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Designing Post-Genomic Future Together

Brief communication in response to the publication of the UK Government report “Genomics Beyond Healthcare”

Robert Chapman¹, Yulia Kovas², Fatos Selita³

On January 26, 2022 the UK government released a report: “Genomics Beyond Healthcare”⁴. This 198-page document considers ways in which genomic research may impact our lives outside the realm of healthcare. It provides a comprehensive overview of advances in genetics, and what they may mean for people.

It is predicted that in the next few decades during the post genomic era individuals’ genetic information will be used in all spheres of life, including medicine, family, employment, education, insurance, sports, justice systems and policing. This prediction is reflected in the report, which expands the previous focus on health and medicine. The publication of the report is a great development because it examines use of genetics in a wide range of contexts and discusses both potential benefits and risks. Potential benefits and harms brought by genetic advances are also explored in a recent book ‘Oedipus Rex in the Genomic Era’⁵. The book examines, in the light of genetic knowledge, themes that date back for millennia such as free will, fate and chance; prediction, misinterpretation

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⁴Government Office for Science. *Genomics Beyond Health*. <https://www.gov.uk/government/publications/genomics-beyond-health> (2022).

⁵ Kovas, Y. & Selita, F. *Oedipus Rex in the Genomic Era: Human Behaviour, Law and Society*. (Palgrave Macmillan UK, 2021).

and the burden that comes with knowledge of the future; self-fulfilling and self-defeating prophecies; the forces that contribute to similarities and differences among people; roots and lineage; and decision making and judgement of oneself and others. It examines existential, social, ethical, and legal concerns and dilemmas introduced by the genomic era highlighting the relevance of behavioural genetics across humanities, social and life sciences. Much more work is needed to assess implications of using genetics in different contexts, including unexplored areas such as gaming and entertainment, persuasion and decision making, and gene-based life design.

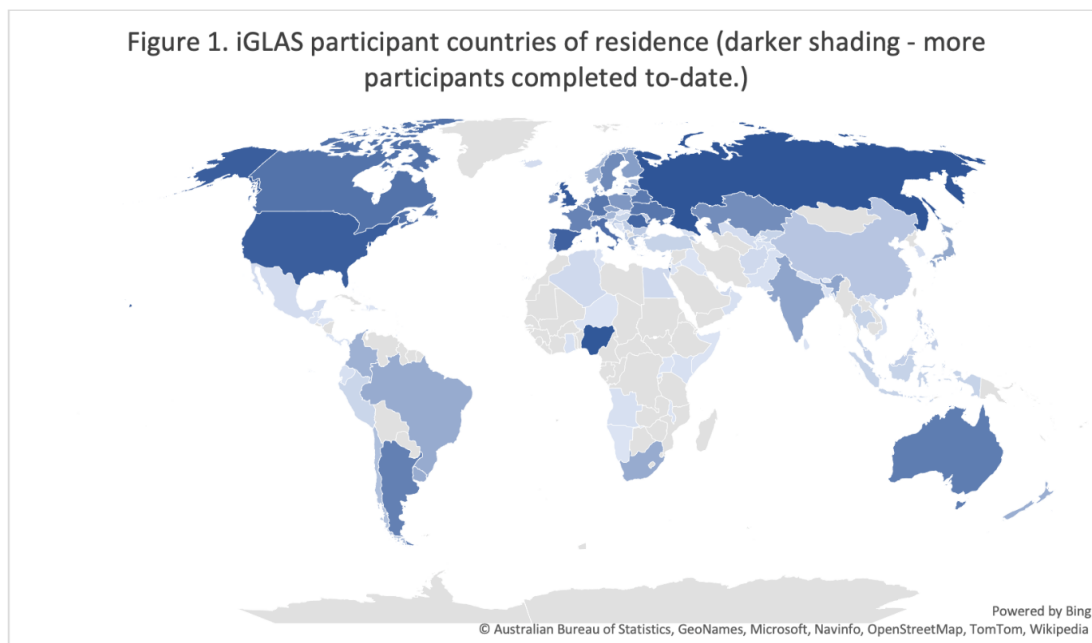
The Government report is also timely as it brings into focus a growing body of research that examines people's opinions and attitudes related to the post-genomic future. The report dedicates a 4-page section to public views on genomics, concluding that "the British public can see benefits of genomic research but expresses some 'red line' concerns regarding its use" (p.170). These 'red lines' include genetic engineering, particularly to enhance human capacity; corporate or state surveillance; administrative and political usage, for example to increase controls on society; predictive insurance tests; and targeted marketing to increase profits. The report suggests that the UK public is concerned that these and other uses could disadvantage people and lead to a stratified society.

