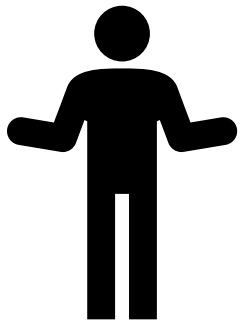


LEVERAGING THE EHDS

Advancing public health and citizen impact

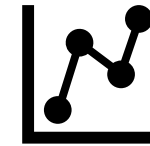
Daily life in a public health institute



Research question
Parliamentary question
Official statistics



Data mobilisation
Data collection



Data analysis



Coffee



Reporting



Knowledge translation
Outreach

Data mobilisation

- The precondition for effective surveillance mechanisms is the ability to collect timely, complete, regular and good-quality information on a broad range of indicators¹
- To create value for society as a whole [...] ensuring the high-quality of data and smooth access to it is crucial²
- Even if data are accurate, they cannot be said to be of good quality if they are produced too late to be useful, or cannot be easily accessed, or appear to conflict with other data³



Data mobilisation

¹Strengthening health systems resilience: key concepts and strategies (Policy brief 36), European Observatory on Health Systems and Policies. 2020

²Advancing data sharing to improve health for all in Europe: Markus Kalliola, Elina Drakvik and Maria Nurmi (Eds.) 2023

³*Data quality*, in OECD Handbook for Internationally Comparative Education Statistics 2018: Concepts, Standards, Definitions and Classifications, OECD 2018

Data mobilisation: quality is key

- The precondition for effective surveillance mechanisms is the ability to collect timely, complete, regular and **good-quality information** on a broad range of indicators¹
- To create value for society as a whole [...] ensuring the **high-quality of data** and smooth access to it is crucial²
- Even if data are accurate, they cannot be said to be of **good quality** if they are produced too late to be useful, or cannot be easily accessed, or appear to conflict with other data³
- « **Garbage in, garbage out** »



Data mobilisation

¹Strengthening health systems resilience: key concepts and strategies (Policy brief 36); European Observatory on Health Systems and Policies. 2020

²Advancing data sharing to improve health for all in Europe; Markus Kalliola, Elina Drakvik and Maria Nurmi (Eds.) 2023

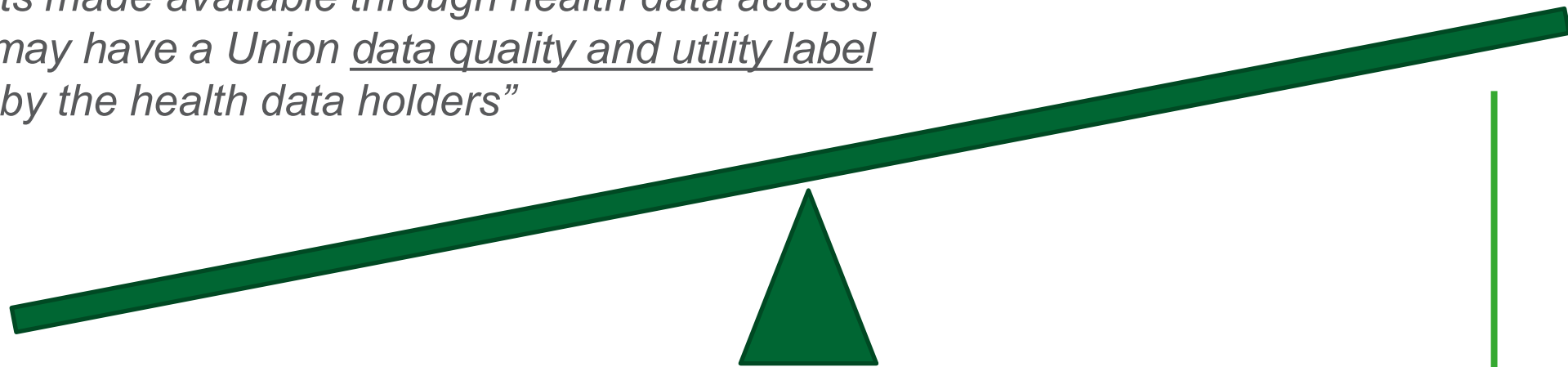
³*Data quality*, in OECD Handbook for Internationally Comparative Education Statistics 2018: Concepts, Standards, Definitions and Classifications; OECD 2018

