

Data solidarity | Datensolidarität

Barbara Prainsack

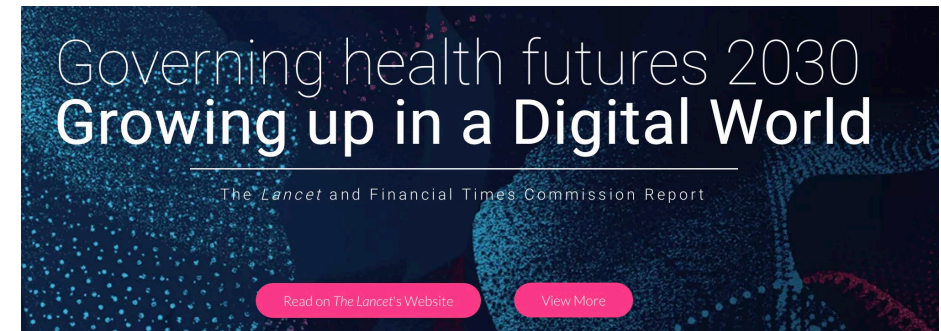
Professor, Department of Political Science, and Research Plattform
Governance of Digital Practices, University of Vienna

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

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



Wissenschaftskolleg zu Berlin





[images: [National Cancer Institute](#), Eduardo Barrios @unsplash, Cristina Victoria Craft @unsplash]

Innovation durch digitale Daten



How Can AI Help in **Achieving the Sustainable Development Goals?**

Valuer



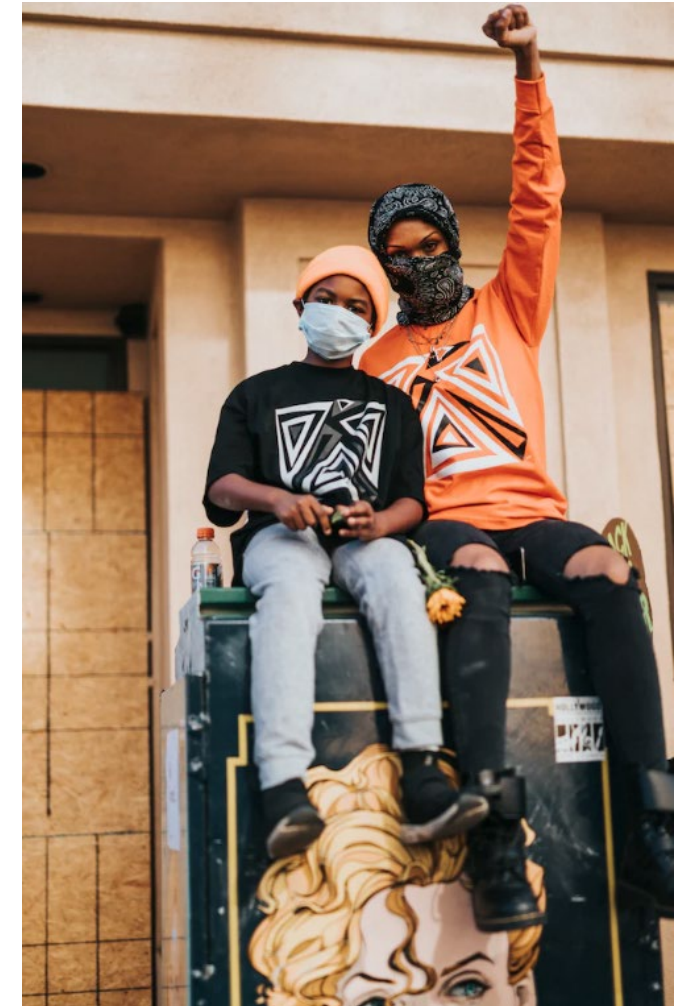
The Harm That Data Do

SCIENTIFIC
AMERICAN.

