

WEBINAR

Personal data management and altruism: how and when are individuals empowered to make data sharing decisions?

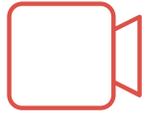
The logo for Data Europa Academy, featuring the text "data.europa academy" in white lowercase letters. The word "data" is on the top line, "europa" is on the second line, and "academy" is on the third line. The dots in "data" and "europa" are colored yellow and orange. The logo is set against a dark blue circular background.

data.
europa
academy

12 April 2024

10.00 — 11.30 CET

Rules of the game



The webinar will be recorded



For questions, please use the ClickMeeting chat.



Please reserve 3 min after the webinar to help us improve by filling in our feedback form

Introduction



Hans Graux
Lawyer IP, IT and data
protection law,
Partner at Timelex



Kai Kuikkaniemi
Senior Advisor,
MyData Global



Manuel Portela
Post-doctoral Researcher
Universitat Pompeu Fabra

Agenda

10.00 – 10.10	Opening and introduction – <i>Hans Graux</i>
10.10 – 10.40	Personal data management – <i>Kai Kuikkaniemi</i>
10.40 – 11.10	Data altruism – <i>Manuel Portela</i>
11.10 – 11.25	Q&A session
11.25 – 11.30	Closing statements



MyData

**Advancing Human-centric
personal data management**



MyData vision



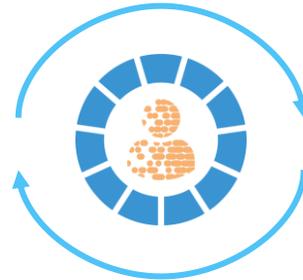
The core idea is that individuals should be **in control of the data about themselves**.

The MyData approach aims at strengthening **digital human rights** while opening new opportunities for businesses to develop innovative **personal data-based services** built on mutual trust.

Fair, sustainable and prosperous digital society through a human-centric approach to personal data

People get value from their data and set the agenda on how it is used.

Need



Offer

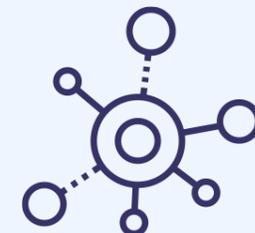
For **organisations**, the ethical use of data is always the most attractive option.



FROM FORMAL TO
ACTIONABLE RIGHTS



FROM DATA PROTECTION TO
DATA EMPOWERMENT



FROM CLOSED TO
OPEN ECOSYSTEMS

For fair, sustainable, and prosperous digital society through a human-centric approach to personal data

People get value from their data and set the agenda on how it is used.



For **organisations**, the ethical use of data is always the most attractive option.

mydata.org / declaration

For a fair, sustainable, and prosperous digital society

- 1 **FORMAL** → **ACTIONABLE RIGHTS**
- 2 **DATA PROTECTION** → **EMPOWERMENT**
- 3 **CLOSED** → **OPEN ECOSYSTEMS**

MyData Principles

1

**Human-centric control
of personal data**

2

**Individual as the point
of integration**

3

**Individual
empowerment**

4

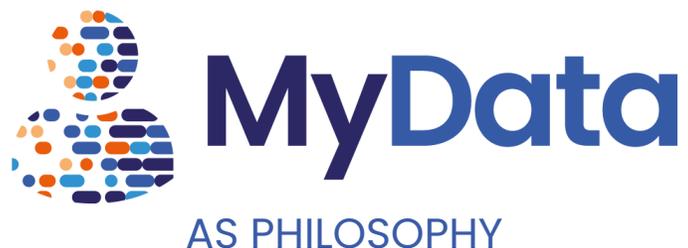
**Portability: access and
re-use**

5

**Transparency and
accountability**

6

Interoperability



We believe in **empowering the individual (and those serving them)** by means of personal data.

When individuals are **in control of the data about themselves**, they open new opportunities for businesses to develop innovative **personal data-based services** built on mutual trust.

Shared personal data enables to improve the operations of businesses by having **up-to-date and verified data from customers and users**.



We exist to **help the enablers of MyData philosophy** (public and private organisations, experts, individuals) to succeed.

Our Association **maintains, develops and promotes the MyData Declaration**.

We are **developing of skills, knowledge and connections** of people in the MyData community and more widely in the digital services industries.

MyData in the EU Data Strategy



MyData is recognized as one of the movements that “promise significant benefits to individuals, including to their health and wellness, better personal finances, reduced environmental footprint, hassle-free access to public and private services and greater oversight and transparency over their personal data.”



MyData Global

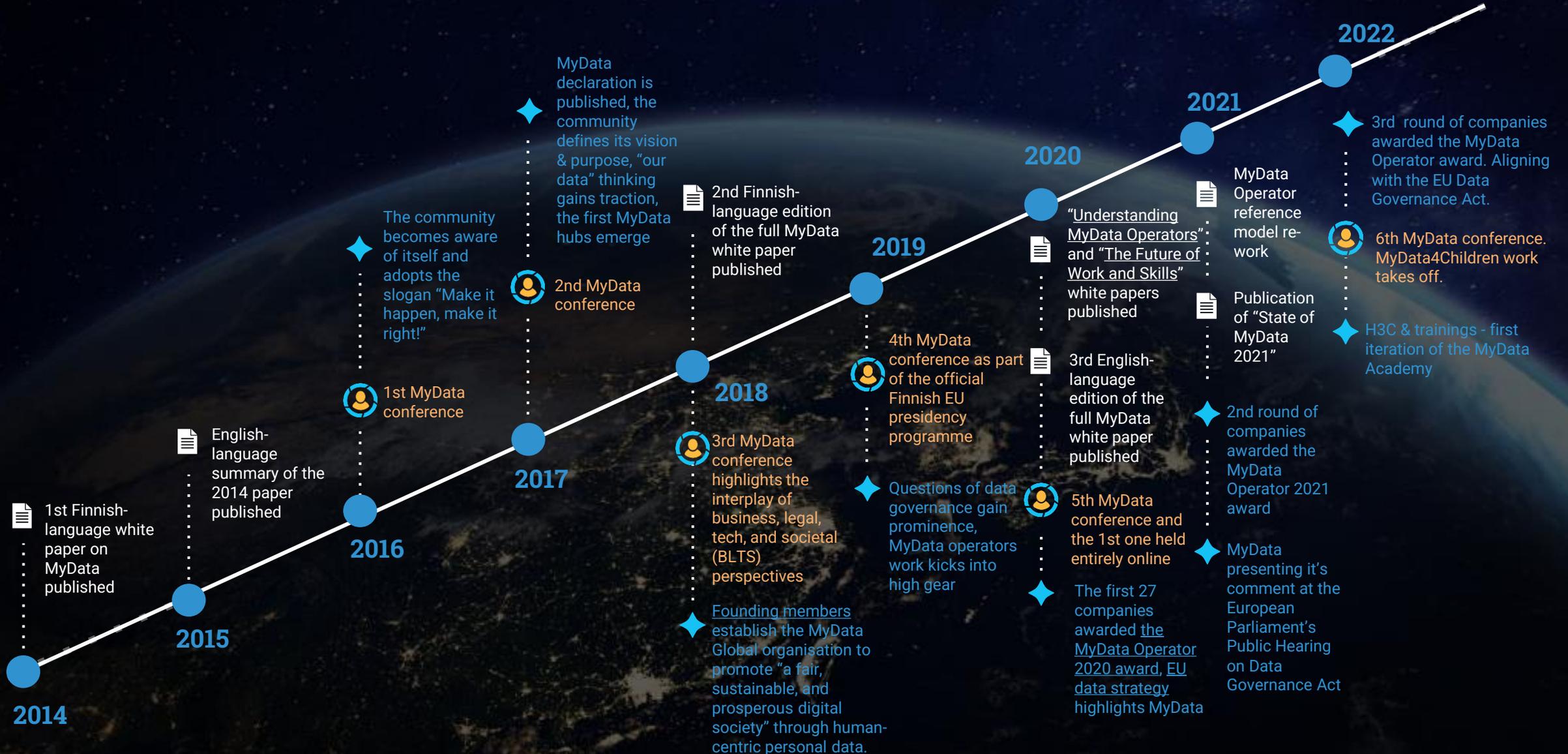


MyData Global

- > **International nonprofit**
- > **Headquartered in Finland**
- > **Founded in 2018**
- > **Over 500 members**
... including over **100** organisations
... from over **50** countries
- > **16** local hubs on **6** continents
- > Emerging international **thematic** groups
- > Organiser of the leading personal data **conference**



