Justice in the genomic and digital era: a 'different world' requiring 'different law'

Fatos Selita[1]
Department of Psychology, Goldsmiths, University of London
Department of Psychology, Tomsk State University

Summary. Discoveries in the last two decades have created a 'different world', which requires 'different' laws. They have created a world where: enormous information on people's past, present and future can be extracted from DNA alone; the DNA of millions of people has already been sequenced; the cost of sequencing is around 30 million times less than in 2003; additional detailed personal information is collected from numerous sources, such as mobile phones, hospitals, bank cards; this information is shared internationally among numerous powerful private and State organisations; and use of this information can be highly profitable for these organisations. Under these conditions, current law is unable to fully protect rights such as that of *data protection*, *privacy*, *a fair trial,* and *non-dis-*

---

[1] Email: fatos.selita@gold.ac.uk.

crimination on genetics and other basis – rights valued by societies. For the law to serve its key purpose, it now must adapt (evolve) to this fast and fundamental change in the ‘environment’. In relation to protection from data misuses, as privacy (genetic and other) is not possible, laws are required which can minimise negative impact of data misuses. Key stakeholders (e.g. judges, policymakers) would need to understand how genes work and how genetic information is used in order to appreciate the urgency of updating laws and to build effective protection.

Keywords: genetic privacy, genetic discrimination, digital era, genomic laws, genetic data protection, genetic risks, genetics and justice.

The ‘different world’ requiring adaptation of the law

Justice systems in advanced economies, such as the UK, EU, US and Canada, pride on ‘providing’ *a fair trial*, *data protection* and *privacy*, and *non-discrimination on genetics and other grounds*. The right to a fair trial, privacy and data are fundamental rights in these countries. Similarly, the right to equal treatment – non-discrimination, including protection from genetic discrimination – is a well-established right in the law.

However, the categorical shifts in knowledge – such as the ability to peer into our text of life (DNA) for information on behaviour – has created a fundamentally different environment for the law. The change means the law cannot ensure justice, unless the law evolves to be suitable for the new environment. There are a number of reasons why a fundamental evolution of the law is required, five of which are identified below.

1. People's data, rich with information on the past, present and the future are shared among numerous private and State bodies internationally.

Data are now collected from numerous sources: hospitals, bank cards, mobile phones, shopping and gym memberships, online media, phone calls, emails, state managed CCTVs, AI Google and other technologies. These data are sufficient to build a clear picture on individuals (Executive Office of the President, 2014), and when combined with genetic data – they provide a powerful source for prediction of future behaviour and traits.

It is now indisputable that genetic data provide in-depth information across virtually all human traits such as health, education performance, downward or upward mobility on the social ladder, intelligence and aggressiveness (e.g. (Belsky et al., 2018; Plomin et al., 2016; Polderman et al., 2015). The information we can extract from genetic data alone is continuously growing for a number of reasons: genetic and technological sciences are progressing fast; larger datasets are available; and genetic data are cross-analysed with other available data, including medical and lifestyle data. Larger samples are enabled due to sequencing costs being incomparably smaller (over 30 million times) than when the first human genomes were sequenced.

There are numerous discrimination and other threats to people stemming from genetic research, with limited protection provided by the law (e.g. (Andrews et al., 2015; Furrow et al., 2013; Selita, 2019b). Threats include discrimination in regard to: access to insurance (e.g. health, disability, long-term care, life); access to employment; access to education and educational funding; access to benefits of genetics; and state surveillance. The information on predicted risks extracted from DNA and other data available is also likely to be used to form groups composed of people falling within certain risk thresholds (e.g. using polygenic scoring) – creating DNA-based groupings / new 'races' that can be discriminated

(Selita, et al., 2020). Groups are likely be formed as to specific traits (e.g. risk of mental health, or intelligence), and all traits combined. Other risks include influencing decisions such as voting and career path; and harm to children's rights as children have no say on whether their genome is sequenced.

A more recent but growing threat is to consumers. Consumers are already being misled into buying products which, for example, claim to enhance or suppress genetic expression; and which may be harmful. For example, products and interventions which claim to 'clean' your genes from the 'dirt' they gain during life, e.g. through smoking, have been advertised (Lynch, 2018; The Jakarta Post, n.d.). Direct to consumer testing results are generally provided for only a few locations in the DNA, leading to misinformation on risks. These are likely to cause psychological, financial and other harms to people (Turnwald et al., 2019).

