EuCARE SEMINAR on 19-20th June 2023

Data privacy, data property, and data sharing:

an interdisciplinary dialogue for post-pandemic transnational research

PROVISIONAL PROGRAMME

SUNDAY 18TH JUNE - 17:00-19:00 p.m. – ARRIVAL AND REGISTRATION OF PARTICIPANTS

MONDAY 19TH JUNE
Zoom link: https://us06web.zoom.us/j/83993765730

11:00 AM	**Arrival and registration of participants**	
12:30 PM	**Welcome Lunch**	
	SESSION ONE	
2:00 PM	**Formal welcome and introduction of seminar objectives** Emerging issues in transnational biomedical research: the example of the EuCARE Project (Francesca Incardona, EuResist)	
2:15 PM	**Setting the scene CHAIR Francesca Incardona** 1. Opportunities for research with data (Anders Sönnerborg, Karolinska Institutet) 2. Law and scientific research: finding a common language (Giorgio Resta, Roma Tre University) 3. Beyond the legal limits of data sharing: ethical and societal perspectives (Mariavittoria Catanzariti, EUI)	
3:15 PM	**Coffee break**	
3:30 PM	**Digitalisation of research and pandemics CHAIR Anders Sönnerborg** 1) Ethics requirements in an EU-Funded research project: The case of ORCHESTRA (Ruth Davis and Lorenzo M. Canziani, University of Verona) 2) Patients - and other experts (Lisa Norén, Swedish COVID Patients Association) 3) Reflections on a multinational COVID19 project (Pontus Hedberg, Karolinska Institutet) 4) An overview of GDPR obligations and biomedical research (Guido Scorza, Garante per la protezione dei dati personali) **Q & A**	**Panel One**
4:30 PM	**Debate**	**Panel Two**
4:50 PM	**End of Day One**	

TUESDAY 20ᵀᴴ JUNE

Zoom link: https://us06web.zoom.us/j/84430668711

	SESSION TWO	
9:00 AM	**Introduction of the day's panels**	
9:10 AM	**Who "owns" data? CHAIR Giorgio Resta** 1. Data control or data ownership? (Giovanni Maria Riccio, University of Salerno) 2. Beyond false dilemmas: developing innovative governance mechanism for data flows beyond the paradigms of privacy and property (Vagias Karavas, University of Lucerne) 3. The value of patients' cohorts and databases (Francesca Incardona, EuResist) 4. The human-centric approach in scientific research: ethics and/or law of data processing (Alessandro Mantelero, Polytechnic University of Turin) **Q & A**	**Panel one**
10:40 AM	**Coffee break**	
11:00 AM	**Sustainable health data sharing CHAIR Mariavittoria Catanzariti** 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. From data governance to European health data spaces (Vincenzo Zeno-Zencovich, Roma Tre University) **Q & A**	**Panel Two**
12:30 PM	**Lunch**	
13:30 PM	**Legal gaps and open issues CHAIR Francesca Incardona** 1. Data protection and data sharing in times of pandemics (Christopher Kuner, Vrije University) 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. Applying European standards to non European countries: the expansion of EU power in healthcare - (Anniek de Ruijter, Amsterdam University tbc) **Q & A**	**Panel Three**
15:00 PM	**Coffee break**	

15:15 PM	**Roundtable: The path towards sustainable transnational research**
	 CHAIR: Vincenzo Zeno-Zencovich
	 All participants
	
	 Interrogation points:
	    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 utopia of anonymisation
	    5. The challenges of data altruism
	    6. What policy recommendations?
	 Q & A
		Panel Four

16:15 PM	**Reflections and discussion of seminar outcomes**	
16:30 PM	**Formal closing**	