On Friday 18th July 2014 an interdisciplinary one-day conference brought together experts from the fields of policy, research, industry, foundations, journalism, and non-governmental organisations at the University of Sussex for the 4th Annual Global Health Conference on “Genetics, Genomics and Global Health – Inequalities, Identities and Insecurities”. It was co-organised by the University of Sussex Centre for Global Health Policy, the Wellcome Trust – Brighton and Sussex Centre for Global Health Research, the Centre for Bionetworking with support from the

Context

Scientific advances in our understanding

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?

The new challenges genomics and genetics pose for global health policy raises a number of ethical, political, social and economic questions and there is considerable concern as to how this will the shape the future of global health.

Keynote Address and Plenary Panel: Genetics, Genomics and Global Health

In his keynote address (Antimicrobial Assemblages: Global Health in a Molecular Age), **Andrew Lakoff**, University of Southern California, explored the impact of the new techniques of molecular biology (genetics and genomics) on global health policy. He started by noting a critical disjuncture in that the world of genomics is still predominantly geared towards the ageing population of the wealthy world, whereas global health policy tends to focus on the developing world, is frequently underfunded and largely under the purview of development agencies. In terms of gauging the impact of genetics and genomics on global health policy the first question to consider, therefore, is what exactly do we mean by global health? Yet looking more closely at 'global health' reveals not a singular field, but at least two different normative orders or regimes: (1) humanitarian biomedicine, which focuses on treating existing diseases afflicting populations in the developing world; and (2) global health security, which prepares for the onset of potential future diseases that might afflict members of the advanced industrial world, and which has witnessed recent controversies exemplifying the necessary considerations of the impact of genetics and genomics on these fields. Take the example in Buenos Aires where population blood samples were taken for genetic research to spot genetic tendencies for developing bipolar disorder despite the fact there were no people with bipolar disease in Buenos Aires.

The emerging infectious disease field, moreover, provides us with two examples of how genetic information has generated new controversies of an ethical, political and economic nature. The issue of 'viral sovereignty' arose during the H5N1 crisis, during which Indonesia refused to share genetic samples of the virus with the WHO based on grounds of equity for low- and middle-income countries divided the global health arena. To some it was undermining global health efforts and putting lives at risk, to others it was a demonstration of a need for more transparent, equitable and fair virus sharing. As a result the new WHO Pandemic Influenza Preparedness framework has acknowledged the principle of sovereignty. In addition, the uncovering of ties between global health agencies and

both editions is that to lessen the long-term attractiveness of using disease as a weapon of war, investment should be made in certain measures within existing public health needs and resources. Underlying this suggestion is the understanding that the same scientific and technical know-how that can be used to open up new opportunities for chemical and biological warfare can also provide defences against potential use. This is an example of “dual-use”. One dilemma created by dual use is, how can we ensure that technology progresses for legitimate purposes whilst ensuring improper use does not occur? A universally accepted definition of what constitutes “dual use” does not exist. How then, are we to identify potential dual use concerns if we cannot agree on what we mean by the term? Traditional top-down policies are insufficient for dealing with dual use issues, so states have engaged with the scientific community and encouraged bottom-up activities such as codes of conduct. These activities still require an inherent understanding of what dual use is and the ability to recognise it. Currently,

for neglected diseases. Duncanson presented data on the nature of health inequalities in impoverished African countries and was careful to explain that genomics remained just one, relatively expensive tool in the fight against a wide range of diseases, that placed a high burden on African societies. Duncanson also highlighted that these countries faced not just health inequalities but also inequalities in access to scientific expertise, with few scientists trained in molecular biology in Africa and a risk of a scientific ‘brain drain’. Duncanson introduced a major genomics capacity building

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Margaret Sleeboom-Faulkner

Stephan Beck
Professor at UCL and leader of PGP-UK

deCODEme to trade genetic information of rare conditions of individuals.

Stephan Beck, in his presentation pointed out that the governance of PGP-UK is still evolving, and was frank about the project's policy not to promise anonymity. Instead, participants are informed about the risk of identification from the genetic data generated by PGP-UK that is stored in public databases, such as the European Bioethics Institute (EBI). For this reason, potential participants are asked to undergo an exam consisting of 27 questions based on a 21-page study guide to test their awareness about PGP-UK and the consequences of donating their DNA-sample. Just one wrong answer means that they will not be able to donate their DNA to PGP-UK. Beck also emphasized the great value of sequencing the whole genome of individuals and the widespread sharing of personal health and genetic data to the development of medicine. Helen Wallace, maintained that not guaranteeing the privacy of genetic data is problematic, as UK Governments have supported plans for the NHS to sequence and store the genome of every baby at birth guaranteeing the anonymity of individuals, and their family relationships. Wallace therefore proposed a third position based on the gradual introduction of genomic information into the NHS in limited areas of expected clinical utility. The benefits of storing and sharing data, then, could be balanced against the downsides, including privacy and costs, and public trust in genomic technologies could be more easily maintained. In contrast with market approaches, Wallace argues, this position supports the tradition of a public health system, which prioritises need. Fred Dubee, asked 'What if George Church is right?', exploring key tensions of genetic governance in an environment in which it becomes effectively impossible to protect the privacy of genetic information. Is it possible in such an environment, he asked, to envisage a governance approach that ensures that the legitimate and dynamic imperatives and goals of all involved can be achieved? Donna Dickenson, answers 'yes'. To achieve a compromise between a genuinely public entity such as UK Biobank and the private biobank maintained by 23andMe?', Dickenson points out, we need to follow a Charitable Trust model, which can introduce a more democratic and trustworthy alternative to model followed by PGP-UK. Such a model does not engage in commercial transaction, and emphasizes the return of the benefits of research to the contributors. The PGP-UK, with its appeal to altruistic values expressed in the slogan 'We love the people behind the data', according to Dickenson, follows a business strategy reliant on maintaining lifelong 'relationships' with participants. This strategy would enable it to collect the epidemiological data that maximises commercial value to a genomic biobank.

