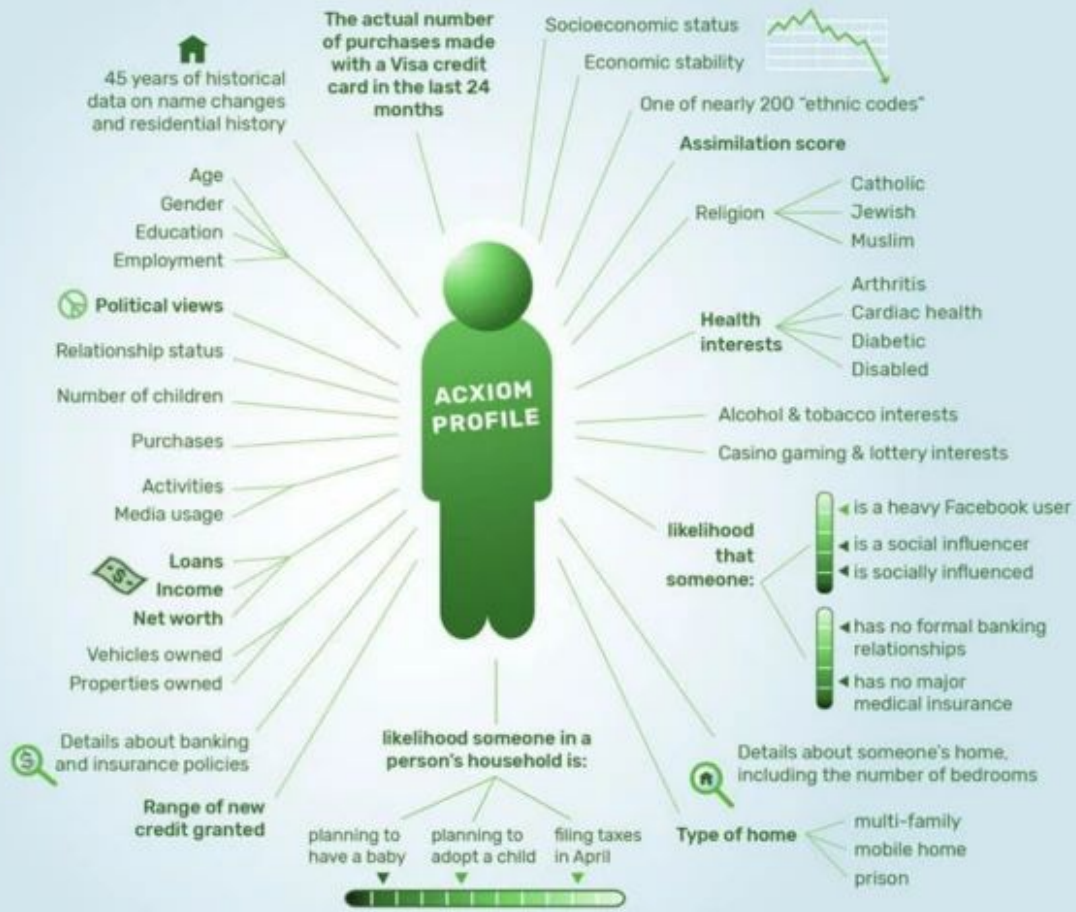


"Cuando se muestra tu perfil a una persona, se te está emparejando contra ella. Si ese contra ti tiene un nivel alto y le gustas, ganas puntos. Pero si tiene un nivel bajo y te ignora, los pierdes", explica El algoritmo del amor.

Fuente: *El Diario*

La Inteligencia Artificial que predice cuándo morirás pero que nadie sabe cómo: "**Está viendo cosas que los humanos no ven**"





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

Miles de suecos están introduciendo chips bajo su piel



¡sensores hasta en el papel de baño!



EVENING, APRIL 16, 1948.

Lowly Machine to Overtake Man, Rule Universe

By HAL BOYLE.

New York—(AP)—The day is drawing nigh when machines will overthrow mankind and rule the world.

Year by year man and his civili-



10 Y

April 16

Cape's many
for inspection
day.

