



Mi huella, mis reglas.

Empoderamiento de la ciudadanía a través de los datos personales

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MY DATA *my rules*



From data extractivism to digital empowerment

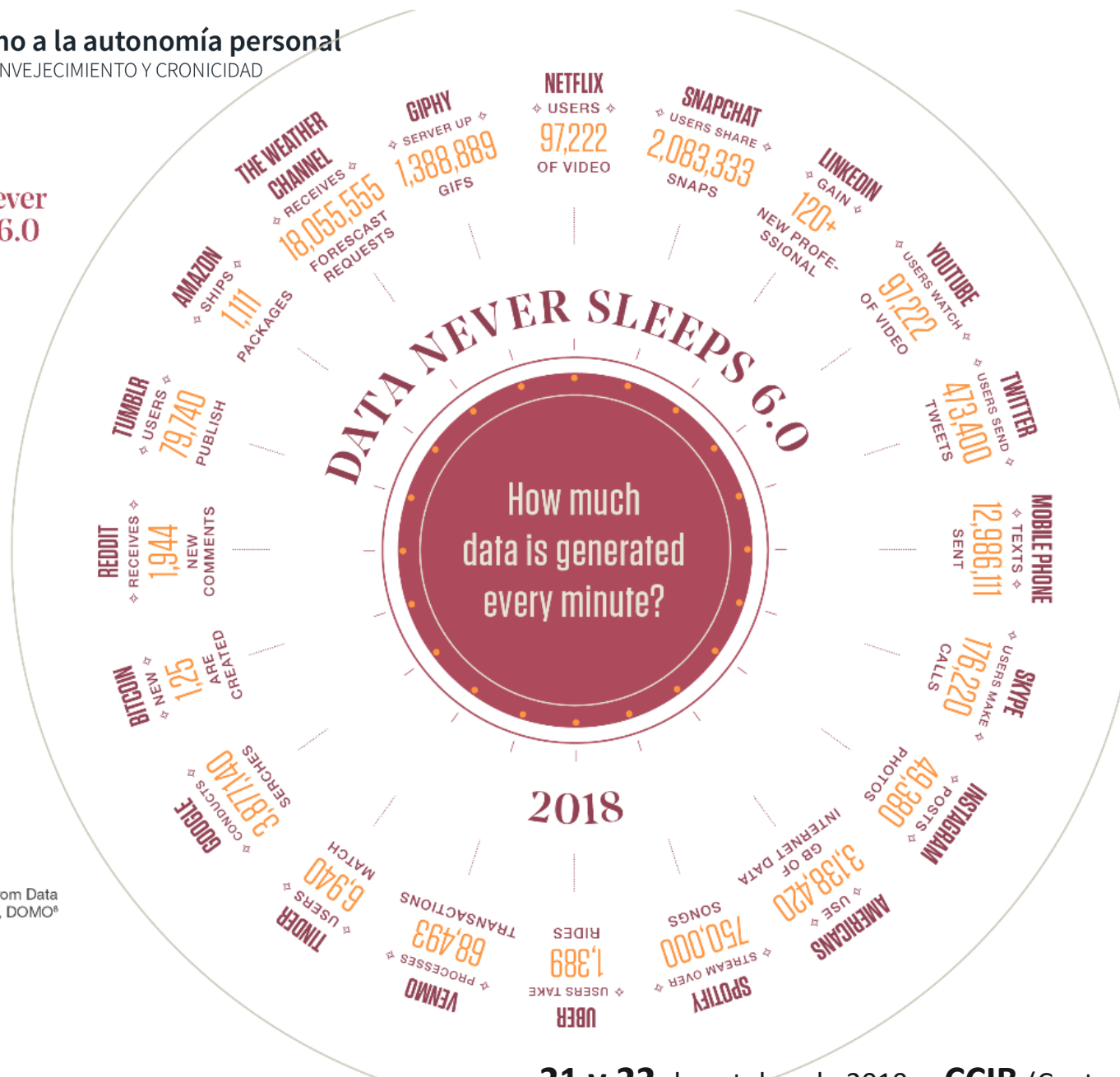
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Innovation (ISI)