Building on the H5N1 discussion, panelists also reflected more broadly about how advances in biology now shape the way we understand

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Margaret Sleeboom-Faulkner

Prasanna Patra
University of Utkal, India; Centre for Bionetworking, University of Sussex

Achim Rosemann
Centre for Bionetworking, University of Sussex

Masae Kato
Centre for Bionetworking, University of Sussex

Suli Sui
Peking Union Medical College; Centre for Bionetworking

Genomics initially focused on mapping the 'human genome', emphasizing human sameness. 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. Nevertheless, debates on genomics and society, widely held in the US and Europe, have triggered questions about 'genetic discrimination' and the responsibilities associated with 'genetic citizenship'. This panel explored the ways in which genetic sampling and data are utilized to newly define the identity of human groups, their rights and livelihoods in diverse societies, including India, Japan the USA and China.

Prasanna Patra illustrated how in tribal India genetic screening malfunctions in cultures of discrimination, depending on background factors such as education, healthcare and tradition. For instance, genetic profiling of sickle cell disease lead to the stigmatisation of individuals and ethnic groups among the Agaria caste group in Sundargarh district of Orissa, which has a 20.5% prevalence rate. The community is stigmatised for its 'unethical and immoral marriage practices among close relatives' by its neighbouring communities.

The shortage of follow-up healthcare and counselling further traps the community in the 'therapeutic gap'. Discussing research in genetics and the neurosciences regarding the biological origins of violence and aggression, Achim Rosemann showed how an increasing number of genetic and neurobiological factors are now associated with the emergence of forms of violent, antisocial and criminal behavior. Comparing scientific trends in the USA and China, two leading countries in genetic research with strict laws and punishments of criminal offenders, Rosemann convincingly argued that the ability to predict and prevent violence is likely to lead to new forms of discrimination and social exclusion of individuals with a particular genetic make-up. In her presentation on genetic testing and the family in Japan, Masae Kato showed how marriage and reproduction become primary problems when a genetic disorder is diagnosed in Japan. Its importance lies in the great value attached in Japanese tradition to the 'family household'. Thus 'flaws in the family line' becomes an issue of bad stock, linked to traditions of ancestor worship. In this view, past immoral behaviour of family members is associated with genetic abnormality, and raises the question of a person with genetic abnormality should have children at all. For this reason, says Kato, 65% of pregnant women visit their family grave: to invoke the protection of ancestor spirits. Suli Sui analyzed China's first legal court case of genetic discrimination. In 2009, Mr Xie, 22 years old, passed a civil service examination as condition for an appointment. But after compulsory genetic and health tests showed him to be a carrier of Thalassemia, he was refused the position. Subsequently, Xie started a court case, arguing that he was in excellent health, evidenced by his time in the army and blood donation. Nevertheless, in 2010, the courts put the council in the right twice. This, Sui argues, sends the wrong message to society, and seems to vindicate genetic discrimination also in other areas, such as in spouse selection and insurance.

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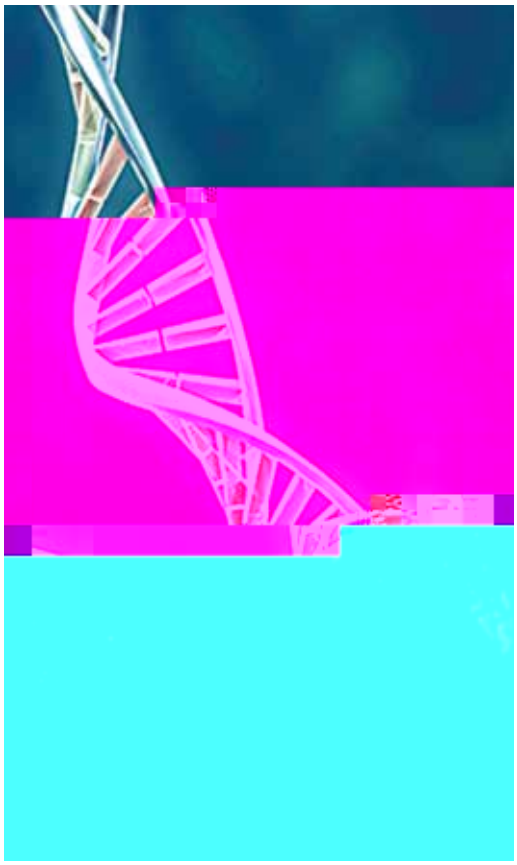
flu virus, and the spread of national claims of ‘sovereignty’ in large scale data projects such as ‘the Mexican genome’. Hinterberger, drawing on co-authored work with Natalie Porter (New Hampshire), argued that national states appeals to sovereignty ‘tether’ biological materials and data to national identity and political projects



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University of Sussex
Centre for Global Health Policy

Further Information

School of Global Studies
University of Sussex
Brighton BN1 9SJ

T +44 (0)1273 876615

E globalhealthpolicy@sussex.ac.uk

www.sussex.ac.uk/globalhealthpolicy

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