EuCARE Brocher Workshop

19th and 20th June 2023

Data privacy, data property, and data sharing: an interdisciplinary dialogue for post-pandemic transnational research

Agenda	
Brocher Foundation, Hermance (Switzerland) - Monday 19th June 2023	
Session one	
Time	**Topic**
12:30	**Welcome Lunch**
13:30	**Registration of participants**
14:00	**Setting the scene** <u>CHAIR</u> **Francesca Incardona:** • Emerging issues in transnational biomedical research: the example of the EuCARE Project (Francesca Incardona, EuResist) • Opportunities for research with data (Anders Sönnerborg, Karolinska Institutet) • Law and scientific research: finding a common language (Giorgio Resta, Roma Tre University) • Beyond the legal limits of data sharing: ethical and societal perspectives (Mariavittoria Catanzariti, EUI)
15:00	**Coffee break**
15:15	**Panel one: Digitalisation of research and pandemics** <u>CHAIR</u> **Anders Sonnerborg:** • An overview of GDPR obligations and biomedical research (Guido Scorza, Garante per la protezione dei dati personali) • Ethics requirements in an EU-Funded research project: The case of ORCHESTRA and the role of the CCB (Ruth Davis and Lorenzo M. Canziani, University of Verona) • Patients - and other experts (Lisa Norén, Swedish COVID Patients Association) • Reflections on a multinational COVID19 project (Pontus Hedberg, Karolinska Institutet) • The human-centric approach in scientific research: ethics and/or law of data processing (Alessandro Mantelero, Polytechnic University of Turin) Q & A
17:00	**End of day one**

Brocher Foundation, Hermance (Switzerland) - Tuesday 20th June 2023	
Session two	
Time	**Topic**
9:00	**Panel one: Who "owns" data?** <u>CHAIR</u> Giorgio Resta • The lexicon of property and the data economy (Ermanno Calzolaio, University of Macerata) • Data control or data ownership? (Giovanni Maria Riccio, University of Salerno) • Beyond false dilemmas: developing innovative governance mechanism for data flows beyond the paradigms of privacy and property (Vagias Karavas, University of Lucerne) • The value of patient cohorts and databases (Francesca Incardona, EuResist) • Data ownership: Empowering Students in the Digital Age (Nadine Toye, OBESSU Board Member) **Q & A**
10:40	**Coffee break**
11:00	**Panel two: Sustainable health data sharing** <u>CHAIR</u> **Mariavittoria Catanzariti** • Models of data sharing and best practice (Gabi Rinck, European Bioinformatics Institute) • Health data sharing for scientific research (Giorgia Bincoletto, University of Trento) • Privacy preserving AI-based solutions (Nico Pfeifer, Tübingen University) • Health data and vulnerable persons (Claudia Morgana Cascione, University of Bari "Aldo Moro") **Q & A**
12:30	**Lunch**
13:30	**Panel three: Legal gaps and open issues** <u>CHAIR</u> **Francesca Incardona** • Data protection and data sharing in times of pandemics (Christopher Kuner, University of Copenhagen) • How to promote trust in scientific research (Joseph Cannataci, University of Malta) • European Technocracy and data interoperability post pandemics (Deirdre Curtin, EUI) • From data governance to European health data spaces (Vincenzo Zeno-Zencovich, Roma Tre University) **Q & A**

Brocher Foundation, Hermance (Switzerland) - Tuesday 20th June 2023	
Session two	
Time	**Topic**
15:00	**Coffee break**
15:15	Panel four: Rountable- The path towards sustainable transnational research CHAIR Vincenzo Zeno-Zencovich (All participants) Interrogation points: • GDPR and AI applications: connections and tensions • The problem of transnational research networks and data sharing beyond borders • Roles and models of ethics committees in Europe • The global reach of EU standards in healthcare • The utopia of anonymisation • The challenges of data altruism • What policy recommendations? Q & A
16:15	Reflections and discussion of workshop outcomes
16:30	**End of the workshop**

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