Conference Report

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

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Summary

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 European Research Council, the Global Health Working Group of the British International Studies Association, and the Galton Institute. Following a keynote and plenary panel on 'Genetics, Genomics and Global Health' participants divided into groups to debate specific topics – including global health gaps, genetic privacy, global health security, molecular diagnostics, genetic identities and bioinformation economies. The general format was for invited experts to give short presentations, followed by wider discussion with the audience. The diversity of disciplines represented coupled with the theme ensured lively and thought-provoking discussion and a number of key points emerged from the day.

Key points

1. Genetics and genomics could prove transformational for global health in the coming decades by generating new opportunities for diagnosing, treating and managing a number of communicable and non-communicable diseases. However, at least two critical barriers remain for low- and middle-income countries: (1) comparatively little research focuses upon locally relevant diseases, taking into local genetic variation and conditions in low-income countries; (2) the high cost of many technologies – which are principally developed through private sector and commercial involvement – makes access to most of these technologies prohibitively expensive for low-income countries.
2. A decade after the first human genome was successfully sequenced, we are gaining a much more nuanced and fine-tuned picture about which diseases genetic and genomic information may help address in future. It is also becoming clear, however, that the impact of genetics and genomics on global health will not be uniform; rather it will likely vary across different diseases as well as different areas of global health – such as humanitarian biomedicine, population health, and global health security.
3. Realising the potential global health benefits of genetic and genomic information will require difficult balances to be struck in the years ahead, including: (1) between the commercial interests driving the advancement of new health technologies versus protecting the privacy of people's genetic and genomic information; and (2) between investing in new capacity for genetic and genomic technologies in low-income countries versus spending on more affordable but well-established technologies with a proven track record in improving global health, as well as on the wider social determinants of health.
4. The impact of genetics and genomics on global health will depend not just on the technologies themselves, but also on the wider social, political, and economic contexts in which new technologies are adopted and/or adapted. In particular, the process of producing genomic information will likely have profound implications for the way in which health care data will be structured and formatted in future, so as to better facilitate its triangulation with genetic data. That process will have potentially far-reaching social consequences – consequences for which societies are not yet fully or even well prepared.
5. Despite the likely long-run benefits of genetics and genomics for global health, history cautions that the introduction of new technologies are also often accompanied by new risks. Here there are dangers that new information about life at the genetic level could be put to nefarious use, or that even well intentioned scientific research on lethal diseases could lead to an accidental release of a dangerous pathogen. Harnessing genetic and genomic knowledge for the advancement of global health will thus have to navigate carefully between realizing the social benefits whilst minimizing possible new dangers.

Conference Resources

Panel videos: www.sussex.ac.uk/globalhealthpolicy/events/conferences/annualconference2014/panelvideos
Photographs: www.sussex.ac.uk/globalhealthpolicy/events/conferences/annualconference2014/photographs
Video blog: www.sussex.ac.uk/globalhealthpolicy/events/conferences/annualconference2014/videoblog
Social media: www.sussex.ac.uk/globalhealthpolicy/events/conferences/annualconference2014/twitter

Conference Organisers

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Centre for Global Health Policy

Guiding questions

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?

Context

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?

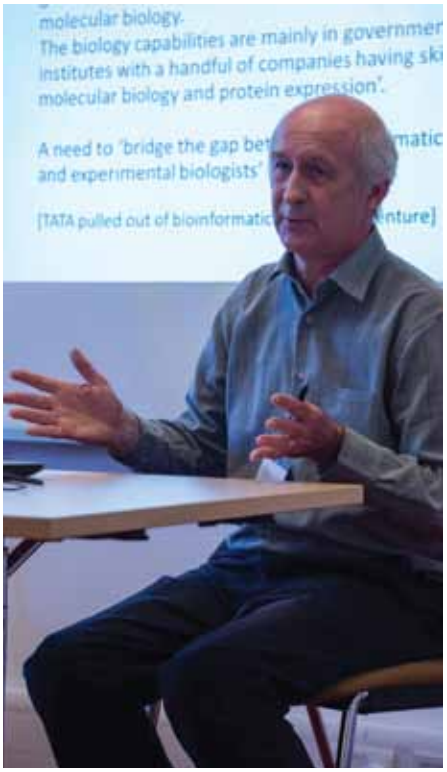
The new challenges genomics and genetics pose for global health policy raises a number of ethical, political, social and economic questions and there is considerable concern as to how this will the shape the future of global health.

