

# **Genomics and Justice:**

Investigating judges', lawyers' and non-lawyers' genetic literacy and views on applications of genomics

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## Publications included in this thesis (abbreviated titles)

*Publication 1:*

### **Genes and Human Rights**

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*Publication 2:*

### **Genes and Inequality**

Fatos Selita\* and Yulia Kovas. 2018. Genes and Gini: what heritability means for inequality. *JBS*. 51 (1), 18-47. <https://doi.org/10.1017/S0021932017000645>

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*Publication 3:*

### **Judges' and Lawyers' Genetic Literacy**

Fatos Selita\*, Vanessa Smereczynska, Robert Chapman, Teemu Toivainen and Yulia Kovas. 2020. Judging in the Genomic era: judges' genetic knowledge, confidence and need for training. *European Journal of Human Genetics*. <https://www.nature.com/articles/s41431-020-0650-8>

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*Publication 4:*

### **Applying Genetic Information in the Justice System**

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\* First and corresponding author

*Publication 5:*

### **Judges' and Lawyers' Views on Applications of Genetics**

Fatos Selita\*, Robert Chapman, Yulia Kovas, Vanessa Smereczynska, Maxim Likhanov and Teemu Toivainen. 2023. Consensus too soon: judges' and lawyers' views on genetic information use. *New Genetics and Society*. <https://doi.org/10.1080/14636778.2023.2197583>

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Yulia Kovas and Fatos Selita. Palgrave Macmillan. 2021. doi: 10.1057/978-1-349-96048-4

[Mastering Public Speaking.](#)

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### **Papers in review/prep.**

[Are we ready for the genomic era? Insights from judges and lawyers.](#)

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\* First and corresponding author

Attitudes towards genetic testing: the role of genetic literacy, motivated cognition, and socio-demographic characteristics.

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\* First and corresponding author

Free will and applications of genetics in sentencing: views from a large international sample of judges, lawyers and non-lawyers.

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## UK Law Students - A Single Voice.

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## Extra Judicial Experience.

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## Personal contribution to the study

As a lawyer with training in behavioural genetics, I have a keen interest in implications of genetics for individuals and societies. As a result, much of my work has been in this area, and has included:

- Co-founding The Accessible Genetics Consortium (TAGC), which has been a center of the work on implications of the Genomic Era;
- Co-creation of the iGLAS, where I lead the research into legal and ethical implications;
- Collection of data on *genetic literacy* from judges and lawyers in Romania, Russia, UK and other countries;
- Collection of data on *views and attitudes* from judges and lawyers in Romania, Russia, UK and other countries;
- Co-ordinating the work of the Working Group on Legal, Ethical and Societal Implications of Genetics (LESIG) in the UK and Russia;
- Leading Erasmus+ funded research in this area;
- Working towards partnerships between the University and Barristers' Chambers for knowledge transfer towards developing genomic legal services; and
- Working on establishing the Goldsmiths *Genomics and Society Interdisciplinary Research, Training and Consultancy Hub*.

This work has led to a number of peer-reviewed publications, on which I am a co-author or a lead author. For the five publications included in this thesis I am the first and corresponding author. My role on these publications included leading all aspects of the reported research: conceptualisation, reviewing the literature, designing the study; developing the methodology and instruments for data collection; facilitating data collection, analysing the data and writing the papers.

## Abstract

Since the arrival of the Genomic Era, we are able to extract from DNA alone increasingly reliable information on human personal characteristics, such as intelligence, academic performance, personality and health. Genetic applications are now relevant to all contexts of life, including medicine (e.g. genomic medicine, pharmacogenomics); lifestyle (e.g. nutrition, partner choice, health-related behaviours, wellbeing); education and career (e.g. personalization, selection); and law and justice (e.g. fairness, praise and punishment; crime prevention).

The world has therefore entered an era where, subject to our readiness to adapt to these advances, our own genes can benefit us (individuals and society) more than ever. At the same time, these advances can bring much harm to individuals and societies - especially now that the use of genetic advances is becoming ubiquitous.

The pathway from genetic advances to personal positive or negative outcomes can be direct (e.g. disease prevention by means of population wide genetic screening); as well as via mediators and moderators (e.g. genetic literacy, regulation of application of advances, personality characteristics, values, cultural norms etc.). For example, people's genetic literacy may affect whether they will seek prophylactic genetic testing; and the use of genetic advances will depend on the regulations in place. This means that individuals and societies can control outcomes through mediators and moderators, subject to having the tools to do so (readiness).

Readiness for the Genomic Era for individuals means having solid genetic knowledge, as well as attitudes towards the use of genetic advances that are based on accurate knowledge. For societies, readiness requires an additional element - that key stakeholders at the forefront of regulating genetic advances possess multidisciplinary knowledge that combines genetics, law and an understanding of societal implications of genetic advances. As developing genetically literate societies is a slow process, current societies' readiness depends to a large extent on readiness of key stakeholders, such as teachers, medical practitioners and policy makers.