Paying attention to how algorithmic systems impact marginalized people worldwide is key to a just and equitable future

By Joanna Redden on November 1, 2018

- Digitale Überwachung
- „Algorithmische Brutalität“ (Mick Chisnall)
- Ungleiche Verteilung kommerzieller und anderer finanzieller Profite
- Verdrängung demokratischer Kontrolle und öffentlicher Expertise



[image: Nathan Dumlao @unsplash]

2. Solidarity-based data governance (data solidarity)

- Gerechtere Verteilung von Risiken und Nutzen
- Stärkung der Vertrauenswürdigkeit von Datennutzung

THE LANCET
Digital Health

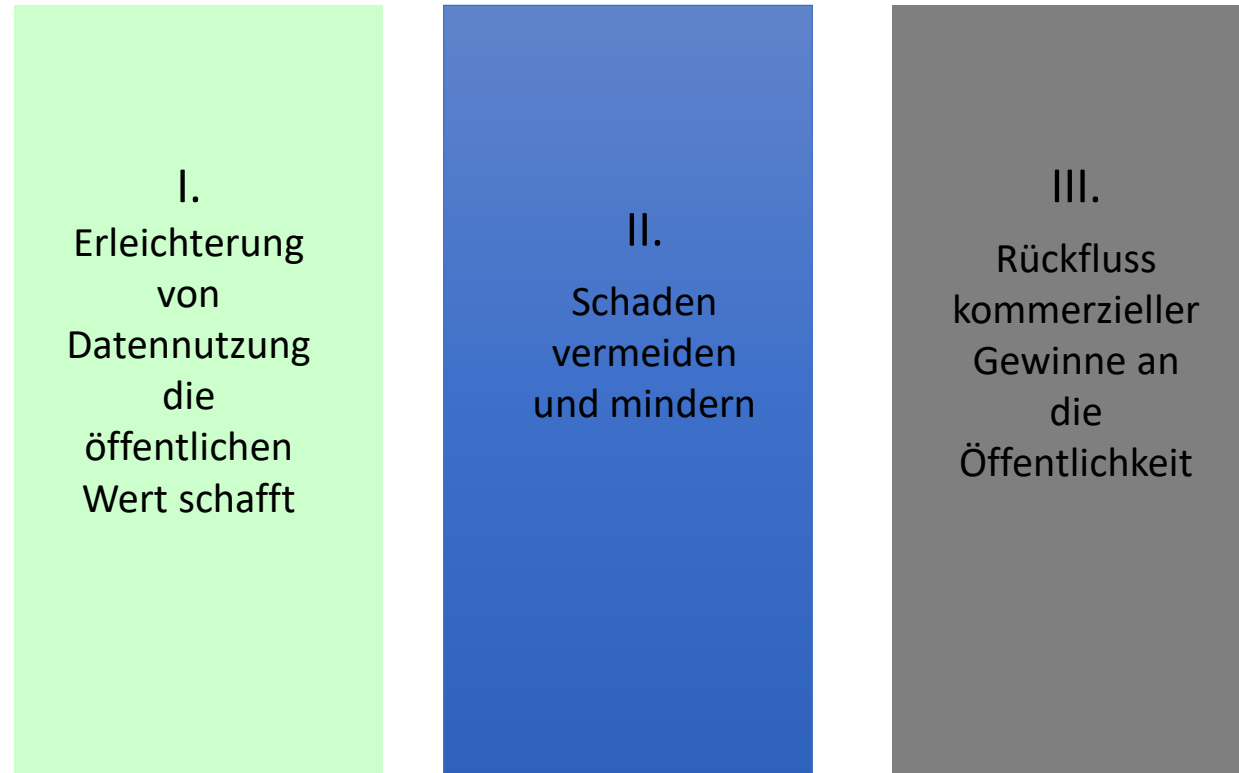
COMMENT | VOLUME 4, ISSUE 11, E773-E774, NOVEMBER 2022

Data solidarity: a blueprint for governing health futures

Barbara Prainsack ✉ • Seliem El-Sayed • Nikolaus Forgó • Łukasz Szoszkiewicz • Philipp Baumer

