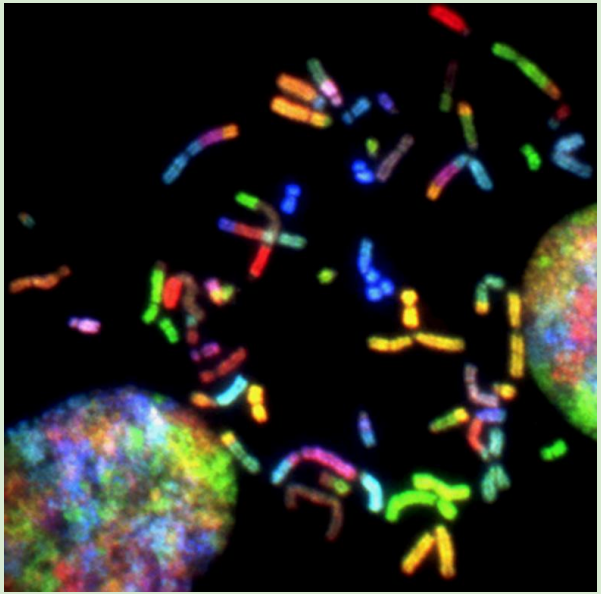
Data solidarity:
Why do we need it, and how can it inform the governance of health data?

Barbara Prainsack

Professor, Department of Political Science, and Research Plattform *Governance of Digital Practices*, University of Vienna

Honorary Professor, Sydney Center for Healthy Societies, University of Sydney

Chair, European Group on Ethics in Science and New Technologies (EGE)



[image: NCI @unsplash]

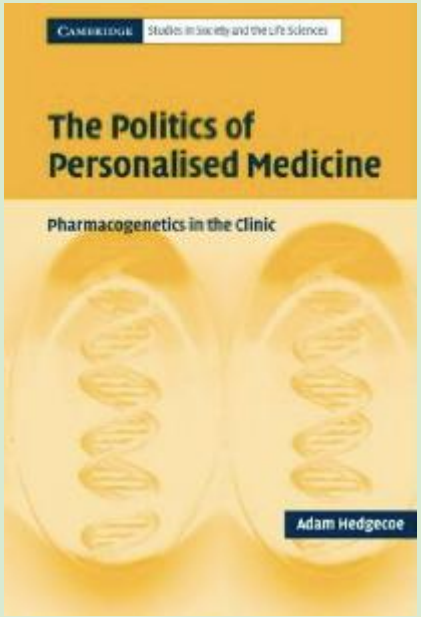
universität wien

CeSCoS
Centre for the Study of Contemporary Solidarity

From Personalised to ’Precision’ Medicine

1967

[Berger J, Mohr J (1967). *A fortunate man. The story of a country doctor*]