Leveraging the EHDS

EHDS Article 78

“Datasets made available through health data access bodies may have a Union data quality and utility label applied by the health data holders”

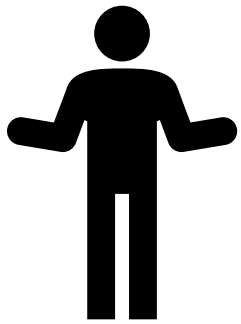
Health data quality



- Better assessment reliability and suitability
- Increase data quality (incentive)
- Increase data valorisation
- Better training AI algorithms
- Better research outcomes

QUANTUM project

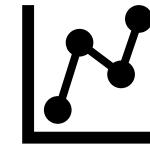
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Knowledge translation
Outreach

Knowledge translation & outreach

Who?

- Policymakers/regulators
 - Regional level, national level, European level
- Research (networks) & academic communities
 - Colleagues, universities, research institutes, project collaborators
- European/international organisations & agencies
 - WHO, IANPHI, Observatory on Health Systems and Policies, OECD, Eurostat, EMA, ECDC, ..
- Health(care) professionals & institutions
- **General public (citizens) & patients**



Knowledge translation
Outreach

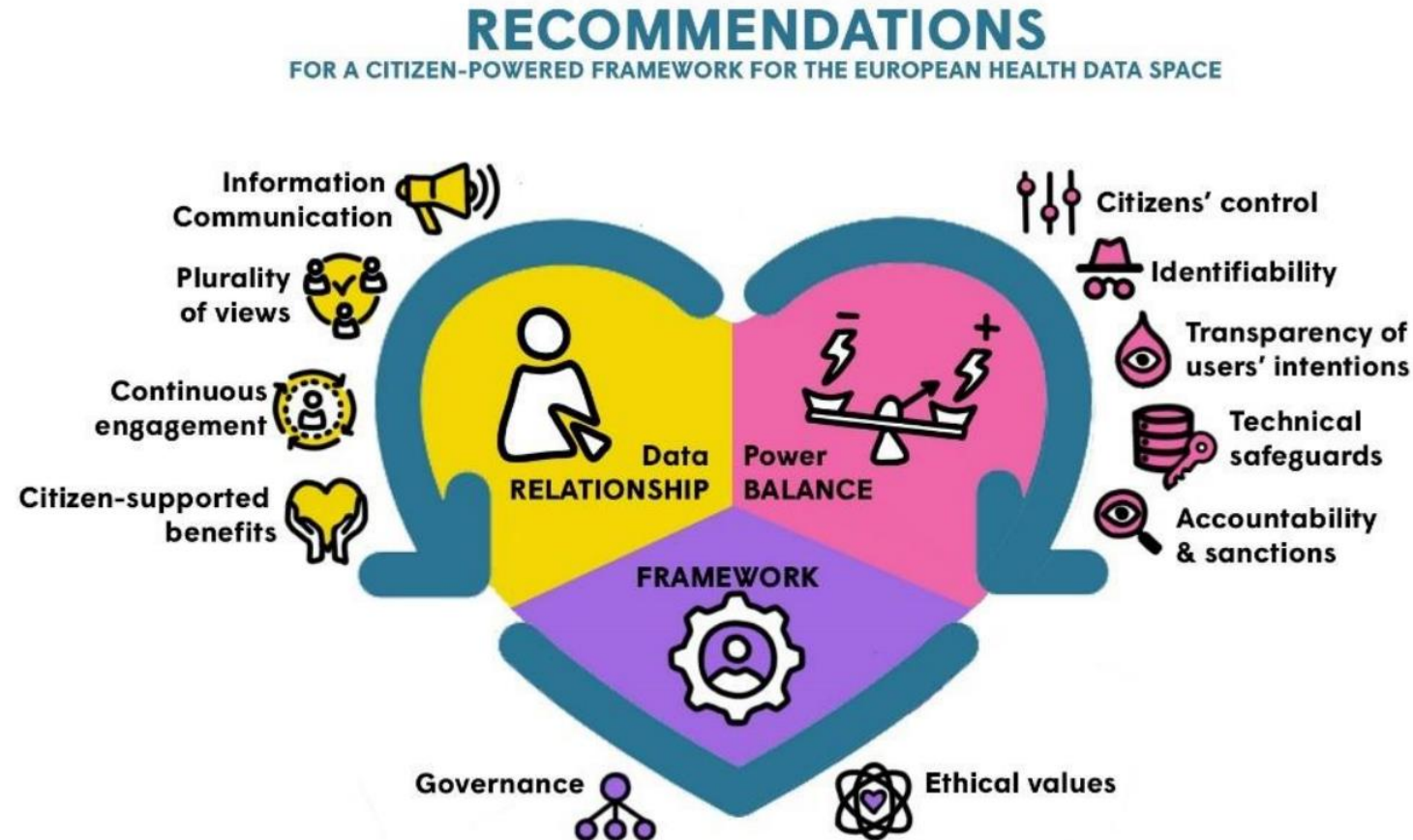
Citizens' perception on sharing health data