Mrs. Rosa
died in Mex

IP
WS

again been
te in the na-
Safety Coun-
Okla., and
ed honors as

Los intereses comerciales marcan el futuro de la inteligencia artificial





“Será crítico entender la diferencia entre un dato capturado y un dato merecido”

Genís Roca



Datos Generados por la Ciudadanía

Producción de datos deliberada, tecnologías transparentes y usables

data for good

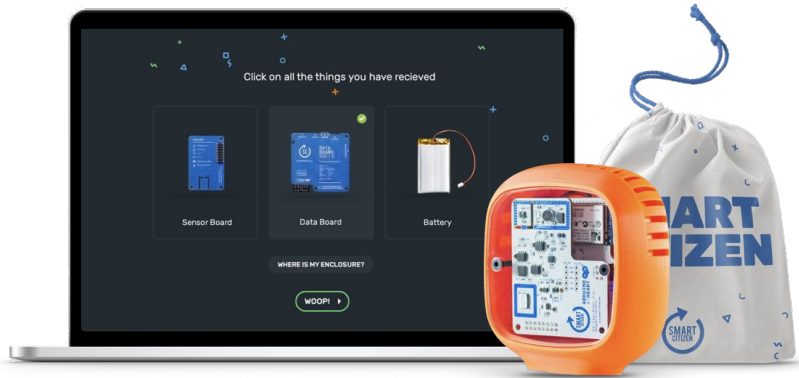
Datos y contaminación medioambiental

Making Sense: Citizen Sensing



Making Sense





Right to produce scientific knowledge and tackle complex environmental issues

DNOSES.eu: Tackling odour pollution through CGD



ESTUDIO PIONERO

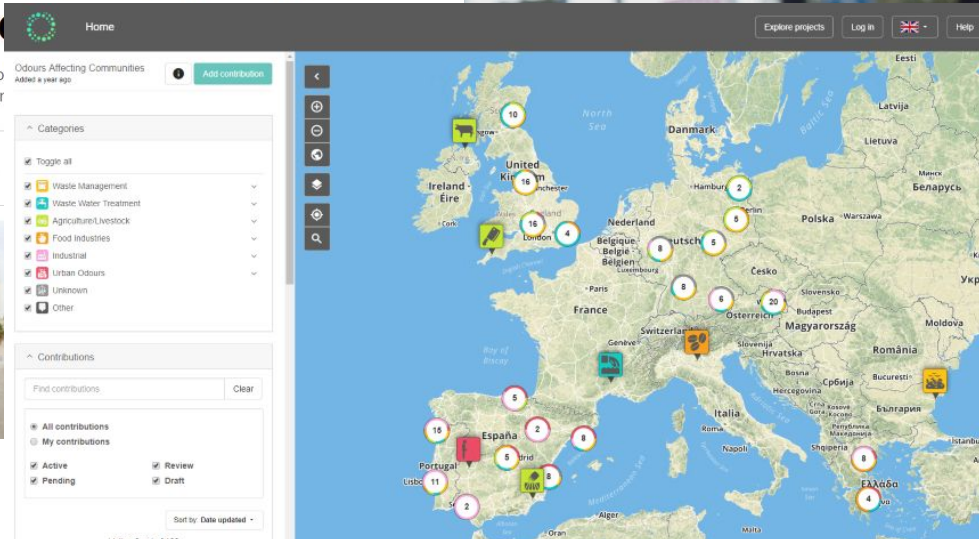
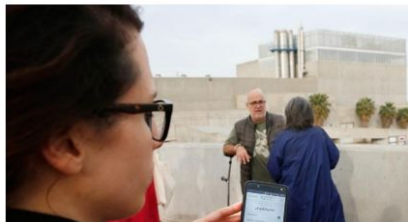
El Fòrum de los hedores: los vecinos chequean la zona

Una iniciativa de ciencia ciudadana inicia un proyecto de plantas de tratamiento de residuos y otras instalaciones