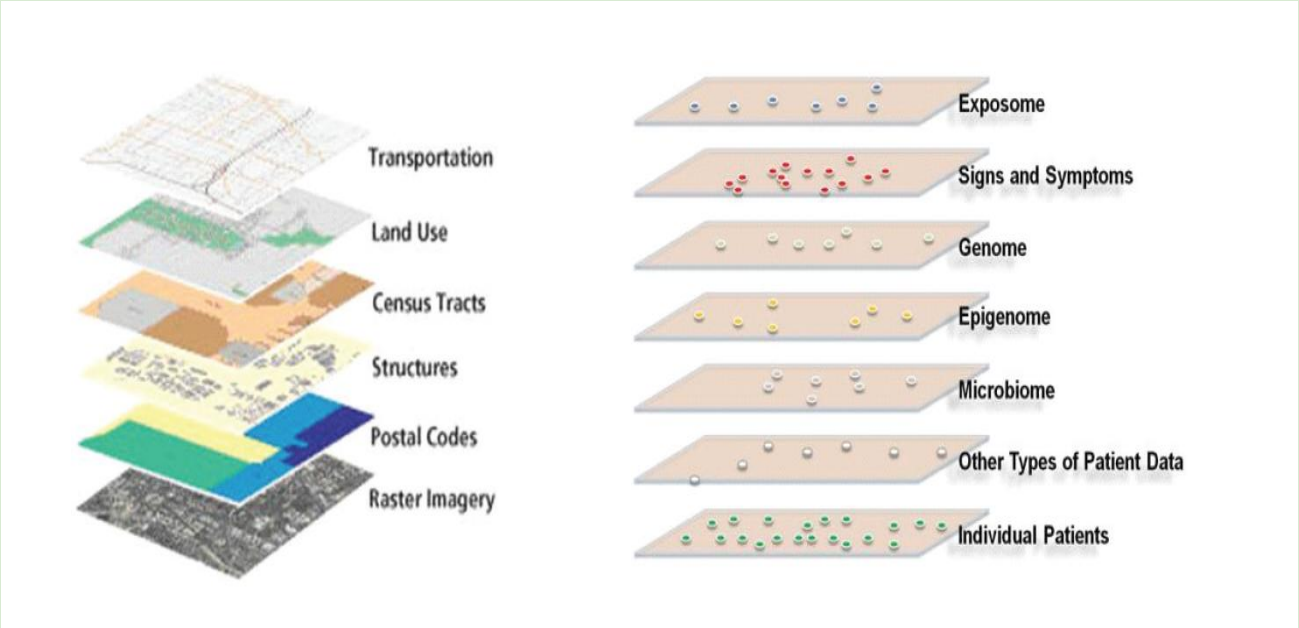


2004

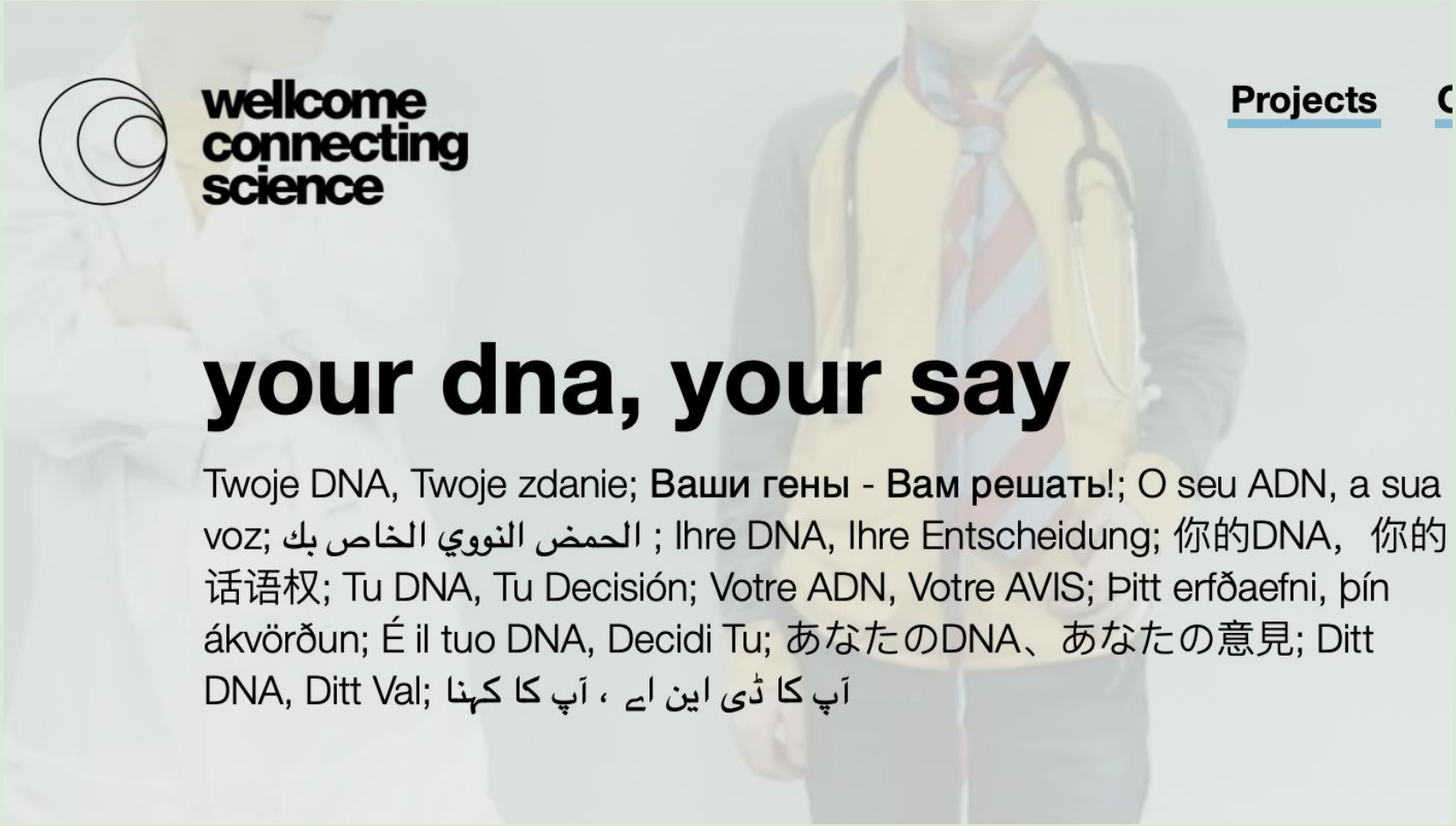
2016

[https://obamawhitehouse.archives.gov/]

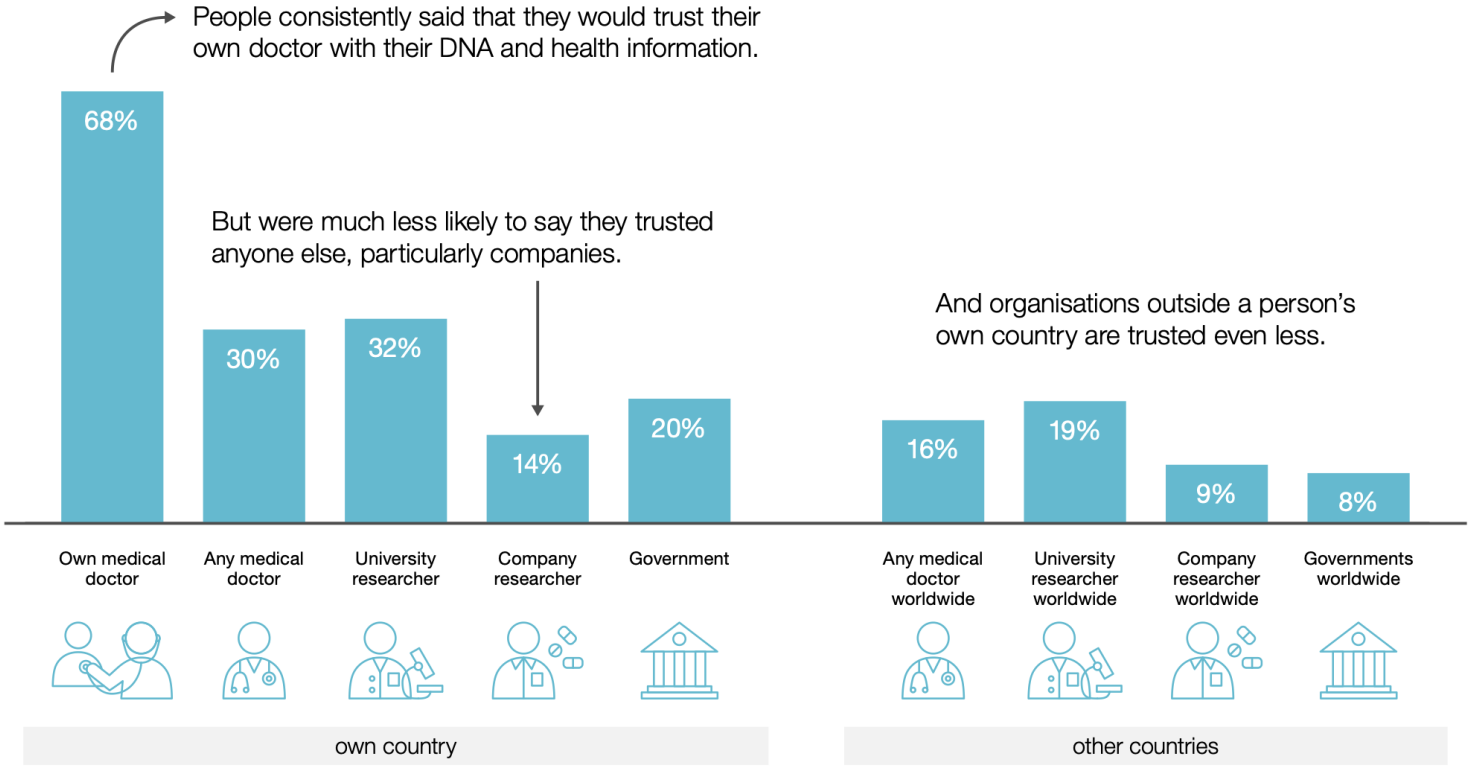
US: Precision Medicine programme 2011



US National Academy of Sciences (NAS) (2011) *Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease*. Washington, DC: NAS.]