Open Access • Published: November, 2022 • DOI: [https://doi.org/10.1016/S2589-7500\(22\)00189-3](https://doi.org/10.1016/S2589-7500(22)00189-3) •

Drei Säulen der Datensolidarität



[Prainsack B. 2017. Research for personalised medicine: Time for solidarity. *Medicine and Law* 36(1): 87-98]

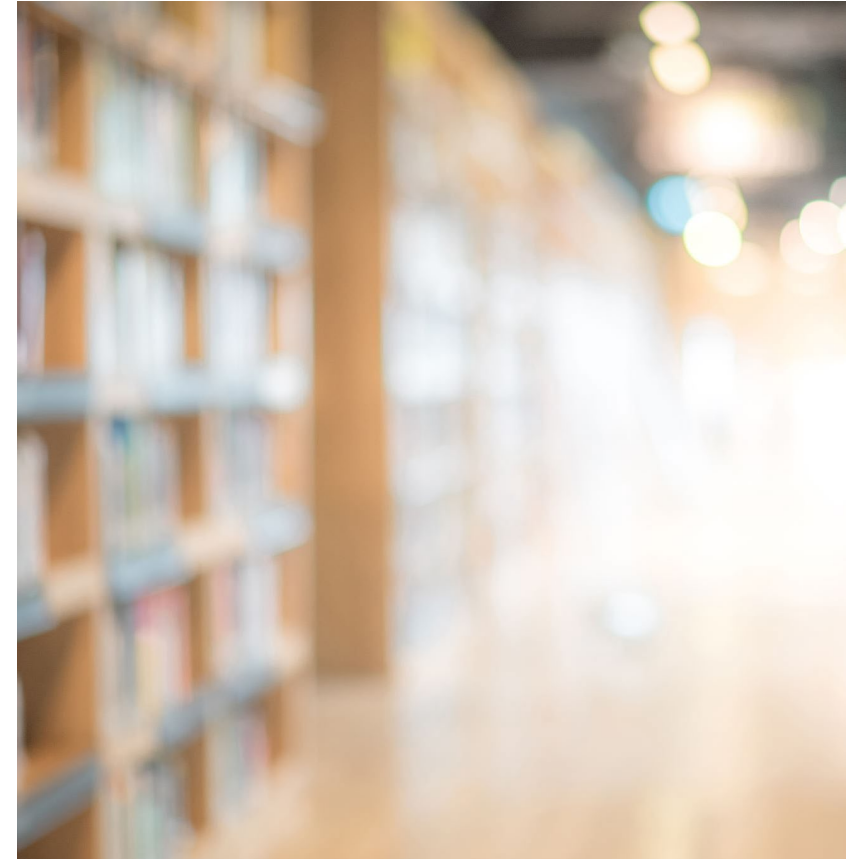
Wann hat Datenutzung öffentlichen Wert?

‘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/PubVal– Public Value Tool

Assessing Public Value: A Tool for Structured Assessment

(developed by Seliem El-Sayed & Barbara Prainsack)



