

CITIZEN ENGAGEMENT IN THE EHDS

Data altruism and citizen participation to share health (and genome) data for research purposes

Engagement initiatives in Belgium (Sciensano)

2017

Implementation of NGS technologies in oncology

- Focusgroups with patients
- Stakeholder involvement

2018-2019

Citizen forum: Mijn DNA, een verhaal van iedereen?/Mon ADN, tous concernés?

2019-2020

Online engagement: DNADebat/DébatADN

2020-2022

TEHDAS: Healthy Data e-consultation

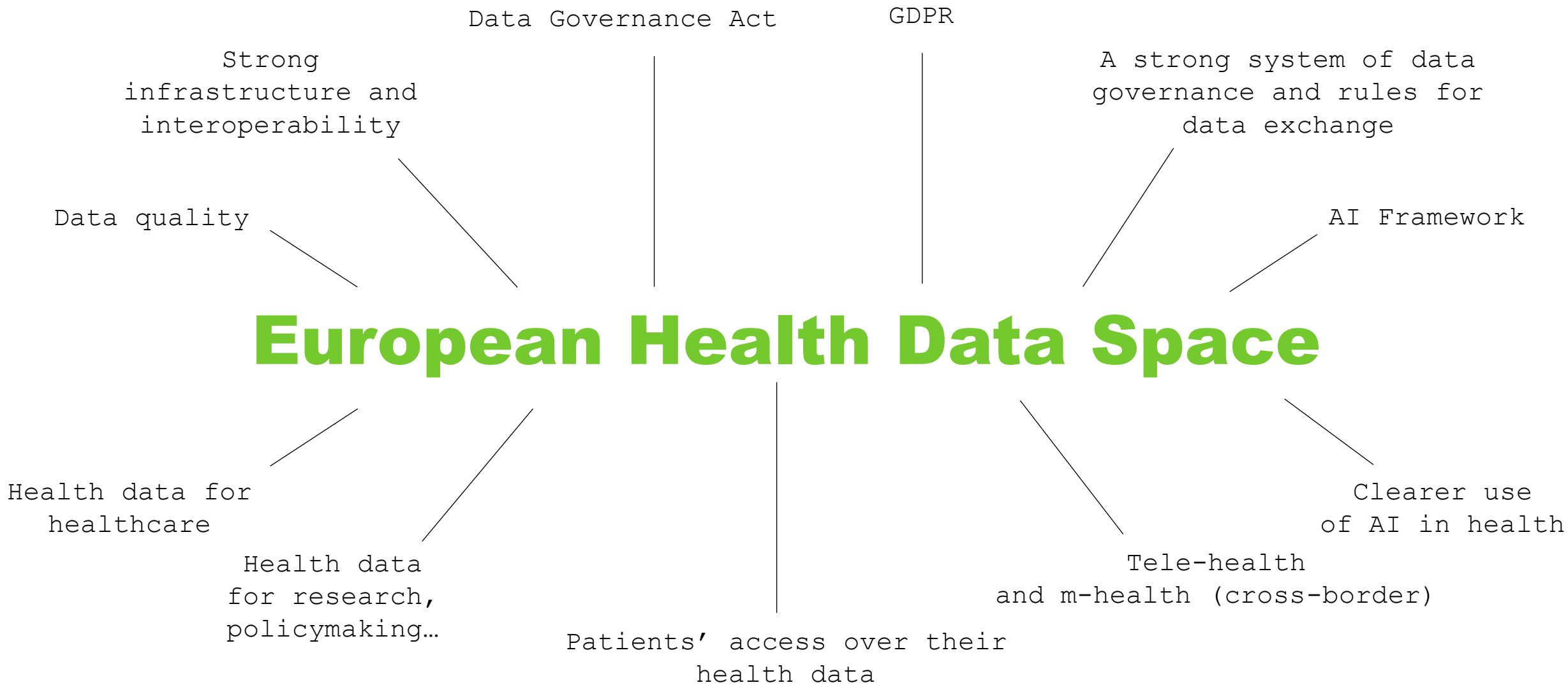
Citizen forum in collaboration with King Baudouin Foundation



The Belgian DNA Debate: An Online Deliberative Platform on the Ethical, Legal, and Social Issues of Genomics

Chloé Mayeur Marlies Saelaert Wannes Van Hoof

Cancer Centre, Sciensano, Brussels, Belgium



TEHDAS mission

The joint action helps the Member States and the Commission in developing and promoting concepts for sharing of data in **secondary use*** for purposes for citizens' health, public health, as well as health research and innovation in Europe.

