

Ethical Risk Assessment in Biomedical Big Data

Brocher Foundation

Hermance, Switzerland

14-15 March 2016

Agenda

Monday, March 14 2016

8:30-9:30 **Registration**

9:30-9:45 **Welcome and Opening Remarks** - Brent Mittelstadt, University of Oxford

Session 1 - Biomedical Big Data in Practice

9:45-10:15 **Using digital health to put patients in control of their health experience** - Mike Denis - University of Oxford

10:15-10:45 **Minimal or Greater than Minimal Risk? How Research Participants and Physicians Assess Data-Sharing in Genomics – empirical data and normative implications** - Eva Winkler - University of Heidelberg

10:45-11:15 **Discussion**

11:15-11:30 **Coffee break**

11:30-12:00 **Creating disease trajectories from big biomedical data covering millions of patients** - Soren Brunak - University of Copenhagen

12:00-12:30 **Ethical Risks in Human Brain Simulation: The Practice of Ethics Management in the Human Brain Project** - Bernd Carsten Stahl – De Montfort University

12:30-13:00 **Discussion**

13:00-14:00 **Lunch**

Session 2 – Privacy

14:00-14:30 **What do people find important in the privacy protection of their digital healthcare data?** - Sara Belfrage - Karolinska Institute

14:30-15:00 **Protecting privacy through design** - Ronan Lyons - University of Swansea

15:00-15:30 **Discussion**

15:30-16:00 **Coffee break**

16:00-16:30 **Data privacy law in the post-deidentification world** - Mark Phillips - McGill University

- 16:30-17:00 **The Duty of Group Privacy in Biomedical Big Data** - Brent Mittelstadt - University of Oxford
- 17:00-17:30 **Discussion**

Evening

- 19:00 **Dinner at Restaurant Café Papon** – 1 rue Henry Fazy (directions in welcome pack)

Tuesday, March 15 2016

Session 3 - Lessons for Ethical Risk Assessment

- 9:00-9:30 **Risk-benefit assessment in big biomedical data: Reassessing concepts and mechanisms** - Effy Vayena - University of Zurich
- 9:30-10:00 **Does solidarity have a role in ethical risk assessment?** - Barbara Prainsack - King's College London
- 10:00-10:30 **Discussion**
- 10:30-10:45 **Coffee break**
- 10:45-11:15 **Big data, social inequalities in health and primary care** - Kristin Voigt – University of Oxford
- 11:15-11:45 **Big Data, Predictive Analytics in Health Care, and Research Ethics** - I. Glenn Cohen - Harvard Law School
- 11:45-12:15 **Discussion**
- 12:15-13:00 **Wrap-up panel and Closing Remarks** – Moderator: Brent Mittelstadt
- 13:00-14:00 **Lunch**