Gemma Buckland Merrett

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 pharmaceutical corporations consisting of contractual agreements to secure national stocks of vaccines in preparation for the H1N1 influenza outbreak further exposes the disconnect between the two global health regimes. There was a surfeit of medicines for H1N1 in the



global north, and the US only used half of the vaccines that they had ordered, consequently countries tried to offload their surplus on to developing countries. In this case biomedical humanitarianism loses out to global health security and indeed fuels the criticism that whilst the spending on pandemic scenarios whose evidence base is weak continues, only lip service is paid to the great killers currently affecting global health. These cases indicate that bridging the gap of scientific advances and addressing issues of global health is a fragile antimicrobial assemblage requiring a dedicated political awareness. Addressing the global health problems requires harmonization across these varying regimes, which is not only a technical problem, but an ethical and political one. However, the co-existence of these two regimes of global health also means that the techniques of molecular biology are not having a unitary effect on the field of global health; rather, their impact depends on the normative order to which they are applied.

The plenary panel took up many of these themes. **Helen Wallace**, Director at GeneWatch UK, raised the issue of genomic risk prediction for non-communicable diseases and presented the insecurities it could lead to. There is both a technology-led commercial approach and a medical-led approach; however, it is important to stress not only the genuine limit this research has in predicting disease risk but more importantly the permanent biological link between your body and any stored data which could ensue from such research. Such information could serve as an immensely powerful tool for states to identify you and also people related to you. Anonymisation of genetic information like this is practically impossible. There are also a host of privacy issues implicit to widespread data-sharing; access to medical records and genomes will be sold to private companies. Privacy will no longer exist and could perpetuate stigma, this poses worrying implications for developing countries where sexuality and ethnicity could be stored on records and used to negatively target individuals. Safeguards would be hard to enforce. Moreover, there would be shifting focus from disease prevention to medicalization rather than concentrating on behaviour change to improve health. As such, this means already limited resources will be diverted from other health priorities to support this genomics research. There should be a more focused approach rather than a blanket approach which has security risks and not many benefits.

Frederick C. Dubee, Member of the Advisor Board and Honorary Professor, BGI; Senior Advisor United Nations Global Compact Office, United Nations, focused on the post-2015 bioscience agenda and the need to set future goals as "one world" goals moving "from great for some to effective for all" and "from reactive to proactive". We need to use the information we have available – creating integrated systems based on availability of personal electronic health records. Key points are accessing the latest technologies (especially diagnostics), applying biomedical research discoveries, altering the balance (over time) between prevention and treatment. He argues that we should view medicine as an informational science. There are too many silos and the sharing of data and ideas needs to be faster, however, can the current state of governance cope?

Caitriona McLeish, Senior Fellow at SPRU and co-director of the Harvard Sussex Program on Chemical and Biological Weapons discussed the WHO technical guidance on public health responses to chemical and biological weapons. The first set of guidance was published in 1970, thirty years later they produced a second edition, updated to reflect the changes in science, technology and geopolitics. What is suggested in

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, there is uneven knowledge, uneven interest and uneven application of 'dual use' measures; why for example did Ebola aerosolization research not receive the same attention as influenza virus gain-of-function experiments?

Panel 1: Closing the Gap in Health Inequalities – is Genomics Part of the Solution?

Michael Hopkins

Audrey Duncanson
Senior Portfolio Developer,
The Wellcome Trust

Michael Hopkins,
The Science Policy Research Unit (SPRU), University of Sussex

Stuart Hogarth
Wellcome Trust Senior Research Fellow, Kings College London

Anticipated advances in genetic and genomic knowledge that bring major improvements in human health also bring concerns that such advances 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?

Audrey Duncanson opened the session by highlighting the promise of genomics for African countries, and in particular the ways in which genomic research could feed into efforts to better understand the epidemiology of disease in African populations and develop treatments 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 initiative – Human Health and Heredity in Africa (H3Africa), an NIH-Wellcome Trust initiative that supports genomics research in Africa, which was discussed as being an important first stage in developing a research base to begin to bring genomics to bear on the health challenges of Africa.