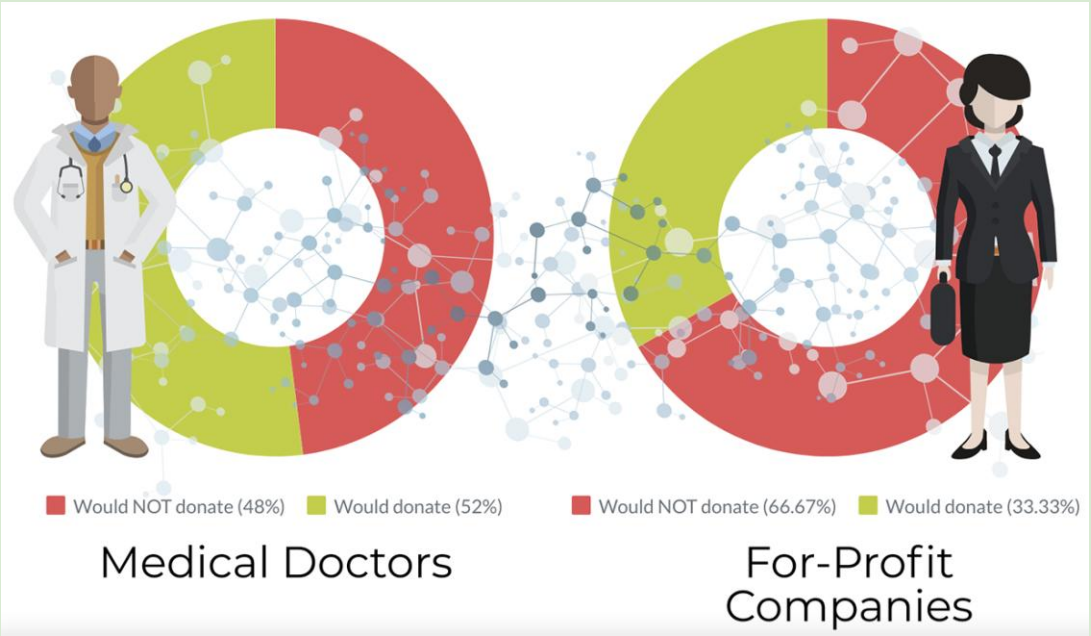

wellcome
connecting
science
Projects
your dna, your say
Twoje DNA, Twoje zdanie; Ваши гены - Вам решать!; O seu ADN, a sua voz; الحمض النووي الخاص بك ; Ihre DNA, Ihre Entscheidung; 你的DNA，你的话语权; Tu DNA, Tu Decisión; Votre ADN, Votre AVIS; Þitt erfðaefni, þín ákvörðun; É il tuo DNA, Decidi Tu; あなたのDNA、あなたの意見; Ditt DNA, Ditt Val; آپ کا ڈی این اے ، آپ کا کہنا

People trust different organisations differently with data



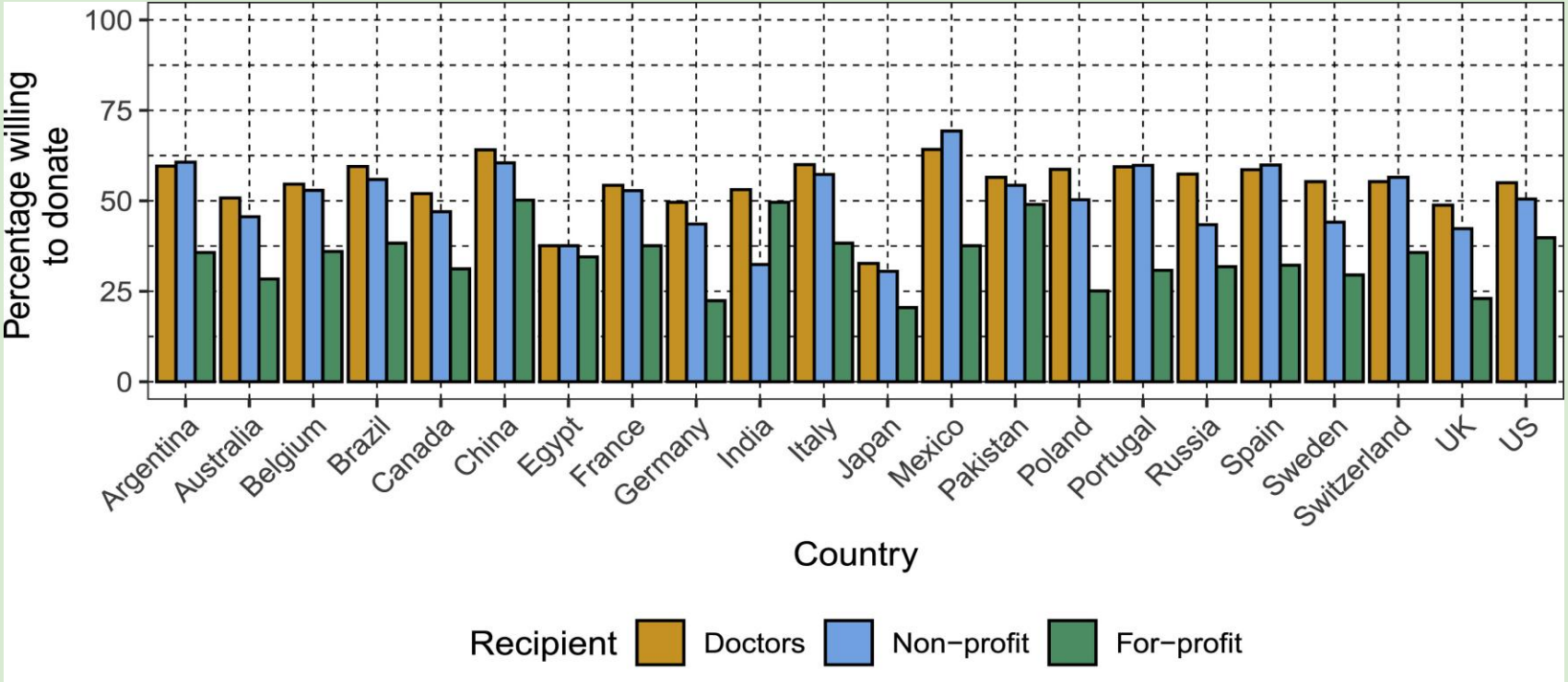
[https://societyandethicsresearch.wellcomeconnectingscience.org/wp-content/uploads/2021/11/Your-DNA-Your-Say-infographics_Nov2023.pdf]