Furthermore, States are also likely to have an interest in interstate genetic data sharing for several purposes, such as crime, immigration and border control. For example, genetic data are likely to be used in immigration, such as when determining visa applications, or application to extend stay or remain. In the US, under a new policy, now being challenged in the US courts, the border agency is to assess any risk of a person being a burden, including health risks, in determining whether a person is given a visa to the US, an extension of stay or a right to remain (Federal Register, 2018; *Cook Cnty. V. McAleenan*, n.d.; [USC02] 8 USC 1182: Inadmissible aliens, 2019). In such cases, data banks which include genetic information provide probabilistic prediction, and so are highly likely to be used.

2. Data are processed in large data banks by multiple parties across the world, and are accessible from anywhere with an internet connection and password – making data highly vulnerable to breaches.

Technological advances have made possible that we process data in a way which allows tailored access to researchers – to as much data as they need and can pay for. However, this means that anyone with similar digital access information, can access the data. This allows for large-scale data breaches from anywhere on the planet (with an internet connection). This is evident from the number of reported large-scale data breaches, which reaches billions per year (e.g. 1,378,509,261 in 2016 alone (Cyentia Institute, 2016)). Moreover, breaches are large scale, for example the reported average size of data breaches for 2019 was 25,575 records (Ponemon Institute, 2019).

Moreover, this multi-national multi-party processing makes enforcement by people practically impossible. This is because it is difficult to assess the jurisdiction of breach; which party breached the data (e.g. whether they happened due to a hack, a system glitch, or an intentional breach); and which part of data were breached. In addition, data protection laws are vague and with numerous loopholes, and conflict with laws that forbid hindrances to data sharing; computing laws are undeveloped; damages are difficult to calculate; and expert involvement in all areas concerned are required, exacerbating the already high costs of court action (e.g. see (Moorhead et al., 2005; Selita, 2018, 2019b)).

3. Data are fused - processed in data-banks combining genetic, phenotypic, medical and other data – making it difficult to determine from which type data the harm resulted.

Data fusion makes it difficult to assess whether discrimination resulted from use of, for example, medical data, genetic data, lifestyle data, or from analysis of all of these data combined. This allows for discriminatory outcomes which are based on forbidden use of data (e.g. genetic data for health insurance determination), to be ‘hidden’ claiming that information was obtained from data which are allowed (e.g. medical data for insurance determination). Similarly, discrimination (e.g. in surveillance by enforcement agencies) could be excused on the basis of information obtained from data available online from some unknown breach.

The data would also have generally originated from different sources, such health care providers, mobile phone companies, research institutions, enforcement agencies. This makes difficult determining the source of data, and therefore award damages to the injured party. For example, discrimination could have resulted from data sourced from mobile phone companies, from hospitals, from genotyping companies, or from geno-pheno banks. For practical purposes, therefore, data fusion means that data-related rights become only theoretical.

Regardless of this negative outcome, the data fusion of genetic and other data will grow – primarily because it enables reaching the goal of processing, such as predicting and influencing behaviour, and better understanding of the aetiology of traits. The human genome and its functioning are highly complex and vary for each individual. For example, DNA of each new person has been found to contain over 8000 mutations not seen in other sequenced genomes (Telenti et al., 2016). Moreover, genes expressing differently in different environments, makes understanding of aetiology of traits also largely reliant on cross-analyses of genetic data with other big data.

4. The large value of data, now being the new 'gold mines' and seen as exploitable raw material – has led to a strong interest in data collecting, analysing and sharing, as well as numerous large-scale data breaches.

Data now account for a significant amount of the GDP of advanced economies (e.g. around 4 percent for the EU) (EC Data Policy and Innovation, 2018). Moreover, data are valuable in many industries, including advertising, scientific research, market research, voting, and development of drugs. States have also shown a strong interest in using various data for crime prediction and immigration control (Hao, 2019; The Law Society, 2019). Genes accounting for around 50% of differences in traits – means that genetic data are highly informative for prediction, including of criminal behaviour. Surveillance on genetic prediction would decrease surveillance costs (continuously assessing video surveillance is likely to be more costly) and may be more precise, especially when genetic data are analysed in combination with other big data. Moreover, States would have an interest in using predictive information for immigration and border control, to grant visas and stay to only people who are likely to only bring benefits to the economy.