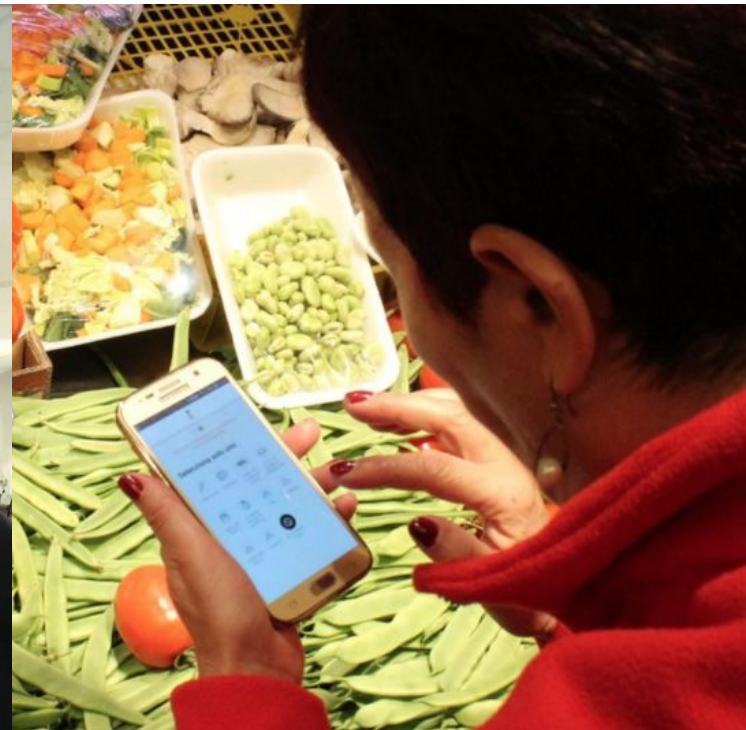
Luis Benavides

Domingo, 12/05/2019 | Actualizado a las 20:50 CEST



Datos para informar políticas públicas

FoodMapping: Entornos alimentarios y hábitos



Right to produce scientific knowledge and tackle complex environmental issues and inform policy

CITIES-HEALTH: Bio-sensores



#Maduixaire
Vigilantes del aire

**Estació de control de qualitat de
l'aire de ciència ciutadana**

Posa'l nom
a la planta

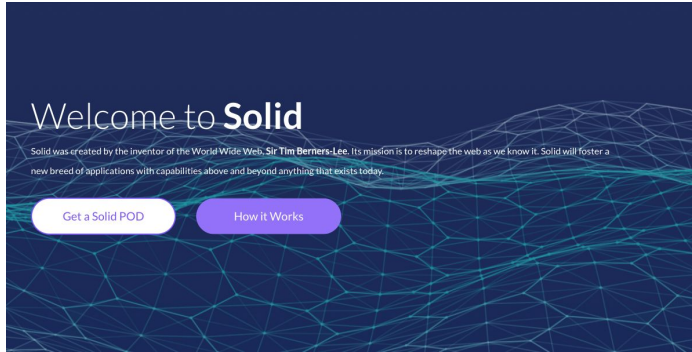
- **Una arquitectura
tecnològica
distribuida**



**“Hay que separar los datos
de las aplicaciones”**

TIM BERNES LEE
Inventor del www

Repositoris personals

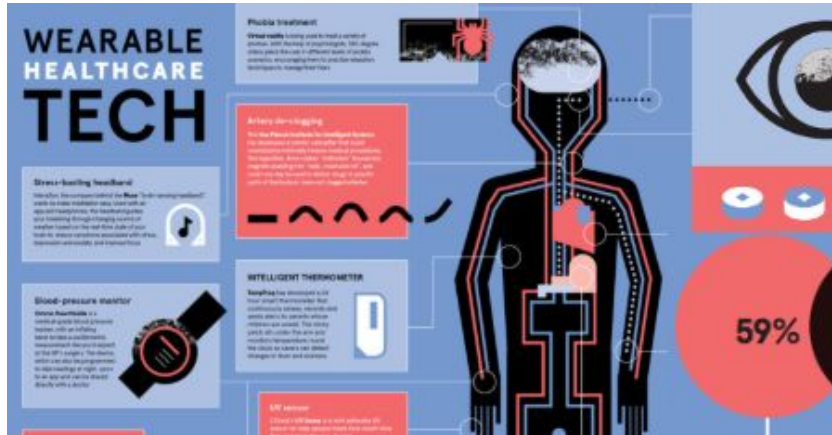


MyData  **Global**

Founding Meeting 11 Oct. 2018

Sensors personals

WEARABLE HEALTHCARE TECH



Fluidic treatment
What really is going on? To track a patient's condition, wear tracking is important. The biggest data point for us is different parts of society, especially, the way people use the devices. We're going to see the future of the devices.