Global results



[Middleton, A., Milne, R., Almarri, M.A., Anwer, S., Atutornu, J., Baranova, E.E., Bevan, P., Cerezo, M., Cong, Y., Critchley, C. and Fernow, J., 2020. Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data?. *The American Journal of Human Genetics*, *107*(4), pp.743-752.]

Figure 1



The American Journal of Human Genetics 2020 107743-752DOI: (10.1016/j.ajhg.2020.08.023)

[Middleton, A., et al., 2020. Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data?. *The American Journal of Human Genetics*, *107*(4), pp.743-752.

Ranking of what might help people trust

1. Information about **<u>who</u> will benefit** from the data access

2. The **option to withdraw** your data

3. Knowing **who is using your data and for what purpose**

4. Information about **<u>how</u> others will benefit** from the data access

5. The **option to opt out** of having your data accessed by other researchers

6. **Details about sanctions** if your data is misused

7. The **ability to access your own data**

8. A **website** that explains the pros and cons of data access

9. Being able to **communicate directly with gatekeepers** of your data

10. **Biographies and photos** of researchers who would access the data

[https://societyandethicsresearch.wellcomeconnectingscience.org/wp-content/uploads/2021/11/Your-DNA-Your-Say-infographics_Nov2023.pdf]

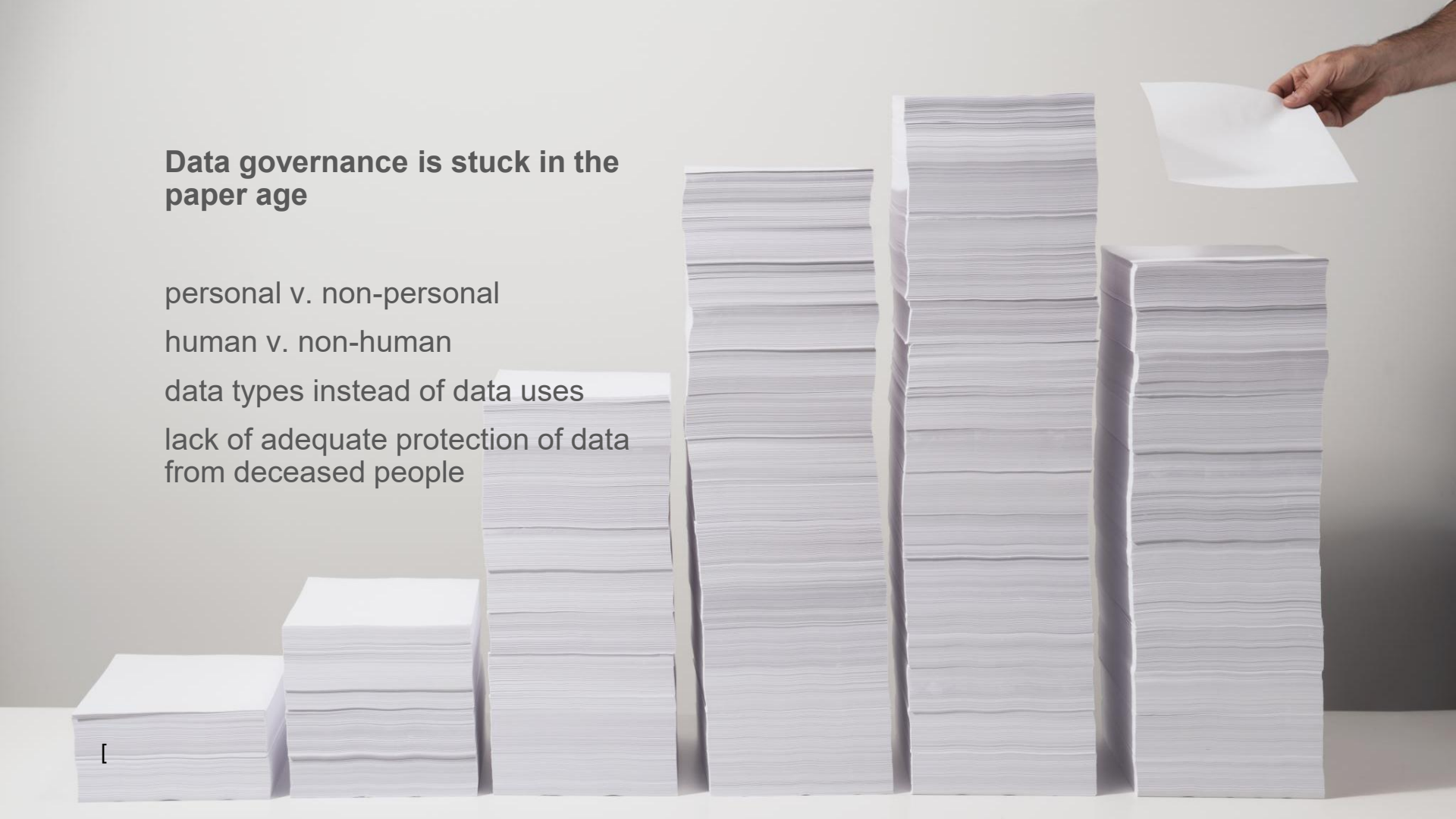
Data governance is stuck in the paper age

