

## Genetics, Genomics and Global Health – Inequalities, Identities and Insecurities

4<sup>th</sup> Annual Global Health Conference  
18 July 2014  
University of Sussex Conference Centre  
Brighton, United Kingdom

### Programme

9:30 – 10:00	Arrival and Registration
10:00 – 10:15	<p><b>Opening Remarks:</b></p> <p><b>Melanie Newport</b>, Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research</p>
10:15 – 11:15	<p><b>Keynote Lecture:</b></p> <p><u>Chair:</u></p> <p><b>Stefan Elbe</b>, Director, Centre for Global Health Policy</p> <p><u>Keynote Speaker:</u></p> <p><b>Andrew Lakoff</b>, Associate Professor of Sociology, Anthropology and Communication, University of Southern California</p> <p><i>"Antimicrobial Assemblages: Global Health in a Molecular Age"</i></p> <p>This talk will analyse tensions that have emerged as the new techniques of molecular biology have been applied to the broad problem-area of "global health." It begins by distinguishing between two normative orders within global health: humanitarian biomedicine, which focuses on treating existing diseases afflicting populations in the developing world; and global health security, which prepares for the onset of potential future diseases that might afflict members of the advanced industrial world. The techniques of molecular biology do not have a unitary effect on the field of global health; rather, their impact depends on the normative order to which they are applied. The talk will focus on a series of recent global health controversies to elaborate this argument.</p>

11:15 – 12:45	<p><b>Plenary Panel – Genetics, Genomics &amp; Global Health:</b></p> <p><u>Panel Chair:</u></p> <p><b>Margaret Sleebloom-Faulkner</b>, Director, Centre for Bionetworking</p> <p><u>Speakers:</u></p> <p><b>Helen Wallace</b>, Director, GeneWatch UK, <i>‘Genomics: realities and mirage’</i></p> <p><b>Frederick C. Dubee</b>, Member of the Advisor Board and Honorary Professor, BGI; Senior Officer in the Executive Office of the Secretary General, United Nations, <i>‘Bioscience and the post 2015 Development Agenda’</i></p> <p><b>Caitriona McLeish</b>, Co-Director of the Harvard-Sussex Programme on Chemical and Biological Weapons</p>
12:45 – 1:45	Lunch (provided)
1:45 – 3:15	<b>1<sup>st</sup> Concurrent Panel Session:</b>
	<p><b>Panel 1. Closing the Gap in Health Inequalities – is Genomics Part of the Solution?</b></p> <p><u>Panel Organisers:</u></p> <p><b>Melanie Newport</b>, Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research</p> <p><b>Michael Hopkins</b>, Senior Lecturer, SPRU (the Science Policy Research Unit), University of Sussex</p> <p><u>Panel Chair:</u></p> <p><b>Melissa Leach</b>, Director, Institute of Development Studies</p> <p><u>Speakers:</u></p> <p><b>Audrey Duncanson</b>, Senior Portfolio Developer, The Wellcome Trust, <i>‘H3Africa: levelling the genomics playing field?’</i></p> <p><b>Michael Hopkins</b>, Senior Lecturer, SPRU (the Science Policy Research Unit), <i>‘Is the ‘genomics revolution’ really is having a revolutionary impact on healthcare, even in HICs?’</i></p> <p><b>Stuart Hogarth</b>, Wellcome Trust Senior Research Fellow, Kings College London, <i>‘Prospects for molecular based diagnostics in LIC’</i></p>

Abstract:

Unprecedented scientific and technological advances in genetics and genomics research have led to the elucidation of the human genome sequence and characterisation of the variation within it between individuals and populations. Whilst many anticipate that this knowledge will underpin major improvements in human health there are also concerns that it could widen the existing health equity gap between high-income countries (HICs), where the majority of genomic research has taken place, and low- and middle- income countries (LMICs) which disproportionately bear the burden of poor health yet have least access to the benefits of medical research. Research done in HICs is often not relevant to LMIC populations because of geographically differing disease epidemiology or because data generated in HIC populations cannot be extrapolated to LMIC populations even for diseases that have a global distribution, as biological and social determinants of disease will vary. However, what is the evidence that the genomics revolution really is having a revolutionary impact on healthcare, even in HICs? Is there a need to be more sanguine about the incremental nature of major technological advances? Is it ethical to invest in expensive technology when established low-cost life-saving interventions are still not being implemented in many LMIC settings? This panel will examine the implications of such disparities for socio-economic and health inequalities and debate interventions, from genomics capacity building initiatives such as Human Health and Heredity in Africa (H3Africa), an NIH-Wellcome Trust initiative that supports genomics research in Africa, to a radical re-think of the models for advancing genomic medicine.