Artificial intelligence
For the future, the devices will be able to track the patient's condition and provide a more accurate diagnosis. The devices will be able to track the patient's condition and provide a more accurate diagnosis. The devices will be able to track the patient's condition and provide a more accurate diagnosis.

Stress-tracking headband
The future of wearables is not just about tracking the patient's condition, but also about tracking the patient's stress. The devices will be able to track the patient's stress and provide a more accurate diagnosis. The devices will be able to track the patient's stress and provide a more accurate diagnosis.

Blood pressure monitor
The future of wearables is not just about tracking the patient's condition, but also about tracking the patient's blood pressure. The devices will be able to track the patient's blood pressure and provide a more accurate diagnosis. The devices will be able to track the patient's blood pressure and provide a more accurate diagnosis.

Intelligent thermometer
The future of wearables is not just about tracking the patient's condition, but also about tracking the patient's temperature. The devices will be able to track the patient's temperature and provide a more accurate diagnosis. The devices will be able to track the patient's temperature and provide a more accurate diagnosis.

ECG sensor
The future of wearables is not just about tracking the patient's condition, but also about tracking the patient's heart rate. The devices will be able to track the patient's heart rate and provide a more accurate diagnosis. The devices will be able to track the patient's heart rate and provide a more accurate diagnosis.

59%



HEALTH & MEDICINE

Using Wearable Device, Researchers Capture Sleep for the First Time

Measuring human sleep just advanced dramatically.

Jhelissa Gohd | December 28th 2017



NEWS

/ Health Medicine
/ Activity Tracker
/ Sleep Lab
/ Sleep Study

Creative Commons

IA distribuïda i federada

MIT
Technology
Review

Intelligent Machines

A little-known AI method can train on your health data without threatening your privacy

Machine learning has great potential to transform disease diagnosis and detection, but it's been held back by patients' reluctance to give up access to sensitive information.



Net neutrality: Decentralization is the future of the Internet

By Siavash Alamouti January 11, 2018 Web



Edge computing:

IA de forma local sin necesidad de que los datos se suban en ningún momento a la nube.