ACUP ASSOCIACIÓ CATALANA
D'UNIVERSITATS PÚBLIQUES


"la Caixa"

FIGURE 1
Data Never
Sleeps 6.0



Source:
Adaptation from Data
never sleeps, DOMO®



The importance attached to data also led to radical shifts in business models, which contributed to the disempowerment of digital citizens

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“At large [tech] companies, we often launch products not for the revenue but for the data...and we monetize the data through a different product”

Andrew Ng, Baidu's head of AI, 2017²



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*“The web has evolved into an engine of inequity and division, swayed by powerful forces that use it for their own agendas. **People want apps that help them do what they want and need to do—without spying on them, Apps that don't have an ulterior motive of distracting them with propositions to buy this or that**”*

**Tim Berners-Lee,
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Today, only

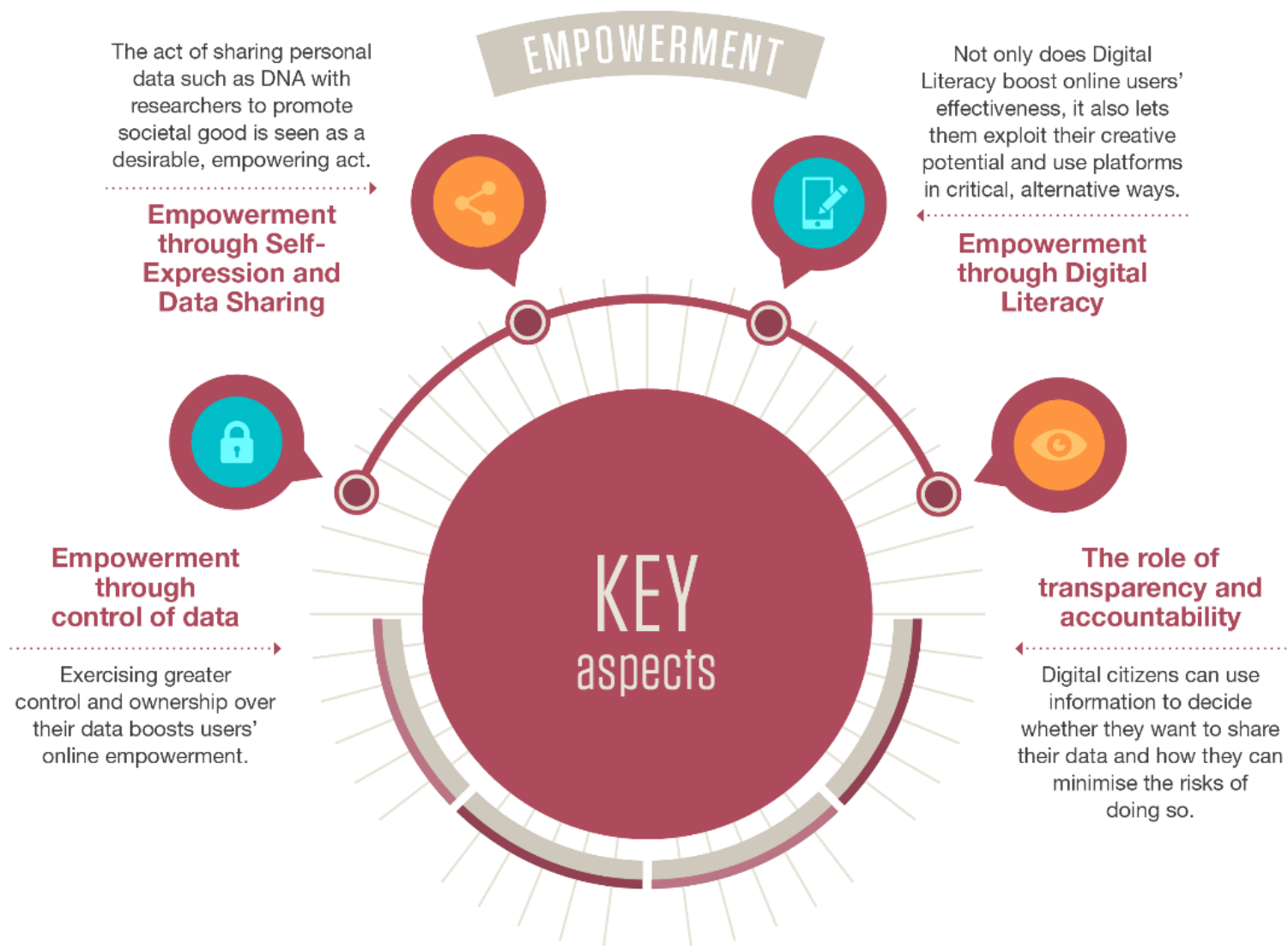
55%

of customers think that big tech companies protect their data (Edelman, 2019)

while

63%

of internet users are worried about how companies use their personal data





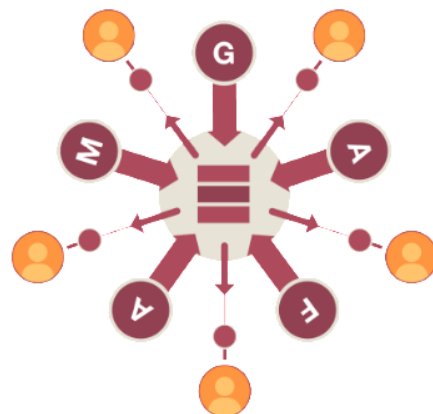
I Congreso sobre el derecho a la autonomía personal

DISCAPACIDAD FÍSICA Y ORGÁNICA, ENVEJECIMIENTO Y CRONICIDAD



COCEMFE

—
Breaking
down
data silos



21 y 22 de octubre de 2019 — **CCIB** (Centro de convenciones de Barcelona)



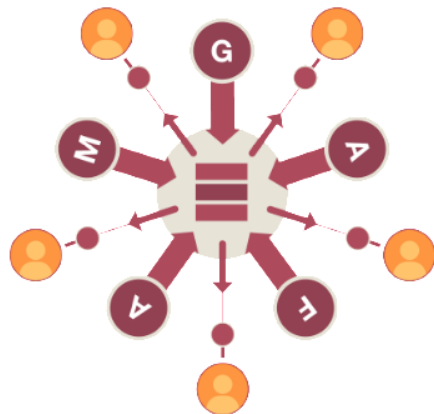
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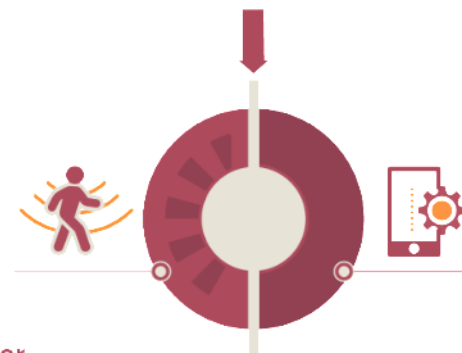


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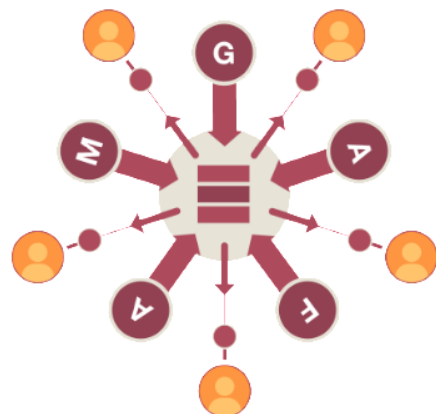
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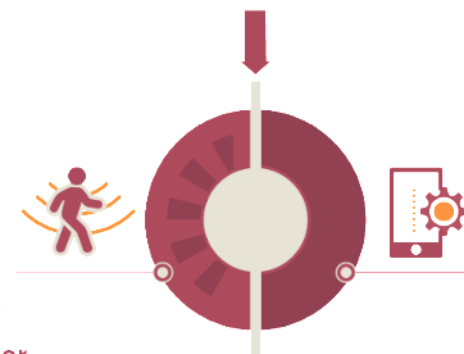
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Differentiate
data collector
& service editor



