GENE Workshop V:

(In)equity in the context of large-scale genomic programmes

Ethox, Big Data Institute Building, Oxford, 15th-16th December 2025

Abstract:

In our 2024 **Genomics and Ethics Network (GENE) workshop** entitled 'The value of large-scale programmes in human genomics', we highlighted the importance of taking into account the different kinds of benefits of genomics at various levels of society when implementing large-scale genomics programmes. Despite the important insights regarding these benefits that were gained at the workshop, we established that more in-depth analyses of the benefits and limits of genomics within each of the levels discussed are needed. Until these are accomplished, a translational path for the benefits of genomics to reach clinical practice remains incomplete, and thus questions the return of benefits to ***all*** groups and communities of society. Alongside further analyses of values and benefits, the need for a renewed focus on the issue of **equity in the context of genomic medicine** has emerged.

In this new workshop, GENE proposes to take this task seriously and explore various aspects of in-/equity that emerge within the context of large-scale genomics programmes, and the benefits or shortcomings these imply for all groups of society, including marginalised groups.

This requires looking at those communities deprived of equitable access to genomic medicine in a number of realms. Hence, the topics of our workshop shall include: representative and diverse genetic data resources; access to adequate genomic testing/diagnoses and healthcare; continuous social security safety net during and after treatment; extended family care if needed; lifespan care and follow-up in tandem with new genomic discoveries.

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

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

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Programme

Monday, December 15th

14:00-14:30 **Welcome & Introduction** (Ruth Horn, Jennifer Merchant)

Session 1: Equity in genomic medicine (Chair: Angeliki Kerasidou, University of Oxford)

14:30-15:15 **Barbara Prainsack** (University of Vienna): 'Solidarity and its role for equity and inequity in genomics'

15:15-16:00 **Angus Clarke** (Cardiff University): 'The tension between the individual and the collective aspects of genomics: How does this play out for public health, welfare and equity?'

16:00-16:30 Coffee & Tea Break

Session 2: Equity and collective responsibility (Chair: Mike Parker, University of Oxford)

16:30-17:15 **Anne Cambon-Thomsen** (Inserm, University of Toulouse): 'Emerging and evolving values in the changing landscape of genomics'

17:15-18:00 **Emmanuelle Génin** (Inserm, University of Bretagne Occidentale): 'The challenge of a reference population in Genomic medicine'

Tuesday, December 16th

Session 3: Equity, engagement and involvement (Chair: Herve Chneiweiss, Inserm Ethics Committee)

09:00-09:45 **Fiona Maleady-Crowe** (Our Future Health, UK), Harriet Etheredge (Genomics England): 'Diversity and engagement with minority groups'

09:45-10:30 **Eva Winkler** (University of Heidelberg): 'Patient Involvement and Representation in the Governance of Genomic Data Archives: Methodological challenges for fair and equal access'

10:30-11:00 Coffee & Tea Break

Session 4: Equity in the clinic (Chair: Anneke Lucassen, University of Oxford)

11:00-11:45 **Mike Parker** (University of Oxford): 'Equity and timeliness as factors in the effectiveness of an ethical prenatal sequencing service: Reflections from parents and professionals'

11:45-12:30 **Helena Carley** (University of Oxford, NHS): 'Ancestry, race and ethnicity: the role and relevance of language in clinical genetics practice'

12:30-12:50 **Wrap-up summary** (Mark Bale, Our Future Health; Mike Parker; Natalie Banner)

12:50-13:00 **Conclusion & Farewell** (Jennifer Merchant, Ruth Horn)

VENUE:

Big Data Institute | University of Oxford
Li Ka Shing Centre for Health Information and Discovery | Old Road Campus | Oxford OX3 7LF | UK

LG Seminar Room 1 (please go to reception)
Old Road Campus Map: Building #11

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Old Road Campus Map