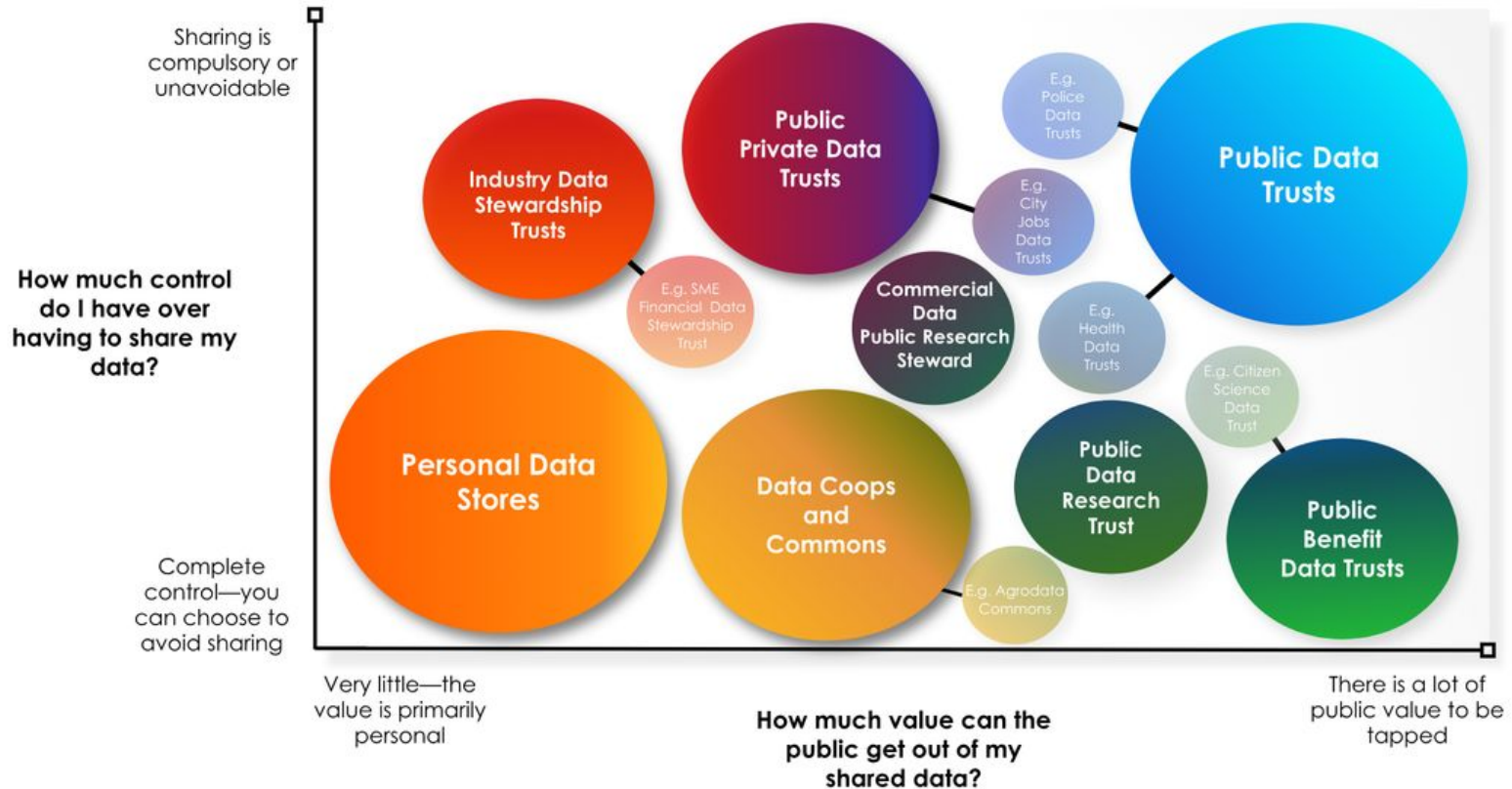




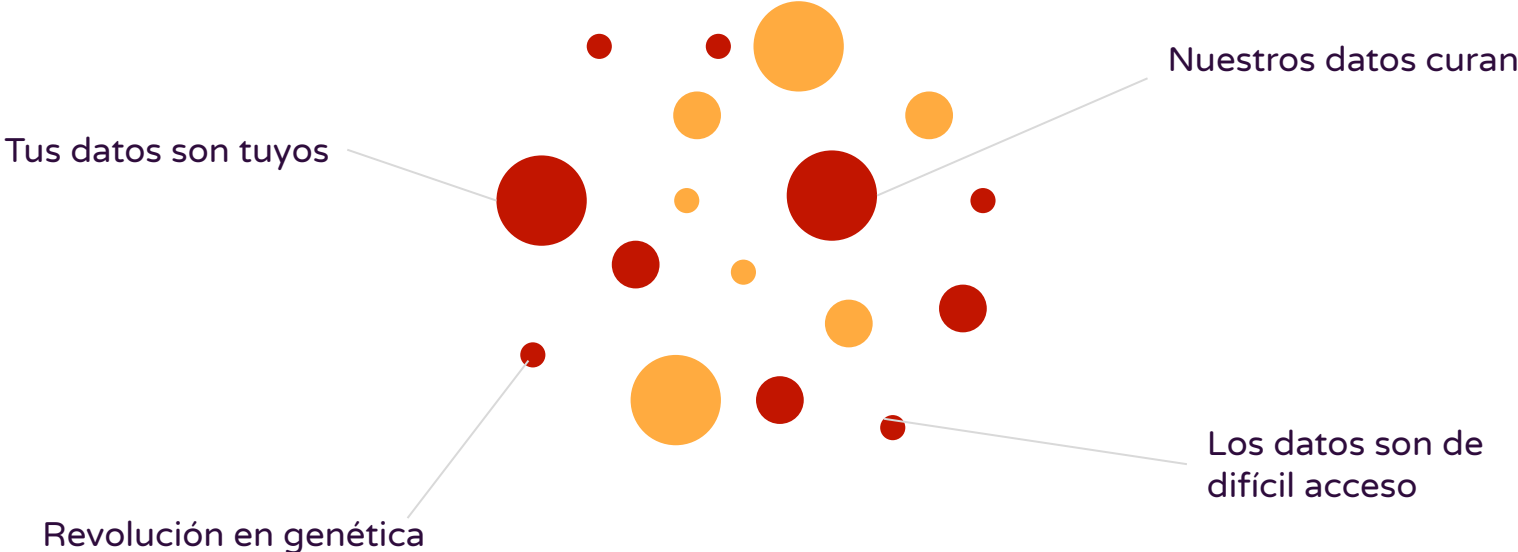
**Nuevas Instituciones
Sociales para el gobierno
colectivo de los datos
para el bien común**