The unique features of genetic data make them also useful for determining criminal liability. The use of genetic information in court is growing in a number of countries (de Kogel & Westgeest, 2015; Farahany, 2015), and is likely to expand further with developments of AI.

5. A key pride of law is the undertaking to provide a fair trial to all people, but findings on human traits and behaviour, including 'free' will, show that under the current law that is not possible.

Law is based on incorrect long-held beliefs that (beyond insanity) people have equal control over their behaviour (free will), that they choose what they do, and that therefore they must be held accountable for their action; and a wide discretion is left to decision-makers (Nanau et al., In review). Research shows that will is like any other trait, and therefore similar in origin and variability – namely, a product of complex gene and environment processes; and of enormous variability, similar to that of intelligence, motivation and schooling (Malanchini et al., 2017; OECD, 2012).

The law therefore cannot provide a fair trial with one-size-fits-all system, and especially one that is not designed for the general public, but only for trained lawyers (The Lord Chief Justice, 2015). Neither can the law issue fair sentence though using incorrect basis of origin of behaviour or control over it, and allowing for individual judges to decide using own discretion, it also inevitably having a wide variability – for example, 63 % variability among judges within cities in sentence issued for same offence with similar circumstances (US Sentencing Commission, 2019).

Other key considerations

Several additional interconnected factors undermine protection of people’s rights in the genomic era.

The powerful parties such as corporations and State organisations have capacity to discriminate using sophisticated data processing; and the benefits of data breaches outweigh the related risks. The current laws generally tilt heavily in favour of large players. This is evident from a number of past and recent breaches, such as that of the Tuskegee Syphilis Study; and that of GlaxoSmithKline (GSK) recently. Tuskegee Syphilis Study of the US National Institute of Health, which lasted for 40 years, tricked black people into joining the study by lying to them; concealed information on whether they had the virus; and withheld medication when it became easily accessible (penicillin) – despite the virus being deadly and transmittable through sexual intercourse and congenially (The White House, 1997). The outcome was that the victims received an apology from the US president, and no one faced criminal liability. Similarly, but at a greater scale, GSK admitted criminal liability to numerous serious crimes in the US, including to selling for many years unproved drugs which for example increased suicide thought on teenagers; faking research results; and bribing doctors to prescribe these drugs (GSK) (*United States v. GlaxoSmithKline*, 2012). Yet, no individual faced criminal liability. These examples show that people's rights related to misuse of data are not protected.

The line is blurry between the State, which is to arrange for the protecting of people, and private corporations, which have commercial interests as a primary motivation. This is evident from that fact that large private corporations are often a key part of the process in election of governments and are seen by governments as 'too big to fail'. This interferes with passing of effective laws and actions against corporations. For example, following the serious crimes committed and admitted by GSK (above), which affected large numbers of people – the result was not *decision against*, but an *agreement with*, and no individual facing criminal liability. In contrast, a shoplifting by an individual, when the shoplifting is of a low value, could lead to imprisonment of up to 6 months by Magistrates (Sentencing Council, n.d.).

The enforcement is limited even for straight-forward *fundamental* rights. Examples include, there being no clarity in the law for use of children's heel prick blood samples (Arnold, 2013; Bearder v. Minnesota State 2011); or for access to personal data that are being processed by a public and private body (subject access request). This is primarily because the law allows for numerous exceptions when these rights will not be available; the process of enforcement is highly lengthy and complicated; and the law is not clear, presenting risks for litigation costs of both sides.

Despite many uncertainties in regards to the use of genetic information in the justice system, research shows that the majority of key stakeholders (e.g. judiciary and lawyers) endorse use of genetic data by the State for crime prevention (Selita, et al., In Review; Selita, et al., 2020). The situation is further worsened by the fact that legal professions are generally not representative of societies (e.g. in England and Wales) – with a disconnect in, for example, values and experiences – affecting representation and judgement outcomes (Selita, 2019a).

Conclusion: what next for justice systems?