The MyData journey





Local Hubs

MyData Operators

supports the development of **infrastructure for human centric personal data management** by **developing the definitions and processes** associated with the MyData Operator, as described in the MyData declaration and the 'Understanding MyData Operators' -whitepaper.

Skillsdata

unites the organisations around Europe to **build a human centric skills data space**.

MyData Literacy

provides **adequate means and tools** to those who are willing and capable of supporting others in **becoming "data literate"**, ultimately increasing the number of people in the world who are "data literate".

MyData-4-Pandemics

enables responsible and secure freedom for movement of individuals - based on their personal conditions and their surroundings - and help sustain and revive the economy in pandemics like COVID-19.

MyData Design*

advances human-centred design culture and practices within the MyData community. We create **design tools and approaches** to be used by MyData community members and partners, and aim to support their work through our design skills.

MyData Health*

Advocates for **international healthcare policy and state-of-the-art technological systems** that are designed to **place the patient at the fulcrum of all decision-making** on how their personal health data is managed, used, and shared in close coordination with fiduciary professionals.

MyData Children*

builds collaborations with different actors to protect children's digital rights and empower them. Their purpose is to empower children, their families and their circle of trust as they navigate and construct their digital world.



Thematic Groups

* Emerging

Case: MyData Awards

MyData Operator Awards

The MyData Operator Award recognises personal data companies that have shown leadership by providing human-centric solutions that empower individuals to manage their personal data.

To date, **40+ service providers have received the MyData Operator Award**. Awarded organisations are required to demonstrate how they create agency for human-centric data control, and how the data and value flows in their ecosystems. [More information about the award and awardees!](#)

Starting 2023, Awards are also given to practical cases that demonstrate human-centricity. (see next slide)

MYDATA OPERATORS 2022





MyData Operator

A W A R D 2 0 2 3



my:D

mydata^{share}



sensotrend

-SOWL



MyData in Practice

A W A R D 2 0 2 3



reliable employee



Why join MyData Global?

Community

Policy

Markets

Impact

Supporting a global movement

We provide a space for collaboration and learning across sectors and the world.

Shaping

the rules that matter

We work with thought leaders and policymakers to design a data future that puts people first.

Enabling

better business

We help organisations hone their models, find their markets, and demonstrate sustainability.

Value for
members

Community Networking

Find allies: to share ideas, compare lessons, start consortia, and collaborate on projects

Be seen: get your products and contributions in front of a global audience

Policy Influence

Guide policy: join consultations and collective advocacy, have your voice heard in expert groups

Build the future: co-create technical white papers, interoperability standards, and building blocks for data sharing.

Market Insights

Understand trends: see cutting edge innovations and business models before they hit market

Signal values: showcase your MyData affiliation to strengthen your brand

International community and movement



DATALOG

DADES PEL BENESTAR PLANETARI



Universitat
Pompeu Fabra
Barcelona

IDEAS
FOR
CHANGE



EU Recognised
Data Altruism
Organisation



Ajuntament
de Barcelona

IN
BARCELONA
OVA

Data Governance Act (DGA) Regulation (EU) 2022/868

→ **Data altruism (Articles 15-22)**

Article 2 - Definition 16: 'data altruism' means the voluntary sharing of data on the basis of the consent of data subjects to process personal data pertaining to them, or permissions of data holders to allow the **use of their non-personal data without seeking or receiving a reward that goes beyond compensation related to the costs that they incur** where they **make their data available for objectives of general interest** as provided for in national law, where applicable, such as 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;**

<https://eur-lex.europa.eu/eli/reg/2022/868/oj>

DATA LOG

DADES PEL BENESTAR PLANETARI



EU Recognised
Data Altruism
Organisation

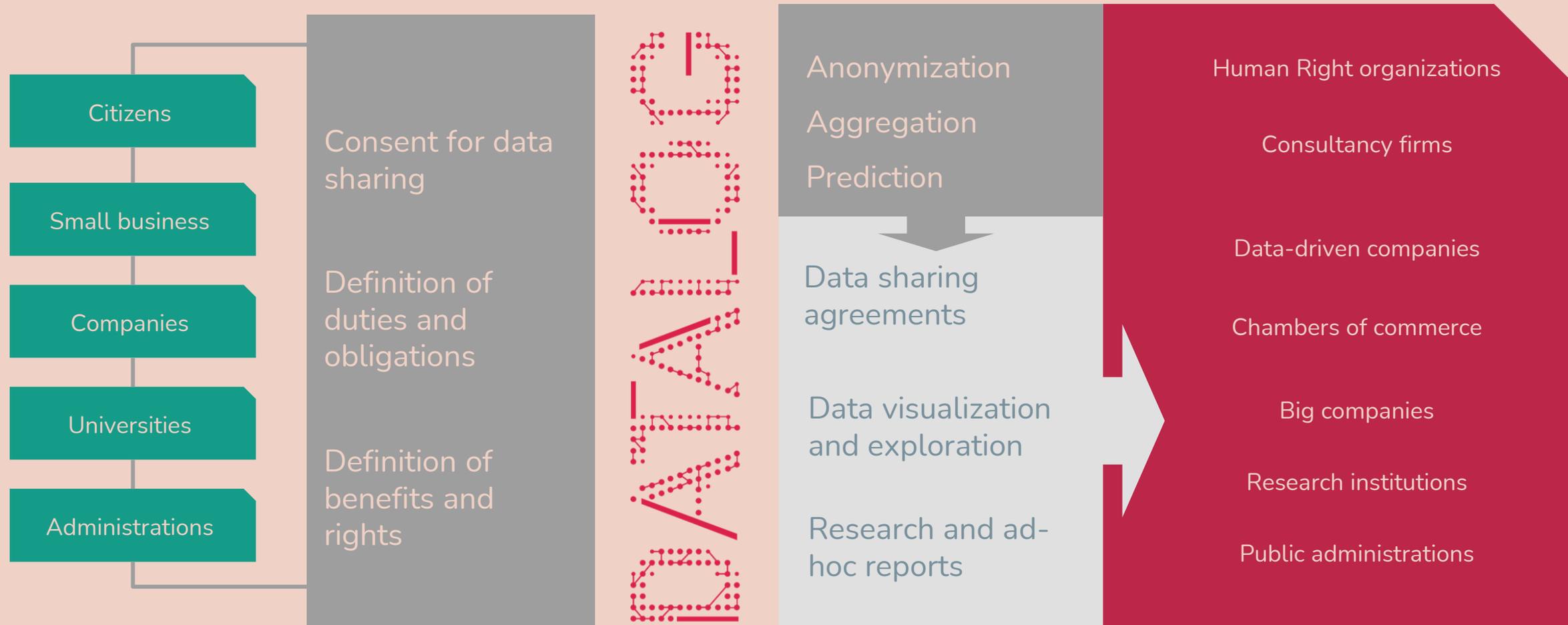
A legal entity enabling data altruism for the common good, encompassing legal, technological, procedural, and governance mechanisms.

