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EuCARE WORKSHOP
19th- 20th of June 2023

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

PROGRAMME

MONDAY 19th of JUNE

12:30 PM	Welcome Lunch	
1:30 PM	Registration of participants	
	SESSION ONE	
2:00 PM	Setting the scene - CHAIR: Francesca Incardona <ol 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) 	
3:00 PM	Coffee break	
3:15 PM	Digitalisation of research and pandemics - CHAIR: Anders Sönnnerborg <ol 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) 	Panel One
	Q & A	
5:00 PM	End of Day One	

TUESDAY 20th of JUNE

SESSION TWO		
9:00 AM	<p>Who "owns" data? CHAIR: Giorgio Resta</p> <ol style="list-style-type: none"> 1. The lexicon of property and the data economy (Ermanno Calzolaio, University of Macerata) 2. Data control or data ownership? (Giovanni Maria Riccio, University of Salerno) 3. Beyond false dilemmas: developing innovative governance mechanism for data flows beyond the paradigms of privacy and property (Vagias Karavas, University of Lucerne) 4. The value of patient cohorts and databases (Francesca Incardona, EuResist) 5. Data ownership: Empowering Students in the Digital Age (Nadine Toye, OBESSU Board Member) <p>Q & A</p>	Panel one
10:40 AM	Coffee break	
11:00 AM	<p>Sustainable health data sharing - CHAIR: Mariavittoria Catanzariti</p> <ol style="list-style-type: none"> 1. Models of data sharing and best practice (Gabi Rinck, European Bioinformatics Institute) 2. Health data sharing for scientific research (Giorgia Bincoletto, University of Trento) 3. Privacy preserving AI-based solutions (Nico Pfeifer, Tübingen University) 4. Health data and vulnerable persons (Claudia Morgana Cascione, University of Bari "Aldo Moro") <p>Q & A</p>	Panel Two
12:30 PM	Lunch	
1:30 PM	<p>Legal gaps and open issues - CHAIR: Francesca Incardona</p> <ol style="list-style-type: none"> 1. Data protection and data sharing in times of pandemics (Christopher Kuner, University of Copenhagen) 2. How to promote trust in scientific research (Joseph Cannataci, University of Malta) 3. European Technocracy and data interoperability post pandemics (Deirdre Curtin, EUI) 4. From data governance to European health data spaces (Vincenzo Zeno-Zencovich, Roma Tre University) <p>Q & A</p>	Panel Three
3:00 PM	Coffee break	

3:15 PM	<p>Roundtable: The path towards sustainable transnational research - CHAIR: Vincenzo Zeno-Zencovich <i>All participants</i></p> <p>Interrogation points:</p> <ol style="list-style-type: none"> 1. GDPR and AI applications: connections and tensions 2. The problem of transnational research networks and data sharing beyond borders 3. Roles and models of ethics committees in Europe 4. The global reach of EU standards in healthcare 5. The utopia of anonymisation 6. The challenges of data altruism 7. What policy recommendations? <p>Q & A</p>	Panel Four
4:15 PM	Reflections and discussion of workshop outcomes	
4:30 PM	End of the workshop	

