

Data solidarity: What is it, and why do we need it?

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CeSCoS
Centre for
the Study of
Contemporary
Solidarity



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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; Pitt erfðaeefni, 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



[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.]

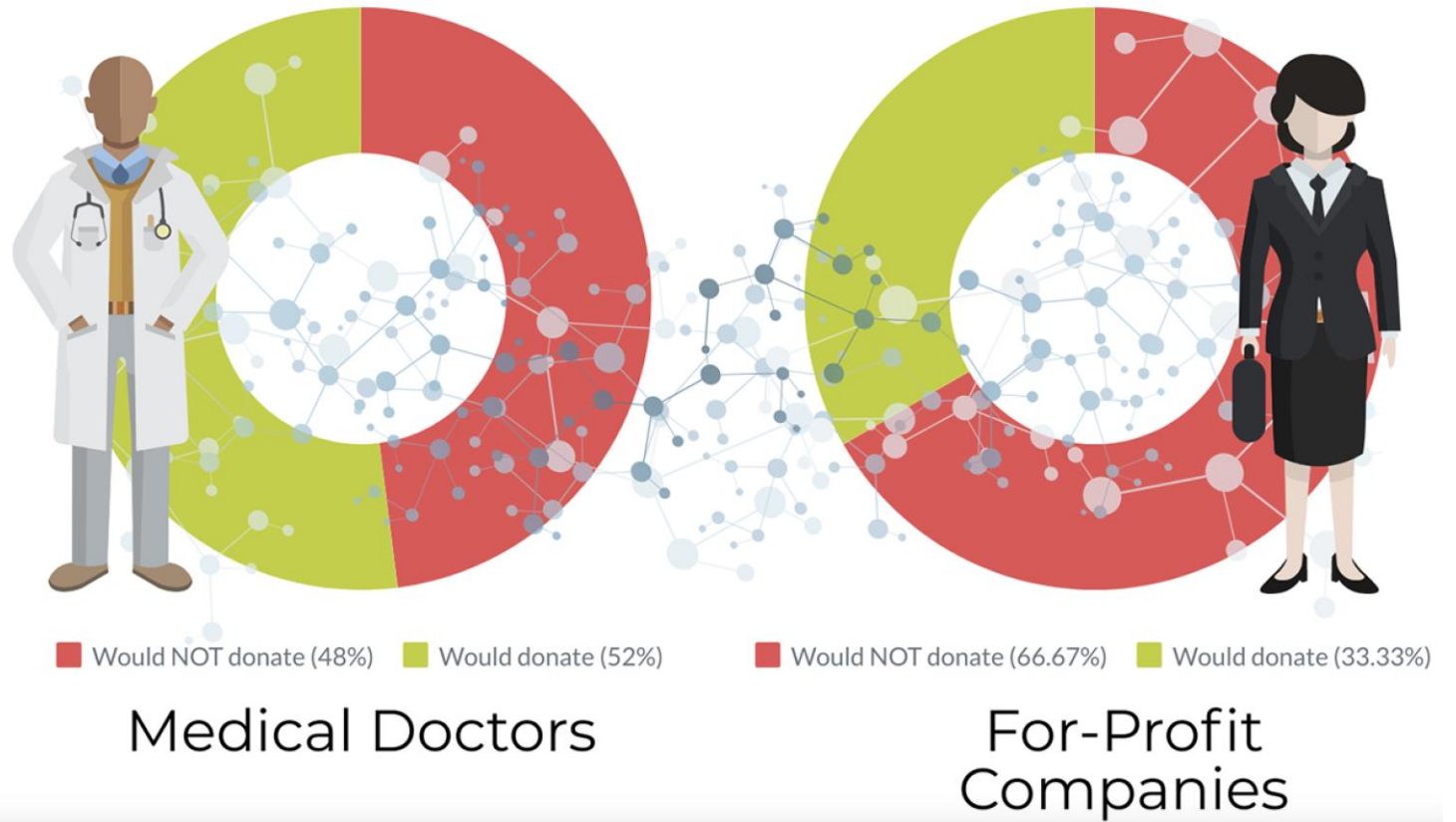
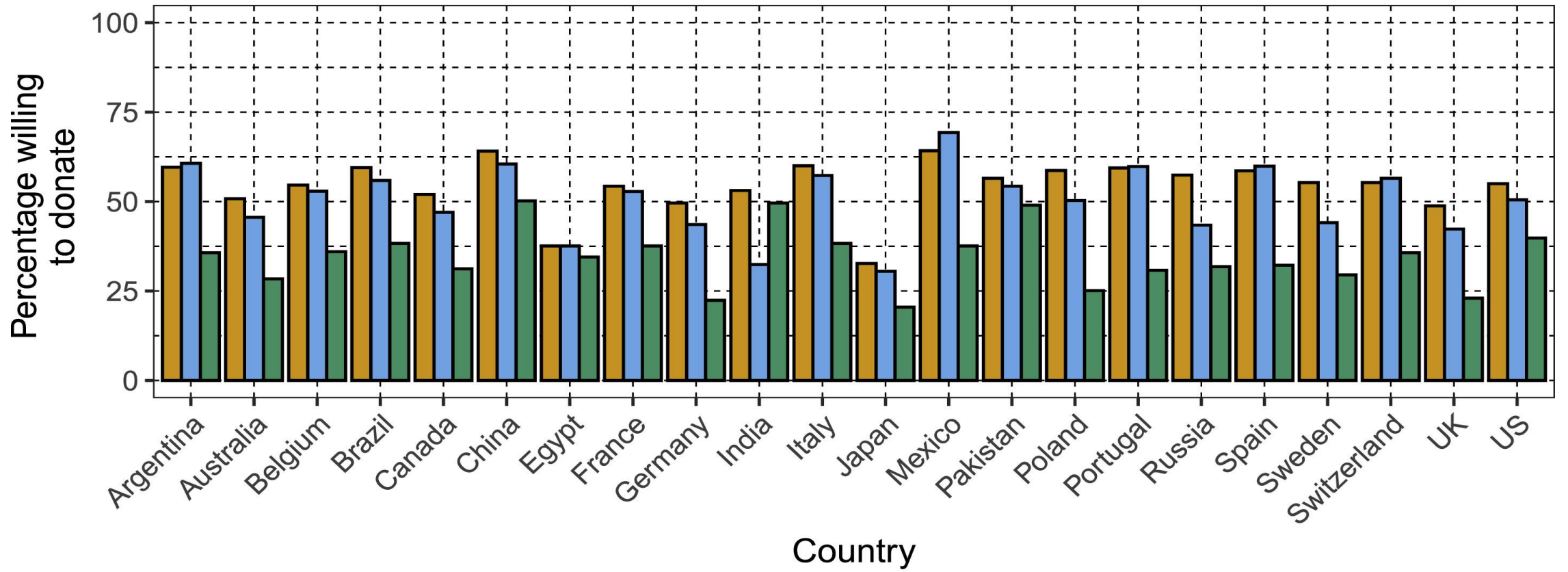