Utility consumption data

water, electricity and gas

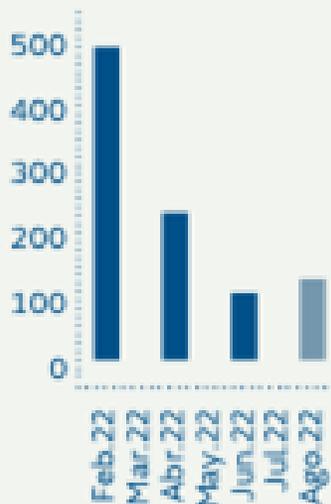
Geographical application

Barcelona Metropolitan Area



Consumo real

■ Periodo 1

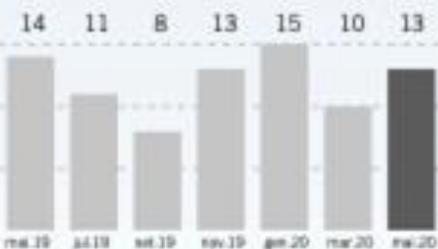


Consumo estimado

■ Periodo 1

SU GASTO DIARIO

Su gasto medio en este periodo ha sido de 0,63 €/día de los cuales 0,34 €/día corresponden al suministro del agua.



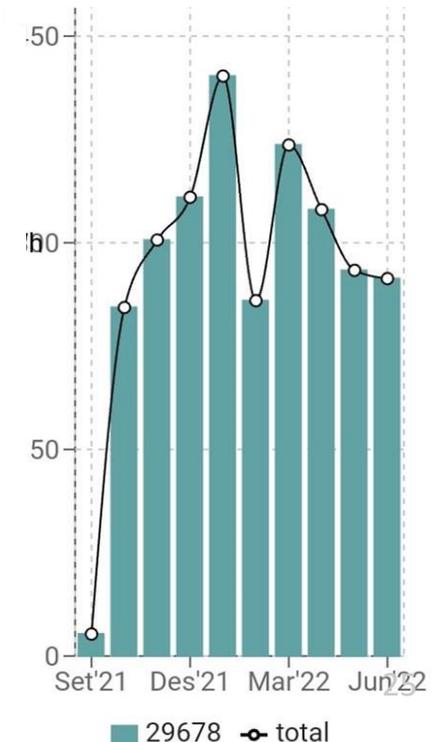
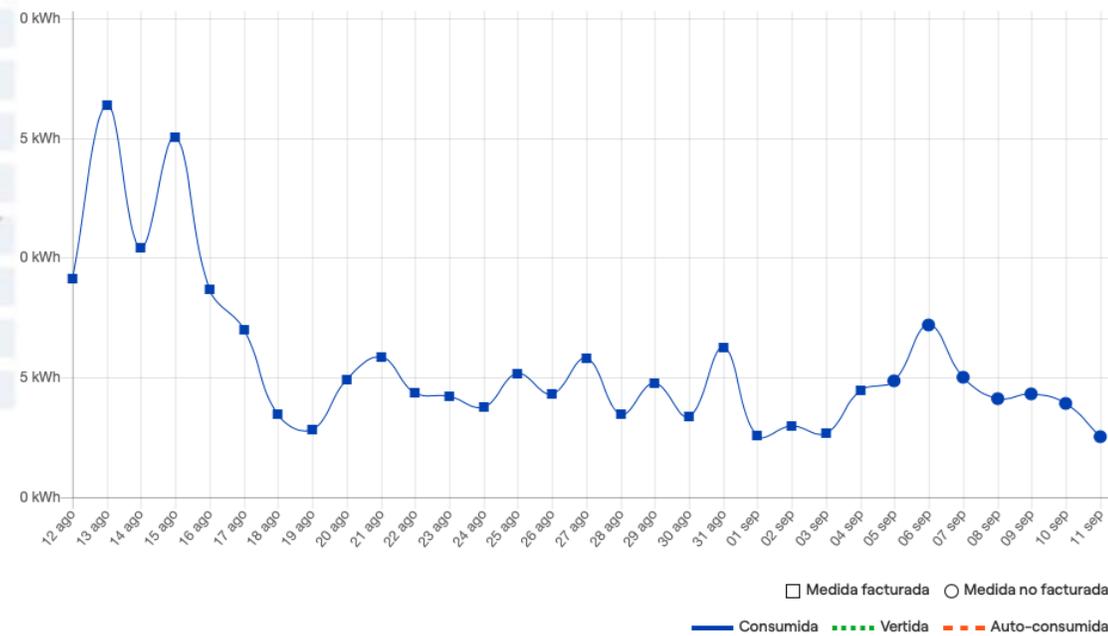
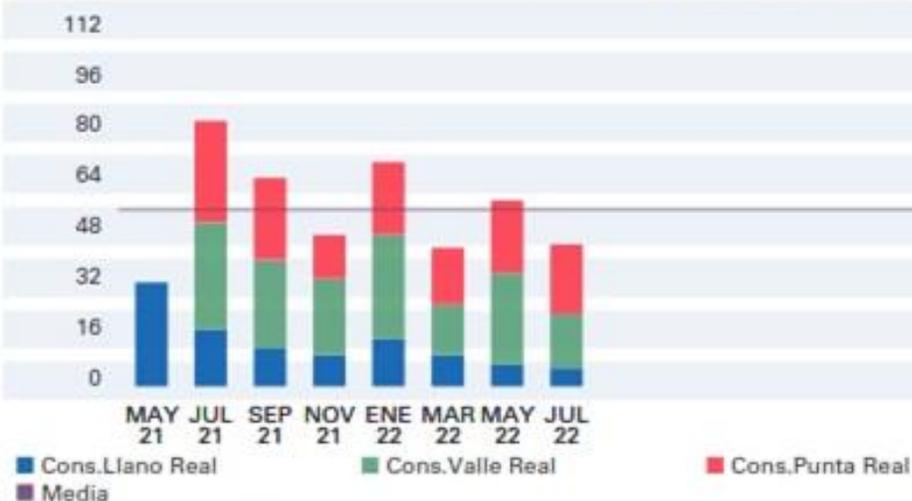
Consums històrics anteriors en kWh