Univ.-Ass. Seliem El-Sayed

Research Platform:
Governance of Digital
Practices



Univ.-Prof. Torsten Möller, PhD



Research Group Visualization and Data Analysis

Head

<https://pluto.univie.ac.at>

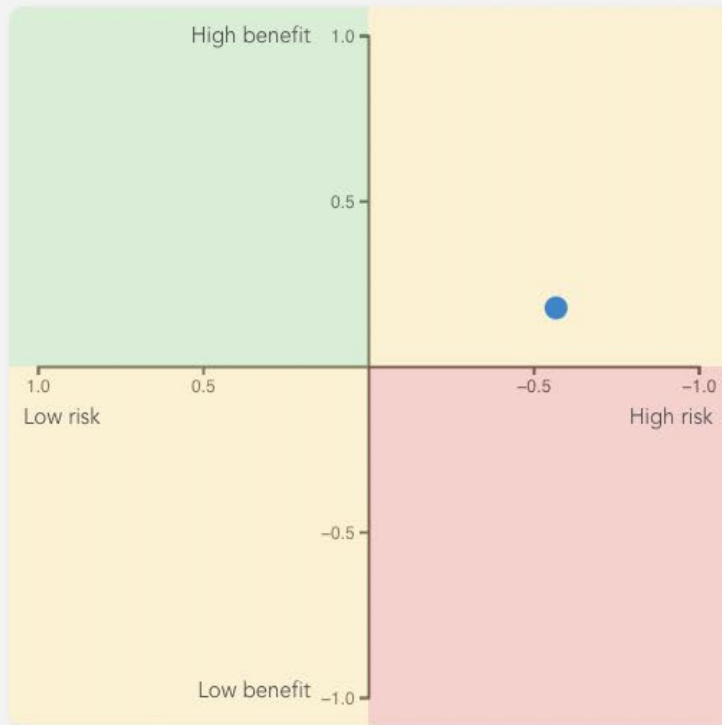
PLUTO - Public Value Assessment Tool

The risks and harms of digital data do not lie in the data themselves; they come from how the data is used. PLUTO is a tool for assessing the benefits and risks of specific instances of data use. The weighing of risks and benefits results in a score that indicates the public value of data use.

PLUTO can be used by anyone wanting to know how much public value the use of data for a specific purpose generates: By companies, organisations, public bodies, or citizens. It asks 24 questions in four categories:

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

This is your result



Please contact: Connor.hogan@univie.ac.at

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

- if the organisation's data use did not mainly benefit the organisation itself, but also the wider public or specific groups

The risks would be lower...

- if the organisation complied (better) with information requests regarding data use
- if the organisation's data use posed fewer other (beyond physical, financial and informational) risks to people
- if the negative environmental impacts of the organisation's data use were lower
- if fewer/lower risks were incidentally associated the organisation's data use
- if the organisation provided more information about risks of its data use to the public
- if the dual use potential of the organisation's data use was lower
- if the risk of dual use of the organisation's data use was less likely to materialise
- if the organisation's risk assessment included independent experts from outside the organisation
- if findings from your risk assessment could be binding
- if the risk assessment included individuals with specific ethics training and expertise
- if it were possible to end the harm-causing activity immediately
- if the organisation had a complaint procedure regarding their data use in place

Comment | Published: 18 March 2024

New AI regulation in the EU seeks to reduce risk without assessing public benefit

[Barbara Prainsack](#)  & [Nikolaus Forgó](#)

Nature Medicine **30**, 1235–1237 (2024) | [Cite this article](#)