Figure 1



Recipient ■ Doctors ■ Non-profit ■ For-profit



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 **who 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 **how others will benefit** from the data access



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



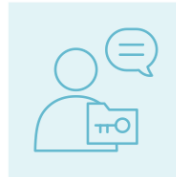
6. **Details about sanctions** if your data is misused



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

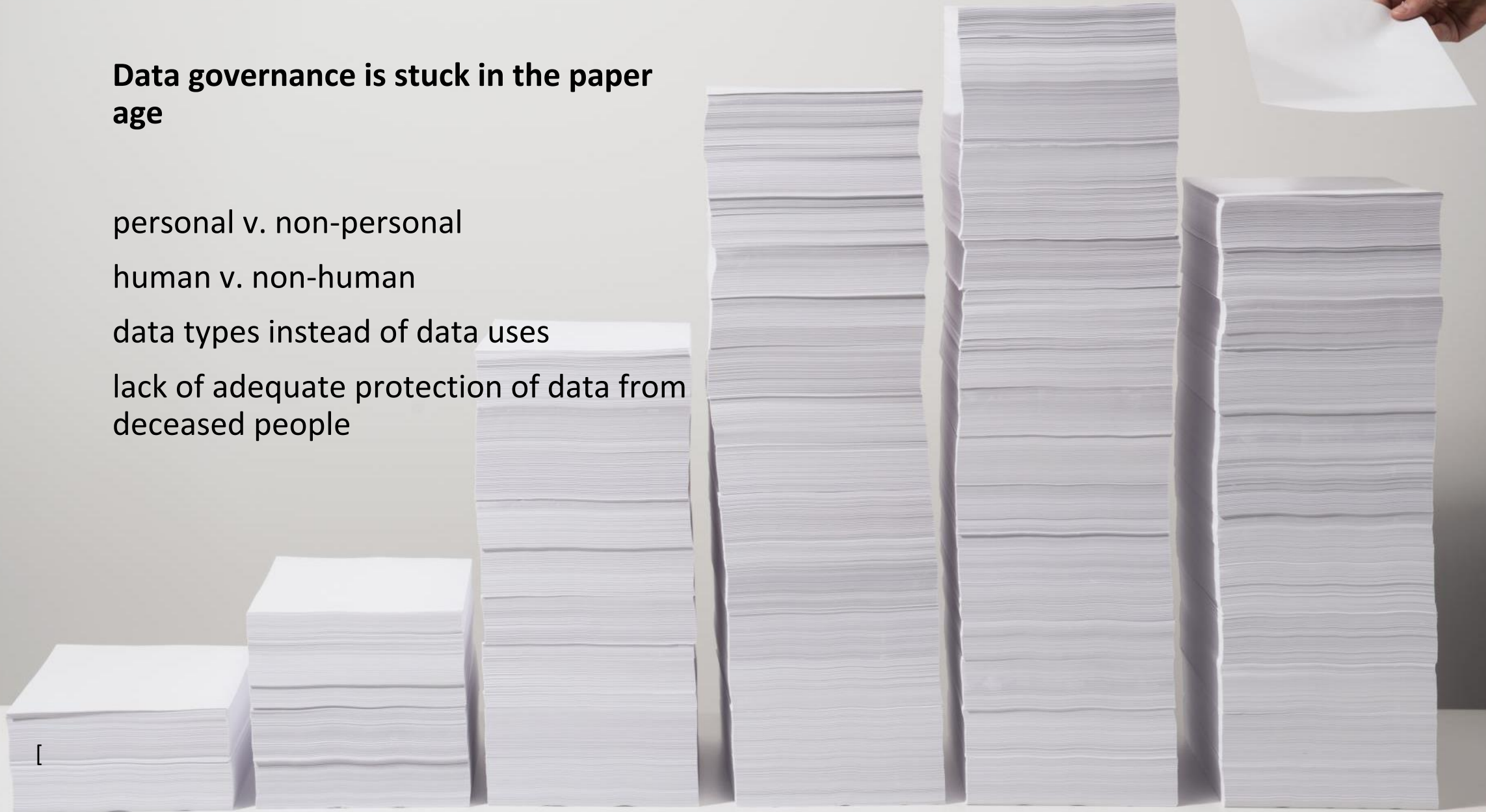
Data governance is stuck in the paper age

