Annual Conference 2014

# Genetics, Genomics and Global Health

## Inequalities, Identities and Insecurities

**Date:** 18th July 2014
**Time:** 9:30am–6:30pm

**Venue:** Conference Centre
University of Sussex

For more information and details of how to register, please visit:
**www.sussex.ac.uk/globalhealthpolicy**

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Annual Conference

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

**Scientific advances in our understanding of genetics and genomics may generate major improvements for human health in the coming decades. From a global health perspective, however, the translation of genomics into new medical treatments also raises profound international and local issues around inequality, identity and insecurity:**

## Inequalities

The development of novel gene-based therapies could further widen the gap in health outcomes between high-income countries, and low- and middle- income countries. Many people living in low- and middle- income countries bear a disproportionate burden of disease and premature mortality from avoidable causes compared to other world regions; and yet they also currently have least access to the benefits of medical research through healthcare delivery systems. Many such countries do not have the capacity to undertake their own genetic research on important endemic diseases, and scientific research is often not undertaken for the direct benefit of those communities, or even transferable to them. What will be the implications of such disparities for socio-economic and health inequalities? What are the global health access challenges around genetic and genomics-based therapies? What is the complex role that low- and middle-income countries play in the rise of genomic medicine today?

## Identities

The genetic and genomic information generated in the search of biomedical advances plays into an array of shifting individual and social identities. Genetic information has already provided many patients and families with important health knowledge and is increasingly central to research, drug screening and drug prescription – including the promise of 'personalised' medicine. Yet genetic information is also used to define ethnicity, disease, and socio-psychological abnormality. At stake here are not just the ways in which people identify themselves subjectively as persons or groups in terms of ethnicity, health, and character; the way in which socio-economic groups such as employers, insurance companies, schools, local communities, families, public administrations and politicians appraise subjects and make decisions about them also has become a major concern to those subjected to 'genetic appraisal'. The recently established Personal Genome Project-UK (PGP-UK) exemplifies the uncertainties and controversies around commercialisation and privacy associated with genomics. What are the ethical, political and socio-economic issues prompted by the politics of genetic health?

## Insecurities

The rise of genetic and genomic knowledge generates concern about sources of vulnerability and insecurity. The ability to genetically manipulate organisms provokes fears around the accidental – or even intentional – release of new, genetically modified organisms that could dramatically threaten public health. Commercial and civil liberty sensitivities also arise given that bioinformation has become an invaluable resource not just for life science research, but is rapidly emerging as a lucrative commodity. For citizens, moreover, additional insecurities arise from the fact that genetic data of patients and healthy citizens have become a controversial source of data mining, and may be especially problematic when health records are linked to genetic data. What are the newly created sources and forms of insecurity generated by the accumulation of biological samples and the storage of genetic data in laboratories, biobanks, cohorts, companies, repositories and databases? What is the regulatory and policy response?

**This interdisciplinary one-day conference brings together experts from the fields of policy, research, industry, foundations, journalism, and non-governmental organisations in order to assess how the rise of genetic and genomic challenges has begun to shape to the field of global health, and what new challenges it poses for global health policy.**

## Key questions to be addressed on the day include:

- What can be done to address issues of inequality, insecurity and discrimination based on genetic and genomic information?
- What role do low- and middle- income countries play in genomics?
- How can genomic research be used to improve global health equity?
- Why is there unequal access to genetic technology and genomic research?
- What is the scope of interdisciplinary collaboration in genomic global health?
- What are the healthcare challenges of genomic developments?

## Who Should Attend?

- Pharmacogenomics companies researching and developing medicines used in global health
- Companies and research institutes involved in genomic sequencing, genomic banking, and diagnostics
- Policy makers from government and international organisations concerned about access to, and regulation of, medicines
- Social scientists analysing the social, economic, political, legal, security, cultural and ethical aspects of genomics
- Non-governmental organisations dedicated to improving drug safety, personal genomics, genetic counseling, genetic diagnostics and public health
- Foundations, donors, research funders and scientists interested in new models of innovation, diagnostics, and drug screening
- Media, reporters and journals covering genomics, large genomic data collections, genetic diagnosis, genetic privacy and genetic discrimination

## Why Should You Attend?

- Learn about and share the latest thinking on access to medicines and pharmaceutical innovation in global health
- Network with other experts and leaders on pharmaceuticals in global health drawn from industry, government, research, non-governmental organisations, and the media
- Tailor your day by selecting from a range of themed and specialised panels on access, innovation, regulation, intellectual property, ethics, and health security/protection