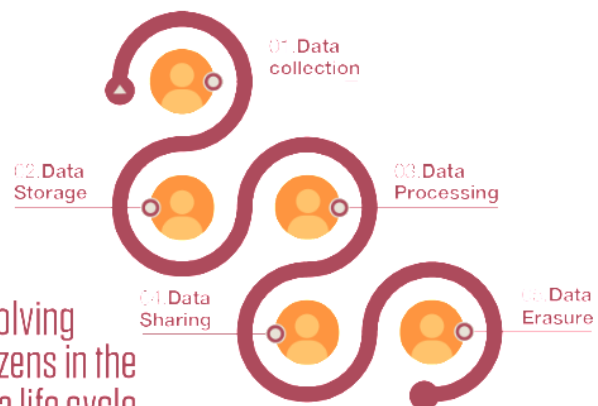
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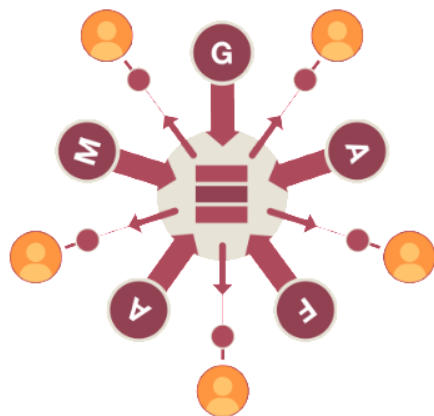
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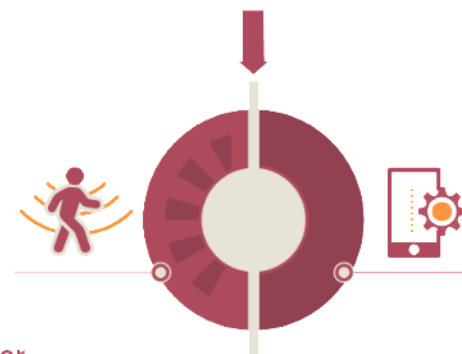
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Involving
citizens in the
data life cycle



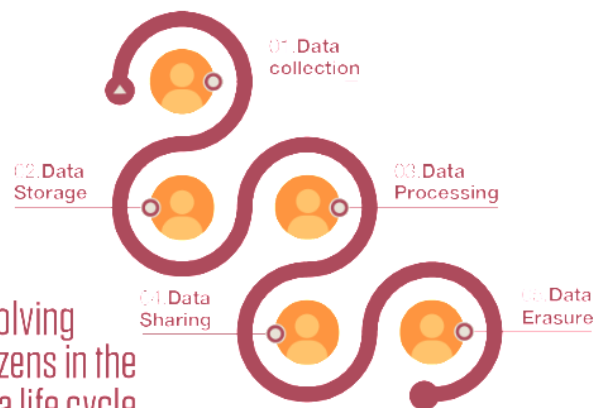
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—
Money is
not the only
reward



List of icons used

Key aspects



Empowerment through control of data



Empowerment through Self-Expression and Data Sharing



Empowerment through Digital Literacy



The role of transparency and accountability

Four principles



Breaking down data silos



Differentiate data collector & service editor



Involving citizens in the data life cycle



Money is not the only reward

5 variables of Social Innovation



Social Impact



Financial Sustainability



Innovation type

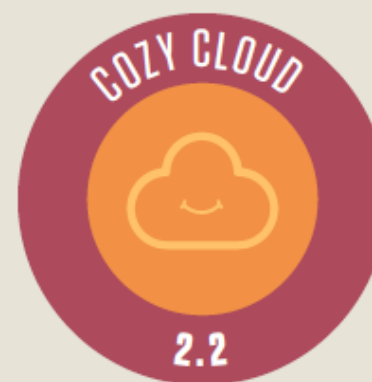


Cross-Sector Collaboration



Replicability and Scalability

In this chapter, we analyse three cases of social innovation under the lens of digital empowerment through personal data. We have selected three different approaches, all based on digital platforms that take a person-centric vision of The Data Economy and that nurture users' digital sovereignty



