

EuCARE Brocher Workshop

19th and 20th June 2023

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

Sunday 18th June- 17:00-19:00 p.m- Arrival and Registration of Participants

Agenda	
Brocher Foundation, Hermance (Switzerland) - Monday 19th June 2023	
Session one	
Time	Topic
12:30	Welcome Lunch
13:30	Registration of participants
14:00	<p>Setting the scene <u>CHAIR</u> Francesca Incardona:</p> <ul style="list-style-type: none"> Emerging issues in transnational biomedical research: the example of the EuCARE Project (Francesca Incardona, EuResist) Opportunities for research with data (Anders Sönnnerborg, 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	<p>Panel one: Digitalisation of research and pandemics <u>CHAIR</u> Anders Sonnerborg:</p> <ul style="list-style-type: none"> 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) <p>Q & A</p>
17:00	End of day one

Brocher Foundation, Hermance (Switzerland) – Monday 20th June 2023

Session two

Time	Topic
9:00	<p>Panel one: Who "owns" data? <u>CHAIR</u> Giorgio Resta</p> <ul style="list-style-type: none"> • 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, OBESU Board Member) <p>Q & A</p>
10:40	Coffee break
11:00	<p>Panel two: Sustainable health data sharing <u>CHAIR</u> Mariavittoria Catanzariti</p> <ul style="list-style-type: none"> • 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") <p>Q & A</p>
12:30	Lunch
13:30	<p>Panel three: Legal gaps and open issues <u>CHAIR</u> Francesca Incardona</p> <ul style="list-style-type: none"> • 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) <p>Q & A</p>

Brocher Foundation, Hermance (Switzerland) – Monday 20th June 2023

Session two

Time	Topic
15:00	Coffee break
15:15	<p>Panel four: Rountable- The path towards sustainable transnational research <u>CHAIR</u> Vincenzo Zeno-Zencovich (All participants)</p> <p>Interrogation points:</p> <ul style="list-style-type: none"> • 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? <p>Q & A</p>
16:15	Reflections and discussion of workshop outcomes
16:30	End of the workshop

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