personal v. non-personal

human v. non-human

data types instead of data uses

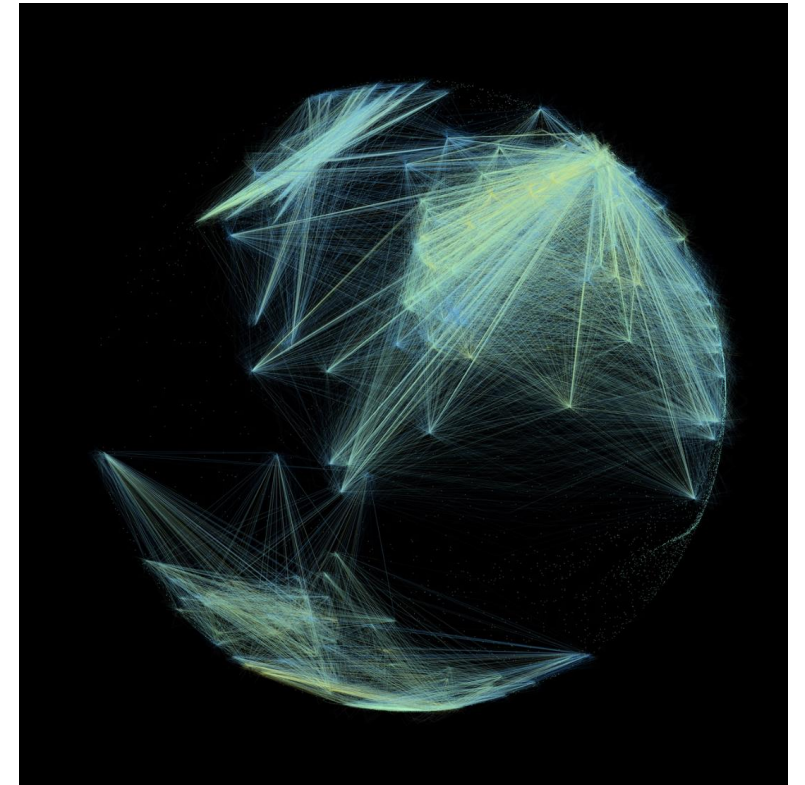
lack of adequate protection of data from deceased people



The Relational Nature of Data

Data ≠ Isolated Facts

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



Relational Data, Real Consequences

Invisible Labour, Invisible Contributions

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



[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.]

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May 6th 2017

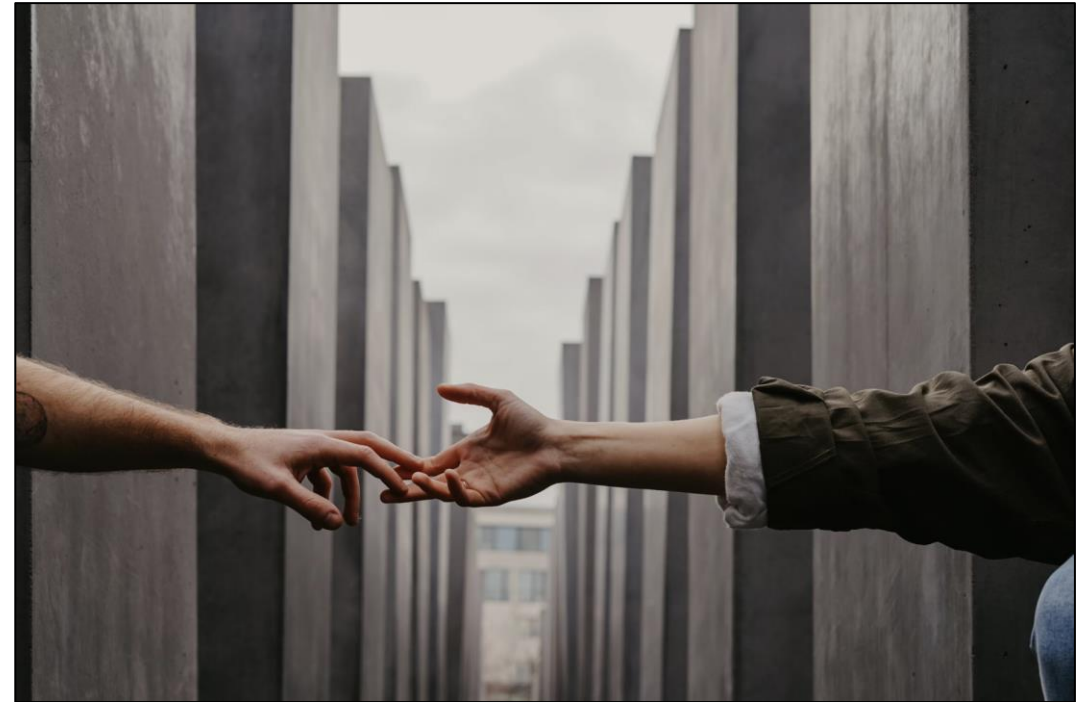


[image: The Economist]

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.]

