

esade  
RAMON LLULL UNIVERSITY

Institute for Social  
Innovation (IIS)



ACUP ASSOCIACIÓ CATALANA  
D'UNIVERSITATS PÚBLIQUES

The authors

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David Murillo

# MY DATA *my rules*



From data extractivism to digital empowerment

2019



**Why?**

“



*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,  
2018<sup>1</sup>**



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**Tim Berners-Lee,  
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**TECHLASH**  
Word of the year 2018

**What?**

How can digital platforms  
**empower** digital users with  
their **own data**?

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What **other data uses** can be unlocked? (monetary and **non monetary**)

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What **other data uses** can be unlocked? (monetary and **non monetary**)

What if we turned **data** into a **common good**?



**How?**

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PART 1



Executive Summary  
& Introduction

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CONTEXT

Context:  
empowerment and  
disempowerment  
in the digital era

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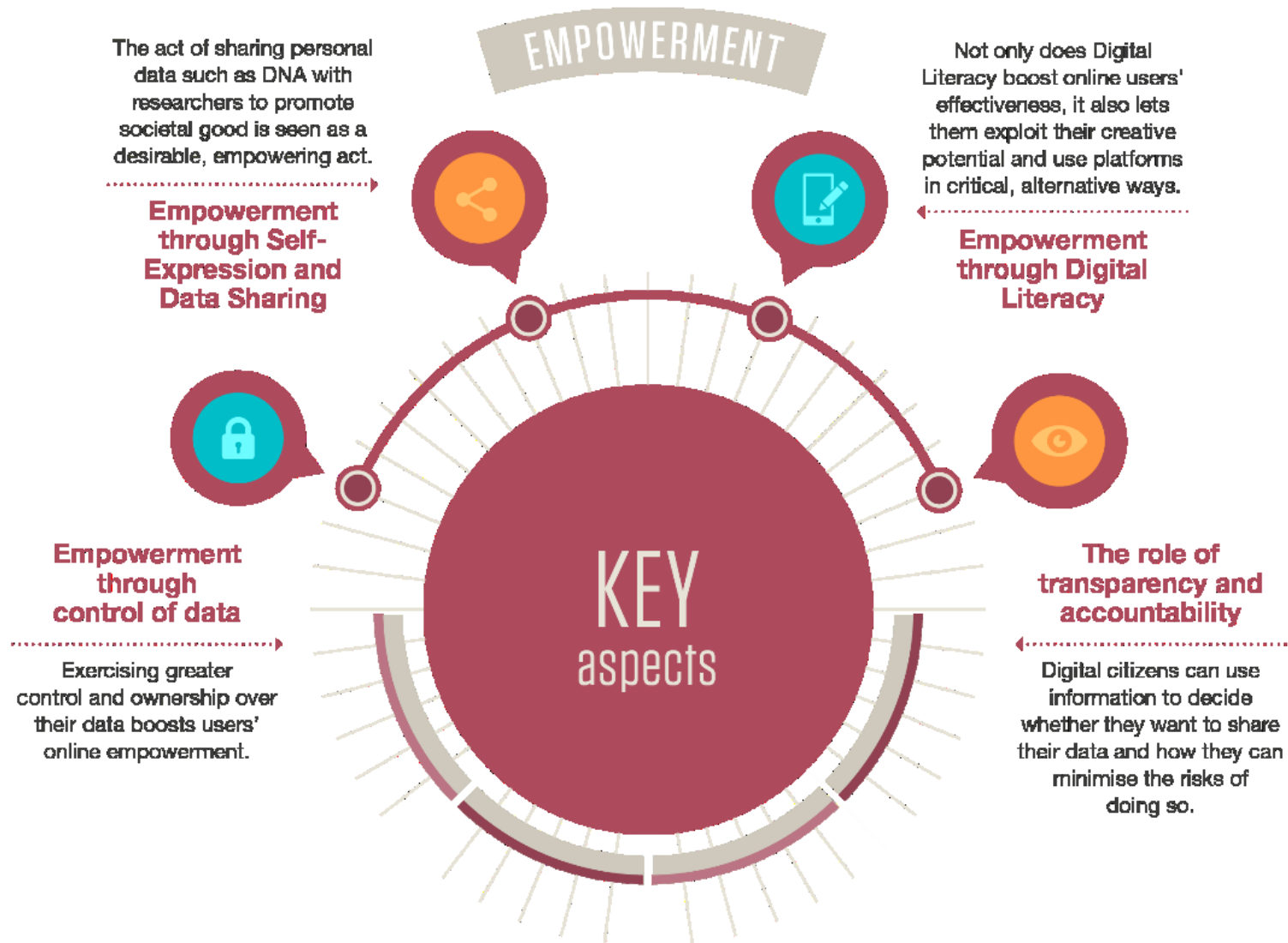


