

4th UK-FR+ GENE Workshop

Value(s) of large-scale genomic initiatives

17th-18th June 2024

Big Data Institute, Oxford

Abstract:

Genomic medicine has the potential to make significant contributions to society such as improving health, and driving science, innovation and the economy. To advance the implementation of genomics into routine clinical care, large national genomic initiatives have been created in many countries, including France, England and Germany, collecting, managing and analysing large scale genomic datasets to realise the genomic project.

While there is much talk about the importance of genomics, there is little in-depth analysis of the actual value of genomics for society at a variety of levels: economic, societal, individual, clinical, and population level. This workshop proposes a structured first overview of the value(s) of large-scale genomic programmes at these levels, bringing together academics, policy-makers, and clinicians from various fields and countries.

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

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); University of Augsburg (GER); French Embassy in London (UK)

Monday, 17th June*

**Each panel consists of two 15-20 min presentations, one 5 min commentary, discussion.*

14:30 – 15:10 **Welcome and Introduction** (Ruth and Jennifer)

15:10-16:10 **Economic level**

James Buchanan (Queen Mary University of London)

Cost-effectiveness of national population sequencing initiatives

Lene Cividanes (Danish National Genome Center)

Insights, considerations and challenges on how to work with cost-effectiveness and economic impact.

Case studies of the Danish National Genome Center and the 1+ Million Genomes

Chair and Discussant: Herve Chneiweiss (CNRS)



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16:10-17:10 **Societal level**

Angeliki Kerasidou (University of Oxford)
Gaining public trust or losing it

Angus Clarke (Cardiff University)
Benefit or burden of genomic sequencing for health care services and society

Chair and Discussant: Natalie Banner (Genomics England)

17:10-17:20 **Break**

17:20-18:20 **Individual level**

Celine Lewis (University College London)
Patients' experiences of genomic sequencing: knowledge gain, decision regret, navigation of hope

Janneke Kuiper (KU Leuven)
Dealing with ambivalence in the provision of genomic healthcare

Chair and Discussant: Mike Parker (University of Oxford)

Tuesday, 18th June

09:00-09:30 **Coffee/tea**

09:30-10:30 **Clinical level**

Anneke Lucassen (University of Oxford)
The value and meaning of a genomic 'result'

Eva Winkler (University of Heidelberg)
Gains and pitfalls of precision medicine

Chair and Discussant: Liz Ormondroyd (University of Oxford)

10:30-11:30 **Population level**

Andrezj Rys (European Commission)
Achieving genomic health at EU level

Anne Cambon-Thomsen (University of Toulouse, Inserm)
The value of genomic sequencing for public health programmes

Chair and Discussant: Mark Bale (Senior policy advisor)

11:30-12:00 **Wrap-up and Farewell** (Jennifer and Ruth)



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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:

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