Data Solidarity

Data solidarity: a blueprint for governing health futures

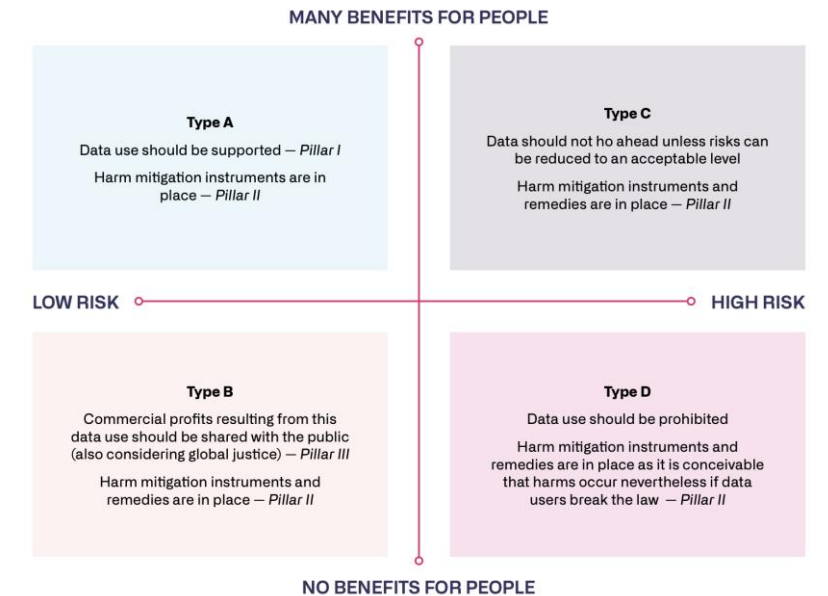
[Barbara Prainsack](#)^a  · [Seliem El-Sayed](#)^b · [Nikolaus Forgó](#)^c · [Łukasz Szoszkiewicz](#)^d · [Philipp Baumer](#)^b

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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)

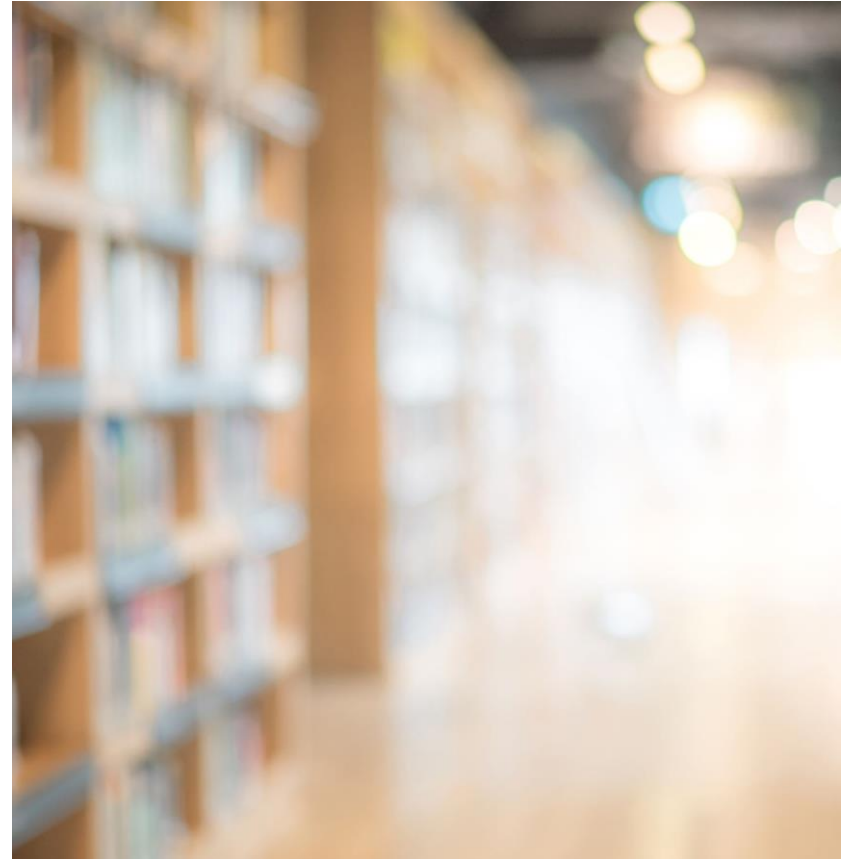
When does data use have public value?