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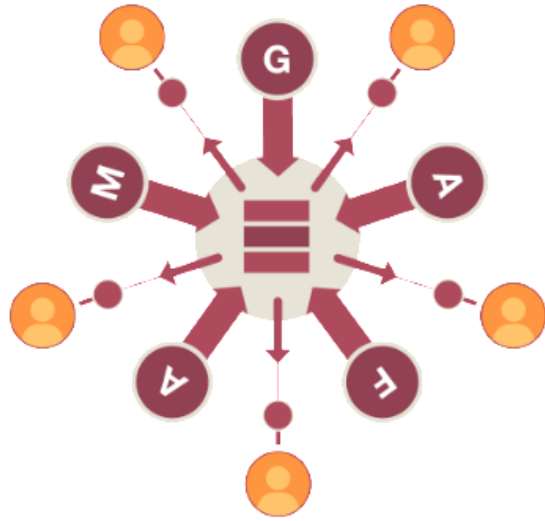
**Empowerment?**



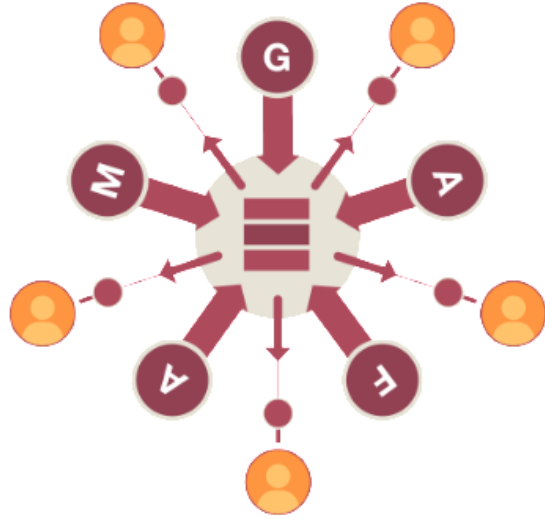
# The four principles



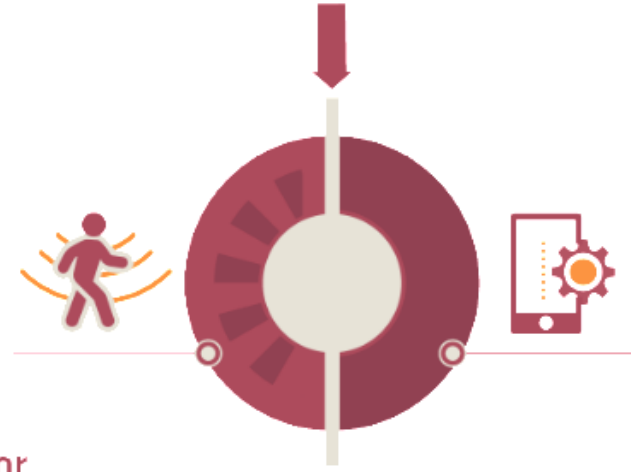
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Breaking  
down  
data silos



