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 30th 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

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

14:30-15:00 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 1st 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  
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

Old Road Campus Map

11) Big Data Institute