Overall, the law cannot sufficiently protect the well-established fundamental rights affected by misuses of personal data, such as discrimination and privacy. Having non-enforceable laws is similar to having non-effective medication, but the 'placebo' effect is unlikely to apply in cases where laws make strong promises for protection of highly valued rights such as that of data and privacy. Some solution to protecting people from misuse of data in the current era needs to be found. A large number of people are negatively affected and to be affected, with implication for all people (County Health Rankings and Roadmaps, 2015). There is a likely growing tension within societies, further harming social cohesion, which is already at high risk (e.g. due to high inequality (Selita & Kovas, 2018).

Data-based (genetic and other) discrimination, will affect those at higher risk and their families, which means millions of people. Millions of genomes have already been sequenced despite sequencing being expensive. The first sequencing which was completed in 2003 cost over 30 million times more than today (10,000 researchers, over 10 years and 2.7 billion USD vs. 40 minutes and 399 USD (Dante Labs, n.d.; Goyal et al., 2017)) – soon therefore sequencing will become common. Only a small proportion that have low risks (e.g. health, aggressiveness), would not be negatively affected.

The law will therefore need to: either follow what societies value (e.g. protect people's privacy or from harm caused from lack of privacy); or make people follow the law as it is (e.g. make clear to people that there are no such rights, e.g. privacy, data protection, protection from genetic discrimination).

One option is to focus on making provisions that would render genetic information unusable for harm. For example, instead of preventing insurers from using genetic data, provision of health, disability and life insurance should be regulated by the State, making it accessible to all. This could, for example, be done using similar models to those of Netherlands and Switzerland. This would also save the industry, which is otherwise unlikely to survive the genomic era. Where possible, merely theoretical access to provisions (rights) should be avoided. For example, healthcare in the UK, being funded mostly through general taxation, is free to access. However, based on numerous examples, access is made difficult though numerous hurdles. These include long waits, very limited availability of doctors (e.g. two fixed slots in three months), and unwelcoming treatment (through insurance, one can generally get seen within a week, and receive an outstanding service).

A number of other recommendations specific to the genomic era have been put forward in previous research (Chapman et al., 2018; Karelin et al., 2018; Nanau et al., In review; Selita, 2019b; Selita, et al., In review). These include, creating interdisciplinary working groups to work on updating law and policy in the area; consolidating laws rather than adding new legislation to the already immense pool of laws (Law Commission, 2018); training of key stakeholders such as judiciary as part of professional development, and members of *Committees / Working Groups* allocated the task of overseeing the need for legal updates in this area, such as the House of Lords Science and Technology Committee (Parliament.uk, n.d.); and inclusion of training on genetics in the legal training and other curricula. Without these and other steps, the misfit will continue to grow between the law and the society it serves.

References

Andrews, L. B., Mehlman, M. J., & Rothstein, M. A., Eds. (2015). *Genetics: Ethics, Law and Policy* (4th Edition). West Academic. https://faculty.westacademic.com/Book/Detail?id=31475

Belsky, D. W., Domingue, B. W., Wedow, R., Arseneault, L., Boardman, J. D., Caspi, A., Conley, D., Fletcher, J. M., Freese, J., Herd, P., Moffitt, T. E., Poulton, R., Sicinski, K., Wertz, J., & Harris, K. M. (2018). Genetic analysis of social-class mobility in five longitudinal studies. *Proceedings of the National Academy of Sciences*, 201801238. https://doi.org/10.1073/pnas.1801238115

Chapman, R., Likhanov, M., Selita, F., Zakharov, I., Smith-Woolley, E., & Kovas, Y. (2018). New literacy challenge for the twenty-first century: Genetic knowledge is poor even among well educated. *Journal of Community Genetics*. https://doi.org/10.1007/s12687-018-0363-7

County Health Rankings and Roadmaps. (2015). *2015 Key Findings Report*. rwjf.org/content/dam/farm/reports/reports/2015/rwjf418649

Cyentia Institute. (2016). *Mining for Database Gold: Findings from 2016 Breach Level Index*. https://cyentia.com/library-item/2016-mining-for-database-gold-findings-from-2016-breach-level-index/

Dante Labs. (n.d.). *Whole Genome Sequencing (WGS)—Full DNA analysis for Rare Diseases*. Dante Labs. Retrieved 25 September 2018, from https://www.dantelabs.com/products/whole-genome-sequencing

de Kogel, C. H., & Westgeest, E. J. M. C. (2015). Neuroscientific and behavioral genetic information in criminal cases in the Netherlands. *Journal of Law and the Biosciences*, lsv024. https://doi.org/10.1093/jlb/lsv024