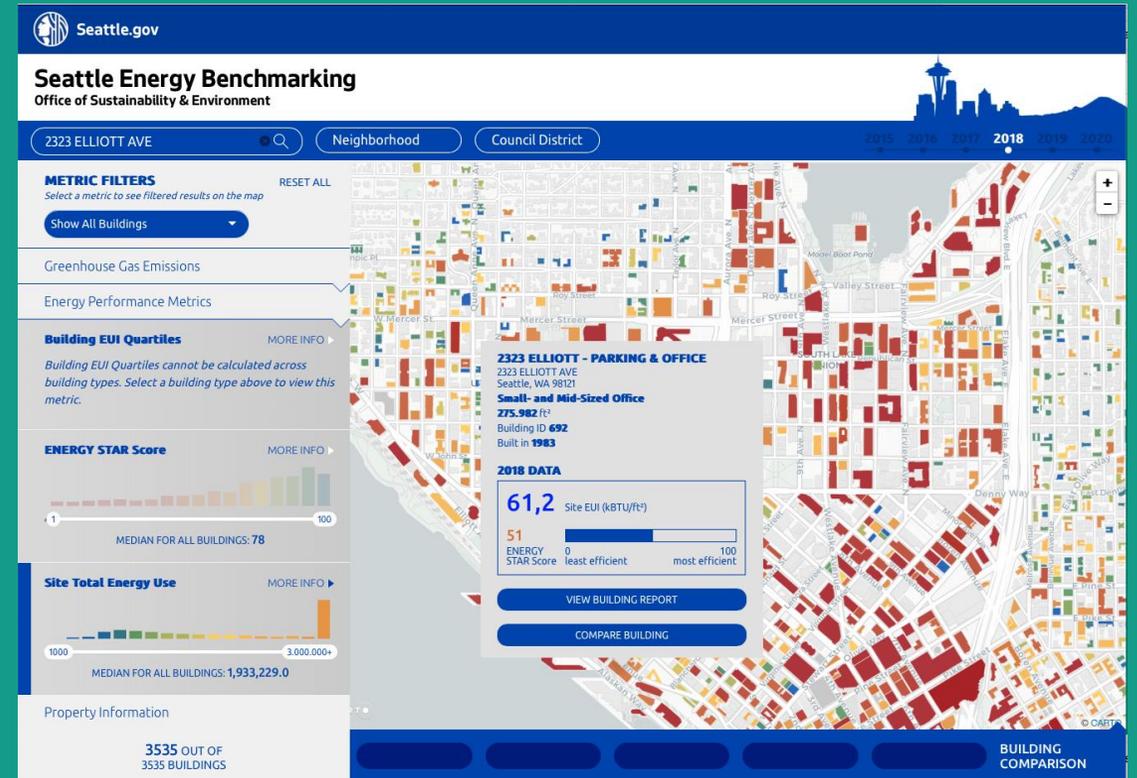
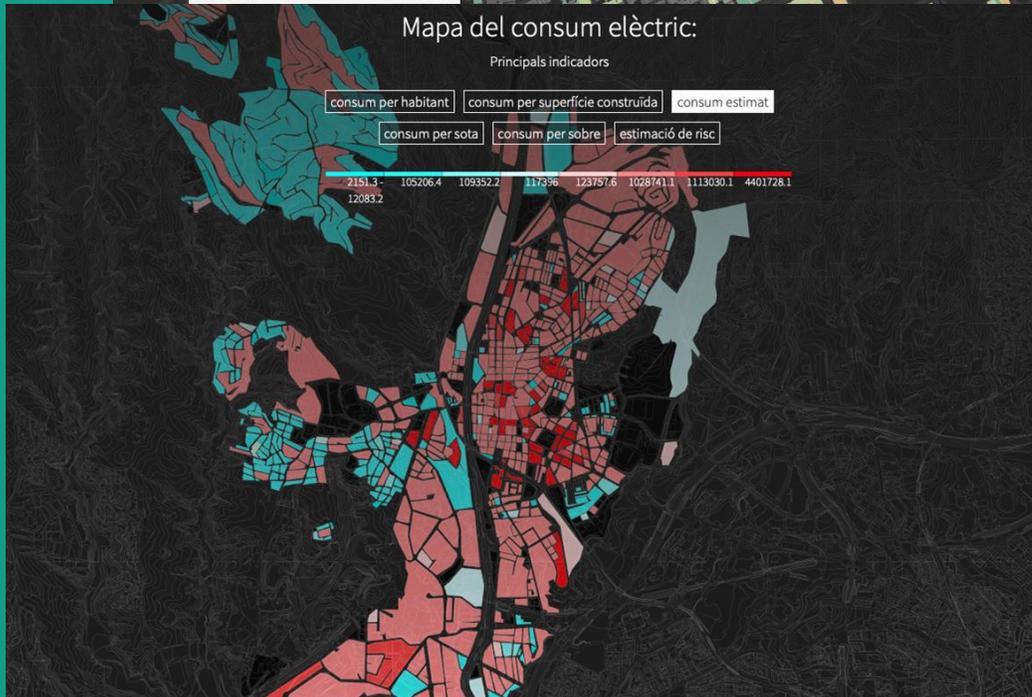
kWh

Evolución del consumo /h - días

Total consumida 173,674 kWh



Coste en esta factura 1,45 €/día
 Coste últimos 14 meses 1,55 €/día
 Consumo último año 414 kWh
 Las potencias máximas demandadas en el último año han sido 2.6 kW en P1 (punta) y 1.2 kW en P3 (valle).



<https://www.seattle.gov/energybenchmarkingmap/#seattle/>

<https://mapaenergia.elprat.cat/geovisor/>
http://300000kms.net/_rubibrilla/

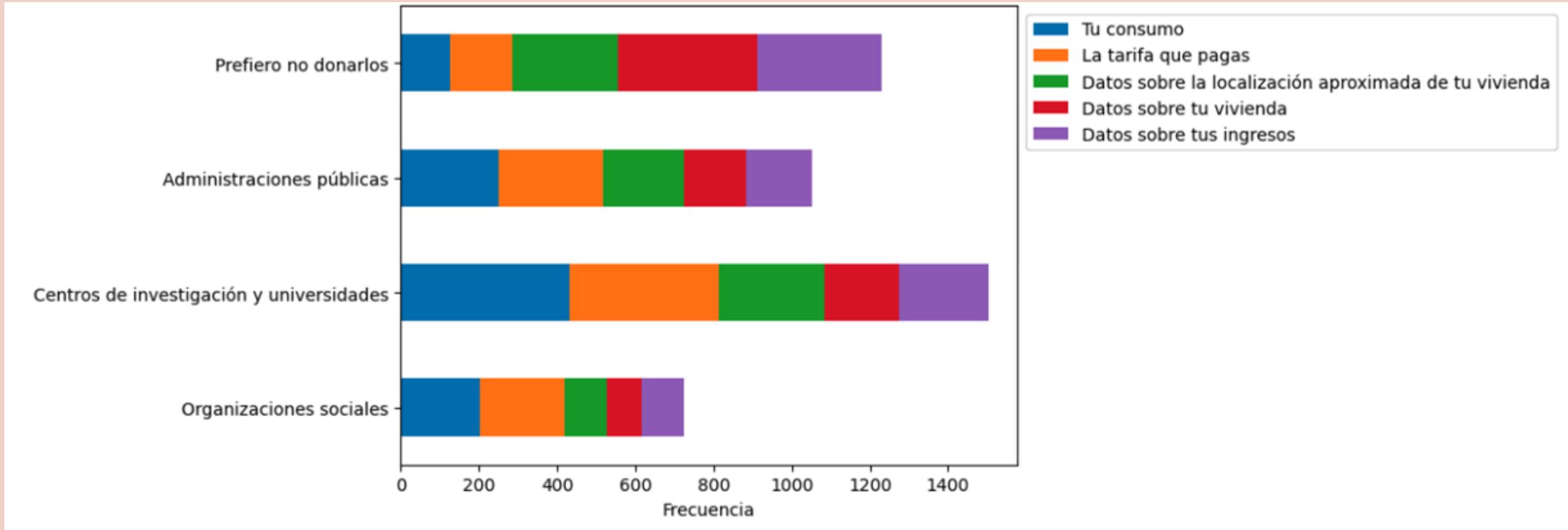
GOVERNANCE MODEL

DATALOG

BUILDING TRUST

PROBLEM

PEOPLE LACK OF TRUST TOWARDS PRIVATE ORGANIZATIONS AND, SOMETIMES, PUBLIC ADMINISTRATIONS



ASSOCIATION “DATA FOR PLANETARY WELLBEING”

- Its constitution has an advisory committee on data protection and a data protection officer
- Became the first data altruism organization in Spain

VISION

The aim of the association is to generate, promote the knowledge of cities and their actors through data and intelligent systems with an impact on planetary well-being: the fight against climate change, energy poverty, sustainable mobility, the circular economy and the well-being of people and the environment in general.