Among the most influential stakeholders at this stage, are those entrusted with decisions on legal questions and disputes, and who play a key role in developing policy and legislation – the judiciary and other lawyers. Their genetic literacy, views and attitudes form the core part of the examination of readiness in this thesis.

The thesis brings together work from 5 publications – two reviews and three empirical psychological investigations – forming a comprehensive overview of: genetic advances and the powers they create; the path from these advances and powers to outcomes for individuals and societies; and societies' readiness to control these outcomes.

The two reviews analyse the challenges of the three key powers created by genetic advances – power of polygenic prediction, power of environmental engineering and power of genetic engineering. This analysis suggests that these powers present immense opportunities for societies but also many risks; and that developing effective regulation of these powers is an urgent and challenging task for societies.

For the three empirical investigations data were collected from 10,373 participants, including samples of Supreme Court judges (N=73), lawyers (N=116; and N= 486), as well as unselected

participants from different countries. The data were collected using the International Genetic Literacy and Attitudes Survey (iGLAS) – a validated instrument available in 9 languages. In the studies reported here, data were collected using 25 items for literacy and 51 items for views and attitudes, including on use of genetic data in different contexts, gene editing and regulation of genetic advances.

Results from the empirical investigation show that societies are not ready for the Genomic Era. This is true both in terms of low genetic literacy and of many unrealistic views. The results also show that key stakeholders – the judiciary and other lawyers – have uneven genetic knowledge that is not sufficient for ‘judging in the genomic era’. It is primarily poor for questions about the post-genome sequencing findings that cannot be answered by general reasoning. Judges’ and lawyers’ confidence in their genetic knowledge is a poor predictor of their actual knowledge. Significant differences among the groups were found on many issues, both in terms of means (e.g. strength of endorsement) and in terms of variance (e.g. variability in views). For example, judges overall showed stronger agreement (less variability in views) than other lawyers and non-lawyers on how genetic information should be used and by whom, including on controversial matters.

The results showed high agreement on some controversial issues among judges and lawyers. For example, most judges and lawyers thought the State should use genetic information on propensity for violence for prevention of crime (e.g. through surveillance). The qualitative analysis uncovered some reasons for and against such use. Similar high endorsement was found for allowing people to opt for gene editing in order to improve themselves/their children.

These findings on societal readiness for the Genomic Era call for a number of short- and long-term interventions to regulate the outcomes of advances. For example, providing opportunities for the key stakeholders to gain the genetic literacy required for meaningful assessment of benefits and risks. This need was acknowledged by all of the judges in this research. The final part of this thesis provides an overview of the steps needed for achieving Genomic Era readiness.

## Thesis outline

We live in an era marked by the increased application of genetics in different life contexts, with many challenges for individuals and societies - the Genomic Era. Using psychological research methods and an interdisciplinary approach, this thesis explores the challenges brought by this era; and societies' readiness for this era. Readiness for the Genomic Era includes the ability to use genetic advances beneficially; and to prevent misuses of these advances. Examples of potential misuses include violations of some of the rights we value the most – the right to non-discrimination and the right to a private life. These rights can be under threat via changes brought by genetic advances.

This thesis is designed to present: 1) a comprehensive overview of benefits and risks of genetic advances; 2) research into the pathways from advances to outcomes for societies, and societies' readiness for the Genomic Era); and 3) suggestions for short- and long-term interventions designed to prepare key stakeholders for the Genomic Era. This research has been published in five research papers. The thesis comprises three parts:

Part I is based on two review papers (Publications 1 and 2 in the Appendix). It explores genetic advances and the powers these advances create: the power of prediction (e.g. of future illness); the power of environmental engineering (adapting environments to people's genetic propensities); and the power of genetic engineering (editing DNA in human adults' cells or at pre-implantation). This part of the thesis also reviews potential applications of these powers – leading to beneficial or harmful outcomes for individuals and societies.

Part II is based on three empirical papers (Publications 3, 4 and 5 in the Appendix) – exploring individuals' and societies' readiness for the Genomic Era. It explores the paths from genetic advances to personal outcomes, including mediator and moderator factors, such as regulation of advances and key stakeholders' genetic literacy and views. For example, this part of the thesis explores genetic literacy and views of judges; and compares them with those of other lawyers and non-lawyers. This section also analyses what these key stakeholders know about genetics (genetic literacy); their confidence in their own knowledge; their views and attitudes towards the use of genetic advances in different life contexts, such as in crime prevention, sentencing, insurance and improving traits through gene editing. The Part also explores the psychological origins of such views and attitudes. These studies are the first to explore literacy and opinions of judges on a comprehensive set of genetic applications, as well as their views on updating relevant laws and the inclusion of genetics in judges' training.

Part III presents a synthesis of the research reported in the thesis and formulates future research directions. In addition, it outlines suggestions for short- and long-term interventions towards building a Genomic-era-proof society.