personal v. non-personal

human v. non-human

data types instead of data uses

lack of adequate protection of data from deceased people

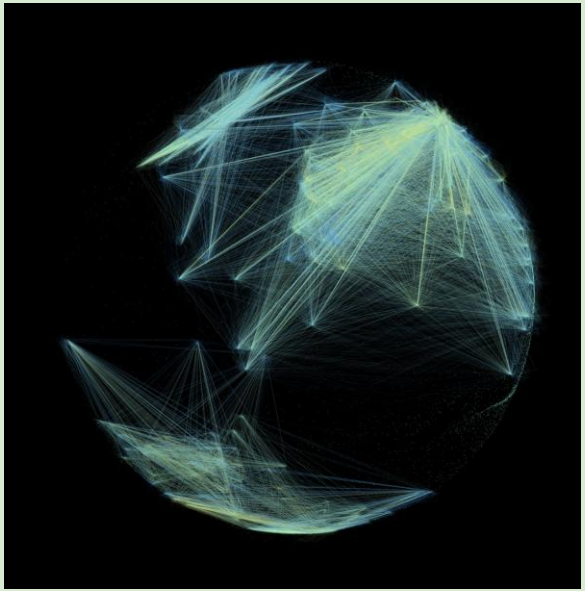


[

The Relational Nature of Data

Data ≠ Isolated Facts

- Data emerge from relationships (e.g., patient-doctor, user-platform)
- Data cleaning removes context



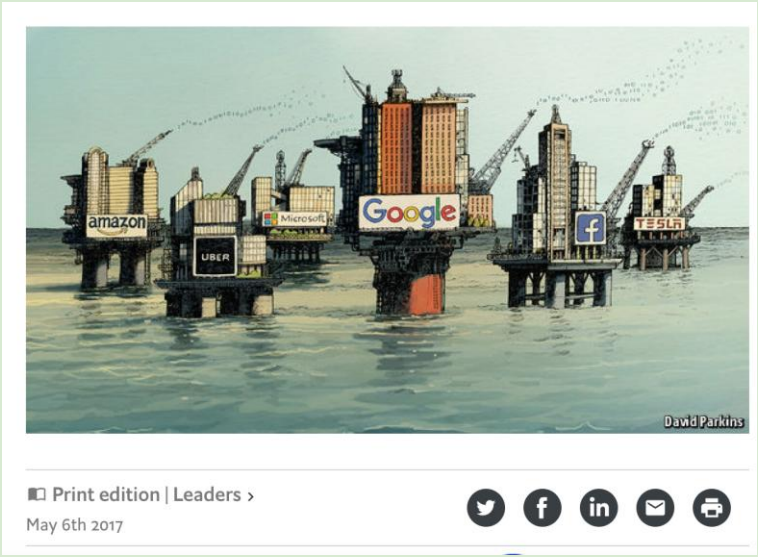
[Prainsack B (2025). “Our Stakes in Data: How Do We (Re)Gain Democratic Control Over Digital Practices? In: Jurgen Goossens, Esther Keymolen, and Antonia Stanojević (eds). *Public Governance and Emerging Technologies: Values, Trust, and Regulatory Compliance*. Cham, Switzerland: Springer. 131-147.]

[image: Mario Verduzco @unsplash]

Relational Data, Real Consequences

Invisible Labour, Invisible Contributions

- Data comes from social infrastructures: education, public health, broadband
- “Data as oil” is a misleading metaphor



[image: The Economist]

[Kitchin, R., Davret, J., Kayanan, C.M. and Mutter, S., 2025. Data mobilities: Rethinking the movement and circulation of digital data. *Mobilities*, pp.1-19.]

[Birch, K., 2023. Data enclaves. In *Data Enclaves* (pp. 83-105). Cham: Springer Nature Switzerland.]

[Prainsack, B., 2020. Oil crisis: the political economy of digital data. *Policy Studies*, *41*(5), pp.563-566.]

Data Solidarity

New Questions Emerge:

- Who contributes to data production?
- Who benefits from it?
- How can we share responsibility and value more fairly?

[Prainsack, B. and El-Sayed, S., 2023. Beyond individual rights: How data solidarity gives people meaningful control over data. *The American Journal of Bioethics*, *23*(11), pp.36-39.]

[Eitenberger, M., Prainsack, B. and Sabatello, M., 2025. Consent at the Ease of a Click? Technosolutionist Fixes Cannot Replace Human Relations and Solidarity. *The American Journal of Bioethics*, *25*(4), pp.121-123.]

[image: Toa Heftiba @unsplash]

Data Solidarity

Data solidarity: a blueprint for governing health futures

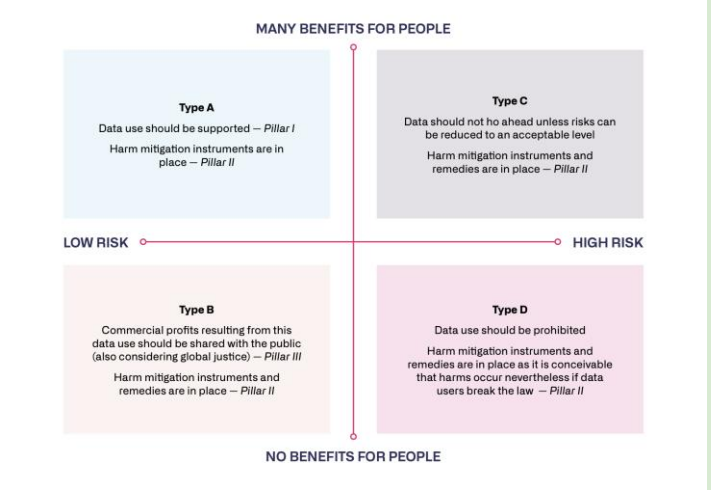
Barbara Prainsack [a] ✉ · Seliem El-Sayed [b] · Nikolaus Forgó [c] · Łukasz Szoszkiewicz [d] · Philipp Baumer [b]

Affiliations & Notes ⌄ Article Info ⌄

THE LANCET
Digital Health

A New Approach to Ethical Data Governance

- Fairness, reciprocity, and shared benefits
- Responds to both risk and value distribution



The 3 Pillars of Data Solidarity

01

Support high-public-value uses (e.g. climate, health, education)

02

Prevent and mitigate harm (bias, opacity, unfair profiling)

03

Ensure fair returns (taxation, benefit-sharing, community return)

