

**Ethical and social implications of public-private partnerships
in the context of genomic/big health data collection**

Big Data Institute, Oxford

4th-5th April 2023

Abstract

In our third UK-FR GENE⁺ (Genomics and Ethics Network) workshop, we would like to explore how England, France and Germany, and also other countries like Israel, address the challenge of public-private partnerships in genomic data collection, storage and transfer. More often than naught, these partnerships are perceived by patients and the public at large as lacking transparency, which creates an uncertain environment for patients/participants about what they can expect in terms of benefits, outcome, and future usage of their data. Surveys in countries with solidarity based public health care systems that are committed to benefit the good of the public, have shown that public trust in large-scale health data initiatives decreases when private, profit-driven companies come in. Indeed, when participant data leaves the initial trusted environment and transit downstream through a public-private partnership, it becomes difficult for patients/public to trust the upstream data safeguarding and future use. In this regard, our 2023 meeting proposes to further examine these partnerships and how public trust is maintained (or challenged).

Organisers: Ruth Horn, Universitites of Oxford (UK) and Augsburg (GER) and Jennifer Merchant, University of Paris 2, Institut Universitaire de France

UK-FR GENE steering-committee: Michael Parker, University of Oxford (UK); Mark Bale, Genomics England (UK); Natalie Banner, Genomics England (UK); Anne Cambon-Thomsen, CNRS (FR); Herve Chneiweiss, CNRS (FR)

Financial support: Wellcome Centre for Ethics and Humanities (WEH), Oxford (UK); Inserm Ethics Committee (FR); Institut Universitaire de France (FR); French Embassy in London (FR); University of Augsburg (GER)

Tuesday, 4th April

14:00-14:40 Welcome and Introduction (Ruth Horn and Jennifer Merchant)

Chair: Mike Parker, University of Oxford

14:40-15:20 Ruth Horn^{1,2} and Angeliki Kerasidou¹, ¹University of Oxford (UK), ²University of Augsburg (GER)
Sharing whilst caring: solidarity and public trust in a data-driven healthcare system

15:20-16:00 Natalie Banner, Genomics England (UK)
The use of Trusted Research/Secure Data Environments and the implications for perceptions of public-private partnerships and trust

16:00-16:20 Coffee



3rd UK-FR⁺ GENE Workshop

Chair: Angus Clarke, Cardiff University

- 16:20-17:00 Jennifer Merchant (FR)
French perspectives on the ethics of public-private partnerships in the realm of genomics
- 17:00-17:40 Aviad Raz & Yael Hashiloni-Dolev, Ben-Gurion University of the Negev (IL) – online via Zoom
“It has to somehow permeate to the public”: Expert Views on Public-Private Relations and Benefit-Sharing in Israel's Planned National Genomic Biobank Initiative (co-authored with Tamar Nov-Klaiman)
- 17:40-18:20 Eva Winkler, University of Heidelberg (GER)
Commercial use of patient data generated in a publicly funded healthcare system

Wednesday, 5th April

Chair: Nina Hallowell, University of Oxford

- 09:00-09:40 Barbara Prainsack, University of Vienna (AUT) – online via Zoom
Why paying individual people for their health data is a bad idea
- 09:40-10:20 Gesine Richter, Kiel University (GER)
Patients' reservations against commercial data usage in Germany
- 10:20-10:40 *Coffee*

Chair: Anneke Lucassen, University of Oxford

- 10:40-11:20 Jessica Morley, Ben Goldacre, University of Oxford (UK)
The implications of commercial use of electronic health record data
- 11:20-12:00 Jessie Dubief, EURORDIS (FR)
Share and protect our health data: rare disease patients' perspectives on data sharing with private companies
- 12:00-12:30 Conclusions and next steps (Ruth Horn, Jennifer Merchant)

VENUE:

Big Data Institute | University of Oxford

Li Ka Shing Centre for Health Information and Discovery | Old Road Campus | Oxford OX3 7LF | UK

Seminar Room 1 (please go to reception)

Old Road Campus Map: Building #11

Journey from the train station to the Big Data Institute (Ethox Centre):

- Bus 280 (Thame): Railway Station (Stop R5) to Sandfield Road
- Bus 8 (Barton): Westgate (Stop E2) to Sandfield Road

Journey from Christ Church, St Aldates to the Big Data Institute (Ethox Centre):

- Bus 15 City : High Street (Stop G2) to Old Road Campus (Stop C3)

Further information: ruth.horn@ethox.ox.ac.uk ; jennifer.merchant@u-paris2.fr

Old Road Campus Map : How to find the Big Data Institute

