



DATAETHICS Summer School 2022

Big Data, Big Implications: Data Protection in Biomedicine

Hosted by the University of Barcelona
Venue: Aula Magna, UB historical Building

Hosted by:



UNIVERSITAT DE BARCELONA

	Monday, 4th July	Tuesday, 5th July	Wednesday, 6th July	Thursday, 7th July	Friday, 8th July
9:00 - 10:00	9:30 - Registration. Room: Aula Magna	S3. New challenges and opportunities posed by big DATA at the time of COVID. <i>Ciana Stoughton (EURAC Italy)</i> Discussion (20 minutes)	S7. The rare disease challenge: ELSI implications of Rare disease research <i>Deborah Mascalon (Medical University of Innsbruck)</i> Discussion (20 minutes)	S11. Creating the infrastructures to allow Data exploitation: The RD connect project <i>Sergi Beltran (CNAG)</i> Discussion (20 minutes)	Preparation for student presentations / role play
10:00 - 11:00	10:00 - Registration continues 10:20 - Welcome <i>Jordi Garcia (Vice-rector for Research, UB)</i> <i>Xavier Gosull (Eurolife Education Alliance, UB)</i> <i>Karim Lekadir & Deborah Mascalon (Directors of the Summer School)</i>	S4. AI and Big Data: Ethical and Legal Considerations <i>P.J. Will (Trinity College Dublin)</i> Discussion (20 minutes)	S8. Rare diseases and FAIR data <i>Marco Roos (Leiden University Medical Center)</i> Discussion (20 minutes)	S12. The European Data Space <i>Rosie Richards (EU dataspaz)</i> Discussion (20 minutes)	Closing Keynote A world ethical framework for progressing medicine? <i>Mahsa Shabani (UGent)</i> Discussion (15 minutes)
11:00 - 11:30	Coffee break	Coffee break	Coffee break	Coffee break	Coffee break
11:30 - 12:30	Opening Keynote Ethics and health data: the more, the better? <i>Niklas Juth (Karolinska Institutet)</i> Discussion (15 minutes)	S5. Creating the infrastructures to allow Data exploitation <i>Beysa Yaman and Kris McGinn (Trinity College Dublin)</i> Discussion (20 minutes)	S9. GDPR and Human Rights approaches for the use of data for research <i>Oriol Pujol (Univ. Barcelona)</i> Discussion (20 minutes)	S13. Infrastructure and Machine Learning allowing distributed data exploitation <i>Anne Hauschild (University Medical Center Göttingen)</i> Discussion (20 minutes)	Student role play (15 min per group) Moderator: Sieglinde Weyringer (AVaKE) Experts panned: Karim Lekadir (UB), Deborah Mascalon (MU)
12:30 - 13:30	S1. Patient's approaches in rare diseases <i>Veronika Popa (EURORDIS)</i> Discussion (20 minutes)	S6. Navigating Participant Protection and Research Promotion: the Global alliance <i>Edward Dove (University of Edinburgh)</i> Discussion (20 minutes)	S10. Genetic alliance: from the patient for the patients: engagement and participation in rare disease research <i>Jas Houwink and Rick Overkleeft (Leiden University Medical Center)</i> Discussion (20 minutes)	Open discussion on case story (students) + Student Working Group Moderators: Jean-Luc Patry and Sieglinde Weyringer (AVaKE)	Student role play (15 min per group)
13:30 - 14:45	lunch	lunch	lunch	lunch + video testimonial filming	lunch + video testimonial filming
14:45 - 15:45	S2. Which meta-ethics will AI bring for the 21st century? <i>Pierre Collet (Univ. Strasbourg)</i> Discussion (20 minutes)	Introduction to group exercise Student Working Group Moderators: Jean-Luc Patry and Sieglinde Weyringer (AVaKE)	World Café exercise Room: Capella Moderator: Sieglinde Weyringer (AVaKE)	Parallel sessions: Student Working Group (students) + Open discussion on case story (speakers) Moderators: Jean-Luc Patry and Sieglinde Weyringer (AVaKE)	Concluding remarks. Survey-evaluation. Goodbye!!
15:45 - 16:45	break	break	break	break	break
16:15 - 17:30	VAKE Introduction for students and trainers <i>Jean-Luc Patry, Sieglinde Weyringer and Sandra Santos (AVaKE)</i>	Student Working Group continues (16:00h instruction of the table hosts - separate room)	World Café exercise Room: Capella Moderator: Sieglinde Weyringer (AVaKE)	Parallel sessions: Student Working Group (students) + Open discussion on case story (speakers) Moderators: Jean-Luc Patry and Sieglinde Weyringer (AVaKE)	
17:30 - 18:30	Case Story presentation <i>Jean-Luc Patry and Sieglinde Weyringer (AVaKE)</i>	Parallel sessions: Student Working Group (students) + Open discussion on case story (speakers) Moderators: Jean-Luc Patry and Sieglinde Weyringer (AVaKE)	Social activity: Room: Capella Led by Adriana Espinet	Preparation for student presentations / role play	
		UB Historical Building visit	Social dinner. Historical Building Garden	Universität Bamberg Franz-Josef-Museum Deutsch-Französische Hochschule	Co-funded by the Erasmus+ Programme of the European Union