EC Data Policy and Innovation. (2018). *Elements of the European data economy strategy* [Text]. https://ec.europa.eu/digital-single-market/en/towards-thriving-data-driven-economy

Executive Office of the President. (2014). *Big Data: Seizing Opportunities, Preserving Values*. https://obamawhitehouse-

.archives.gov/sites/default/files/docs/big_data_privacy_report_may_1_2014.pdf

Farahany, N. A. (2015). Neuroscience and behavioral genetics in US criminal law: An empirical analysis. *Journal of Law and the Biosciences*, *2*(3), 485–509. https://doi.org/10.1093/jlb/lsv059

Federal Register. (2018, October 10). *Inadmissibility on Public Charge Grounds*. Federal Register. https://www.federalregister.gov/documents/2018/10/10/2018-21106/inadmissibility-on-public-charge-grounds

Furrow, B., Greaney, T., Johnson, S., Stoltzfus, T. J., & Schwartz, R. L. (2013). *Health Law, Cases, Materials and Problems* (7th Edition). West Academic Publishing. https://faculty.westacademic.com/Book/Detail?id=2028

Goyal, A., Kwon, H. J., Lee, K., Garg, R., Yun, S. Y., Kim, Y. H., Lee, S., & Lee, M. S. (2017). Ultra-Fast Next Generation Human Genome Sequencing Data Processing Using DRAGENTM Bio-IT Processor for Precision Medicine. *Open Journal of Genetics*, *07*, 9. https://doi.org/10.4236/ojgen.2017.71002

Hao, K. (2019, January 21). AI is sending people to jail—And getting it wrong. *MIT Technology Review*. https://www.technologyreview.com/s/612775/algorithms-criminal-justice-ai/

Cook Cnty. V. McAleenan, (US District Court for the Northern District of Illinois). Retrieved 31 December 2019, from https://casetext.com/case/cook-cnty-v-mcaleenan?resultsNav=false

Karelin, D. V., Matsepuro, D., & Selita, F. (2018). Criminal Legal Protection of Genetic Data of The Person: To Statement of a Problem. *Vestnik Tomskogo Gosudarstvennogo Universiteta. Pravo*, *29*, 79–90. https://doi.org/10.17223/22253513/29/7

Law Commission. (2018). *The Sentencing Code*.

Lynch, B. (2018). *Dirty Genes: A Breakthrough Program to Treat the Root Cause of Illness and Optimize Your Health* (1 edition). HarperOne.

Malanchini, M., Wang, Z., Voronin, I., Schenker, V. J., Plomin, R., Petrill, S. A., & Kovas, Y. (2017). Reading self-perceived ability, enjoyment and achievement: A genetically informative study of their reciprocal links over time. *Developmental Psychology*, *53*(4), 698–712. https://doi.org/10.1037/dev0000209

Moorhead, R., Sefton, M., Great Britain, & Department for Constitutional Affairs. (2005). *Litigants in person: Unrepresented litigants in first instance proceedings*. DCA Research Unit.

Nanau, V., Chapman, R., Metzer, A., Toivainen, T., Kovas, Y., & Selita, F. (In review). *Computer says 'what?!' Mitigating and aggravating factors in sentencing*.

OECD. (2012). *Key findings—PISA*. http://www.oecd.org/pisa/keyfindings/pisa-2012-results.htm

Parliament.uk. (n.d.). *Science and Technology Committee (Lords)*. UK Parliament. Retrieved 31 December 2019, from https://www.parliament.uk/business/committees/committees-a-z/lords-select/science-and-technology-committee/

Plomin, R., DeFries, J. C., Knopik, V. S., & Neiderhiser, J. M. (2016). Top 10 Replicated Findings From Behavioral Genetics. *Perspectives on Psychological Science: A Journal of the Association for Psychological Science*, *11*(1), 3–23. https://doi.org/10.1177/1745691615617439

Polderman, T. J. C., Benyamin, B., Leeuw, C. A. de, Sullivan, P. F., Bochoven, A. van, Visscher, P. M., & Posthuma, D. (2015). Meta-analysis of the heritability of human traits based on fifty years of twin studies. *Nature Genetics*, *47*(7), 702–709. https://doi.org/10.1038/ng.3285

Ponemon Institute. (2019). *Cost of a Data Breach Report*. https://www.all-about-security.de/fileadmin/micropages/Fachartikel_28/2019_Cost_of_a_Data_Breach_Report_final.pdf

Selita, F. (2018). Unrepresented Litigants in Modern Courts – Ordeal by Combat. *Legal Issues Journal*, *6*(1), 35.