Michael Hopkins sought to put the "genomics revolution" in historical context by referring to patterns seen during industrial revolutions, such as the slow, incremental nature of technological advance, and the high costs of organisational and societal changes that are needed to facilitate new technologies to become economically viable. Given these costs, particularly in the early decades of a promising technology, Hopkins questioned whether genomics offered an effective solution to the disease burdens of developing countries, particularly given that the types of healthcare intervention to which the highest health gain are attributed in the UK (e.g. smoking cessation, use of Aspirin, statins) have nothing to do with genomics. Where genomics had yielded new drugs, these remain prohibitively expensive. An area where genetics has had longer impact is genetic testing however the means by which diagnostic tests are adapted to local use and evaluation of local population (health economic and epidemiological research) are themselves expensive and the equitable delivery genetic testing remains a challenge for the healthcare systems even of well provisioned Western countries.

Stuart Hogarth continued the discussion on genetics and diagnostics, focusing on the case of tests for HPV infection used in screening for cervical cancer and tests for breast cancer prognosis. Hogarth highlighted how genetic technology opened up testing applications related not just to the genome we inherit, but to the detection of somatic mutations in cancers and the genomes of pathogens. The latter was emphasised to be a major source of revenue for diagnostics firms, some of which have been patenting biomarkers (including, but not limited to, genes), and charging high prices for new tests, raising fears that health inequalities related to genomics could become a problem not just for low income countries but also for high income countries. Hogarth outlined a trend – the pharmaceuticalisation of diagnostics – drawing on the case of HPV tests developed by a US biotech firm, Digene. These tests offer an alternative to the Pap test, long used in cervical cancer screening, but reliant on expensive laboratory infrastructures and also an error prone technology. In the USA HPV testing has been protected by a patent monopoly and has been widely sold using pharmaceutical style marketing tactics. However the commercial development of HPV testing has also led to a cheaper way to deliver cervical cancer screening which has been advanced through a public private partnership, yielding a low cost testing that can be used in developing country settings, recently approved for use in China. In another case, US firm Genomic health has developed a prognostic test for breast cancer cancer which has a sale price of over $4000. This test was recently deemed too expensive to use in the NHS prompting fears that the fruits of genomics are too expensive to use even in high income countries.

Panel 2: Personal Genome Project (PGP)-UK and Genetic Privacy

Margaret Sleeboom-Faulkner

Stephan Beck
Professor at UCL and leader of PGP-UK

Helen Wallace
Director of GeneWatch UK

Fred Dubee
Honorary Professor at the Beijing Genomics Institute (BGI, Shenzhen, China)

Donna Dickenson
Emeritus Professor at the University of London

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, 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, Prime Minister David Cameron announced the 100K Genome Project, which aims to sequence the genome of 100K patients within five years. Ethical protocol was to protect the privacy of patients. But Britain now has started opening up the NHS to both academic and commercially researchers. Last November, Stephan Beck (University College London, 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 discussed the protection of the privacy of individuals who have entrusted genomic data to PGP-UK, the broad consent used by international consortia sharing data and large population studies, and the ability of direct to consumer companies such as 23andMe and

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.

Panel 3: Manipulated Microbes: Genetics, Genomics and Global Health Security

Stefan Elbe

Christian Enemark
Department of International Politics, Aberystwyth University

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

James Revill
SPRU, University of Sussex

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

How are advances in our understanding of the genetics and genomics of pathogens also generating new concerns about global health security? The ongoing controversy around scientific experiments that deliberately alter the genetic make-up of influenza viruses to make them more easily transmissible attracted particular attention by this interdisciplinary panel. Such 'gain-of-function research' has already provoked widespread contestation about whether this kind of research should be undertaken, under which conditions, and what risks it poses to the wider international community. Yet an underappreciated aspect of this controversy are the complex and ongoing legal questions it has given rise to in terms of the applicability of European regulations concerning the export of dual use materials. Specifically, an unresolved issue remains whether – for legal purposes – the research conducted on H5N1 constitutes 'basic' or 'applied' research, and who ultimately has the authority to make that determination. The panel also noted recent concerns about laboratory safety reported in the United States, as well as the changing composition of the National Science Advisory Board for Biosecurity (NSABB) that was announced in the days before the conference.