*Secondary use of health data = uses beyond individual care, through research and planning for example

TEHDAS vision

In the future Europe, citizens, communities and companies benefit from protected and secure access to seamless health data regardless where it is stored.



Co-funded by
The Health Programme
of the European Union

SITRA

WP8 iCitizen

**FEB 2021
NOV 2021**

T8.1 preliminary Work

A literature review

Interviews with 60 stakeholders from the health data ecosystem

**NOV 2021
JUN 2022**

T8.2 e-consultation

An e-consultation dedicated to **citizens** to better understand their perceptions, preferences and expectations

**JUN 2022
JAN 2023**

T8.3 Preparing Recommendations

workshops with national and EU stakeholders

FINAL DELIVERABLE

Recommendations on citizens **sensitisation to and engagement with health data** in the future EHDS

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FOR TEACHERS





Healthy Data

Your views on the reuse of your health data

Have your say!

What can health data be used for?



How should health data be kept safe?



How could citizens be involved?





The e-consultation Healthy Data

Learn

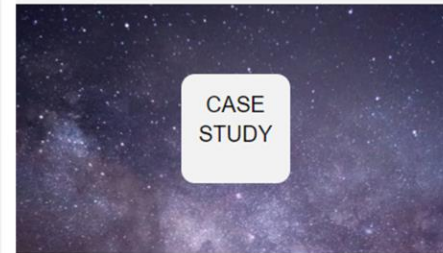
What can we expect from the reuse and sharing of health data?



Reusing health data has a huge potential to make better use of information to implement the right changes and improve public health and healthcare:

- From the patients' perspective, they would not have to undergo similar procedures or repeat their health histories since their healthcare provider would directly access their health information.
- For researchers, reusing health data could also be time-saving and avoid duplicating efforts. Rather than collecting data from research participants, scientists could directly access data already available.
- Policy-makers can also implement more-informed and real-time policy, when it is needed (such as during the COVID-19 pandemic).

News



Using techniques from astronomy to diagnose dementia

08-11-2021 The Astrodem study uses techniques developed for studying galaxies to analyse GP data, looking for the early warning signs of dementia. It is hoped... [Read more](#)



Understanding the needs of children with vision impairment or blindness

08-11-2021 Around 2 in every 1,000 children in the UK have severe vision impairment in both eyes. Studies on national data showed for the first time that risk... [Read more](#)



Targeting back pain treatment to those most in need

08-11-2021 The STarT Back screening tool uses patient data to help doctors work out the chances of someone with back pain going on to develop a long term disa... [Read more](#)



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The e-consultation Healthy Data

