Data Access and Usage in Health Care: Toward Responsibility and Trust

Data access and usage in medical research – clinical trials in particular – have become the new "gold standard" in the entire health care domain (and beyond).
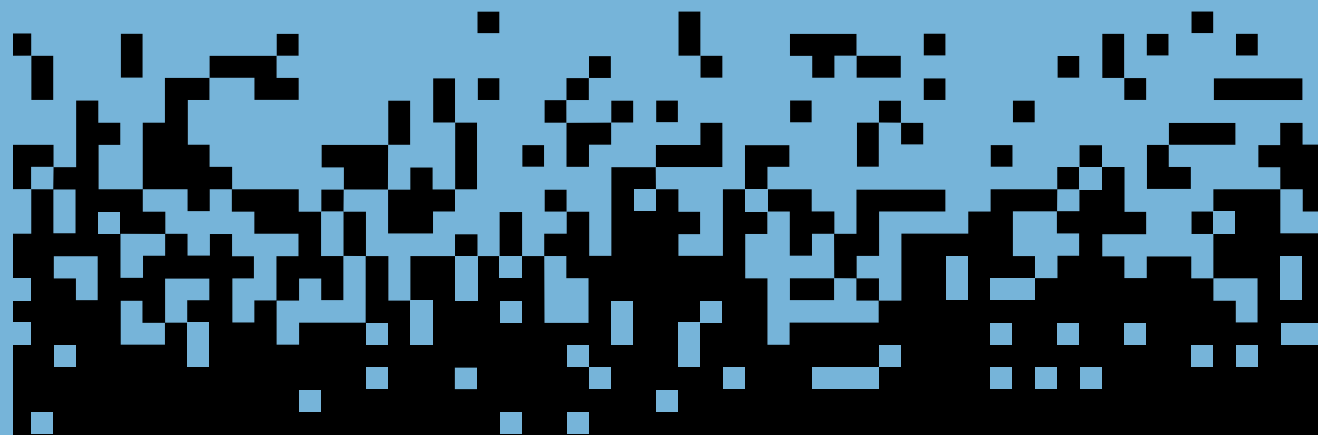
Access to and usage of this data, however, bear the potential of several "moral hazards" in terms of responsibility and trust which jeopardize their very usefulness and exacerbate long-standing critical tendencies in scientific research.

Open access to trial data, and transparency of related processes, is seen as a response to these hazards, and a means for restoring key warranties of the respect of human dignity which characterize sound scientific practice as well as medical care.

The conference brings together academics and practitioners in order to promote both the advancement of scientific research and the development of responsible practices and sustainable solutions in health data processing.

euphur
Europia Platform on Human Dignity and Human Rights

Freie Universität Bozen
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PIANO NAZIONALE DI RIPRESA E RESILIENZA

Ministero dell'Università e della Ricerca

Finanziato dall'Unione europea
NextGenerationEU

5+6 June 2025
Room F6, Free University of Bozen-Bolzano

Programme Thursday, 5 June 2025

11:00–12:30 · Room F6
Project Presentation: *Clinical Trial Data between Privatization of Knowledge and Open Science*

16:00 · Room F6
Opening and Greetings

16:15 · Room F6
Robert Simon (Euphur, Free University of Bozen-Bolzano)
Introduction: Challenges of Ethical Technology Assessment

16:45 · Room F6
Simona Tiribelli (Università di Macerata)
Beyond Bias and Discrimination: Redefining the AI Ethics Principle of Fairness in Healthcare Machine-learning Algorithms

*** Coffee break ***

18:30 · Room D1.02
KEY NOTE SPEECH w/ Ulrich Kelber
(Bundesbeauftragter für Datenschutz 2019–2024)
Datennutzung in der Medizin: Zwischen Fortschritt und Datenschutz – Die Rolle von Regulierung, Transparenz und Vertrauen?
(con traduzione simultanea)

Programme Friday, 6 June 2025

9:00 · Room F6
Lars Pithan, Daniela Riegler (Nortal AG Berlin)
X-Road and Opportunities for Crossborder Healthcare

9:45 · Room F6
Vittorio Iacovella (Università di Trento)
Data Collections are not Self-explanatory. Adopting Standard Metadata Schemas by Design Fosters Accurate Data Description, Long-term Preservation and Responsible Dissemination of Information

10:30 · Room F6
Sergiusz Kazmierski (Universität Regensburg)
Back to the Future of Medicine. Trust and Responsibility in the Hippocratic Oath

*** Coffee break ***

11:30 · Room F6
Deborah Mascalzoni (Eurac Research)
Population Studies and Biobanking: For a Strong Trusthworthy Data Ecosystem in the Val Venosta CHRIS STUDY

12:15 · Room F6
Pedro Kringen (ARCADA University Helsinki)
Z-Inspection®: Navigating the Path to Trustworthy AI

13:00 · Room F6
Stefan Gasslitter, Alessio Trazzi (SIAG Bozen)
Development of AI-driven Applications in Healthcare in South Tyrol

15:15 · Room F6
Maurizio Borghi (Università di Torino)
Clinical Trial Data in Health Care – Opening Talk for the Round Table Discussion

Round table with:
Ivo De Gennaro (Free University Bozen-Bolzano),
Ralf Lüfter (Free University Bozen-Bolzano) and the speakers of the conference

15:15 · Room F6
Final discussion and conclusions