'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.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

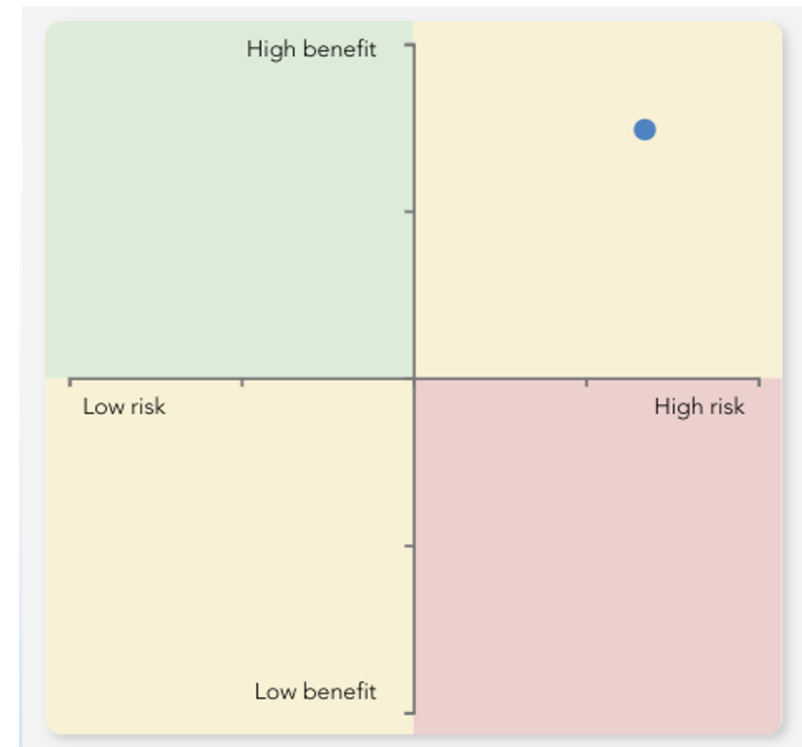


Our Public Value Assessment Tool <https://pluto.univie.ac.at>



Evaluating Public Value in Practice

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

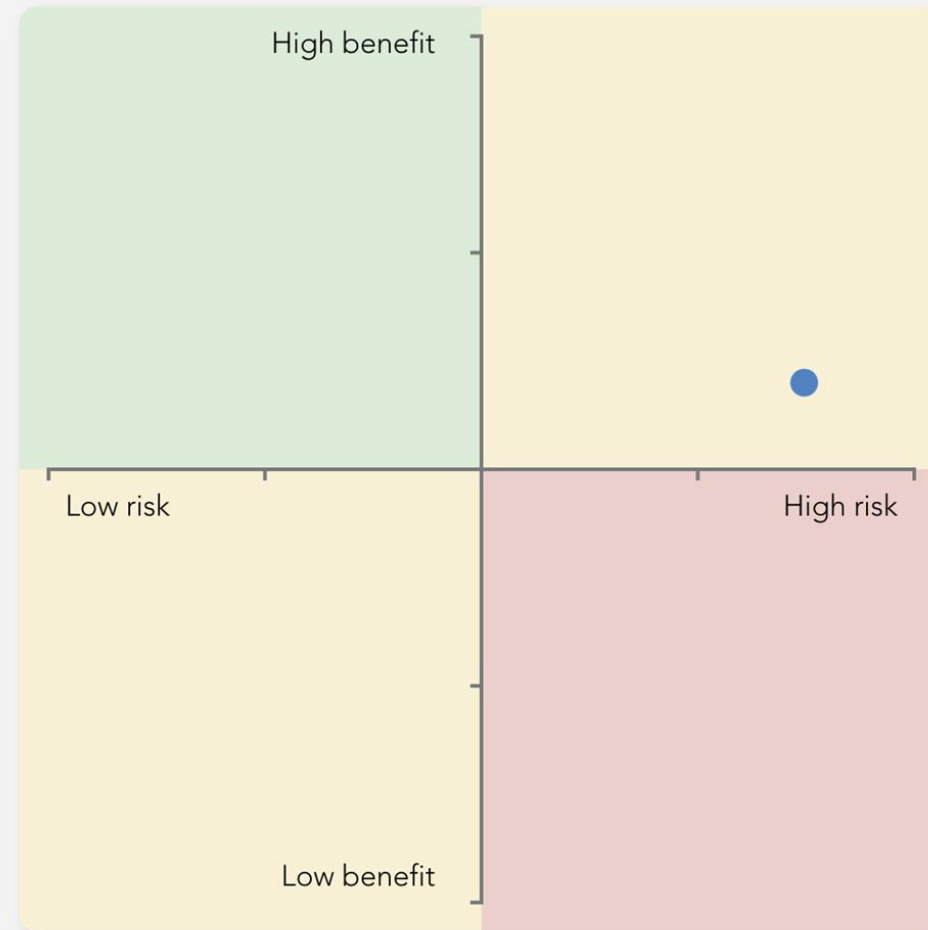


Your result is ready to be analysed

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

GLOSSARY

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

[Download the Glossary](#)

Data Solidarity 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 ↗](#)