A new framework for data governance

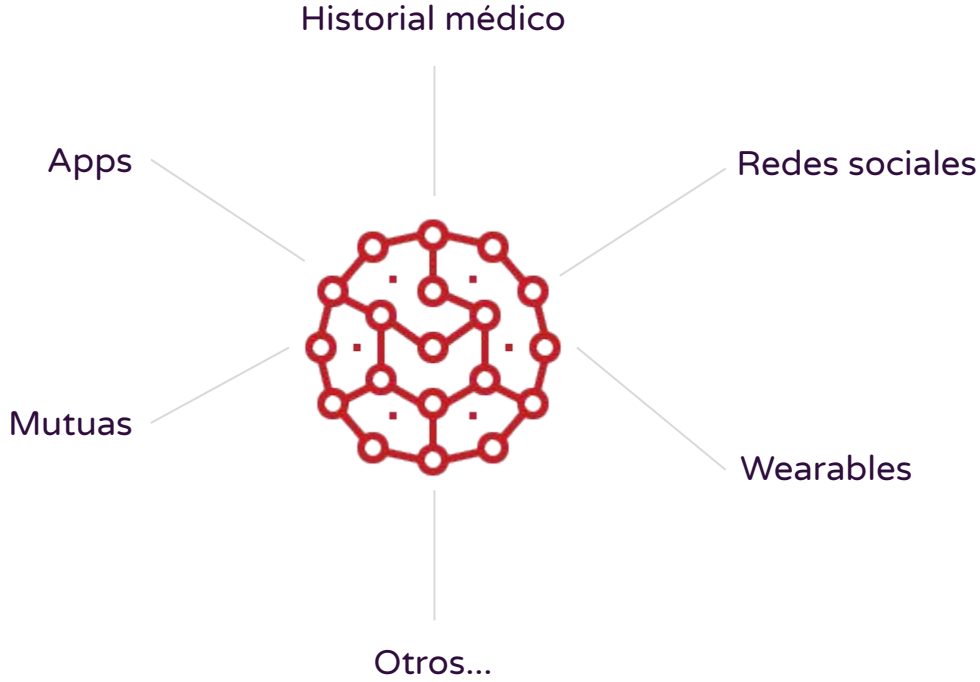
— Lines point to an example (small bubbles)
■ Colour indicates institutional overlap
● Bubble size indicates size of sector