1 Citations | 72 Altmetric | [Metrics](#)

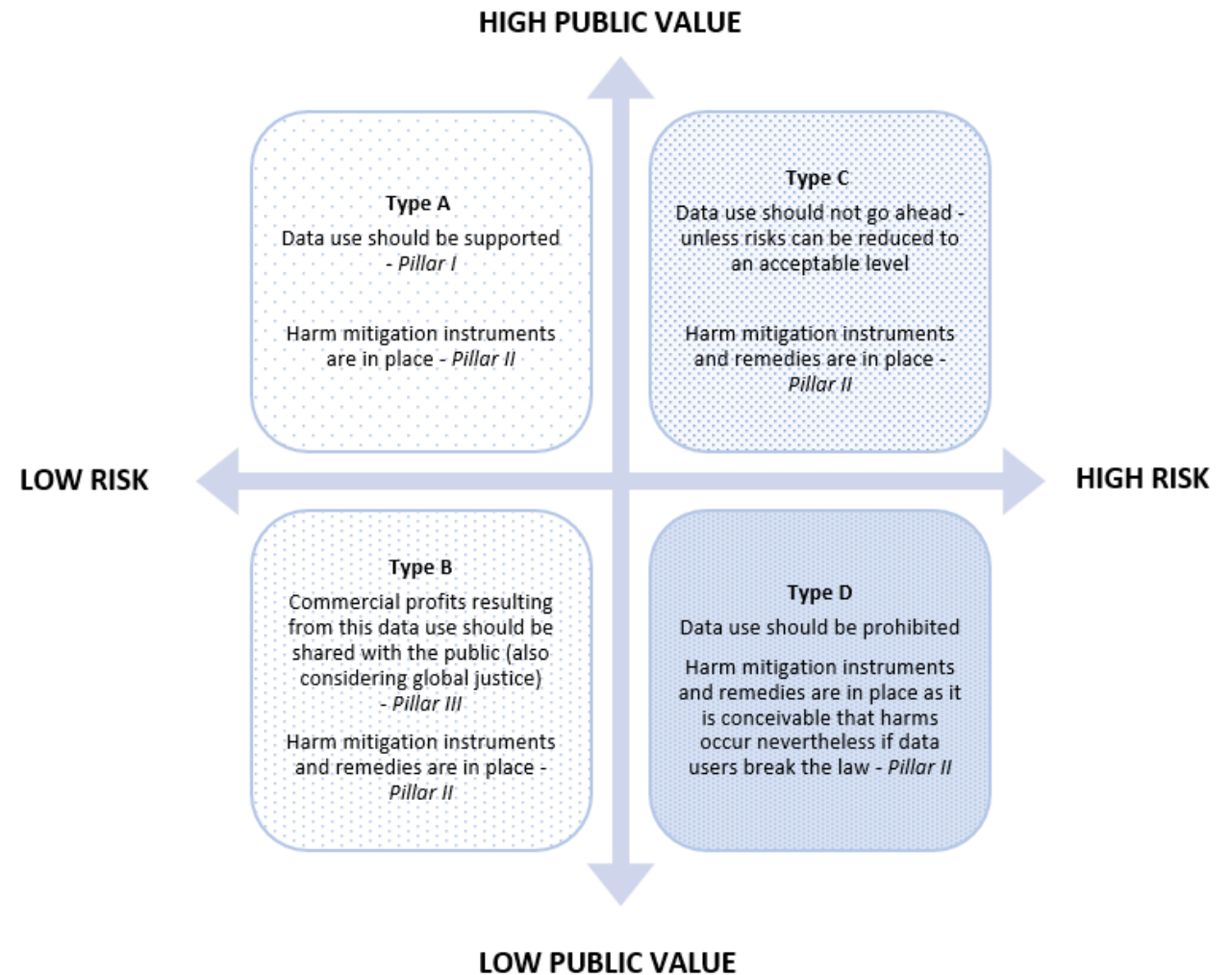
The European Union's new AI Act focuses on risk without considering benefits, which could hinder the development of new technology while failing to protect the public.

Not many regulatory initiatives have received as much public attention as the draft of the European Union (EU) Artificial Intelligence (AI) Act, a binding regulation that will be directly applicable in all EU member countries. The act will enter into force 20 days after its official publication, and its provisions will become applicable (in different stages) starting 6 months after that date¹.

Von Datentypen zu Typen von Datennutzung

[Barbara Prainsack, Seliem El-Sayed, Nikolaus Forgó, Lukasz Szoszkiewicz, and Philipp Baumer. White Paper Data Solidarity (online)]

[Prainsack, B., El-Sayed, S., Forgó, N., Szoszkiewicz, Ł. and Baumer, P., 2022. Data solidarity: a blueprint for governing health futures. *The Lancet Digital Health*, 4(11), pp.e773-e774.]



Spezifische Politikinstrumente

I.
Erleichterung
von
Datennutzung
die
öffentlichen
Wert schafft

II.
Schaden
vermeiden
und mindern

III.
Rückfluss
kommerzieller
Gewinne an
die
Öffentlichkeit



WHITE PAPER

**DATA
SOLIDARITY**

December 2022

I.
Erleichterung
von
Datennutzung
die
öffentlichen
Wert schafft



**INFORMATION
REGULATOR
(SOUTH AFRICA)**

*Ensuring protection of your personal information
and effective access to information*

FINDATA

Social and Health Data Permit Authority

+ mehr
Aufmerksamkeit für
die politische
Ökonomie, in die
diese Praktiken
eingebettet sind

II.