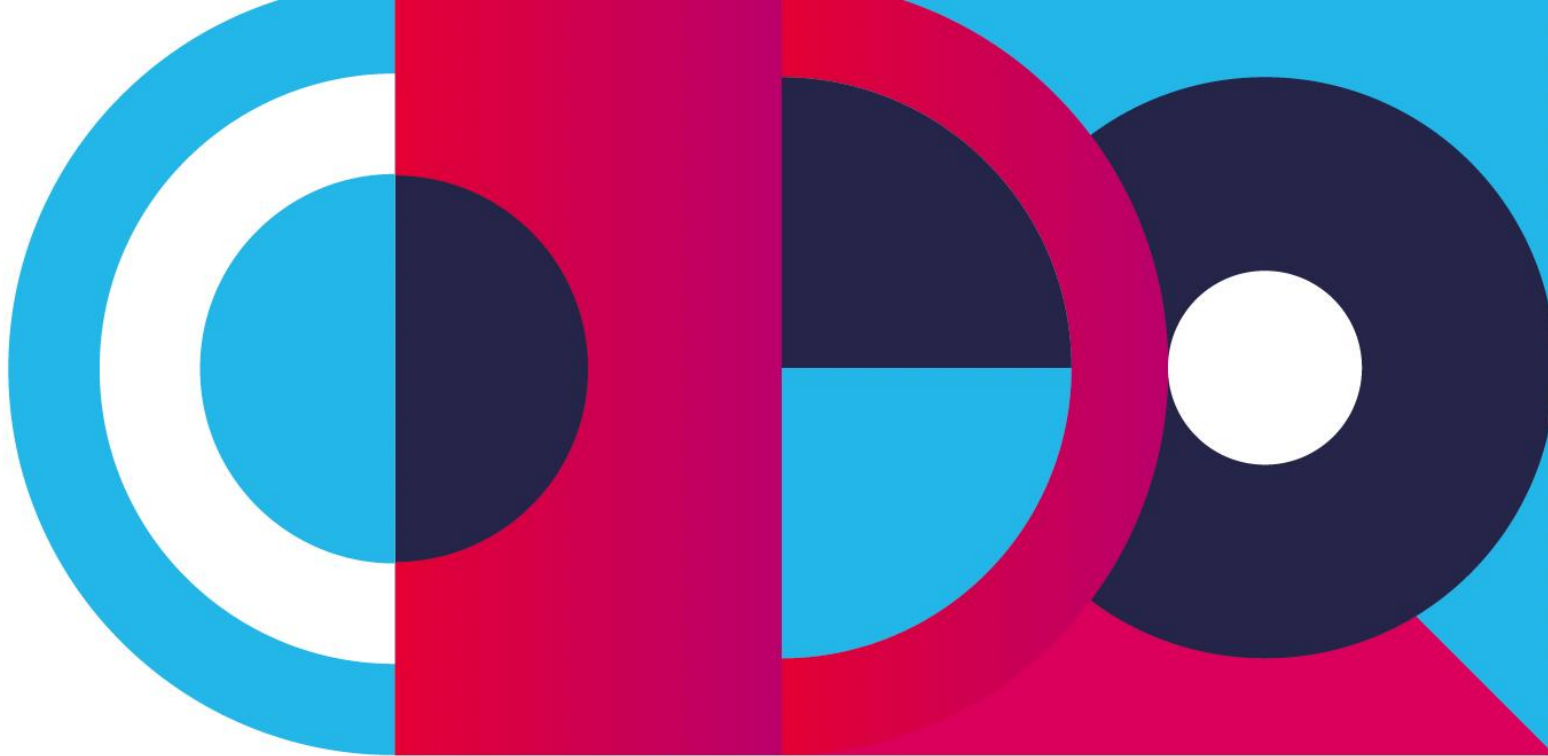
2.3 Data stewardship

[Learn more ↗](#)