Building on the H5N1 discussion, panelists also reflected more broadly about how advances in biology now shape the way we understand security, seek to secure populations, and even fight wars. At a deeper level, the rise of genetics, genomics and the life sciences is thus generating difficult policy dilemmas about how much (bio) security is too much, and how we will know when we have achieved enough security?

Moving into the adjacent sphere of bioterrorism, the panel further discussed how the proliferation of synthetic biology – both in terms of its global spatial distribution and the growing number of people practicing it – raises new challenges for countering the threat of bioterrorism. However, panelists felt the question of overall balance was key. Some panelists found that even though there is much 'hype' around the threat of bioterrorism, this does not mean that there are not also difficult underlying challenges in this area that need addressing.

With that point in the mind, the panel concluded with an overview of how governments have been trying to manage this problem – in part – through the development of new medicines and medical countermeasures. The key point to emerge here is that the rise of genetics and genomics is not only shaping threat perceptions in the area of health security, but also giving rise to new medical countermeasures for protecting populations against health-based threats – encouraging what one panelist referred to as the 'pharmaceuticalization' of security policy. However, governments have also been encountering considerable obstacles in this area because in developing such medicines they are reliant on inputs from pharmaceutical and biotech companies. Those companies, in turn, face significant challenges in developing medical countermeasures because of high opportunity costs, low profit margins and uncertain market forecasts. Attempts to bridge this gap through the creation of public-private partnerships has revealed a significant number of tensions, stimulating interest in new business models for more effectively incentivizing the commercial development of medical countermeasures. Overall, the panel and discussion thus found considerable evidence that the rise of genetics and genomics is beginning to profoundly shape our understandings, logics and practices of security in the twenty-first century.

Panel 4: Emerging Molecular Diagnostics – What are the Challenges to Widespread Implementation?

Melanie Newport

Eddie Blair
Integrated Medicines Ltd, Cambridge, UK

Martin Colla
Programme Director Asia, Cepheid High Burden and Developing Countries

Annie Wilkinson
Institute of Development Studies, University of Sussex

This panel explored how advances in molecular diagnostics (MDx) made possible by advances in genomics could potentially benefit those living in low and middle income countries (LMICs). The advantages seem obvious but many questions arise. Is it feasible to develop the infrastructure to support MDx in LIMCs? What is the relevance of tests developed in high income countries (HICs) to populations living in LMICs? What regulatory frameworks are required and how might they differ from those in HICs?

Eddie Blair spoke about 'the development of value-based diagnostics in HICs'. Increasing demand for healthcare from aging and emerging markets drives a need for earlier diagnosis that could lead to better treatment outcomes. Many stakeholders are involved: healthcare providers, industry, governments, regulators, payors and patients. The market model for pharmaceuticals is moving from a 'one size fits all' approach where drugs are cheap but not always effective and there is a high risk of serious adverse events, to a model where expensive drugs are targeted to specific patients determined by predictive tests. The assessment of MDx value was discussed. Also, even if new MDx lead to better health outcomes will health services pay the high prices that are inevitable? Another question arising was whether diagnostic tests developed in HICs can be applied in LMIC where population genetic structure is different. Finally, does early diagnosis lead to health benefits rather than just identifying individuals who are at risk but healthy.

Martin Colla gave his perspectives on 'delivering MDx to LMICs' drawing on the Xpert MTB/Rif test which can diagnose tuberculosis (TB), including rifampicin-resistant TB. The WHO identified a gap in TB testing technology and the Xpert MTB/Rif test was developed based on existing chemistry. The advantages of Xpert MTB/Rif are that it is quicker than and as sensitive as culture, yet requires less technical expertise. It is near patient, can quickly detect rifampicin-resistance and can be stored at room temperature. However, it is more costly. An interesting equality point was made: whilst access to Xpert became available in LIMCs in 2010, it was not available in the USA until 2013. Cepheid also developed the instrument required to do the test, which is scalable (i.e. the system can grow with increasing testing needs) and can be used for other MDx. Although the initial cost was high at $22, with support from donors it is now <$10. As a result of the implementation of this technology, TB, drug resistant TB and HIV case detection has increased.