MISSION

Facilitate the access and analysis of the data in a granular, interoperable way and maintaining the privacy and confidentiality of these; Enable digital tools for users to explore data; Inform better public policies; and, Collaborate with research and development projects with various public and private entities.

GOVERNANCE - four key governance structures

BOARD OF DIRECTORS

Members of the board are elected every 3 years

Responsible for daily management and project development

GENERAL ASSEMBLY OF MEMBERS

Members subscribed to the association with contribution

Meet annually to define the strategy and course of action. Monitoring and control functions.

DATA PROTECTION COUNCIL

Invited advisors (can't be part of the Board of Directors)

Contribute through knowledge and expertise and will validate infrastructure, management practices, and project development.

CITIZENS COUNCIL

IN THE FUTURE

Open participation

Will contribute through their visions and ideas. Can be grouped by community or geographical areas. Monitoring and control functions.

ENGAGEMENT MODEL

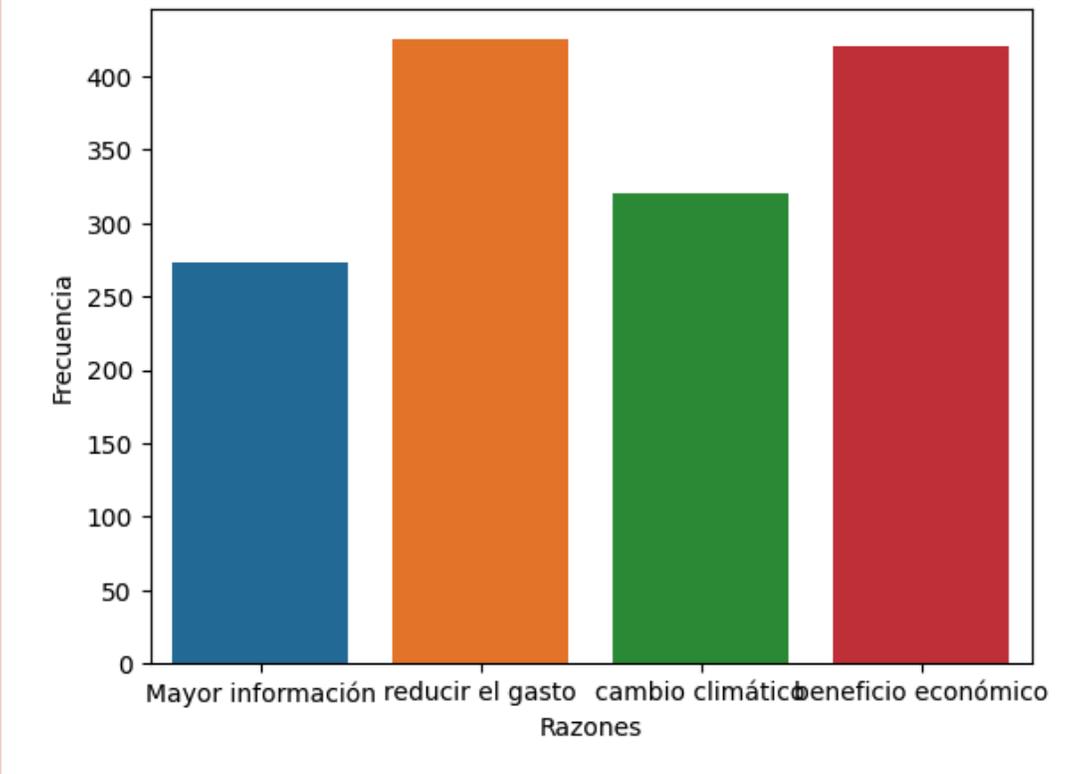
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ENGAGING CITIZEN TO DONATE DATA

PROBLEM

FEW PEOPLE UNDERSTAND THE VALUE OF DATA AND THE BENEFIT OF USING DATA FOR ENVIRONMENTAL REASONS

LACK OF AWARENESS, TIME AND SKILLS



Data Governance Act (DGA) Regulation (EU) 2022/868

→ Data altruism (Articles 15-22)

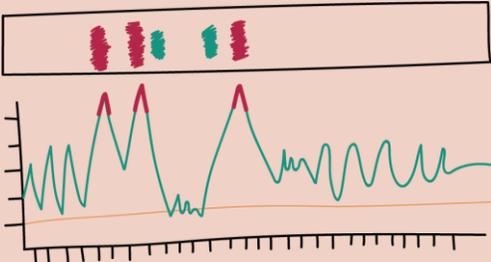
Article 2 - Definition 16: [...] to allow the use of their non-personal data **without seeking or receiving a reward that goes beyond compensation related to the costs that they incur where they make their data available for objectives of general interest as provided for in national law, [...]**

Challenge

How do we incentivise (the first) participants to share their data?

ENGAGING DATA DONORS

INDIVIDUAL



Discovery of abnormal consumption patterns.



Analysis of individual consumption patterns and definition of savings goals.

COLLECTIVE



Individual and collective comparison within consumer profiles.



Prediction models at city level for the study of the carbon footprint.

PUBLIC CAMPAIGN

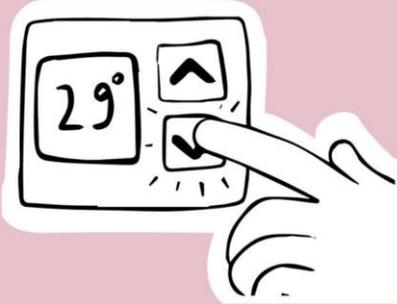
Challenge

In the near future we need to raise money to keep our systems running and volunteers to keep working on our developments and campaigns.



ideas_4_change

¿Cuántos hábitos podríamos corregir que **no son sanos para el planeta?**



DATALOG
DATOS PARA EL BIENESTAR PLANETARIO

upf Universitat Pompeu Fabra Barcelona IDEAS FOR CHANGE IN BARCELONA OVA Ajuntament de Barcelona

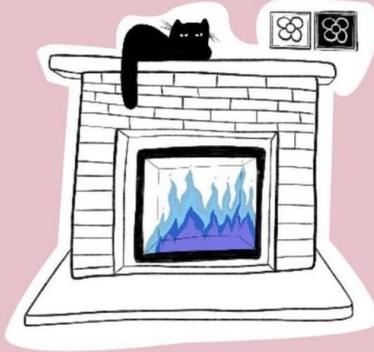
Les gusta a irene_polinelli y 4 personas más ideas_4_change ¿Cuántas veces dejamos alguna luz de la habitación encendida? ¿Cuántas veces dejamos cosas enchufadas y creemos que no repercute... más

Hace 3 días



ideas_4_change

Decide qué papel juegas con las decisiones que tomas cada día



DATALOG
DATOS PARA EL BIENESTAR PLANETARIO

upf Universitat Pompeu Fabra Barcelona IDEAS FOR CHANGE IN BARCELONA OVA Ajuntament de Barcelona

Les gusta a baarbaaramii y 34 personas más ideas_4_change ¡Optimiza tu consumo de gas! La plataforma #DATALOG te proporciona una visión de tus recursos domésticos, ayudándote a gestionar eficazmente tu consumo de gas. Gracias a DATALOG, puedes conocer tus recursos de forma integrada y así podrás gestionar bien tus hábitos de consumo, corregir, ahorrar y ayudar al planeta. ¿A qué esperas? ¡Descubre más sobre el proyecto y empieza a ahorrar de forma inteligente! El planeta te lo agradecerá.