—  
Breaking  
down  
data silos



—  
Differentiate  
data collector  
& service editor



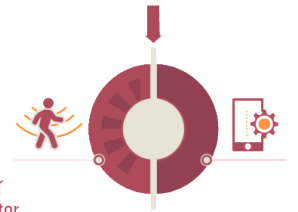
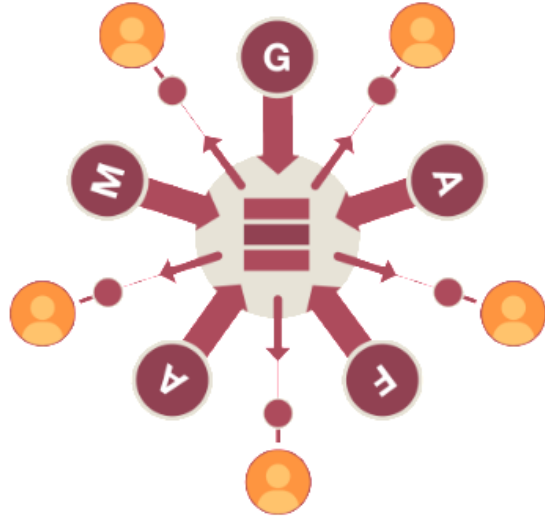


IMAGE 14 -Analogy between the layers of information in a map and in the personal and health data that can be stored

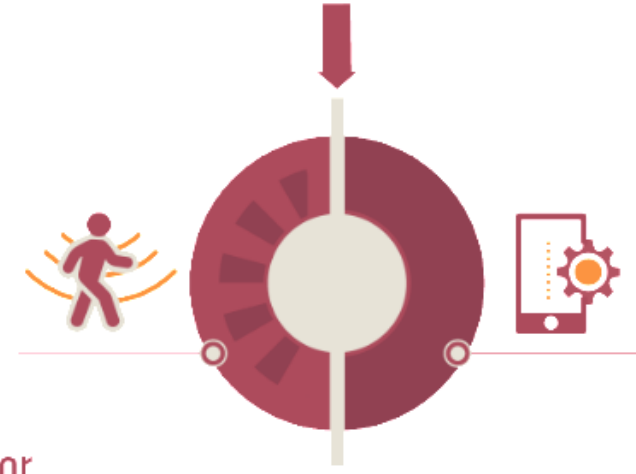


All that is needed is an integration point that relates all the data. In the case of a map, the aggregation is of GPS co-ordinates, whereas in the case of Health Data, it is the individual (and his/her blood pressure, fitness data, personal genomics, MRI, prescriptions and medical history)

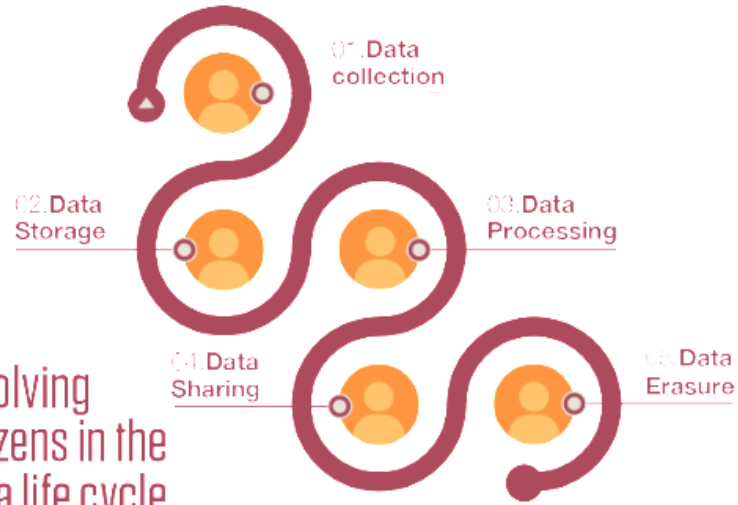
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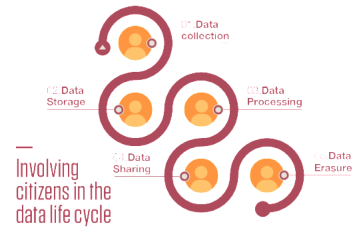