2.3 MIDATA.coop



“We are developing an ethical and legal framework for governing privacy, data ownership and consent in biomedical citizen science projects using citizen-generated data held and controlled by the citizens in a co-operative structure”

DESCRIPTION

This platform enables citizens and patients to gather health data in one place, while offering a management system for actively administrating data sharing on their terms. Members and account holders can participate in app-based research projects and benefit from app-based services. There are no financial rewards for data sharers, as MIDATA promotes collective interests such as active contribution to medical research.



SOCIAL IMPACT

MIDATA promotes digital self-determination and gives its users complete, granular control over who can access their data. Also generates awareness about data donation for research purposes, for advancing towards precision medicine. This personal data store allow account holders to manage their consent for participating in specific projects. Over 14 projects have been launched in three years, Ally Science being the biggest one with almost 10,000 users.



ECONOMIC SUSTAINABILITY

It is currently funded on a project-basis, with money coming from private foundations, research grants, and industry collaboration. A business model under development foresees fees for companies willing to reuse data for research purposes. As a non-profit co-operative, all benefits are reinvested within the project or returned to society at large.



INNOVATION TYPE

Citizen-controlled secondary use of personal data is a new model of data access sharing and data integration. They are developing an ethical and legal framework for governing privacy, data ownership and consent in biomedical Citizen Science projects drawing on user-generated data held and controlled by citizens in a co-operative structure.



CROSS-SECTOR COLLABORATION

It already runs projects with Swiss University Hospitals, supporting patients' reported outcomes research and clinical trials.



REPLICABILITY AND SCALABILITY

The MIDATA model is designed for regional adaptation: MIDATA Switzerland supports the foundation of regional and/or national MIDATA co-operatives that share the data platform infrastructure.

PRIZES, AWARDS, MENTIONS

- Best of Swiss Apps shortlist 2018.

GLOBAL REACH

Currently Switzerland, but with global reach through international partners.

FOUNDED

2015
Zurich (Switzerland).

LEGAL FORM

Data Co-operative,
Not-for-Profit.

WEBSITE

<https://www.midata.coop/>
(Login Portal, Swiss only:
<https://ch.midata.coop/>).

The promise of personalised medicine

TABLE 6 - Challenges in the one-size-fits-all health care model, potentially addressed by Personalised Health

One-size fits all	Personalised health
Many common medicines are not efficient for many patients	Treat patients with therapies that work best for them
As Europe's population ages, chronic diseases become more prevalent	Efficiency, cut healthcare costs
6% of acute hospital admissions are due to serious adverse reactions to medicines	Avoid adverse reactions to medicines



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COCEMFE

**By early 2018, over 12 million individuals |
had been tested by consumer genetics companies**

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FIGURE 5 - Costs of DNA sequencing compared to the curve under Moore's Law