Explore the
Glossary





Putting data solidarity into practice

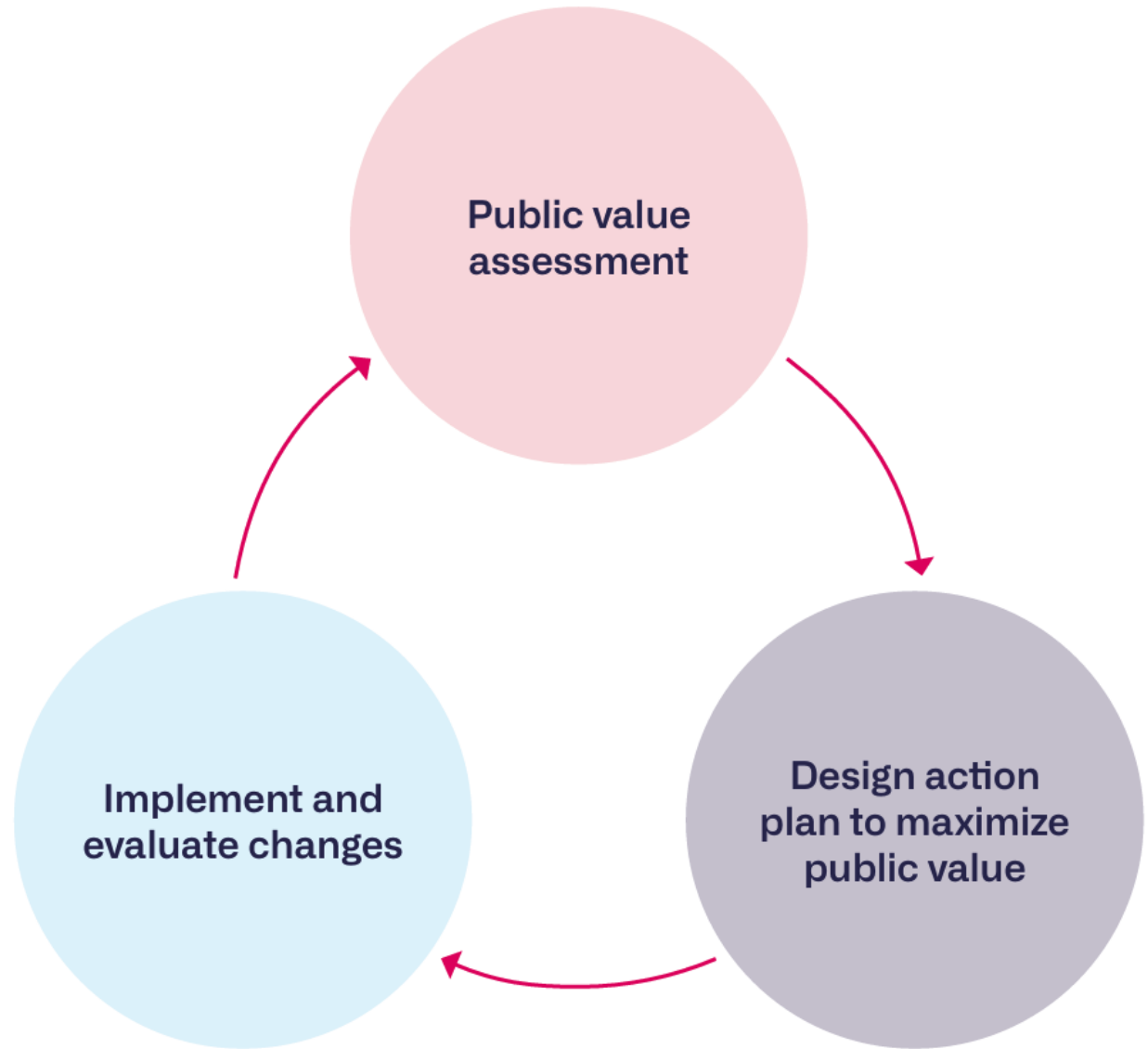
A guide for public and private organizations,
authorities and policymakers