Big Data Governance Needs More Collective Responsibility: The Role of Harm Mitigation in the Governance of Data Use in Medicine and Beyond

Aisling McMahon ✉, Alena Buyx, Barbara Prainsack

Medical Law Review, fwz016, https://doi.org/10.1093/medlaw/fwz016
Published: 04 August 2019

Abstract

Harms arising from digital data use in the big data context are often systemic and cannot always be captured by linear cause and effect. Individual data subjects and third parties can bear the main downstream costs arising from increasingly complex forms of data uses—without being able to trace the exact data flows. Because current regulatory frameworks do not adequately address this situation, we propose a move towards harm mitigation tools to complement existing legal remedies. In this article, we make a normative and practical case for why individuals should be offered support in such contexts and how harm mitigation tools can achieve this. We put forward the idea of 'Harm Mitigation Bodies' (HMBs), which people could turn to when they feel they were harmed by data use but do not qualify for legal remedies, or where existing legal remedies do not address their specific circumstances. HMBs would help to obtain a better understanding of the nature, severity, and frequency of harms occurring from both lawful and unlawful data use, and they could also provide financial support in some cases. We set out the role and form of these HMBs for the first time in this article.

Growing up 2030 in a digital world

GOVERNING HEALTH FUTURES
THE LANCET & FINANCIAL TIMES COMMISSION

WHITE PAPER

DATA SOLIDARITY

December 2022

The 3 Pillars of Data Solidarity

01

Support high-public-value uses (e.g. climate, health, education)

02

Prevent and mitigate harm (bias, opacity, unfair profiling)

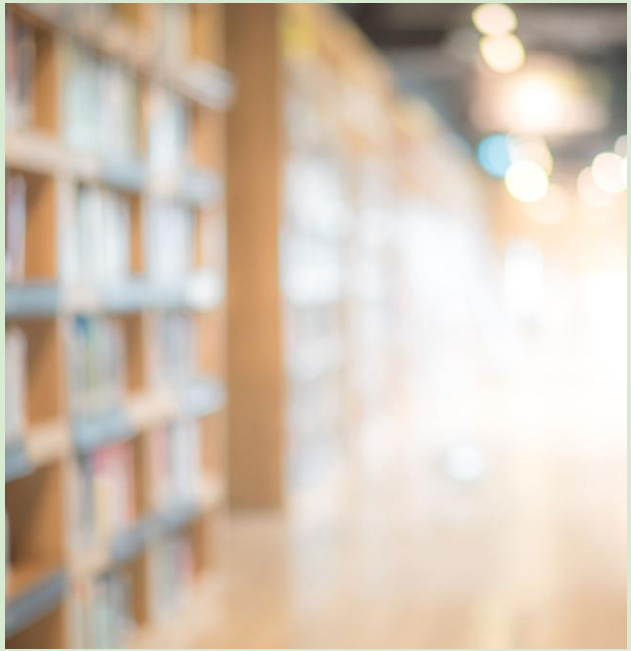
03

Ensure fair returns (taxation, benefit-sharing, community return)

When does data use have public value?

‘if it can be plausibly assumed that the data use will have clear *benefits* for either many [people], for society as a whole, or for future generations, and no person or group will experience *significant [and undue] harm*.

[…public value] is more pronounced if the benefits are likely to materialise for *underprivileged* groups than for privileged people, due to the overall lower baseline, and potential size of impact’]



[Prainsack & Buyx. 2016. Thinking ethical and regulatory frameworks in medicine from the perspective of solidarity on both sides of the Atlantic. Theoretical Medicine and Bioethics 37(6): 489-501, 493.

See also Prainsack & Buyx. 2017. *Solidarity in Biomedicine and Beyond*. CUP. p 97]

PLUTO
PUBLIC VALUE ASSESSMENT TOOL

pluto.univie.ac.at

PLUTO - Public Value Assessment Tool

Understanding and governing data use for the betterment of society has become increasingly important. Governments worldwide are formulating strategies to release 'high value' open data with the aim of benefiting the environment, economy, and society as a whole.

The tool asks 25 questions in four categories:

- Information about the data user
- Benefits of the data use
- Risks of the data use
- Institutional safeguards

PLUTO
PUBLIC VALUE ASSESSMENT TOOL

Our Public Value Assessment Tool
https://pluto.univie.ac.at

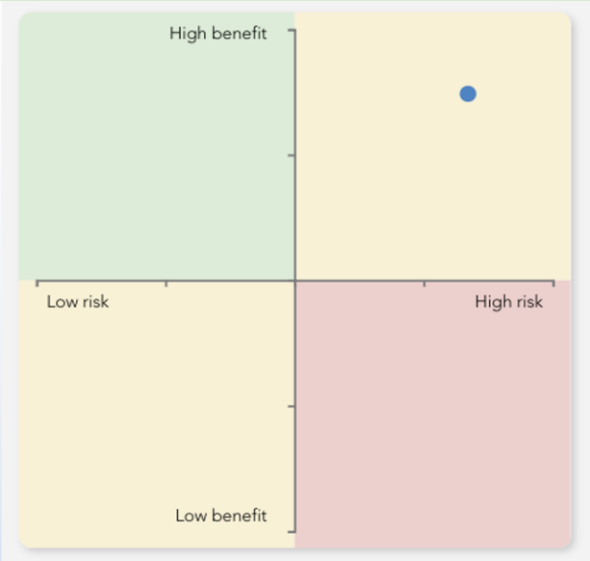
PLUTO
PUBLIC VALUE ASSESSMENT TOOL

Digitize!
Computational Social Sciences

universität wien
Institut für Politikwissenschaft

Evaluating Public Value in Practice

- Criteria: Benefits, risks, inclusion, redistribution
- Three zones:
- ✅ Facilitate
- ⚠️ Mitigate / Share
- ❌ Prohibit