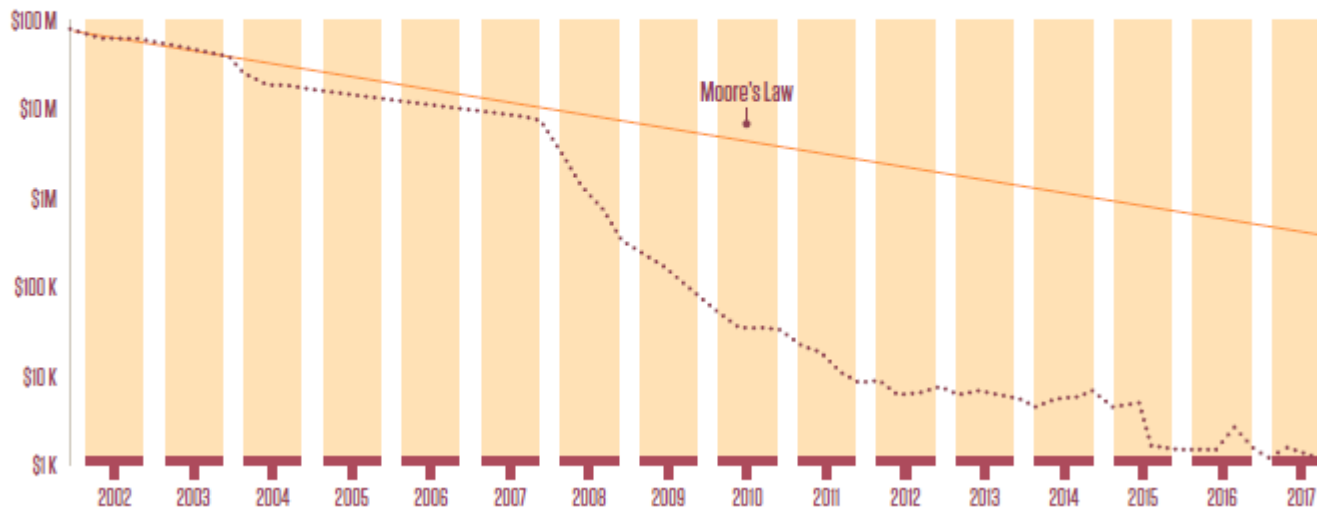
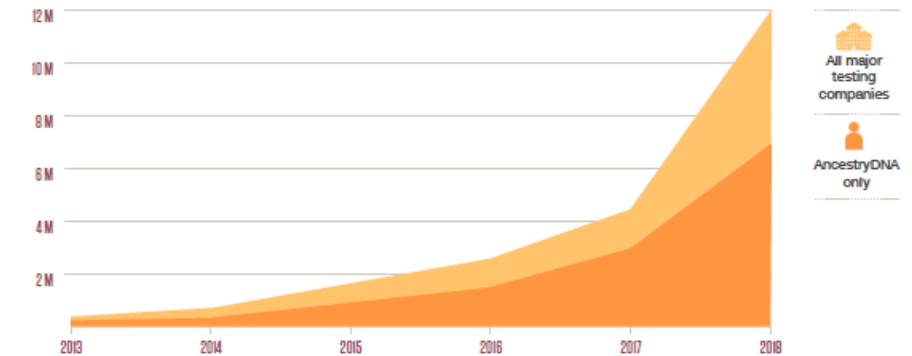
