Panels

The day will consist of two parallel panels, each parallel panel will have 3 panels.

First cycle

Panel 1: Personal Genome Project (PGP)-UK and genetic privacy

Panel organiser: Professor Margaret Sleeboom-Faulkner

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 American company 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 companies such as 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 2: Manipulated Microbes: Genetics, Genomics and Global Health Security

Panel organiser: Professor Stefan Elbe

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 become more widely available, with high school and amateur bio-hacking groups now routinely experimenting of 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?

Panel 3: Closing the gap in health inequalities – is genomics part of the solution?

Panel organisers: Professor Melanie Newport and Dr Michael Hopkins

There have been unprecedented scientific and technological advances in genetics and genomics research which are anticipated by many to translate into major improvements for human health. Potential outcomes include early and more accurate diagnosis, the development of new drugs and 'personalized medicine'. There are concerns that these advances will 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 LIMC populations even for diseases that have a global distribution, e.g. due to varying prevalence of genetic differences across populations.

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.

Second cycle

Panel 4: Bioinformation Economies: benefits and insecurities for genomic global health

Panel organiser: Dr Alex Faulkner

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?

Panel 5: Genetic Discrimination and Genetic Identities in Non-Western Societies

Panel organiser: Professor Margaret Sleeboom-Faulkner

Genomics initially focused on mapping the 'human genome', emphasizing 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, Social and Issues (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: Emerging molecular diagnostics – what are the challenges to widespread implementation? Regulation/harmonization

Panel organisers: Dr Michael Hopkins and Professor Melanie Newport

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 which have taken longer than expected to develop even in high income countries (HICs) (Hopkins et al. 2006).

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 (Tutton et al. 2008).

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?