

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

4<sup>th</sup> Annual Global Health Conference

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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 issues around inequality, identity and insecurity:

1. 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-countries play in the rise of genomic medicine today?

2. 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 is 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?

3. 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 the field of global health, and what new challenges it poses for global health policy. Key questions to be addressed (on the day) include:

- 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 & genomic research?
- What is the scope of interdisciplinary collaboration in genomic global health?
- What are the healthcare challenges of genomic developments?