Genetics, Genomics and

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University of Sussex
Centre for Global Health Policy

Annual Conference

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

Scienti c 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 bene ts 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 scienti c research is often not undertaken for the direct bene t 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 de ne 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) exempli es 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 modi ed 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 elds 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 eld of global health, and what new challenges it poses for global health policy.

Key questions to be addressed on the day include:

- 8IBU DBO CF EPOF UP BEESFTT JOFRVBMJUJFT BOE EJTDSJNJOBUJPO CBTFE PO HFOFUJD BOE HFOPNJD JOGPSNBUJPO?
- 8IBU SPMF EP MPX BOE NJEEMF JODPNF countries play in genomics?
-)PX DBO HFOPNJD SFTFBSDI C improve global health equity?
- 8IZ JT UIFSF VOFRVBM BDDFTT technology and genomic research?
- 8IBU JT UIF TDPQF PG JOUFSE collaboration in genomic global health?
- 8IBU BSF UIF IFBMUIDBSF DIBM genomic developments?

Who Should Attend?

- 1IBSNBDPHFOPNJDT DPNQBOJF and developing medicines used in global health
- $PNQBOJFT BOE SFTFBSDI JOT in genomic sequencing, genomic banking, and diagnostics
- 1PMJDZ NBLFST GSPN HPWFSO international organisations concerned about access to, and regulation of, medicines
- 4PDJBM TDJFOUJTUT BOBMZTJ economic, political, legal, security, cultural and ethical aspects of genomics
- /PO HPWFSONFOUBM PSHBOJT to improving drug safety, personal genomics, genetic counseling, genetic diagnostics and public health
- 'PVOEBUJPOT EPOPST SFTFB and scientists interested in new models of innovation, diagnostics, and drug screening
- .FEJB SFQPSUFST BOE KPVSO genomics, large genomic data collections, genetic diagnosis, genetic privacy and genetic discrimination

Why Should You Attend?

- -FBSO BCPVU BOE TIBSF UIF M on access to medicines and pharmaceutical innovation in global health
- /FUXPSL XJUI PUIFS FYQFSUT pharmaceuticals in global health drawn from industry, government, research, non-governmental organisations, and the media
- 5BJMPS ZPVS EBZ CZ TFMFDUJ themed and specialised panels on access, innovation, regulation, intellectual property, ethics, and health security/protection

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

Con rmed 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 Of cer in the Executive Of ce 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)
Scienti c Policy Advisor, Of ce 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

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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. Scienti c gain-of-function research on enhancing the transmissibility of lethal in uenza 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 scienti c 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 dif cult 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- rst 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 ‘strati ed’ 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 bene t from them. Low and middle-income countries (LMICs) theoretically could bene t 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,