2021-2022 Citizen consultation on secondary use of health data

- Online EU-wide consultation
- Close to 6000 suggestions concerning the use of health data



Knowledge translation
Outreach

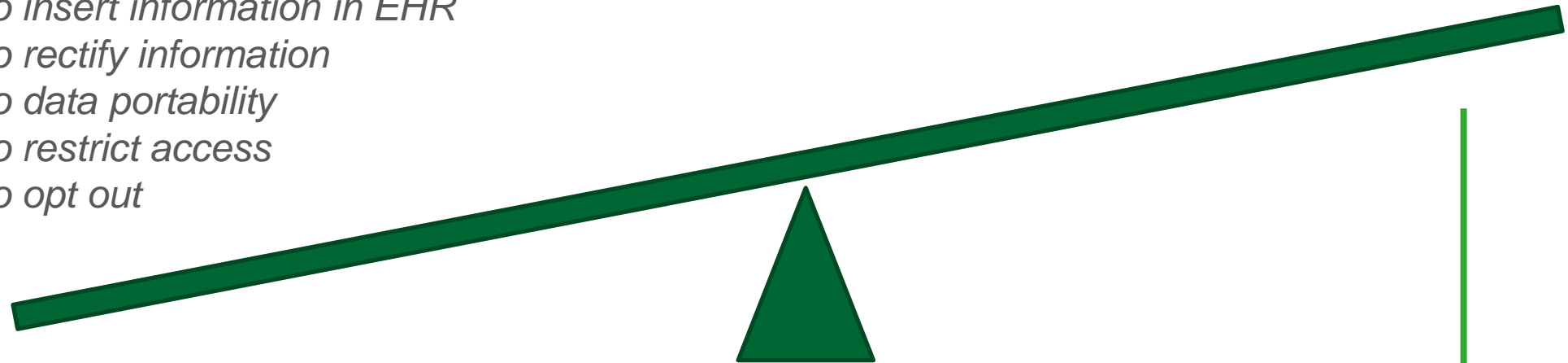


Leveraging the EHDS

EHDS Articles 3-10

- *Right to access/know who accessed personal data*
- *Right to authorise others*
- *Right to insert information in EHR*
- *Right to rectify information*
- *Right to data portability*
- *Right to restrict access*
- *Right to opt out*

Citizens at the centre of their healthcare



xSHARE project

The xShare Yellow Button to be featured across health portals and patient apps and allow people to exercise their data portability rights under GDPR.

