

Sharing Human Data for Biomedical Research: Technical, Legal and Ethical Considerations

22 February 2019 Aula 204, Dept of Biosciences, University of Milan, Via Celoria 22, 20133 Milan

Program:

10.30: The ELIXIR Beacon and GDPR: considerations, mitigations, and implementations Gary Saunders (ELIXIR Human Data Coordinator)

11.10: **The EGA beacon and other GA4GH-related projects** Arcadi Navarro (Universitat Pompeu Fabra)

11.50: **The BBMRI-ERIC code of conduct** Deborah Mascalzoni (Institute for Biomedicine, Bolzano, Centre for Research Ethics & Bioethics (CRB), Uppsala)

Lunch

14.00: GDPR and EU Regulation 536/2014 change consent to research using samples and personal data: BBMRI.it informed consent matrix Sara Casati (Milano Bicocca University) 14.40: Genetic data processing in light of the EU GeneralData Protection RegulationLuca Marelli (Centre for Sociological Research, KU Leuven)

15.20: **University Perspective?** Pierluigi Perri (Data Protection Officer, University of Milan)

Coffee

16.20: The pilot project on rare diseases in Andalusia (genomic and clinical data), database of Spanish variability with a beacon Joaquin Dopazo (Fundacion Progreso y Salud CDCA)

17.00: Somatic alterations in cancer: are they "genetic" data?

Luca Mazzarella (European Institute of Oncology)

Registration FREE at: <u>https://www.eventbrite.co.uk</u> event ID: 56099754877