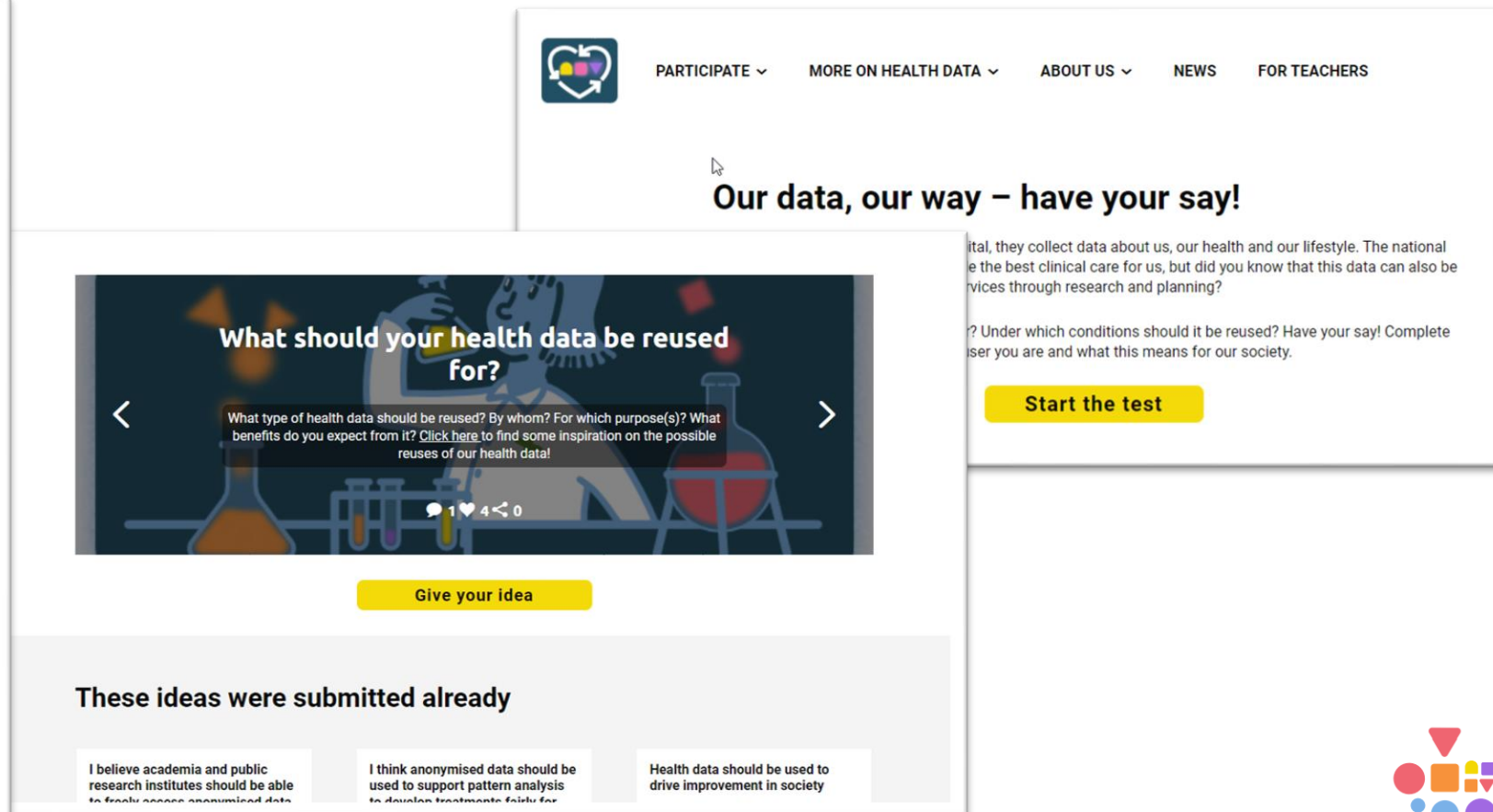
Participate

What can Robert's data be used for?

The data that was accumulated during Robert's diagnosis and treatment can be useful for other purposes.



Scientific research proved that the treatment Robert received is effective, so the **healthcare system** reimburses it. Researchers keep monitoring the treatment's effectiveness by assessing it in other recent cases.



The screenshot shows the website's navigation bar with the logo and links: PARTICIPATE, MORE ON HEALTH DATA, ABOUT US, NEWS, and FOR TEACHERS. The main heading is "Our data, our way – have your say!". Below it, a banner asks "What should your health data be reused for?" with a subtext: "What type of health data should be reused? By whom? For which purpose(s)? What benefits do you expect from it? [Click here](#) to find some inspiration on the possible reuses of our health data!". A yellow button labeled "Give your idea" is visible. To the right, a sidebar contains the text: "In a hospital, they collect data about us, our health and our lifestyle. The national healthcare system provides the best clinical care for us, but did you know that this data can also be reused for other purposes through research and planning?" and "Under which conditions should it be reused? Have your say! Complete the survey, share your opinion and what this means for our society." with a yellow button labeled "Start the test". At the bottom, a section titled "These ideas were submitted already" lists three ideas: "I believe academia and public research institutes should be able to freely access anonymised data", "I think anonymised data should be used to support pattern analysis to develop treatments fairly for", and "Health data should be used to drive improvement in society".



Communication strategy

Dissemination by the Health Data team	Dissemination by involved organizations	Dissemination by external stakeholders	Dissemination through social media optimization
Newsletters Regular feed of the platform with new content	Publications on social media channels Publications on their respective websites Publication on their own newsletter Contacting and supporting external partners in disseminating the platform	More than 1100 organizations/actors contacted to disseminate the platform through their social media channels, websites, newsletters Development of strategies: • Toolkit of language elements • Creation of specific content adapted to their audience • Email template to disseminate directly to their audience	Recruitment of a provider to disseminate sponsored content about the consultation Audience: three participating countries Facebook and Twitter

Specific initiatives

France video, infographic, inclusion of questions in external survey, webinar, citizen engagement, involvement of pharmacy students