CONTEXTO ACTUAL

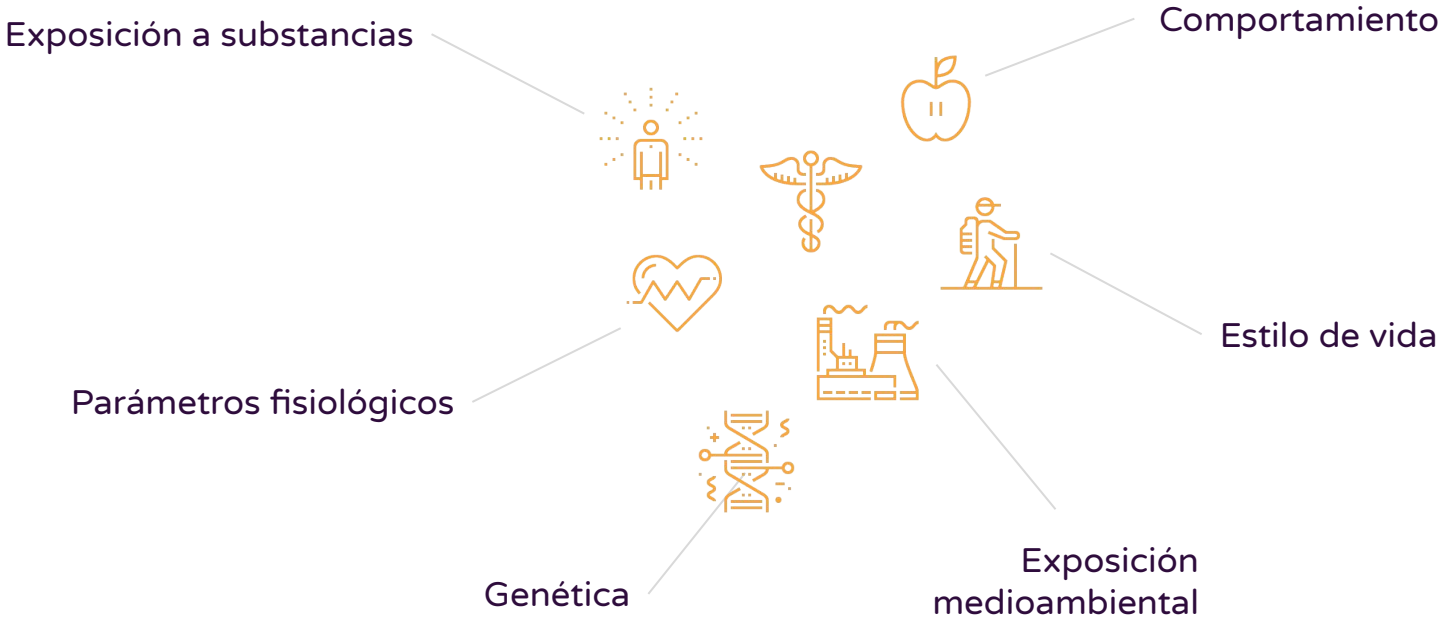


LOS DATOS SON DE DIFÍCIL ACCESO



NUESTROS DATOS CURAN

Entender las enfermedades



Saluscoop, cooperativa ciudadana de datos para la investigación en salud



Emisores



Ciudadanos como donantes de datos



Receptores

Custodios de Datos

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



Usuarios de Datos Proveedores de Servicios

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



Usuarios de Datos Para la investigación

- Research centres
- Universities
- Research units in companies

Right to donate health data for the common good

SalusCoop: Enabling health data sovereignty





Una nueva arquitectura legal

GDPR, Smart Contracts, licencias standard...

la UE: un súper poder regulatorio

EU GDPR 2018



Los ciudadanos somos los **titulares de los datos** de carácter personal.



Como titular de los datos, tengo **derecho de acceso** a esa información y obtener una copia de la misma.



