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
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:

- 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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<tr>
<th>Time</th>
<th>Session详情</th>
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<tr>
<td>9:30 - 10:00</td>
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| 10:00 – 10:15 | Opening remarks  
**Melanie Newport**, Director, Wellcome Trust Brighton and Sussex Centre for Global Health Research |
| 10:15 – 11:15 | Keynote Lecture:  
**Chair**: Stefan Elbe, Director, Centre for Global Health Policy  
**Keynote Speaker**: Andrew Lakoff, Associate Professor of Sociology, Anthropology and Communication, University of Southern California |
| 11:15 – 12:45 | Plenary Panel: Genetics, Genomics & Global Health  
**Panel Chair**: Margaret Sleeboom-Faulkner, Director, Centre for Bionetworking  
**Speakers**: Helen Wallace, Director, GeneWatch UK  
Frederick C. Dubee, Member of the Advisor Board and Honorary Professor, BGI; Senior Officer in the Executive Office of the Secretary General, United Nations  
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:  
Panel 1: Closing the Gap in Health Inequalities – is Genomics Part of the Solution?  
Panel 2: Personal Genome Project (PGP)-UK and Genetic Privacy  
Panel 3: Manipulated Microbes: Genetics, Genomics and Global Health Security |
| 3:15 – 3:45 | Tea and refreshment break |
| 3:45 – 5:15 | 2nd Concurrent Panel Session:  
Panel 4: Emerging Molecular Diagnostics – What are the Challenges to Widespread Implementation?  
Panel 5: Genetic Discrimination and Genetic Identities in Non-Western Societies  
Panel 6: Bioinformation Economies: Benefits and Insecurities for Genomic Global Health |
| 5:15 – 5:30 | Closing Comments  
**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 |
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 Pharmaceauticals: Ethics, Markets, Practices* (Duke UP, 2006) and *Biosecurity Interventions: Global Health and Security in Question* (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 Bezuidenhout
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
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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 Sleeboom-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
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 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 in 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?
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?

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.

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 bioworks, and how can they be addressed to advance global health objectives?