CONSENT MODEL

DATALOG

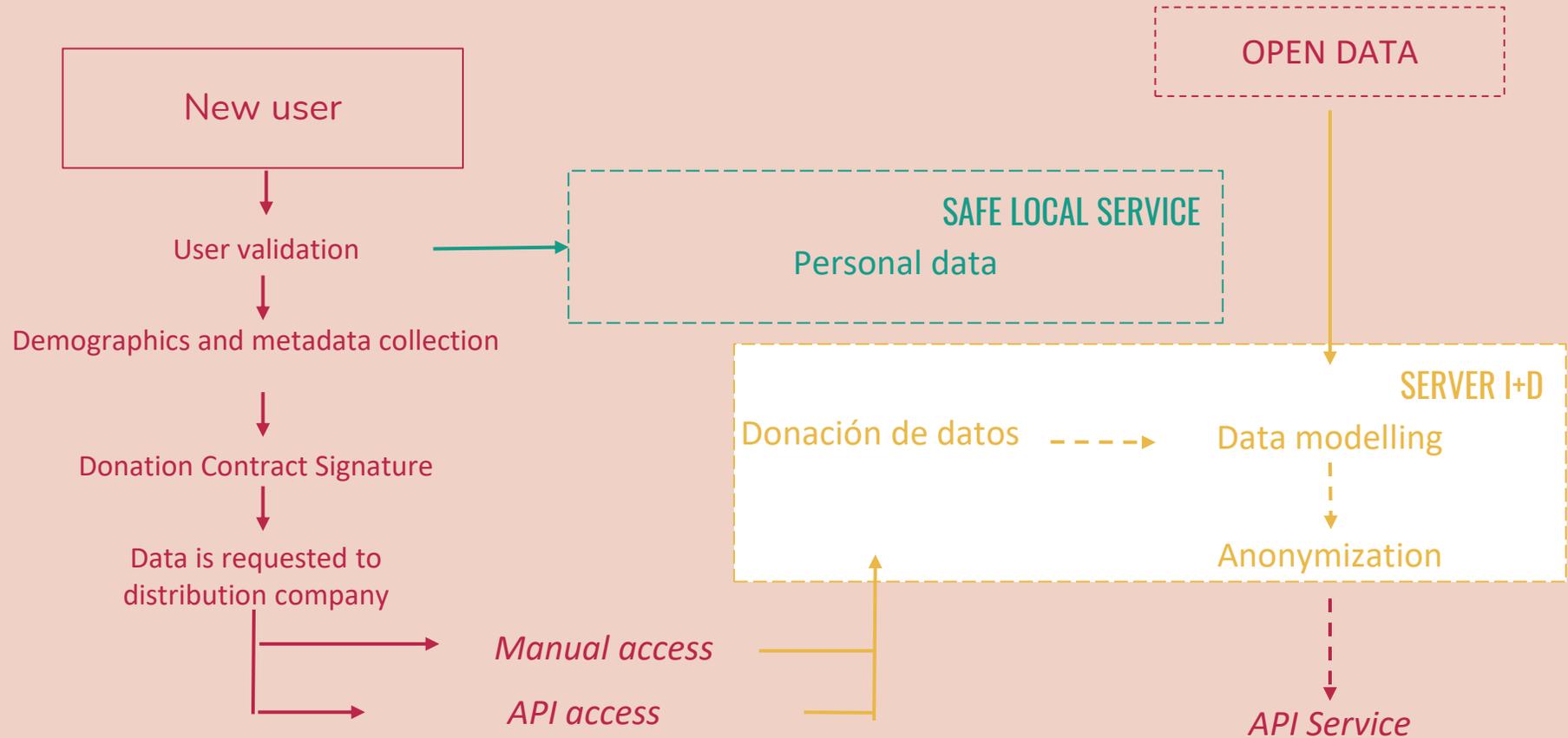
CONSUMPTION DATA

Energy sector law determines that consumption data should be accessible to commercial companies only. However, consumption data is owned by consumers.

Environmental law mandates access to relevant environmental data should be shared under request.

Direct consent is needed to claim data sharing.

CONSENT PROCESS



CONSENT PROCESS

Forms are automatically completed and signature is managed by Docuseal.eu

Challenge

How to automate this process with ID validity and consent validity without requiring users high level of tech expertise?

DATALOG
www.datalog.es

Asociació pel Benestar Planetari (DATALOG)
NIF: G-56474885
info@datalog.es

EJERCICIO DEL DERECHO DE ACCESO

AUTORIZACIÓN
Por medio del presente documento, autorizo a D. Manuel Portela Charnejovsky, CON DNI nº 31043349L en nombre y representación de Asociació pel Benestar Planetari (DATALOG), con NIF nº G-56474885, domiciliada en la calle Democracia 7 4-2, 08018, Barcelona a solicitar en mi nombre la presente solicitud de derecho de acceso.

DATOS DEL RESPONSABLE DEL TRATAMIENTO
Empresa:
Sede social:
Código de Identificación Fiscal N°:

DATOS DEL AFECTADO O REPRESENTANTE LEGAL
Nombre completo:
Domicilio:
DNI:
Correo electrónico:
Contrato N°:
CUPS:
Por medio del presente escrito ejerce el derecho de acceso, de conformidad con lo previsto en el artículo 15 del Reglamento UE 2016/679, General de Protección de Datos (RGPD).

SOLICITA
Que se le facilite gratuitamente el derecho de acceso por ese responsable en el plazo de un mes a contar desde la recepción de esta solicitud, y que se remita, a la dirección arriba indicada, la siguiente información sobre el contador asociado:

- Datos de consumo por hora para el contador desde 2019 a la fecha actual;
- Autorización y acceso a la aplicación o *application programming interface* (API) para consultar a los consumos detallados por hora de forma remota sin fecha de expiración;
- Tipo de tarifa y potencia/caudal contratado.