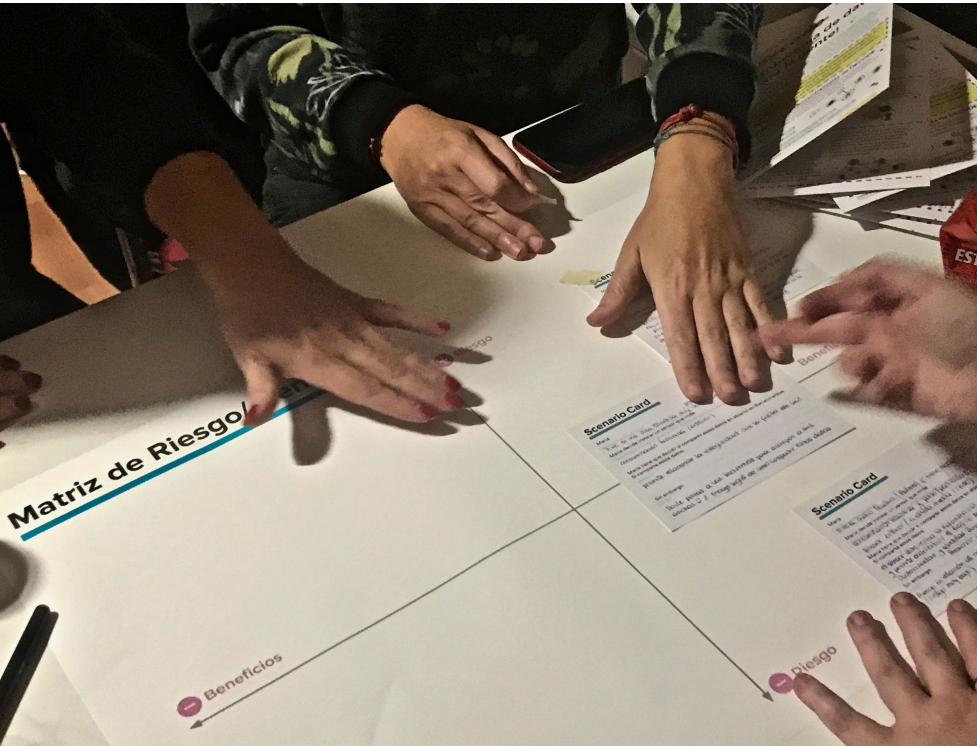
Derecho a la portabilidad: puedo cambiar mis datos de una empresa a otra.



Tengo que dar un **consentimiento expreso** para dar mis datos a terceros.

Right to control how our data are used

DECODE.EU + SMART CITIZEN



Right to govern and manage our data

TRIEM: Ethics crowdsourcing





SALUS CG LICENSE

Salus Common Good Data License for Health Research

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.

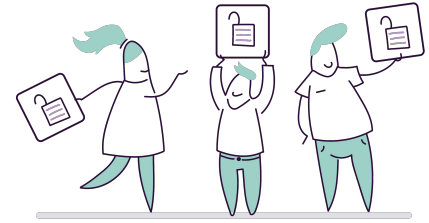
Supporting entities: SALUS CG license has been developed by SalusCoop a citizen cooperative of data for health research created in Barcelona, 2017. Learn more & join at: www.saluscoop.org

- **El nou escenari de la lògica distribuïda**

DEMÀ



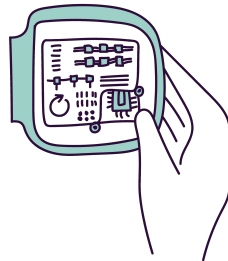
Maria té accés a totes les dades que l'administració té sobre ella (salut, civil, educació ...). Maria integra aquestes dades en el seu repositori personal.



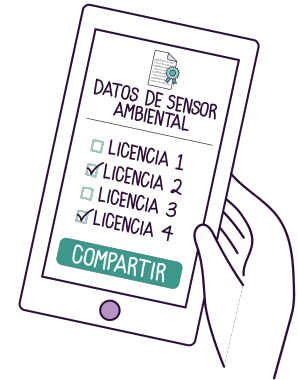
Maria pertany a una cooperativa ciutadana de dades. Gràcies al suport de la cooperativa, Maria assigna llicències a les seves dades, perquè aquestes puguin ser usades per tercers segons les condicions que Maria estableix.



Maria té un repositori personal a Digi.me on afegeix i gestiona totes les seves dades.



Maria té un sensor de qualitat d'aire homologat per l'administració. Maria afegeix les dades del sensor en el seu repositori personal i en la plataforma Qualitat de l'Aire de l'administració.



Maria comparteix les seves dades de salut per a una investigació mèdica, segons les condicions establertes per la llicència assignada.

¿ens hi posem?



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M4Social, BCN 2019

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