Schaden
vermeiden
und mindern

Schaden vermeiden

Effektive Verbote von Datennutzung, die Schäden verursacht (z. B. Strategien, bei denen arme Menschen Daten gegen Dienstleistungen tauschen; Redlining; *surveillance advertising*)

Wirksame Geldstrafen und Durchsetzung

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

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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.

Schaden lindern

Schadensminderungsstellen (Harm mitigation Bodies, HMB) (subsidiär zu rechtlichen Instrumenten)

- Drei Hauptfunktionen:
 - (a) Information über die auftretenden Schäden sammeln
 - (b) Feedback, um Daten-Governance zu verbessern
 - (c) Finanzielle Unterstützung in Härtefällen

III.

Rückfluss
kommerzieller
Gewinne an
die
Öffentlichkeit

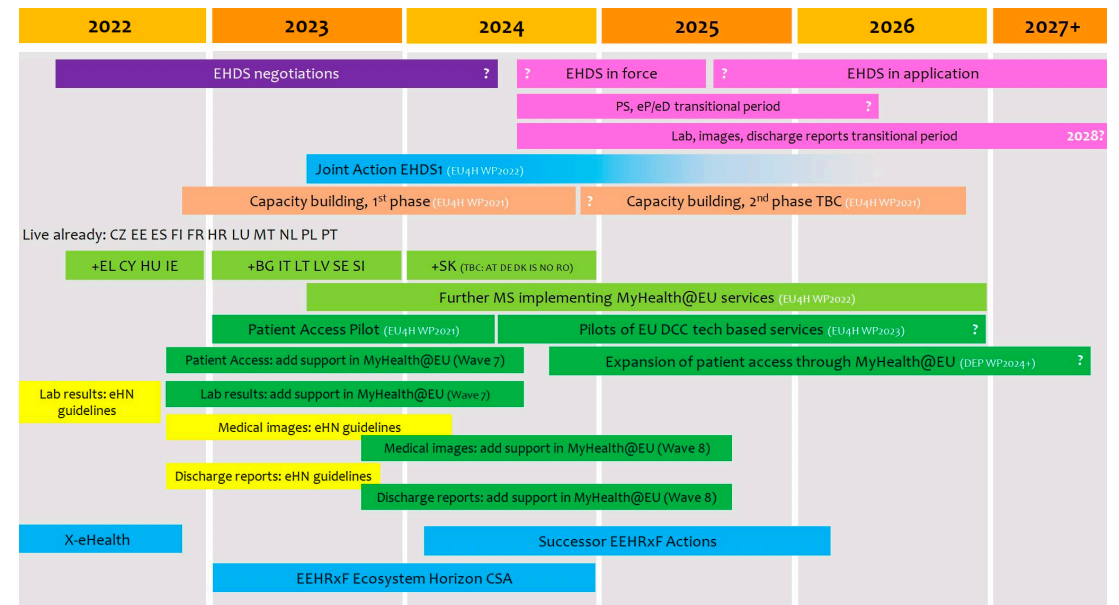
Unternehmenssteuern

Daten(nutzungs)steuern
(z.B. digital service taxes)

Benefit sharing

EHDS

1. Nicht jede Datennutzung im Gesundheitsbereich ist unterstützenswert
2. Eine nuanciertere Beurteilung des öffentlichen Werts unterschiedlicher Formen von Datennutzung kann u.a. dabei helfen, Vertrauen zu stärken
3. Das Konzept des Datenaltruismus als “Leitmotiv” sollte durch Datensolidarität ersetzt werden



Danke für Ihre Aufmerksamkeit!

Research Platform Governance of Digital Practices

<https://digigov.univie.ac.at/>

digigov@univie.ac.at

Department of Political Science

University of Vienna

Universitätsstraße 7 (NIG)

1010 Vienna

<https://politikwissenschaft.univie.ac.at>



PLUTO tool: Please contact: connor.hogan@univie.ac.at