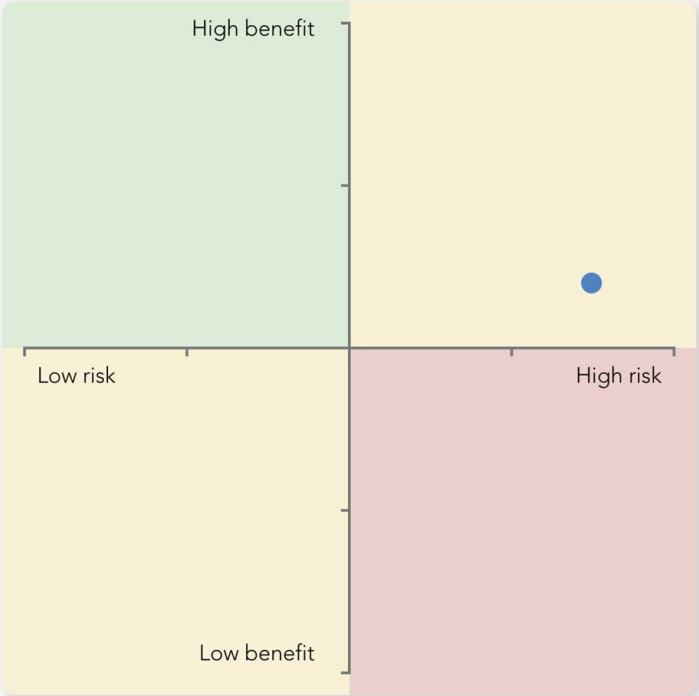


Your result is ready to be analysed

Export results

You have answered 15 out of 21 questions.

6 of your answers impact the riskiness rating and 9 of your answers influence the benefit rating in your result.



The benefits of the data use would be higher...

- if the motivation for the data use went beyond generating commercial profits, and prioritised the collective good
- if the data user had previously ensured that their data use benefits people in low and middle-income countries (LMICs)
- if the data user ensured that their data use also benefits future generations

The risks of the data use would be lower...

- if the data user complied (better) with information requests regarding data use
- if the data use posed lower informational risk to people
- if the data use did not entail possible risks for groups afforded special protection under the law
- if there was a lower risk of the data being used for purposes other than originally intended (dual use)
- if the data user had a (better) risk assessment in place

Traditional models	Data solidarity
Alert fatigue	Fewer and more meaningful alerts
Feasibility and cost	?
Not everybody is able to exercise control	“consent to be governed”, collective responsibility
How realistic is opting out? (monopolies etc)	Collective responsibility entails responsibility to create real alternatives/ensure that monopolies do not harm people
Shifting responsibilities to individuals	✓
Can distract from larger questions (should these data be collected in the first place? Who does this benefit?)	✓ Focuses on these questions
Can conceal power asymmetries	✓ Foregrounds power asymmetries
Remains within the bounds of categories and nomenclatures of the paper age	✓ Reinvents core categories
Does not address the black box problem	Partly addresses the blackbox problem
Individualises accountability	✓ Politicises and collectivises accountability

Data Solidarity Glossary

GLOSSARY

Click on the links below to explore the terms included in the data solidarity glossary.

Download the Glossary

Section 1: Solidarity

- 1.1 Solidarity — Learn more ↗
- 1.2 Data solidarity — Learn more ↗
- 1.3 Digital solidarity — Learn more ↗
- 1.4 Digital justice — Learn more ↗
- 1.5 Data justice — Learn more ↗
- 1.6 Public value — Learn more ↗
- Box: The public value assessment tool (PLUTO) — Learn more ↗

Section 2: Data governance

- 2.1 Data — Learn more ↗
- 2.2 Data governance — Learn more ↗
- 2.3 Data stewardship — Learn more ↗