**Panel 2: Personal Genome Project (PGP)-UK and Genetic Privacy**

Panel Organiser:

**Margaret Sleebloom-Faulkner**, Director, Centre for Bionetworking

Panel Chair:

**Margaret Sleebloom-Faulkner**, Professor of Social and Medical Anthropology, Department of Anthropology, University of Sussex

Speakers:

**Frederick C. Dubee**, Member of the Advisor Board and Honorary Professor, BGI; Senior Officer in the Executive Office of the Secretary General, United Nations, *'What if George Church is right?'*

**Stephan Beck**, Professor of Medical Genomics and Director, PGP-UK, UCL Cancer Institute, University College London, *'PGP-UK: Personal Genome Project UK'*

**Helen Wallace**, Director, GeneWatch UK, *'Personal Genome Project (PGP)-UK and genetic privacy'*

**Donna Dickenson**, Emeritus Professor of Medical Ethics and Humanities, University of London, *'Me Medicine vs. We Medicine'*

Abstract:

Genomic information can reveal the potential of individuals to develop a certain condition. Due to worries about the privacy of individuals, families and social groups, various regulatory tools have been developed to protect the genetic privacy of individuals: the Bermuda Principle and Fort Lauderdale Declaration (1996-2003) and the UNESCO Universal Declaration on Human Data (2003). But new developments make it hard to implement these ideals, also in the UK. In December 2012, David Cameron announced the 100K Genome Project, which aims to sequence the genome of 100K patients within 5 years. Ethical protocol was to protect the privacy of patients. But now Britain is also opening up the NHS to commercially used genome sequencing through the Personal Genomics Project (PGP). Thus, last November, Stephan Beck (UCL) announced the establishment of a British Personal Genome Project (PGP-UK), which will recruit volunteers to provide DNA and health data with no restrictions on their use. This panel discusses the protection of the privacy of individuals who have entrusted genomic data to PGP-UK, in the light of (1) the impossibility of total privacy protection when genetic data are stored online, as they can be triangulated with other information; (2) the broad consent used by international consortia sharing data and large population studies; and (3) the ability of direct to consumer companies such as 23andMe and deCODEme to trade genetic information of rare conditions of individuals. What does privacy mean anno 2014?

**Panel 3. Manipulated Microbes: Genetics, Genomics and Global Health Security**

Panel Organiser:

**Stefan Elbe**, Director, Centre for Global Health Policy

Panel Chair:

**Jan Selby**, Director, Sussex Centre for Conflict and Security Research

Speakers:

**Christian Enemark**, Reader, Department of International Politics, Aberystwyth University, *'Mutated microbes, biosecurity and regulatory reach: dilemmas in governing technology transfers'*

**Rebecca J. Hester**, Assistant Professor of Social Medicine, Institute for the Medical Humanities, University of Texas Medical Branch, *'How Much (Bio) Security is Too Much?: Ethics, Life Science Research, and the H5N1 Controversy'*

**James Revill**, Research Fellow, SPRU (Science and Technology Policy Research), University of Sussex, *'Just because you're paranoid doesn't mean it can't get you'; security and synthetic biology in the 21st Century'*

**Stefan Elbe, Christopher Long, Anne Roemer-Mahler**, Centre for Global Health Policy, *'Pharmaceuticals and security: The role of public-private collaborations in strengthening global health security'*