Belgium inclusion of questions in external survey, debates in high schools, live discussion with citizens

UK targeted workshops, media coverage, presentation in universities

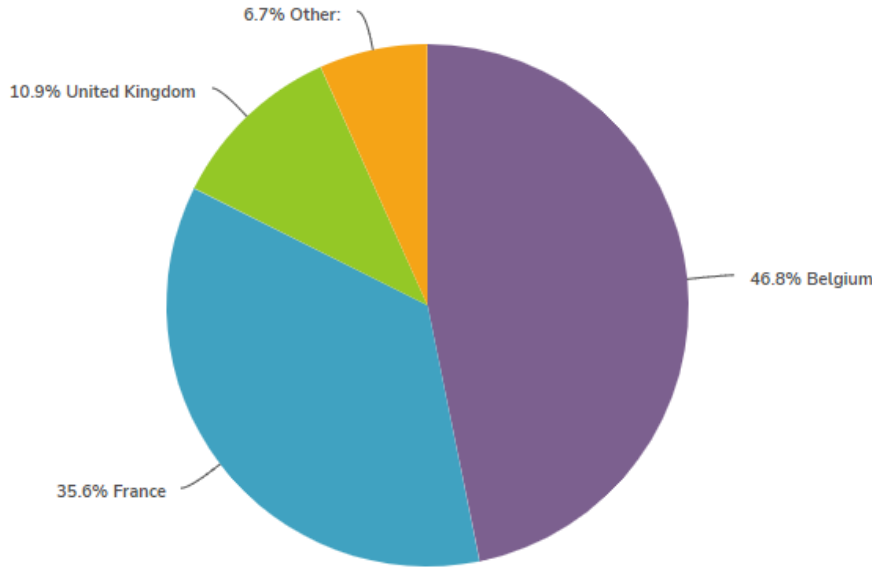
TEHDAS publication in several bulletins, on the TEHDAS website (news item and pop-up), support in identifying and reaching potential dissemination partners



Healthy data platform

Health Data Newsletter	Number of subscribers	893
External partners	Number of organisations and individuals contacted	1,066
Social media optimization	Impressions/ clicks (phase 1)	1,923,836
	Impressions/ clicks (phase 2)	11,622
Results on the Healthy Data website	Number of contributions received	5,932
	Number of contributions retained	5,722
	Number of visitors (date: 09.02.2023)	39,067*

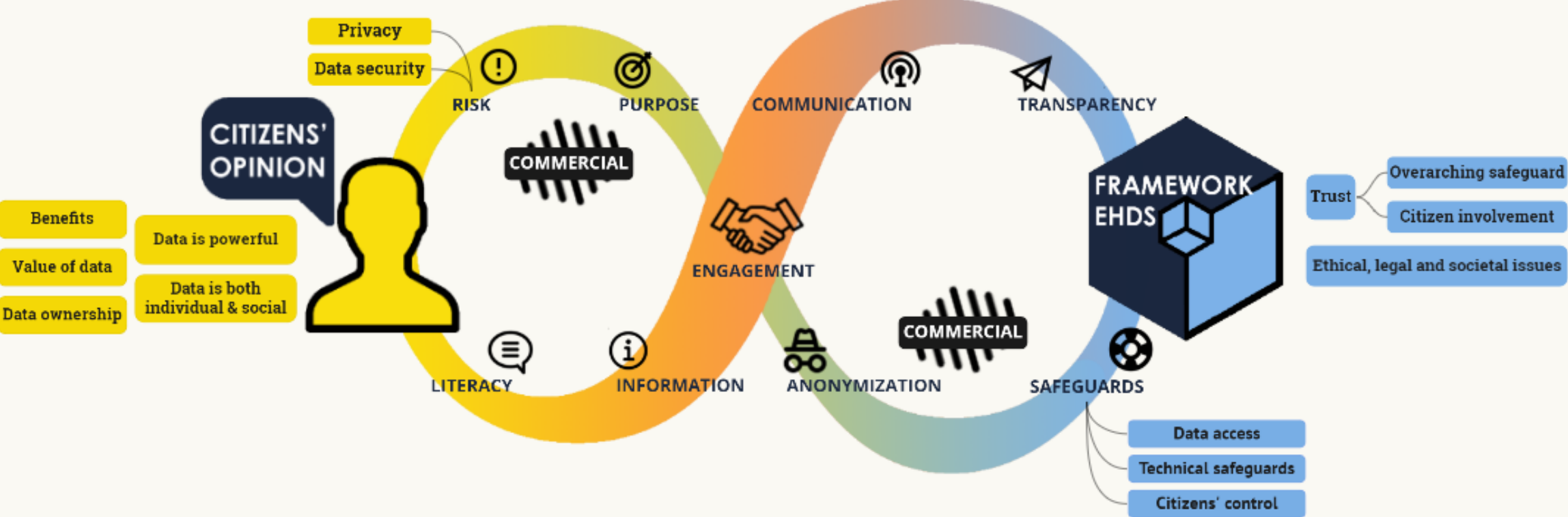
Country of location from interactive quiz:



Other: Albania, Argentina, Australia, Bulgaria, Canada, Croatia, Denmark, Finland, Germany, Greece, Italy, Ireland, Japan, Latvia, Luxemburg, Malta, Mexico, Netherlands, Norway, Poland, Portugal; Romania, Slovakia, Slovenia, Spain, Sweden, Switzerland, Syria

Citizens' voices

How to build the European Health Data Space

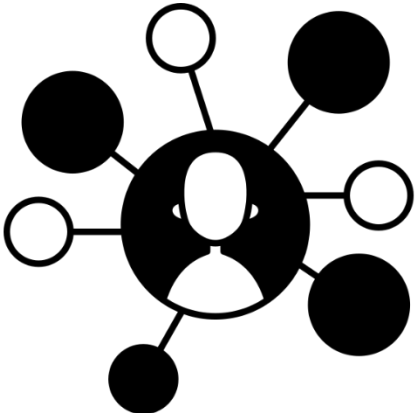
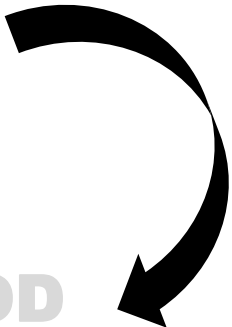
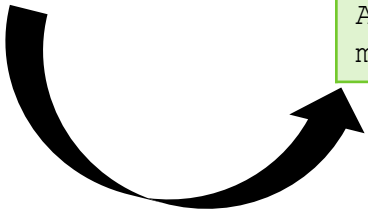


Conceptualization

One concept = different stakeholders= different meanings

DATA OWNERSHIP

Citizen	GDPR	Researcher	Company
Belongs to me	Processor/ Controller	Responsibility	Economic value
A part of me	Consent	Right to use	Transaction



Public interest
PRIVACY COMMON GOOD
 REUSE **TRANSPARENCY** RISK
DATA OWNERSHIP INFORMATION
COMMERCIAL PURPOSE BENEFIT
 CONSENT

Conceptualization

How do citizens talk about health data reuse?

DATA AS POWER

Striking a balance between **risks** and **benefits**

INDIVIDUAL LEVEL

- Control
- Privacy
- Anonymization (risks, usefulness etc.)

SOCIETAL LEVEL

- Health data reuse 'system', institutions
- Commercialization, economy, data market
- Common good