Annie Wilkinson described her research into the delivery of 'precision medicine' to LMIC health systems: 'new diagnostics for Lassa fever in Sierra Leone (SL)'. She focused on three questions: how do new and improved diagnostics get integrated into health systems, particularly in LIMCs? How will this transition come about? Will new diagnostics really lead to the revolution being predicted? Annie argued that the case of Lassa fever is extreme but it highlights the need for focusing beyond the technology to the social aspects of introducing MDx. Diagnostics are important for Lassa fever as mortality rates are significantly reduced if diagnosed and treated early. HICs are interested in developing diagnostics for Lassa fever because of the bioterrorism threat associated with the virus. This has meant millions of dollars of research have been conducted in Sierra Leone on Lassa fever. However, this biodefense funding has been very limited in scope and is directed towards diagnostic kits which can be used and sold anywhere. Their selling point is that they require minimal infrastructure but Annie argues that this means the broader 'diagnostic system' has been neglected. Sierra Leone's very limited public health facilities were highlighted as were social and cultural issues around health-seeking behaviour and the role of money and social connections needed to get to a health facility. An important area of discussion was whether funds should be invested in high-tech diagnostics when the public health facilities were so lacking. Revolutions in health systems are unlikely to be possible without more attention to the social side of diagnostic systems.

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

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.

Panel 6: Bioinformation Economies: Benefits and Insecurities for Genomic Global Health

Alex Faulkner

Phoebe Li
Law, University of Sussex

Louise Bezuidenhout
EGENIS, University of Exeter

Amy Hinterberger
Sociology, University of Warwick

Alex Faulkner
Centre for Global Health Policy, University of Sussex

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The escalation of digital data and internet communication around biological materials acutely heightens and complicates social and political conflicts about benefits, rights, commodification, property regimes, societal access, consent, social responsibility and profitability. A major theme highlighted across the 5 speakers in this session was that of *data property regimes* and *inequality of access* to data. Phoebe Li discussed the patenting issues in *Mayo v Prometheus* and *Myriad* court cases in the US , arguing that because companies are moving from patents to trade secrets as an intellectual property (IP) strategy, with a negative effect on data, governments should be more active in promoting other routes such as early access and licensing. Louise Bezuidenhout challenged the practicality of open access regimes by considering the infrastructures and cultures required to benefit in some low- and middle income (LMIC) countries. She argued that a range of skills, resources, equipment, institutionally-granted autonomy and cultural dispositions are required to avoid 'data poverty', also questioning whether data-driven research meets local genomic research priorities. Notions of data property were also discussed by Amy Hinterberger noting Indonesia's recent controversial assertion of ownership of an avian 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 in a 'primordial' form of property claim that steps outside the economies of IP. Alex Faulkner described the commercial and academic actors and government policies around bioinformatics in India, also showing strong elements of claims and plans to advance national identity projects and political centralisation as well as disease agendas important to the country. He proposed that the major bioinformatics research activity in India currently takes place in elite academic institutions and that in general the commercial sector is tending, though not exclusively, toward outsourcing of database, sequencing and analysis services rather than drug discovery work. The expertise required to advance biomedical and genomic data informatics is a global issue, and this was a major focus of Chiara Garattini's ethnographically-based discussion of bioinformatics' user experience and computing tools. Pointing to the speed of innovation in computing technology, Garattini shed light on the skills and cultural approaches needed to investigate this 'hybrid science'. Discussing the intricacies and needs for software to be integrating and integrated to constant innovation in hardware infrastructures, she advocated an understanding of the ontological implications of data curation and culturally localised 'ecosystems' of data. She suggested that in the global arena more attention should be paid to local strategies and populations in order to comprehend the knowledge inequalities represented in global bio-data exchanges. Group discussion raised important issues including the global salience of US court decisions, the link between medicines approval and scientific publication, dangers of trade secrets around informatics algorithms, the international competition in the genome sequencing market, the inequitability of funding bodies between western-LIMIC states, availability of patented bioinformatic tools, and conflicts of national sovereignty versus patenting approaches to innovation. Looking to the future, the alignment of bio-data projects to national and/or disease agendas, and the skills and sociotechnical infrastructures required for societally beneficial exploitation of biological data, stood out as major issues for further development and action to advance global health goals.

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