

SECONDARY USE OF DATA AND DATA SUBJECT RIGHTS



24-25 MARCH 2026
CONFERENCE ONLINE

Day 1
24 march 2026

9:00–10:00 Opening Ceremony

10:00–11:00 Keynote Address

Prof. Dr Barbara Prainsack

Professor for Comparative Policy Analysis, University of Vienna
Chair, European Group on Ethics in Science and New Technologies (EGE)
Director, Centre for the Study of Contemporary Solidarity

11:00–11:15 Break

11:15–12:30 Panel I Individuals and Fundamental Rights in the EHDS

Moderator: Jan Kuráň, Masaryk Memorial Cancer Institute, Brno

How can Europe unlock the value of health data without compromising individual rights? This panel brings together perspectives on privacy, autonomy, data altruism, and trust at the core of the European Health Data Space.

- **Dr Arianna Rossi**, Sant'Anna School of Advanced Studies, Pisa
Striking a Balance Between Encouraging Health Data Sharing for Research and Safeguarding the Right to Opt-Out
- **Dr Anna Michalska-Falkowska**, Medical University of Białystok
Secondary Use of Health Data in Biobanks: Protecting Data Subjects' Rights under the European Health Data Space – Insights from the Oncological Collection at the Medical University of Białystok Biobank
- **Benedetta Burston**, Bocconi University
The Digital Pulse: Health Sensors and the Privacy Dilemma
- **Dr Dominika Kuźnicka-Błaszowska**, University of Wrocław
Forced Data Altruism and Informational Autonomy under the European Health Data Space

12:30–12:45 Break

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12:45–14:00 Panel II Consent, Opt-Out and Data Governance in the EHDS

Moderator: Dr Dorota Krekora-Zajac, Faculty of Law and Administration, University of Warsaw

As the EHDS moves beyond traditional consent models, this panel explores opt-out mechanisms, new forms of data governance, and the role of transparency and public engagement in building trust.

- **Roxana Albu, Dr Wannes Van Hoof**, Sciensano, Belgium
Embedding Opt-Out in a Democratic EHDS: Rights First, Trust Through Engagement
- **Dr Chiara Castaldo**, University of Turin
Beyond Individual Autonomy: Re-evaluating Consent and Open Data Obligations in the EHDS Secondary Use Framework
- **Dr Inês Neves**, University of Porto; CIJ – Centre for Interdisciplinary Research on Justice
Beyond Consent: Strengthening Informational Self-Determination through Governance in the European Health Data Space
- **Erdina Ene**, BBMRI-ERIC
The Right to Opt-Out in the EHDS Regulation as a Risk and a Safeguard
- **Ciro Maria Ruocco**, PhD Candidate, University of Salerno
From Consent to Health Data Governance: Secondary Use and Accountability in the EHDS Between the EU and Italy

14:00–14:30 Break

14:30–15:45 Panel III EHDS in the EU Digital Regulatory Ecosystem

Moderator: Valentina Colcelli ESBB Councillor, Italian National Research Council (CNR)

What happens when the EHDS meets the AI Act, the Digital Services Act, and other EU digital laws? This panel examines regulatory overlaps, emerging risks, and opportunities for a coherent European data framework.

- **Dr Giovana Peluso Lopes**, Tilburg University
Secondary Use of Health Data for Training Generative AI Models: Risks and the Interplay Between the EHDS and the AI Act

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- **Sumanta Narayan Podder**, PhD candidate at Presidency University, Kolkata
Trained Models as Derivative Artifacts: Reframing the Object of Secondary Use in EHDS Scholarship
- **Vincenzo Forte**, PhD Candidate, University of Naples "Parthenope"
Secondary Use of Health and Health-Related Data in the European Union: Towards Coordination Between the EHDS and the Digital Services Act
- **Radek Halouzka, Jan Kuráň**, Masaryk Memorial Cancer Institute, Brno
EHDS and Secondary Use of Data – The End of Legal Fragmentation?
- **Izabella Kowalczyk-Pakuła**, Attorney-at-law, **Emilia Stępień**, Attorney-at-law Bird & Bird
Data-Driven Innovation and the EHDS: The Relationship Between Secondary Use of Data and the European Biotech Act

15:45–16:00 Break

16:00–17:15 Panel IV Implementing the EHDS: Legal and Technical Architectures

Moderator: **Dr Katarzyna Łakomiec**, Institute of Legal Sciences, Polish Academy of Sciences

Turning regulation into reality requires robust institutions and secure technologies. This panel focuses on health data access bodies, secure processing environments, interoperability, and data quality as key pillars of implementation.

- **Dr Federica Casarosa**, Sant'Anna School of Advanced Studies, Pisa
Interoperability, Sovereignty and Security: Legal and Technical Foundations of Data Spaces for Secondary Use
- **Emma J. Smith**, Legal Advisor, NTNU
EHDS: Centralisation of the Health Data Access Body Function for Population-Based Studies – What Are the Risks?
- **Andrea Palumbo, Leander Samuel Stahler**, PhD Candidates, KU Leuven Centre for IT & IP Law
Secure Processing Environments under EU Law
- **Dr Małgorzata Wileńska**, University of Warsaw
The Data Quality Framework and Its Practical Impact on Data Quality
- **Laura Centeno Casado**, PhD Candidate Institute of Phylosphy, CSIC (Spanish National Research Council) and University of Murcia
Secondary Use of Health Data and the Protection of Individual Rights in Rare Diseases