TECHNOLOGICAL MODEL

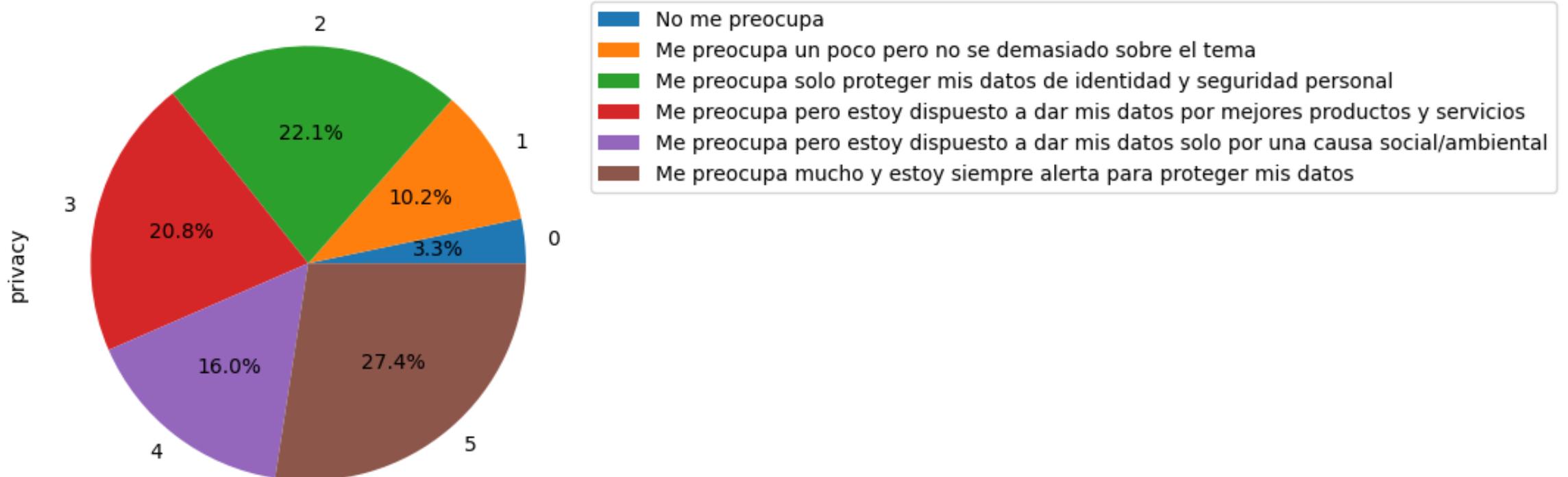
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DATA ARCHITECTURE

PROBLEM

PEOPLE PERCEIVE PRIVACY-RELATED CHALLENGES WHEN SHARING THEIR DATA. NEED FOR A ROBUST AND PRIVACY-BY-DESIGN ARCHITECTURE.

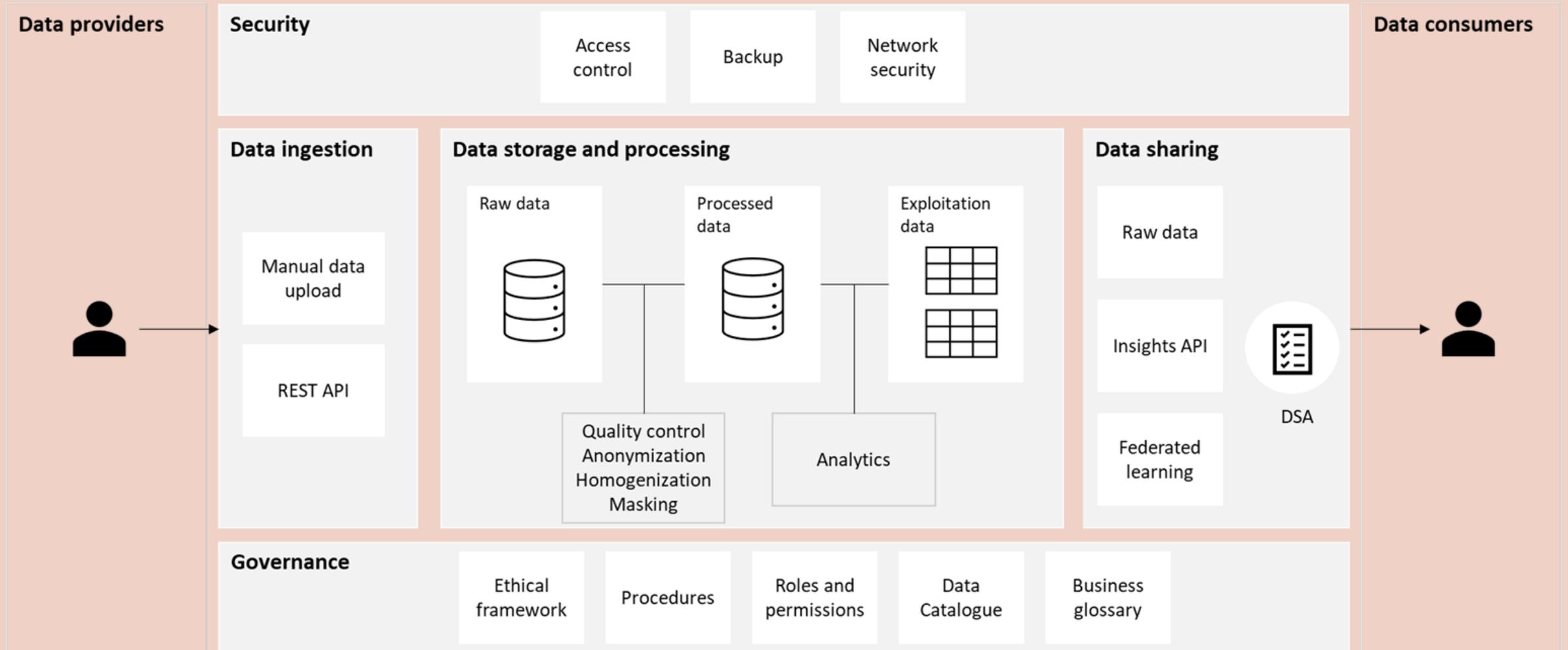
Preocupación sobre la privacidad de los encuestados