	<p><u>Abstract:</u></p> <p>Advances in our understanding of genetics are generating new concerns about global health security. Scientific gain-of-function research on enhancing the transmissibility of lethal influenza viruses (such as H5N1 and H7N9) has provoked widespread contestation about whether such research should be undertaken, under which conditions, and what risks it poses to the wider international community. High-level and acrimonious diplomatic confrontations have been sparked about whether countries have an obligation to share genetic sequence data from newly emerging viruses with other countries, and which rules should govern the scientific and commercial exploitation of such data. Within the context of bioterrorism, further concern still has surfaced about the deliberate genetic manipulation of lethal microorganism in ways that would be difficult to detect and very challenging to treat with existing therapies. All the while the technologies for manipulating genes is becoming more widely available, with high school and amateur bio-hacking groups now routinely experimenting on microorganisms – raising the possibility of accidents. This panel explores the implications of the rise and proliferation of synthetic biology for global health security. What are the new threats to global health security that are emerging? Are such threats exaggerated or underappreciated? How can these new insecurities best be managed in the twenty-first century?</p>
3:15 – 3:45	Tea and refreshment break
3:45 – 5:15	<b>2<sup>nd</sup> Concurrent Panel Session:</b>
	<p><b>Panel 4. Emerging Molecular Diagnostics – What are the Challenges to Widespread Implementation?</b></p> <p><u>Panel Organisers:</u></p> <p><b>Melanie Newport</b>, Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research</p> <p><b>Michael Hopkins</b>, Senior Lecturer, SPRU (the Science Policy Research Unit), University of Sussex</p> <p><u>Panel Chair:</u></p> <p><b>Paul Nightingale</b>, Professor of Strategy, SPRU (the Science Policy Research Unit), University of Sussex</p> <p><u>Speakers:</u></p> <p><b>Edward D Blair</b>, PhD MBA, Integrated Medicines Ltd, Cambridge, UK, <i>‘Value-based diagnostics in high income countries’</i></p> <p><b>Martin Colla</b>, Programme Director Asia, Cepheid High Burden &amp; Developing Countries, <i>‘Xpert MTB/Rif: Delivering MDx to LMICs’</i></p> <p><b>Annie Wilkinson</b>, Post Doctorate Researcher, Institute of Development Studies, University of Sussex, <i>‘Bringing precision medicine to low resource health systems: new diagnostics for Lassa fever in Sierra Leone’</i></p>

Abstract:

Advances in genomics have led to hopes that new diagnostic tools will allow an era of 'personalised' or 'stratified' medicine, with molecular diagnostics being used to facilitate provision of more effective interventions, avoiding adverse drug reactions and targeting expensive therapies to patients who are most likely to benefit from them. Low and middle-income countries (LMICs) theoretically could benefit most from novel diagnostics and drugs developed by pharmacogenomics guidance given the high disease burden. However, these technologies require substantial infrastructures to support them in terms of laboratories, trained clinicians, and regulatory frameworks, all of which have taken longer than expected to develop, even in high-income countries (HICs). Furthermore, it is recognised that populations across the world and even within countries exhibit great genetic diversity, for example harbouring unique allele frequencies and novel genetic variation in pharmacogenetically relevant genes (e.g. of antiretroviral drugs where genetically determined adverse effects are well described) adding an extra layer of complexity when considering 'roll-out' of such tests. This session will explore the drivers of - and challenges for - the introduction of molecular technologies in higher and lower income countries. Do these countries face different challenges in adopting these new technologies? Will tests and drugs developed in HICs be suitable for LMICs? How can healthcare systems adapt to use new diagnostic technologies in an affordable way, whilst ensuring quality?

**Panel 5. Genetic Discrimination and Genetic Identities in Non-Western Societies**

Panel Organiser:

**Margaret Sleebloom-Faulkner**, Director, Centre for Bionetworking

Panel Chair:

**Carrie Heitmeyer**, Postdoctoral Researcher, Department of Anthropology, University of Sussex

Speakers:

**Achim Rosemann**, Postdoctoral Researcher, Department of Anthropology, University of Sussex, *'The Genetic Study of Violence and Aggression: Trends and Challenges for the Social Sciences'*

**Kato Masae**, Postdoctoral Researcher, Department of Anthropology, University of Sussex

**Prasanna Kumar Patra**, Postdoctoral Research Fellow, Department of Anthropology, University of Sussex, *"Screening Cultures": Population genetic screening and emerging healthcare inequalities among tribal and marginalized communities in India'*