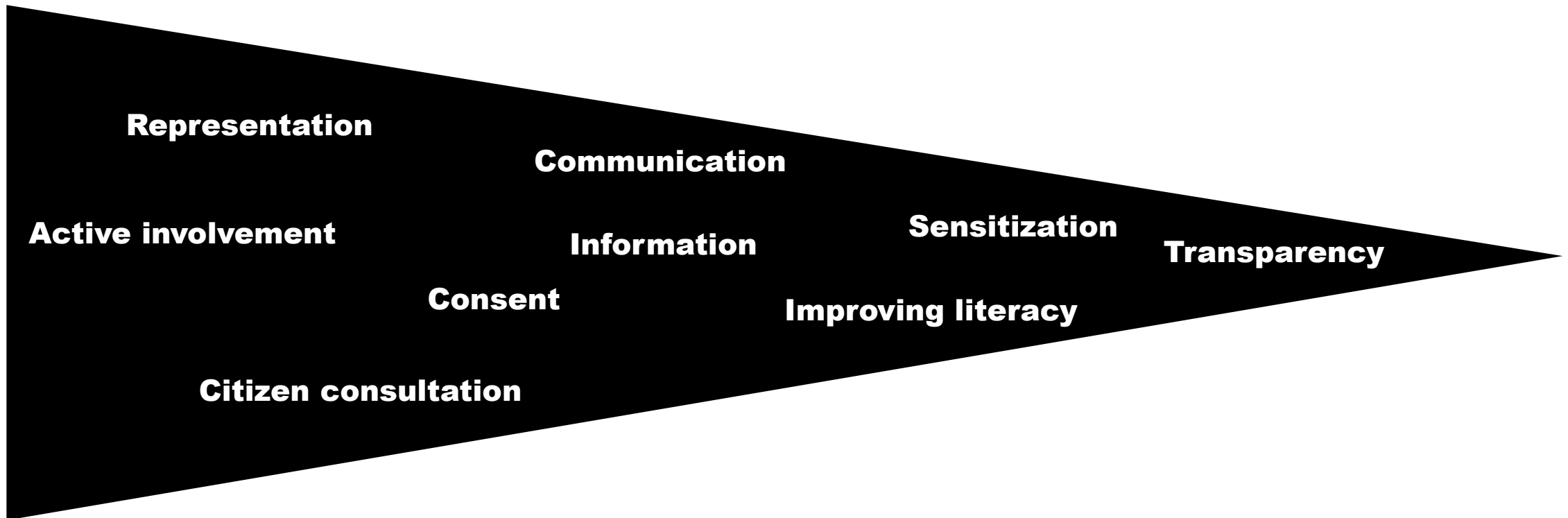


“Behold! I bring you the one true meaning of the term Big Data”

Engagement

How do citizens want to be **informed** and **engaged** regarding health data reuse?

➤ How do these ways of engagement **involve** citizens **as partners**?



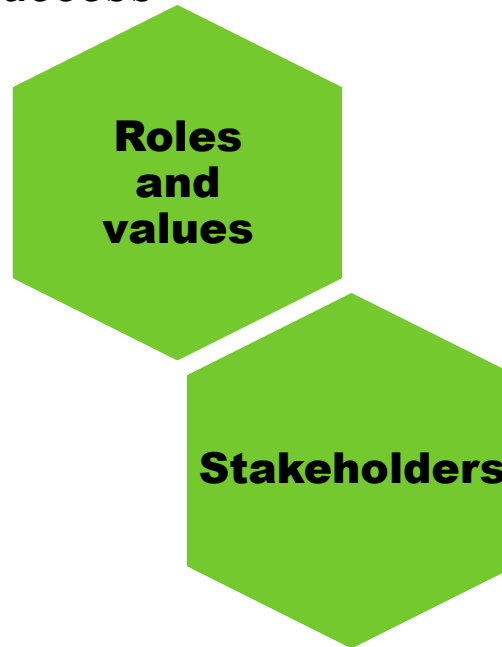
Engagement

Which roles do citizens attribute to **other important stakeholders** in health data reuse?

➤ How should all stakeholders **relate and collaborate**?

Example

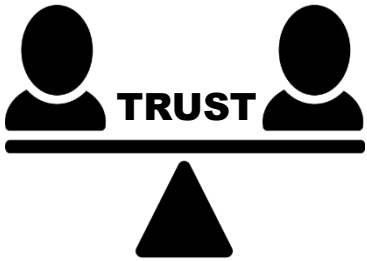
- Data collection and providing access
- Follow-up on reuse
- Data protection
- Accountability
- Building frameworks
- Information and education
- ...



Example

- Citizens
- Government
- Health care providers
- Researchers
- Experts
- Specialized authorities (HDA?)
- Schools
- Media
- ...

Trust



Trust is 'assumed'
described as an 'aim'

vs

What defines trust?
How is it earned?

Trusting something

vs

Trusting someone
When is someone trustworthy?

CONDITIONAL BENEFICENCE

Which conditions need to be fulfilled to foster trust and
incite beneficence towards health data reuse?

Trust

Benefits

- Purpose
- Individual and societal benefits, common good



Risks

- Individual and societal risks (privacy; abusive use, discrimination, health inequalities)
- Cyber risks