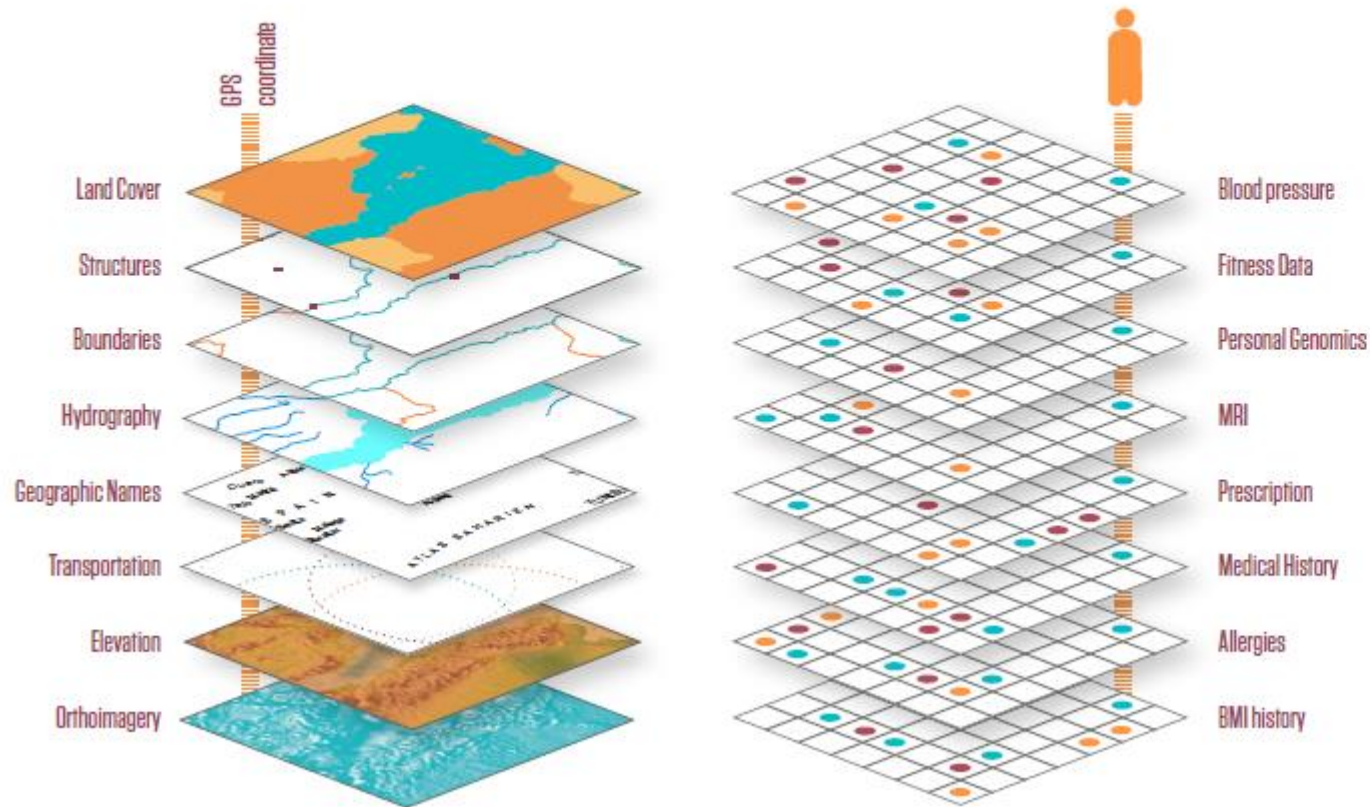