**Suli Sui**, Associate Professor, Peking Union Medical College, PRC, *'Genetic discrimination and its related issues in China - from the perspective of the 'first case on genetic discrimination''*

Abstract:

Genomics initially focused on mapping the 'human genome', emphasising human sameness. But most developments in the field, including personal genomics, epigenomics, and metagenomics, produce knowledge about the interplay between genetic and environmental factors, and the differences between human genomes. Since the 1990s, the frameworks of international bioethics and Ethical, Legal, and Social Implications (ELSI) have defined the ethical and social governance of genetic sampling and banking. But debates on genomics and society, widely held in the US and Europe, have triggered questions about 'genetic discrimination' and the responsibilities associated with 'genetic awareness' and 'genetic citizenship'. Although genetic information has provided many patients and families with important health knowledge, and is invaluable to research, drug screening and drug prescription, genetic information is also used to define ethnicity, disease, and socio-psychological abnormality. Here, widely shared public concerns include the ways in which socio-economic groups such as employers, insurance companies, schools, local communities, families and politicians genetically appraise potential subjects. This panel explores the ways in which genetic sampling and data have become factors in newly defining the identity of human groups, their rights and their livelihoods in non-Western societies. The panel draws on the experience of researchers with genetic sampling, genetic identity formation and genetic citizenship among ethnic communities and patient groups in China, India, South America and Japan.

**Panel 6. Bioinformation Economies: Benefits and Insecurities for Genomic Global Health**

Panel Organiser:

**Alex Faulkner**, Reader, Centre for Global Health Policy, University of Sussex

Chair:

**Gemma Buckland-Merrett**, Research Fellow, Centre for Global health Policy, University of Sussex

Speakers:

**Amy Hinterberger**, Assistant Professor, Department of Sociology, University of Warwick, *'Genomic and Viral Sovereignty: Tethering the Materials of Global Biomedicine'*

**Phoebe Li**, Lecturer, Law, University of Sussex, *'Inequality and intellectual property: Patenting genetic diagnostics methods after Myriad'*

**Louise Bezuidenhot**, Associate Research Fellow, EGENIS, University of Exeter, *'Barriers to openness: contrasting the access to, with the accessibility of, data in South Africa and UK'*

**Alex Faulkner**, Reader, Centre for Global Health Policy, University of Sussex, *'Bioinformatics in India: markets, practices and genomic policy'*

**Chiara Garattini**, Researcher, Intel Health & Life Sciences, *'User experience and bioinformatics: computing tools for a 'hybrid' science'*

	<p><u>Abstract:</u></p> <p>The principle of just and equitable sharing of benefits from the exploitation of genetic resources was established by the Convention on Biological Diversity in 1992, pre-dating the unravelling of the human genome. The case of the licensing of the Icelandic population’s genome map to American company deCode Genetics subsequently provoked controversy about the commercialisation of genetic and genomic information, launching unending debates about ownership, participation, consent, social responsibility and governance. Yet the escalation of digital data and internet communication applied to biological material pushes the ‘big data’ of the life sciences to an unprecedented scale, acutely heightening and complicating these conflicts about benefits, rights, commodification, access and profitability in bio-data. Placing these developments under the spotlight of Global Health, this session discusses the following issues arising for bioinformation economies: the changing regimes of intellectual property rights and patenting; open access, global scientific publication norms and corporate databanks; political alignment of genomic biobanks and databases with national identity projects; biopiracy and theft; new structures of ownership and data re-processing; corporate secrecy and trade secrets; threats to gene donor privacy. What are the recent developments in these issues across the globe and in transnational bionetworks, and how can they be addressed to advance global health objectives?</p>
5:15 – 5:30	<p><b>Closing Comments:</b></p> <p><b>Melanie Newport</b>, Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research</p>
5:30 – 6:30	<p>Wine reception and Book Launch of <i>Global Morality and Life Science Practice in Asia – Assemblages of Life</i> by Margaret Sleeboom-Faulkner. The book is introduced by <b>Donna Dickenson</b>.</p>
6:30	<p>End of Conference</p>