Explore the Glossary

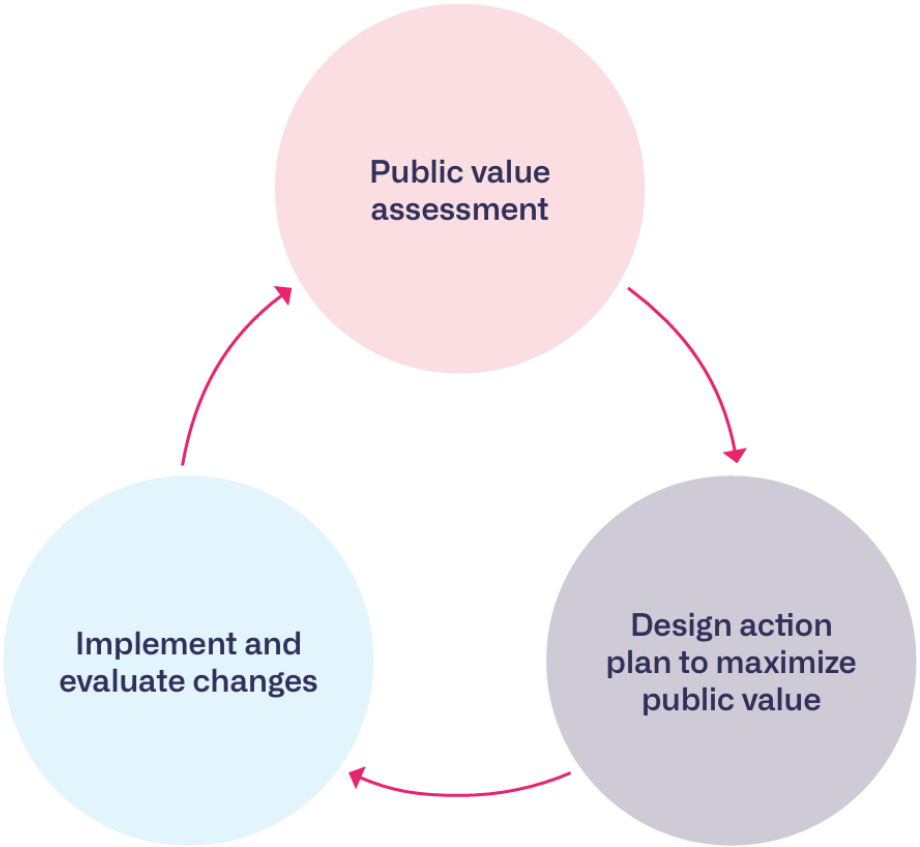
Putting data solidarity into practice

A guide for public and private organizations, authorities and policymakers

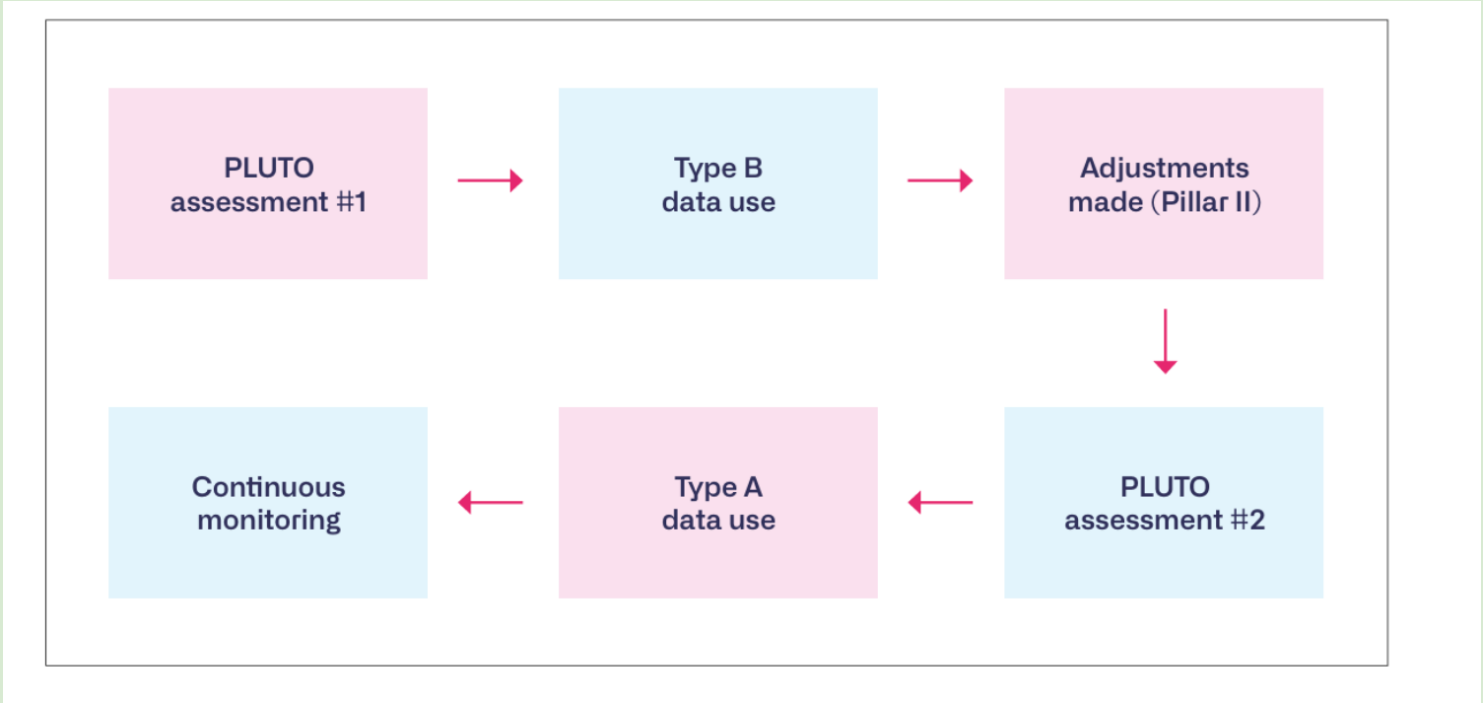
September 2025

Explore the Implementation Guide online

Putting data solidarity into practice

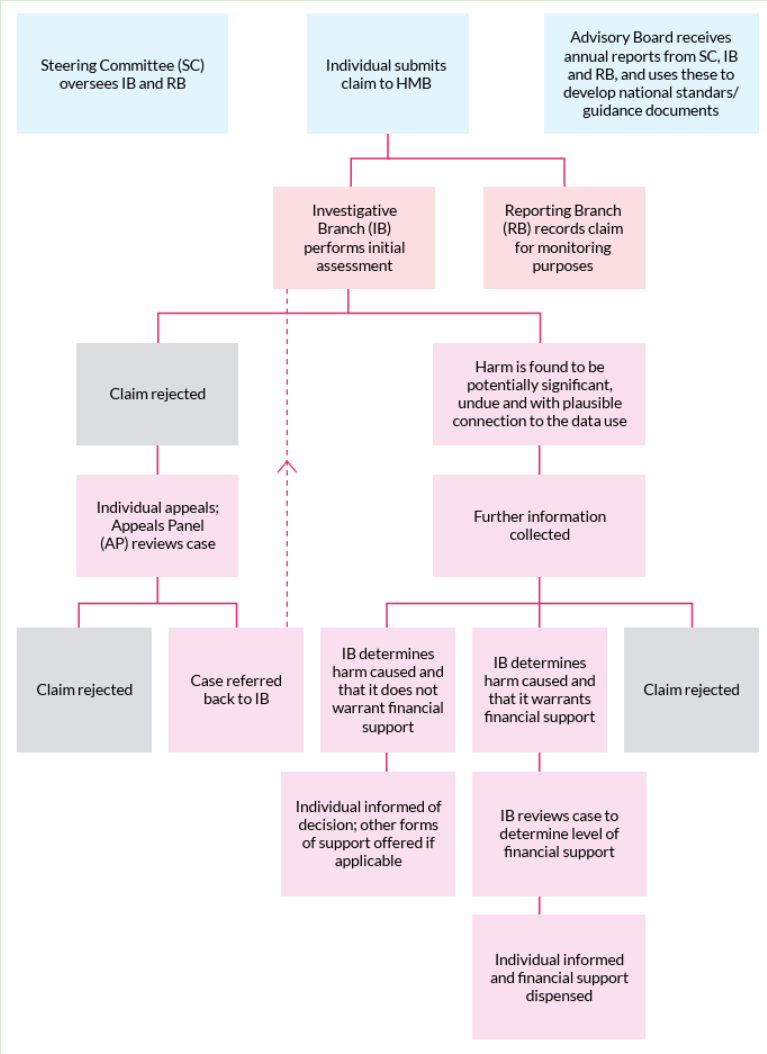


Example of improvements made in data use and data governance following a PLUTO assessment



Proposed decision-making and governance structure

Harm Mitigation Body (HMB)



universität wien

DIGITAL TRANSFORMATIONS FOR HEALTH LAB
GOVERNING HEALTH FUTURES 2030

Thank you for your attention!

Follow the Data Solidarity Project on LinkedIn

Follow DTH-Lab on LinkedIn