September 2025

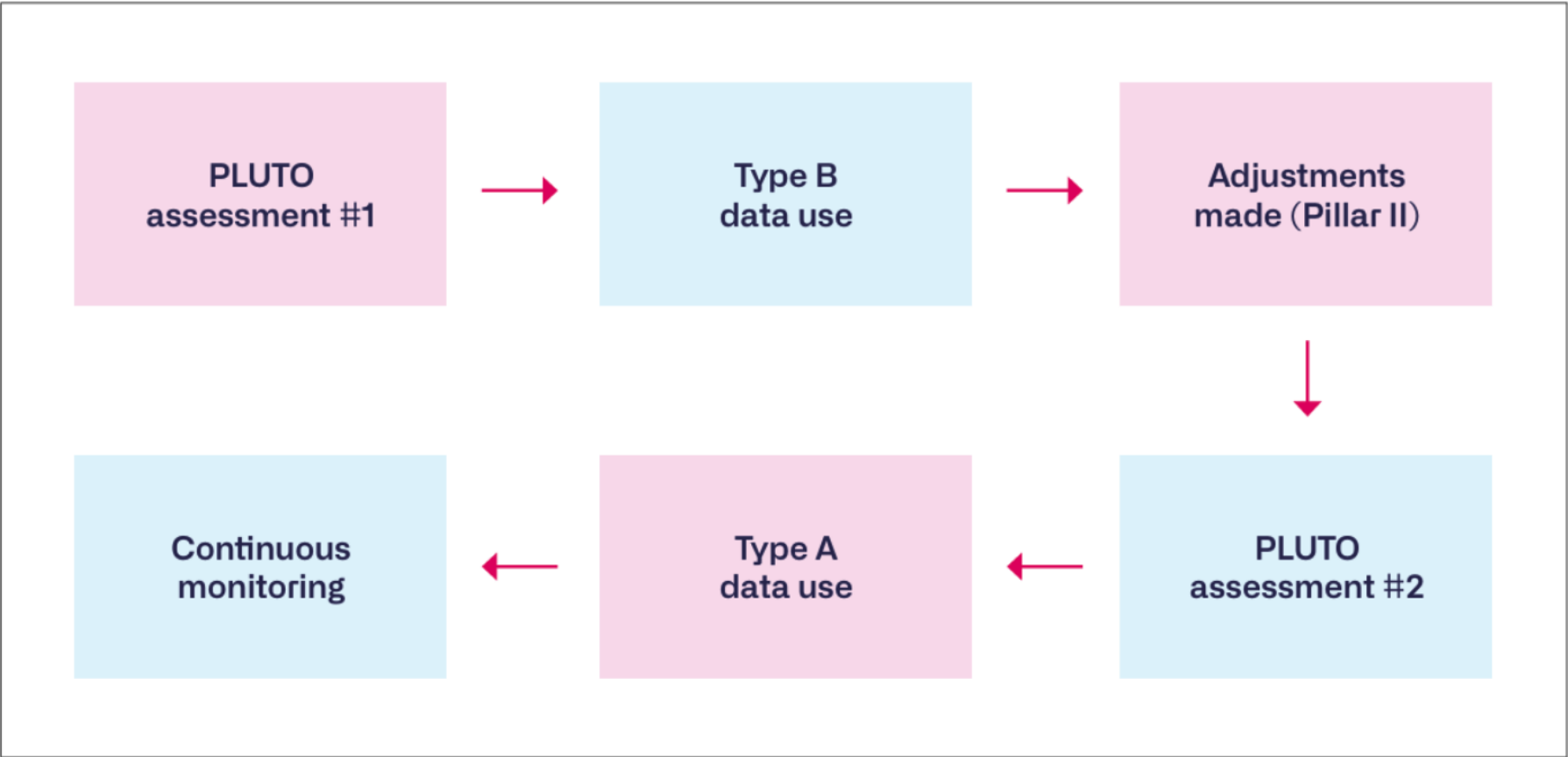
Explore the
Implementation
Guide online



Putting
data
solidarity
into
practice

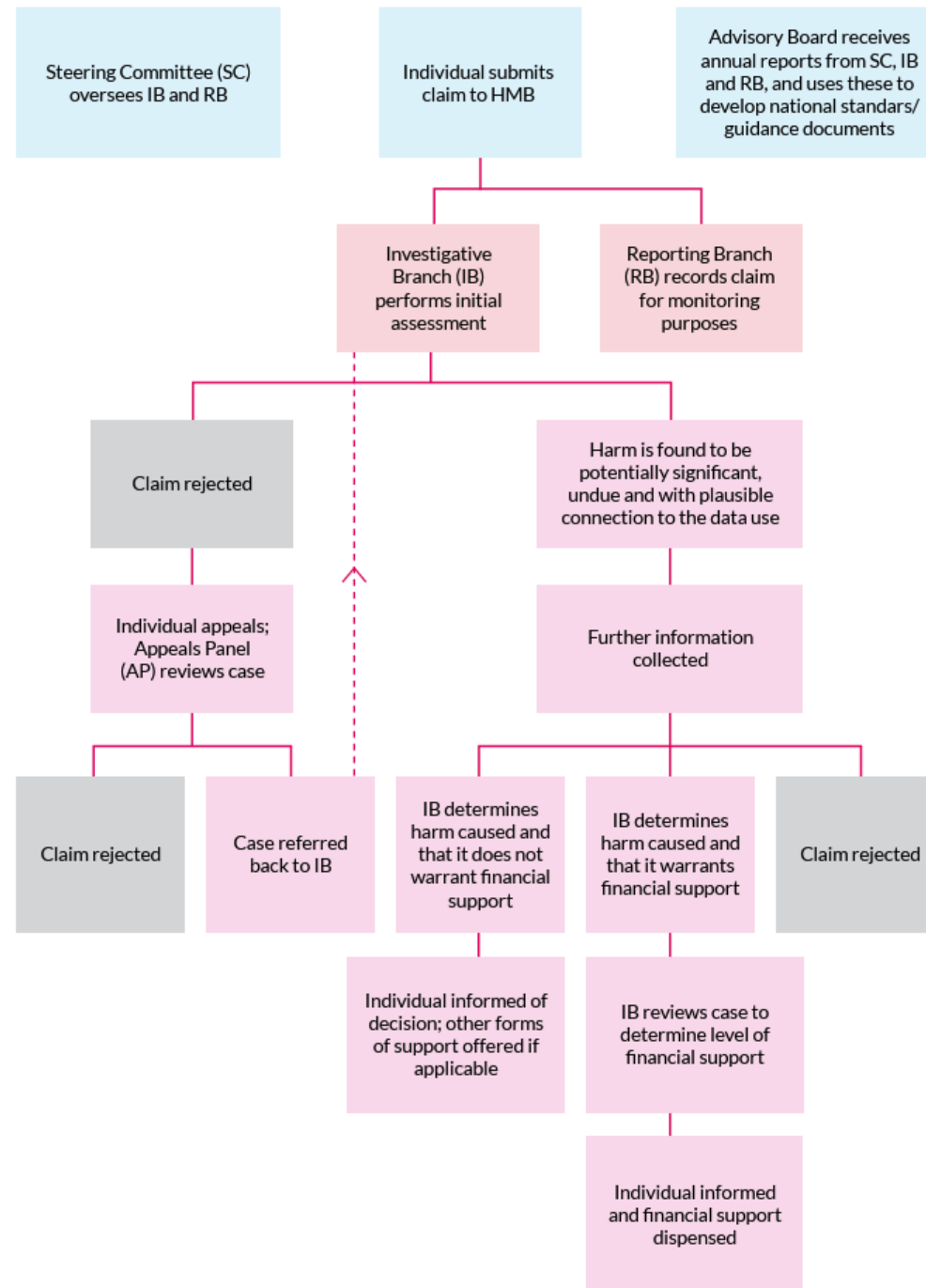


Example of improvements made in data use and data governance following a PLUTO assessment



Proposed decision-making and governance structure

Harm Mitigation Body (HMB)





Thank you for your attention!



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