FIGURE 6 - Total number of people tested by consumer genetics companies

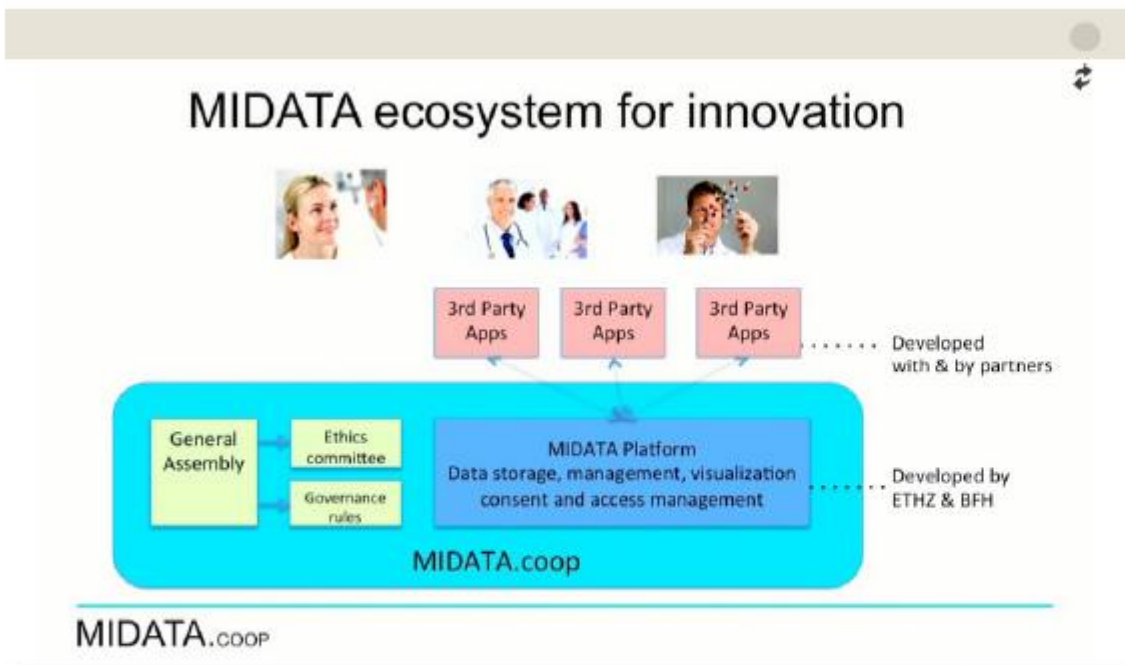


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IMAGE 14 -Analogy between the layers of information in a map and in the personal and health data that can be stored



All that is needed is an integration point that relates all the data. In the case of a map, the aggregation is of GPS co-ordinates, whereas in the case of Health Data, it is the individual (and his/her blood pressure, fitness data, personal genomics, MRI, prescriptions and medical history)



The consent process gives fine-grained control over who gets access to what data, for how long, and for what purpose

The opt-in logic is in place whenever data on the individual is requested. This data can be shared in its original form, a coded form (data being linked to a specific person via a code) or in anonymised form

Citizen-controlled reuse of data

TABLE 7 - Examples of fiduciary mediation, by MIDATA

A data company providing a mHealth app	For research or clinical trials	Data access by Third Parties
MIDATA ensures that access to data (with account holders' permission) is fair and data provided must not be sold to third parties.	Results arising from these personal data will be published (even when the results are unexpected) and the copies generated during the project will be returned to the user.	The co-op ensures a fair price for data access (as a fee by each account holders & sensitive to the amount of data accessed)

Independent patient databases such as MIDATA could also slash the time and money spent on recruiting patients for clinical studies by about

30%

Savvy.Coop



KEY ASPECTS

- ▷ Empowerment through control of data
- ▷ Empowerment through Self-Expression and Data Sharing
- ▷ Empowerment through Digital Literacy
- ▷ The role of transparency and accountability

FOUR PRINCIPLES

- ▷ Breaking down data silos
- ▷ Differentiate data collector & service editor
- ▷ Involving citizens in the data life cycle
- ▷ Money is not the only reward

FOUNDATION

- 2016 - Queens, New York, United States of America

LEGAL FORM

- Co-operative

PRIZES & AWARDS

- Winner of Patient Advocate Award at eyeforpharma conference, 2019
- Winner, MedCity ENGAGE Pitch Perfect competition, 2018
- Winner, Pitch for People Competition by Inspiring Capital, 2017
- 3rd place, Lyfebulb-Novo Nordisk Innovation Summit, 2017
- Jen Horonjeff, Savvy's co-founder, named as The 50 Most Daring Entrepreneurs in 2018 by Entrepreneurship Magazine

WEBSITE AND SOCIAL MEDIA

- <https://www.savvy.coop/>
- <https://www.facebook.com/savvy-coop/>
- https://twitter.com/savvy_coop
- <https://www.linkedin.com/company/savvycoop/>
- <https://www.youtube.com/user/>

DESCRIPTION

Savvy Cooperative is a patient-owned online marketplace platform where healthcare companies and researchers can interact with patients to get their insights. Patients are able to share their health experiences with corporations and researchers of their choosing through these 'gigs', and be rewarded for their participation.

What the foregoing reveals is that citizen empowerment is now a burning issue. There are reasons for thinking that it is set to arouse great social and business interest. It may well be that digital awareness beyond data extractivism, is, from now on, an unavoidable discussion





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Informe disponible!

