

## UK-FR GENE Workshop

### Comparative Perspectives on Ethical, Legal and Social Issues of Genomics in Research and Practice

Big Data Institute, Oxford  
30th September - 1st October 2019

In 2018, France and the UK announced enhanced cooperation between Genomics England and the French ‘Médecine Génomique 2025’ project in order to deliver a global leading public genomic medicine service. The successful achievement of this aim requires the development of common approaches, not only to standardisation of the new technologies, but also to ethical standards in research and practice.

For the first time, two publically funded health care systems will imbed the use of whole genome sequencing into routine patient care; yet each system is based on different values and principles that give rise to different ways of implementing new genomic technologies into clinical practice. In order to develop common approaches to good ethical practice, we need a clear understanding of existing debates, regulations and practices, and of the underlying norms in each country.

**UK-FR GENE (Genomics and Ethics Network)** provides a platform where British and French researchers and other stakeholders in the field can reflect on ethical and social questions of genomic technologies and their clinical application that emerge in each national context. Its aim is to identify pressing ethical issues in each country and understand their socio-cultural and normative underpinnings. Exploring these issues from a comparative perspective will enable us to shed new light on them and offer potential solutions that are adapted to each context. UK-FR GENE creates an opportunity to develop joint research agendas, and collaborative projects and grant applications that will lead to important outcomes informing ethical standards in the use of genomic technologies and their implementation in clinical practice in the UK and France.

This workshop is the first of a series of workshops of our network. It provides an overview of some of the main issues raised by genomics and of the different approaches in each country. The workshop creates an opportunity to identify themes for future workshop and to develop joint research agendas, collaborative projects and joint grant applications.

#### Steering committee:

Ruth Horn (The Ethox Centre, WEH, Oxford), Marie Gaille (SPHERE, CNRS, University Paris Diderot), Michael Parker (The Ethox Centre, WEH, Oxford), Mark Bale (Genomics England), Hervé Chneiweiss (CNRS), Jennifer Merchant (University Paris 2 Panthéon-Assas), Anne Cambon-Thomsen (University of Toulouse, CNRS), Fiona Maleady-Crowe (Genomics England)



# UK-FR GENE Workshop

**Monday 30<sup>th</sup> September**

10:30-11:00 Welcome and Introduction (Marie Gaille and Ruth Horn)

## **Session 1: National initiatives in genomic research and medicine and international challenges**

*Chair: Anne Cambon-Thomsen (CNRS)*

11:00-11:30 Mark Bale, Genomics England and Franck Lethimonnier, France Médecine Génomique  
*Overview of Genomics England and France Médecine Génomique*

11:30-12:00 Edward Dove, University of Edinburgh  
*The EU General Data Protection Regulation: Implications for International Genomic Research*

12:00-12:30 James Buchanan, University of Oxford  
*Improving the health economics evidence base for genomic testing*

12:30-13:30: Lunch Break

## **Session 2: Collecting, storing and curating genomic data**

*Chair: Fiona Maleady-Crowe (Genomics England)*

13:30-14:00 Xavier Guchet, University of Technology of Compiègne  
*Biobanks in the era of Personalized Medicine*

14:30-15:00 Alexandra Soulier, University of Uppsala  
*Politicising research ethics? The case of genomic data*

14:00-14:30 Angus Clarke, University of Cardiff  
*Life World: research participants as co-constructing our knowledge of their deliberations*

15:00-15:30 Coffee Break

## **Session 3: Clinical genomics and data**

*Chair: Elizabeth Ormondroyd (University of Oxford)*

15:30-16:00 Anneke Lucassen, University of Southampton  
*The 'return' of genomic findings in healthcare: an oxymoron belying deterministic views of genetics?*

16:00-16:30 Adam Hedgecoe, University of Cardiff  
*Uncertainty of sequencing in the clinic*

16:30-17:00 Catherine Bourgain, INSERM  
*Making precision medicine doable in the clinic. Insights from a French case study*



# UK-FR GENE Workshop

Tuesday 1<sup>st</sup> October

## Session 4: Social contract, trust and privacy

*Chair: Nina Hallowell (University of Oxford)*

- 09:30-10:00 Arnaud de Guerra, French Ministry of Solidarities and Health  
*Developing consent forms and patient information sheets for genomic testing in the health care context*
- 10:00-10:30 Michael Parker, University of Oxford  
*Ethics and the social contract for genomics*
- 10:30-10:45 Coffee Break
- 10:45-11:15 Angeliki Kerasidou, University of Oxford  
*Genomics data sharing and trust*
- 11:15-11:45 Jennifer Merchant, Paris University Pantheon-Assas  
*The Concept of “Genetic Privacy” and Its Regulation: France/United Kingdom/United States*
- 11:45-12:00 General discussion
- 12:00-13:00 Lunch Break

## Session 5: Ethical issues in pre-/ neonatal genomics

*Chair: Angus Clarke (University of Cardiff)*

- 13:00-13:30 Ruth Horn, University of Oxford  
*Ethical issues of prenatal whole genome/exome sequencing: the PAGE study*
- 13:30-14:00 Marie Gaille, CNRS  
*Ethical issues related to neonatal testing and screening*
- 14:00-14:30 Carine Vassy, Paris University 13  
*Access to cell-free foetal DNA testing in France: national guidelines and economic calculations*
- 14:30-14:45 Coffee Break
- 14:45-15:15 Future directions, projects and collaborations

# UK-FR GENE Workshop

## 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 L1**

Old Road Campus Map: Building #15

Public Transport: Bus 4, 4a, 4b, 4c, U5 (from High Street/Train Station)

Please register here: <https://www.eventbrite.com/e/uk-fr-gene-workshop-tickets-73095551763>

Further information: [ruth.horn@ethox.ox.ac.uk](mailto:ruth.horn@ethox.ox.ac.uk)

## **Old Road Campus Map**

### 11) Big Data Institute