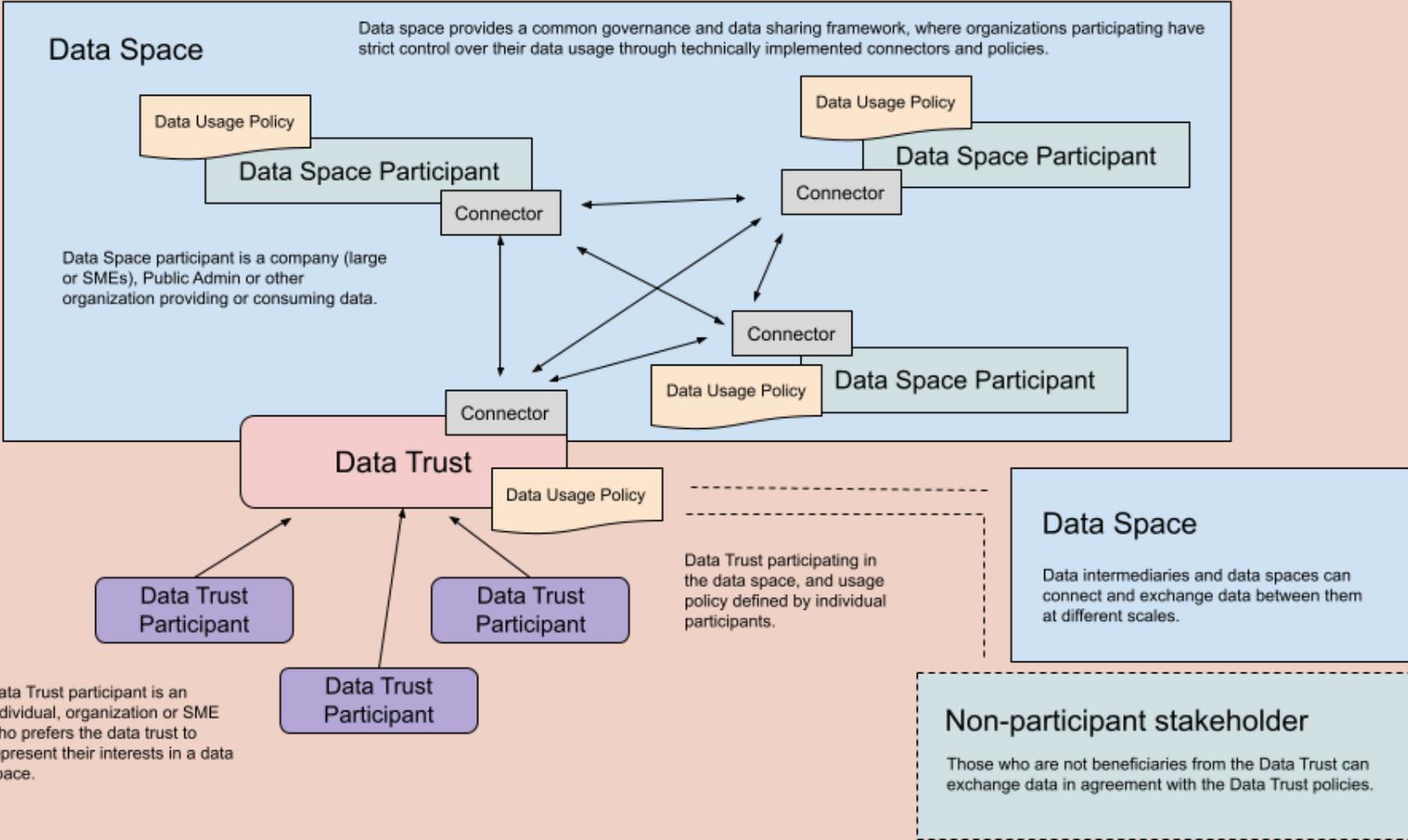
DATA ARCHITECTURE

Challenge

Automate ETL and Data Sharing processes with our specific requirements keeping low cost of operations.



DATA SPACES INTEGRATION



SUSTAINABILITY MODEL

DATALOG

PARTICIPATORY SUSTAINABLE MODEL

Access to infrastructure, data and algorithms

Membership fee

Contribution

Donations

For entities interested in development

Specialized reports on demand

Tenders

Per contract

Consultancy

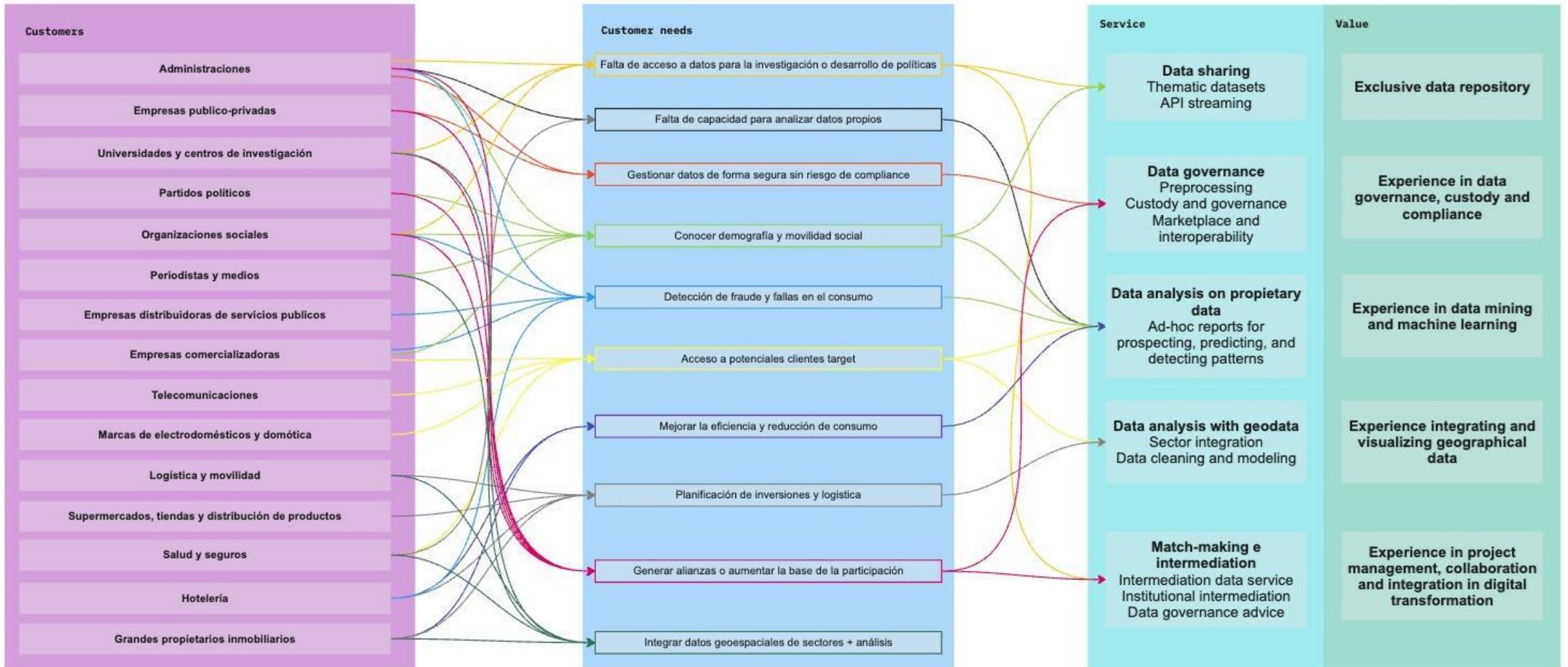
Per contract

Research involvement

Calls for projects with public funds

For participation in calls

SERVICE AND VALUE MAP



CO-CREATION FOR DATA LICENCING AND VALUE CREATION

- Data trust participants (beneficiaries) will define general consent and the code of ethics to data sharing.
- Social organizations and research centres will help to identify and address the relevant societal needs.
- Social organizations will help to reach and engage citizens to become participants of the data trust on their benefit.
- In the future, a one-to-one basis will be possible to select data sharing for specific purposes.

MAIN TAKEAWAYS

- Opportunities for a sustainable model (DGA)
- Release of the european data sharing consent form (DGA)
- Define an affordable technology stack
- Interoperability with multiple Data Spaces
- Raise awareness on altruism organizations at european level to foster building trust towards voluntary donation for the common good

DOWNLOAD WHITEPAPER



whitepaper.datalog.es

info@
DATALOG.ES

Introduction



Hans Graux
Lawyer IP, IT and data
protection law,
Partner at Timelex



Kai Kuikkaniemi
Senior Advisor,
MyData Global



Manuel Portela
Post-doctoral Researcher
Universitat Pompeu Fabra

Stay up-to-date on our
2024 activities!

The logo for Data Europa Academy is located in the bottom left corner. It consists of the words "data.", "europa", and "academy" stacked vertically in a white, lowercase, sans-serif font. The word "data." has a small yellow dot above the 'a'. The word "europa" has a small yellow dot above the 'o'. The word "academy" has a small yellow dot above the 'a'. The logo is set against a dark blue circular background that is part of a larger graphic design of overlapping circles in various shades of blue and white.

data.
europa
academy

Workshop

How to use open data for your research?



data.
europa
academy

10 May 2024

10.00 – 11.30 CET

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academy



Please provide your feedback!



Thank you