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Differentiate  
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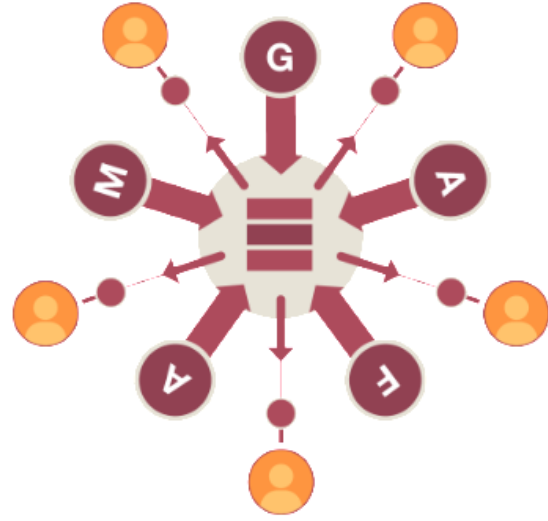
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Involving  
citizens in the  
data life cycle



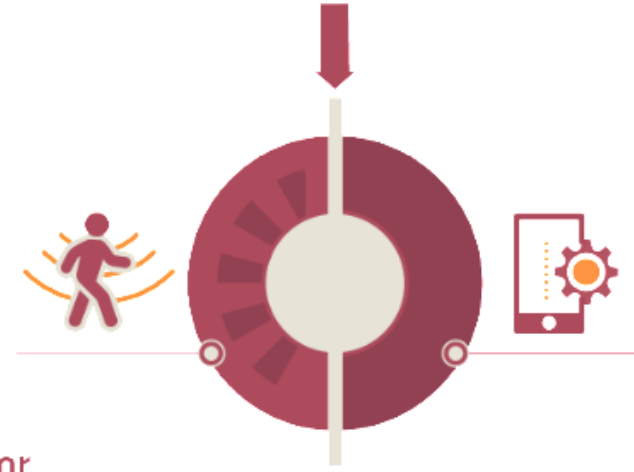


	 <b>PUBLIC SECTOR</b> Estonia Digital Society			 <b>PRIVATE SECTOR</b> Cozy Cloud			 <b>DATA CO-OP</b> MIDATA		
	Citizens	Government	Private organizations	Users	CozyCloud	Third parties	Users	MIDATA Coop	Third parties*
Data collection	Once-only principle followed;	Proactive data collection; no consent needed for official purposes	Request on X-tee	Consent, through the APIs and connectors	Not proactive data collection	Only under consent	Consent, through manual entries, PHR or apps and wearables	No data collection	Only under consent, by prescription (physicians and alike)
Data storage	On information systems of X-tee members;	No centralised database; each service has its own information system	Held in private information system, connected to X-tee	On Cozy servers (in France) or self-hosted	Offers OVH hosting (larger in Europe)	No storage	MIDATA IT platform	MIDATA IT platform	MIDATA IT platform
Data processing	None	Transparent but consent not needed for mandated activities	Permission of government needed for specific uses	Data remix on your choice	None	Only under consent	Some data combination and visualisations in progress	No processing	Yes, under consent and linked to specific projects
Data sharing	Visible to citizen through State Portal	Among governmental agencies and service providers	Government approval needed	User's decision	None	Only under consent	Yes, through the platform and with projects curated by the Ethics Committee and advised by physicians and other health professionals	Restricted by owner's consent	Companies licensing data will be forced to return the product of their studies into data commons
Data erasure	No option for legal uses; citizen's right for non-necessary purposes	Not possible in most cases	Citizens can demand it	User's decision	None	Only under consent	Anytime by the user/member	Anytime by the user/member	Anytime by the user/member

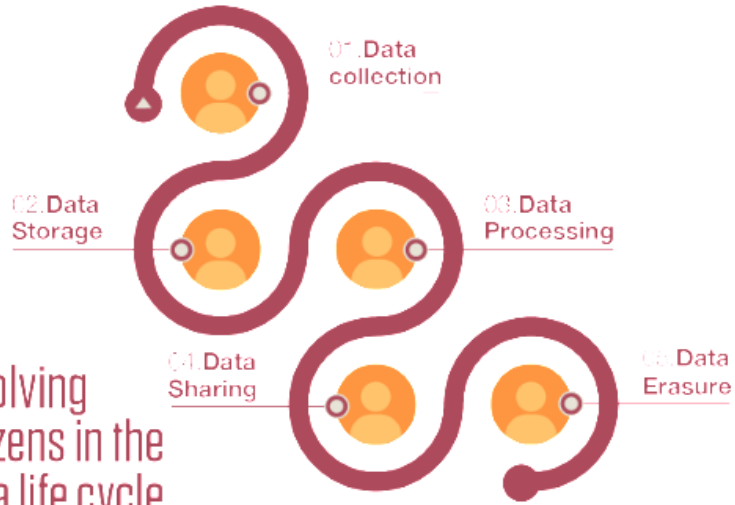
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Breaking  
down  
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—  
Differentiate  
data collector  
& service editor