Public opinions in the UK and internationally have been a focus of our own work over the past 6 years, capturing views from people in 116 countries (see Figure 1). We have to-date analysed in depth data from 7 countries—Italy, Mexico, Nigeria, Romania, Russia, Spain, and the UK (see tagc.world). The results suggest that many people, including lawyers and judges welcome genetic applications in health care, but also some controversial applications such as for prevention of crime and gene editing to improve traits; and disagree with other applications, such as use by insurance companies⁶. Views are particularly divided regarding privacy and some applications such as in sentencing⁷.

⁶Selita, F., Chapman, R. & Kovas, Y. To Use or Not to Use: No Consensus on Whether and How to Apply Genetic Information in the Justice System. *Behavioral Sciences* 9, 149 (2019); Selita, F., et al. Consensus too soon: judges' and lawyers' views on genetic information use. (In Review).

⁷Selita, F., Chapman, R. & Kovas, Y. To Use or Not to Use: No Consensus on Whether and How to Apply Genetic Information in the Justice System. *Behavioral Sciences* 9, 149 (2019); Chapman, R., et al. To Tell or Not to Tell: The Ethics and Law of Disclosing Health-Related Genetic Information to Family Members. *Psych. Rus.* 11, 68–78 (2018).

Figure 1. iGLAS participant countries of residence (darker shading - more participants completed to-date.)



The opinions of wider society are essential for designing our post genomic future where all people can benefit from applications of genetic advances. Yet, to date, very few people are engaged in designing this future, and one major barrier for such engagement is poor genetic literacy. Our research showed that genetic literacy is low even among the well-educated⁸. In our work as part of the Working Group on Legal, Ethical and Societal Implications of Genetics (LESIG)⁹, established in 2016-17 in the UK and Russia, we also found that many lawyers in both jurisdictions did not see how new genetic advances pose risks and dilemmas, some admitting no knowledge in the area. Improving genetic literacy in societies requires engagement of the public at large, including through public dialogue, even debate, as well as changes in school and university curricula, and professional development programmes. We have seen a great shift over the past decade for psychology degrees to include genetic modules. The same needs to happen across education, law and other social sciences.

As genetic science is borderless, its impact cannot be contained within any one jurisdiction. Its regulation needs to also be borderless. The Government report recommends a unified coherent and comprehensive approach to legislating for the timely regulation of genomics in the UK.

⁸Chapman, R., et al. New literacy challenge for the twenty-first century: genetic knowledge is poor even among well educated. *J Community Genet* 10, 73–84 (2019); Selita, F., Smereczynska, V., Chapman, R., Toivainen, T. & Kovas, Y. Judging in the genomic era: judges' genetic knowledge, confidence and need for training. *European Journal of Human Genetics* 1–9 (2020) doi:10.1038/s41431-020-0650-8.

⁹TAGC. LESIG Working Group. tagc.world <http://tagc.world/lesig/>.

This is a necessary but challenging task for all societies, making global input particularly beneficial. For example, in our studies, contributions from the Romanian and Russian judiciaries have proven invaluable to understanding views of key stakeholders on the use of genetic information. They have also helped promote knowledge and dialogue.

Beyond legislation, in our work we have also raised that some societal structures, such as health insurance provision, will require updating, as some areas cannot be regulated by law only¹⁰. This means that international input is also required from other stakeholders, including sociologists, economists, policymakers and educationalists.

Our international instrument is available in several languages and is being used by research teams in many countries, including most recently in Australia, Ecuador, and Japan. We invite researchers and practitioners in different areas from all countries to collaborate.

¹⁰ Selita, F. Justice in the genomic and digital era: a ‘different world’ requiring ‘different law’. *Legal issues Journal* 8, (2020).