# Programme

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| 9:30 -10:00 | Arrival and registration |
| 10:00 – 10:15 | Opening remarks<br>**Melanie Newport**, Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research |
| 10:15 – 11:15 | **Keynote Lecture:**<br>**Chair:**<br>**Stefan Elbe**, Director, Centre for Global Health Policy<br>**Keynote Speaker:**<br>**Andrew Lakoff**, Associate Professor of Sociology, Anthropology and Communication, University of Southern California |
| 11:15 – 12:45 | **Plenary Panel:**<br>**Genetics, Genomics & Global Health**<br>**Panel Chair:**<br>**Margaret Sleebloom-Faulkner**, Director, Centre for Bionetworking<br>**Speakers:**<br>**Helen Wallace**, Director, GeneWatch UK<br>**Frederick C. Dubee**, Member of the Advisor Board and Honorary Professor, BGI; Senior Officer in the Executive Office of the Secretary General, United Nations<br>**Cathy Roth** (TBC), Scientific Policy Advisor, Office of the Assistant Director-General, Health Security and the Environment Cluster, World Health Organization |
| 12:45 – 1:45 | Lunch (provided) |
| 1:45 – 3:15 | **1st Concurrent Panel Session:**<br>**Panel 1**<br>**Closing the Gap in Health Inequalities – is Genomics Part of the Solution?**<br>**Panel 2**<br>**Personal Genome Project (PGP)-UK and Genetic Privacy**<br>**Panel 3**<br>**Manipulated Microbes: Genetics, Genomics and Global Health Security** |
| 3:15 – 3:45 | Tea and refreshment break |
| 3:45 – 5:15 | **2nd Concurrent Panel Session:**<br>**Panel 4**<br>**Emerging Molecular Diagnostics – What are the Challenges to Widespread Implementation?**<br>**Panel 5**<br>**Genetic Discrimination and Genetic Identities in Non-Western Societies**<br>**Panel 6**<br>**Bioinformation Economies: Benefits and Insecurities for Genomic Global Health** |
| 5:15 – 5:30 | Closing Comments<br>**Melanie Newport**, Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research |
| 5:30 – 6:30 | Wine reception and Book Launch of *Global Morality and Life Science Practice in Asia – Assemblages of Life* by Margaret Sleeboom-Faulkner. The book is introduced by Donna Dickenson |
| 6:30 | End of conference |

# Speakers and Participants

## Keynote speaker

**Professor Andrew Lakoff**
Professor Andrew Lakoff is Associate Professor of Sociology, Anthropology and Communication at the University of Southern California, where he directs the Research Cluster in Science, Technology and Society. He is the author of *Pharmaceutical Reason: Knowledge and Value in Global Psychiatry* (Cambridge UP, 2005), co-editor of *Global Pharmaceuticals: Ethics, Markets, Practices* (Duke UP, 2006) and *Biosecurity Interventions: Global Health and Security in Question* (Columbia UP, 2008), and editor of *Disaster and the Politics of Intervention* (Columbia UP, 2010). His current research concerns the articulation of global public health and national security expertise around the problem of emerging infections. This research focuses on the genealogy of techniques of preparedness as they have migrated from Cold War military defence to other domains such as public health and disaster management.

## Chair

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

## Confirmed Speakers and Participants (Selected)

**Stephan Beck**
Professor of Medical Genomics and Director, PGP-UK, UCL Cancer Institute, University College London

**Louise Bezuidenhot**
Associate Research Fellow, EGENIS, University of Exeter

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

**Martin Colla**
Programme Director, Asia, Cepheid High Burden & Developing Countries

**Edward D Blair**
PhD MBA, Integrated Medicines Ltd

**Donna Dickenson**
Emeritus Professor of Medical Ethics and Humanities, University of London

**Frederick C. Dubee**
Member of the Advisor Board and Honorary Professor, BGI; Senior Officer in the Executive Office of the Secretary General, United Nations

**Audrey Duncanson**
Senior Portfolio Developer, The Wellcome Trust

**Stefan Elbe**
Director, Centre for Global Health Policy, University of Sussex

**Christian Enemark**
Reader, Department of International Politics, Aberystwyth University

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

**Chiara Garattini**
Researcher, Intel Health & Life Sciences

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

**Rebecca J Hester**
Assistant Professor of Social Medicine, Institute for the Medical Humanities, University of Texas Medical Branch

**Amy Hinterberger**
Assistant Professor, Department of Sociology, University of Warwick

**Stuart Hogarth**
Wellcome Trust Senior Research Fellow, Kings College London

**Michael Hopkins**
Senior Lecturer, SPRU (the Science Policy Research Unit), University of Sussex

**Andrew Lakoff**
Associate Professor of Sociology, Anthropology and Communication, University of Southern California

**Melissa Leach**
Director, Institute of Development Studies, University of Sussex

**Phoebe Li**
Lecturer, Law, University of Sussex

**Christopher Long**
Centre for Global Health Policy, University of Sussex

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

**Melanie Newport**
Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research

**Paul Nightingale**
Professor of Strategy, SPRU (the Science Policy Research Unit), University of Sussex

**Prasanna K Patra**
Postdoctoral Researcher, Department of Anthropology, University of Sussex

**James Revill**
Research Fellow, SPRU (the Science Policy Research Unit), University of Sussex

**Anne Roemer-Mahler**
Centre for Global Health Policy, University of Sussex

**Achim Rosemann**
Postdoctoral Researcher, Department of Anthropology, University of Sussex

**Cathy Roth (TBC)**
Scientific Policy Advisor, Office of the Assistant Director-General, Health Security and the Environment Cluster, World Health Organization

**Margaret Sleebloom-Faulkner**
Director, Centre for Bionetworking, Professor of Social and Medical Anthropology

**Suli Sui**
Associate Professor, Peking Union Medical College, PRC

**Helen Wallace**
Director, GeneWatch UK

**Annie Wilkinson**
Post Doctorate Researcher, Institute of Development Studies, University of Sussex

# Panel themes

## 1

### Closing the Gap in Health Inequalities – is Genomics Part of the Solution?

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.

## 2

### Personal Genome Project (PGP)-UK and Genetic Privacy

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?

## 3

### Manipulated Microbes: Genetics, Genomics and Global Health Security

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?

# 4

## Emerging Molecular Diagnostics – What are the Challenges to Widespread Implementation?

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?

# 5

## Genetic Discrimination and Genetic Identities in Non-Western Societies

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.

# 6

## Bioinformation Economies: Benefits and Insecurities for Genomic Global Health

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?