—  
Involving  
citizens in the  
data life cycle



—  
Money is  
not the only  
reward



# How to use the report



CONTEXT  
1

BEST  
PRACTICE  
2

ESTONIA  
2.1

COZY  
CLOUD  
2.2

MIDATA.  
COOP  
2.3

SHORT  
CASES  
3

DISCUSS  
4

AUTHORS  
5





## 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

## Mydex CIC



### KEY ASPECTS

▷ Empowerment through control of data

▷ Empowerment through Self-Expression and Data Sharing

▷ The role of transparency and accountability

### FOUR PRINCIPLES

▷ Breaking down data silos

▷ Differentiate data collector & service editor

▷ Involving citizens in the data life cycle

CONTEXT  
1BEST PRACTICES  
2ESTONIA  
2.1COZY CLOUD  
2.2MIDATA COOP  
2.3SHORT CASES  
3DISCUSSION  
4AUTHORS  
5

FOUNDATION ● 2007 - Scotland

LEGAL FORM ● Community Interest Company (CIC)

PRIZES & AWARDS ● • ISO27001 and FairData Certified

WEBSITE AND SOCIAL MEDIA ●

- <https://mydex.org/>
- Documentation: <https://dev.mydex.org/>
- Community: <https://community.mydex.org/>
- Publications: <https://medium.com/mydex>
- <https://twitter.com/mydexcic>
- <https://www.linkedin.com/company/mydex-cic>
- <https://www.youtube.com/user/Mydexcic>

## DESCRIPTION

Mydex CIC wants to empower every individual with his own data so that it can be used to organise and manage one's life better. It does this by enabling easy, safe, secure information exchange between individuals and service providers in ways that protect the individual's privacy and data. In doing so, Mydex CIC wants to help establish a fairer, more efficient and more innovative personal data ecosystem that realises its full potential for users and in socio-economic terms.

## SOCIAL IMPACT

Mydex CIC is present throughout Scotland, serving over 750,000 citizens and 220 collaborating organisations. They have identified over 430 use cases creating re-usable solutions to problems involving personal data, typically covering public services, health and social care, employability, financial services, utilities.

Glasgow Included is a good example: a single integrated service where individuals can access many services catering to their specific circumstances via a single App powered by a personal data store.

Proven impacts include reduction in friction, effort, risk and cost leading to improved outcomes, efficiency, effectiveness and satisfaction. Users report a greater sense of coherence in their lives, and greater choice and access.

## FINANCIAL SUSTAINABILITY

Individuals have free access to and use of Mydex CIC tools and a platform for the management of their identity, and the collection, storage, distribution and control of their personal data.

Organisations pay a low one-off fee for every system they connect to and per citizen they connect to over the platform. Thereafter they pay an annual support fee based on the volume of services and citizens connected.

## INNOVATION TYPE

- Enable a safe, secure and easy-to-use personal data ecosystem (including MydexID and a Personal Data Store) with the citizen as the integration point. They can view their contents and manage their connections.
- The majority come via the services they are working with, who are accessing and storing data in the personal data store.
- This allows clusters of organisations to work together serving a common cohort of citizens seamlessly, safely and securely under a trust framework and data sharing agreements that are GDPR-compliant.

## CROSS-SECTOR COLLABORATION

The Mydex CIC platform is sector neutral and work across public, private and third sector and all sub sectors.

They have been working with the Digital Health and Care Institute across the public, private and third sectors for 5 years now to help develop truly person-centric health services where data from many specialists is incorporated in the individual's health record.

## REPLICABILITY AND SCALABILITY

The platform has been designed to be global in application and is already being used across regions and cities internationally. As a secure certified cloud-based distributed platform, it should scale easily and safely.

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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Download here!



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"la Caixa"