Selita, F. (2019a). Improving Access to Justice: Community-based Solutions. *Asian Journal of Legal Education*, *6*(1–2), 83–90. https://doi.org/10.1177/2322005819855863

Selita, F. (2019b). Genetic Data Misuse: Risk to Fundamental Human Rights in Developed Economies. *Legal Issues Journal*, *7*(1), 53–95. https://doi.org/doi.org/10.6084/m9.figshare.11423724

Selita, F., Chapman, R., & Kovas, Y. (2019). To Use or Not to Use: No Consensus on Whether and How to Apply Genetic Information in the Justice System. *Behavioral Sciences*, *9*(12), 149. https://doi.org/10.3390/bs9120149

Selita, F., & Kovas, Y. (2018). Genes and Gini: What Inequality Means for Heritability. *Journal of Biosocial Science, 51*(1), 18–47. https://doi.org/10.1017/S0021932017000645

Selita, F., Smereczynska, V., Chapman, R., Toivainen, T., & Kovas, Y. (In review). *Judges on genetics and justice: Knowledge, attitudes and opinions*.

Selita, F., Willers, M., & Kovas, Y. (2020). 'Race' and other group discrimination in the genomic era. *Legal Issues Journal,* 8(1) 16-55.

Sentencing Council. (n.d.). *Theft from a shop or stall*. Retrieved 28 December 2019, from https://www.sentencingcouncil.org.uk/offences/magistrates-court/item/theft-from-a-shop-or-stall/

Telenti, A., Pierce, L. C. T., Biggs, W. H., di Iulio, J., Wong, E. H. M., Fabani, M. M., Kirkness, E. F., Moustafa, A., Shah, N., Xie, C., Brewerton, S. C., Bulsara, N., Garner, C., Metzker, G., Sandoval, E., Perkins, B. A., Och, F. J., Turpaz, Y., & Venter, J. C. (2016). Deep sequencing of 10,000 human genomes. *Proceedings of the National Academy of Sciences of the United States of America*, *113*(42), 11901–11906. https://doi.org/10.1073/pnas.1613365113

The Jakarta Post. (n.d.). *Ultimate Duo shields genes, helps anti-aging*. The Jakarta Post. Retrieved 31 December 2019, from https://www.thejakartapost.com/news/2019/03/27/ultimate-duo-shields-genes-helps-anti-aging.html

The Law Society. (2019). *Algorithms in the criminal justice system*. file:///Users/air/Downloads/algorithms-in-criminal-justice-system-report-2019.pdf

The Lord Chief Justice. (2015). *The Lord Chief Justice's Report 2015* (p. 33). Judiciary of England and Wales. https://www.judiciary.uk/wp-content/uploads/2016/01/lcj_report_2015-final.pdf

The White House. (1997, May 16). *Tuskegee Study—Presidential Apology*. https://www.cdc.gov/tuskegee/clintonp.htm

Turnwald, B. P., Goyer, J. P., Boles, D. Z., Silder, A., Delp, S. L., & Crum, A. J. (2019). Learning one's genetic risk changes physiology independent of actual genetic risk. *Nature Human Behaviour*, *3*(1), 48–56. https://doi.org/10.1038/s41562-018-0483-4

United States v. GlaxoSmithKline, C.A. No. 11-10398-RWZ (United States District Court 28 June 2012). https://www.justice.gov/usao-ma/file/872506/download

[USC02] 8 USC 1182: Inadmissible aliens, (2019). https://uscode.house.gov/view.xhtml?req=granuleid%3AUSC-prelim-title8-section1182&num=0&edition=prelim

US Sentencing Commission. (2019). *Intra-City Differences In Federal Sentencing Practices: Federal District Judges in 30 Cities, 2005—2017*. https://www.ussc.gov/sites/default/files/pdf/research-and-publications/research-publications/2019/20190108_Intra-City-Report.pdf