LEGAL FRAMEWORK

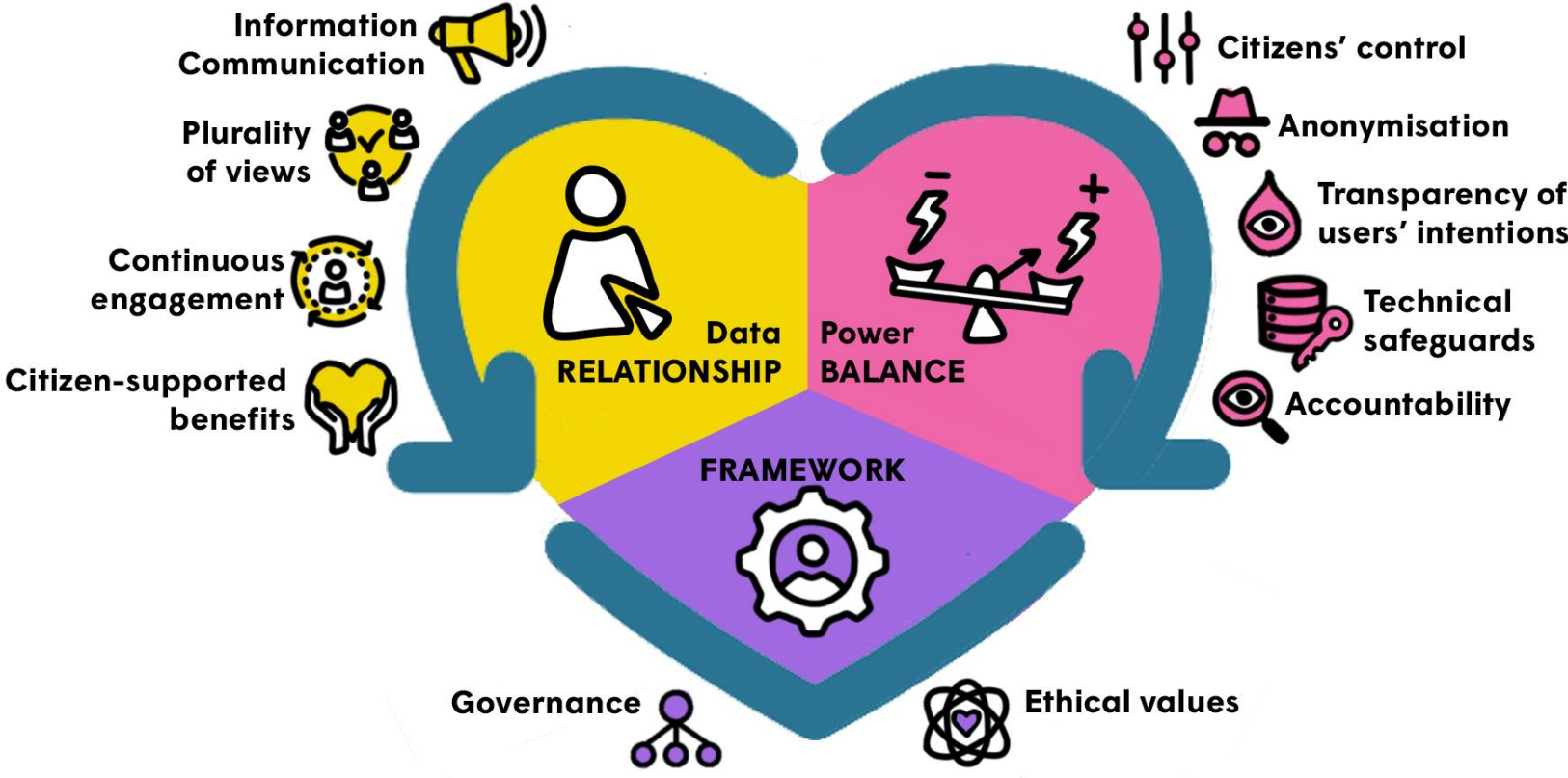
ETHICAL DIMENSION

SANCTIONS FOLLOW
CONTROL ACCESS UP DEFINE THE
INFORMATION PURPOSE
DIFFERENT ACTORS= DIFFERENT
FRAMEWORKS ANONYMISATION
CONSENT FINANCIAL CONDITIONS
CITIZEN INVOLVEMENT ...

SOCIETAL DIMENSION

RECOMMENDATIONS

FOR A CITIZEN-POWERED FRAMEWORK FOR THE EUROPEAN HEALTH DATA SPACE



Implications for genomics and ELSI EHDS

- Purpose inspires trust
 - Define benefit (individual or societal)
 - Proportionality and balance
 - Consent is not necessary for a trustworthy ELSI framework for secondary use of health data
 - Information, education and appropriate involvement remain key factors for trust
 - Need to define the role of commercial actors
-
- Should genomic data be considered as a special type of health data?
 - Is there a difference between clinical data and research data?

Contact

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