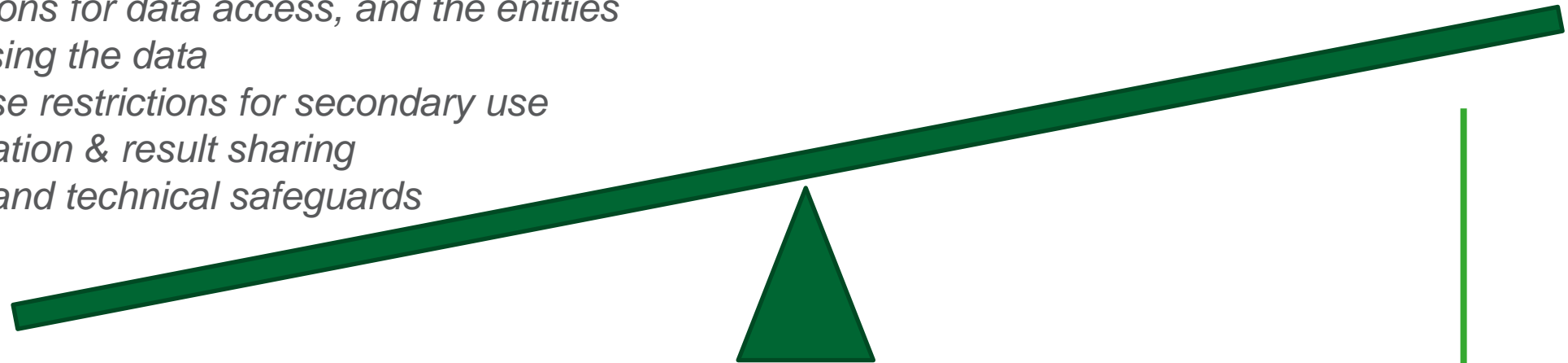


Leveraging the EHDS

EHDS Articles 44, 45, 46, 47, 50

- *Right to opt out*
- *Clear information about secondary use rights, conditions for data access, and the entities accessing the data*
- *Purpose restrictions for secondary use*
- *Publication & result sharing*
- *Legal and technical safeguards*

Citizens' right pertaining to secondary use



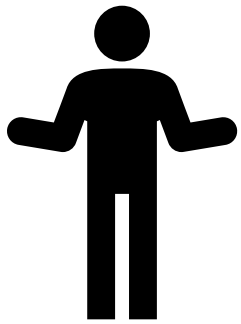
Joint Action TEHDAS2

Strengthen engagement of citizens towards the EHDS:

- Implementing opt-out
- Citizen information point
- Data users' studies regarding research outcomes



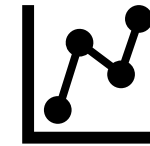
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Data mobilisation
Data collection



Data analysis



Coffee



Reporting



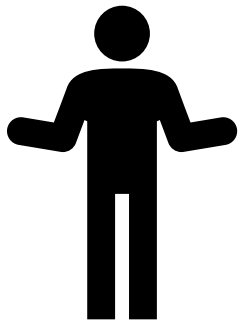
Knowledge translation
Outreach

Right to good coffee



Coffee

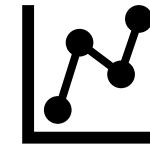
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Data analysis



Coffee

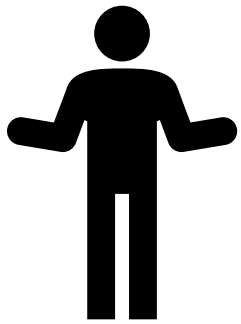


Reporting



Knowledge translation
Outreach

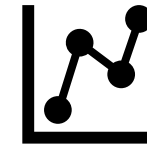
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Knowledge translation
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Affected by
EHDS Regulation

EHDS: are we ready?

Health data management: Data management varies; most countries have fragmented systems and lack full digitalization or unique personal identifiers.

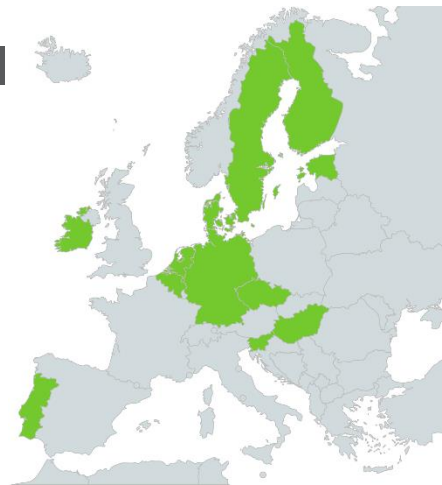
Data quality and interoperability: International standards like HL7 FHIR and ICD-10 are used, but national standards sometimes hinder cross-border interoperability.

Access challenges: Data is stored across multiple organizations with inconsistent access procedures, fees, and delays. Few countries have common metadata catalogues.

Legal and governance issues: GDPR interpretations and absent national laws for secondary use create barriers. Ethical approval processes are complex and vary widely.

Resources and preparedness: Countries need more technical, legal, and financial resources. Preparedness for EHDS implementation varies.

Stakeholder views on EHDS: EHDS is seen as beneficial for data sharing and research but needs harmonized standards, privacy guarantees, and equitable benefits.



Advancing public health and citizen impact

- EHDS is a turning point for the health information landscape in Europe
- EHDS streamlines the use of data for specific purposes within the health system
- EHDS can improve overall data quality
- EHDS provides the citizens with control over their health data
- EHDS has the potential to provide transparency, accessibility, inclusive decision-making, and risk mitigation for trust and responsible data governance

Contact

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