# Part I

## Genetic advances and their implications<sup>1,2</sup>

We entered this century with an enormous achievement for individuals and society – the sequencing of our own text of life, the human genome. At an unexpected pace, this was followed by many other related major advancements, equipping societies with three notable powers:

### 1) The power of genetic prediction.

We can, with growing precision, examine an individual's DNA to evaluate risk of future illness and other behavioural outcomes. This new 'oracular' power is unprecedented in terms of potential impact on our lifestyles, our psychological wellbeing and our relationships. At the same time this brings unique risks of invasion into our private lives by various institutions. Moreover, this power can be harmful in our own hands – through decisions we make (e.g. following test result) and through psychological impact these decisions have on us (e.g. anxiety).

### 2) The power of environmental engineering

Our growing understanding of gene-environment co-action allows for increasingly more calculated environmental interventions. Environments (broadly defined as all non-heritable influences) can have a positive or negative impact on individuals, groups and populations. Such environments include educational set ups, such as the societally imposed compulsory education up to a certain age; national school curriculum vs. decentralised unstandardised school curricula; and inequality reflected in unequal access to educational and healthcare resources, as well as decreased cohesion and increased tensions in the society. One route by which the impact of the environment can be realized is via genetic expression. At the individual's level, changes to environments (e.g. diet) can affect individual's genetic processes. At the societal level, changes in societal set-ups can change the heritability of traits within a population, so that a greater or smaller proportion of the traits' variance is explained by genetic vs. environmental factors. Understanding these mechanisms can harness the power of environmental engineering to serve people's needs. This is coupled with the potential to misuse this information.

### 3) The power of genetic engineering.

New genetic technologies allow in-vivo editing of DNA in human adult cells and embryos, including at the pre-implantation stage. Such *in vivo* editing has been possible since 2017, and at the pre-implantation stage, since 2018 when the DNA of two children was edited pre-birth (Kaiser 2017; Regalado 2019b). Such pre-implantation editing has been branded as *designer babies*. The power of gene editing has already generated much controversy.

These three powers will impact individuals and societies in numerous ways. Much of the impact will depend on how ready (in terms of literacy, attitudes, regulation and fair access) societies are to adapt to this new environment of the Genomic Era.

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<sup>1</sup> Fatos SELITA. 2019. Genetic Data Misuse: Risk to Fundamental Human Rights in Developed Economies. *LJ*, 7 (1).

<sup>2</sup> Fatos SELITA\* and Yulia KOVAS. 2018. Genes and Gini: what heritability means for inequality. *JBS*. 51 (1), 18-47. \*First and corresponding author.

The following three sections assess advances that enable these powers and the related implications across life contexts, including their benefits and risks. The final section considers key reasons for the urgency of regulation of genetic advances.

## The Power of Genetic Prediction

Gene-based (DNA-based) prediction is becoming one of the most reliable methods for predicting future traits. The variation in complex traits is polyfactorial – polygenic and polyenvironmental (e.g. reviewed in (Kovas et al. 2015; Krapohl et al. 2014)) – and so prediction is possible only if the multiple specific genes and environments have been linked to specific traits (Robert Plomin 2018). Genes have been found to account for a substantial proportion of the variation in human traits. For example, a meta-analysis, which examined 17,804 traits from 2,748 publications including 14,558,903 twin pairs, found an average heritability across all traits of 49% (Polderman et al. 2015). This meta-analysis also reported heritabilities for some of the most studied traits, including: 0.54 for blood pressure; 0.50 for conduct disorder; 0.40 for depressive episode; 0.62 for general metabolic function; 0.52 for heart function; 0.50 for immune system function; 0.50 for mental and behavioral disorders due to the use of tobacco; 0.44 for anxiety disorders; and 0.54 for higher-level cognitive functions. Other studies also have found moderate to high heritability for academic achievement (Krapohl et al. 2014; Rimfeld et al. 2016); intelligence in adulthood (de Zeeuw et al. 2015; Nature Editorial 2016a; R. Plomin and Deary 2015); mental health problems (Nikolić et al. 2022); wellbeing and life satisfaction (Lachmann et al. 2021); and behavioural problems (Wertz et al. 2018).

A substantial heritability means that, for many traits, some probability of occurrence can be estimated from family history of disease (e.g. type 1 diabetes), learning problems (e.g. dyslexia), behavioural manifestations (e.g. ADHD, musical or mathematical talent). However, such predictions are not individual-specific, with people in the same family differing on many such characteristics.

Individual-specific prediction requires examination of an individual's DNA. Such prediction is already available for monogenic traits, for which disorders are caused by variation in a single gene. In the past few years, individual-specific prediction has emerged for polygenic traits as well – afforded by the proliferation of Genome Wide Association Studies (GWAS). GWAS examine a large number of genetic variants across many genomes to find variants that are statistically associated with a specific trait or disease (Rimfeld et al. 2019; Sahu and Prasuna 2016; Uffelmann et al. 2021). As the effect of each genetic variant has been found to be weak, prediction requires a constellation of a large number of genetic factors – known as polygenic scores (Kullo et al. 2022; R. Plomin and Deary 2015)).

With continued advances, prediction is getting more precise for polygenic traits (influenced by few or many genes) (Lloyd-Jones et al. 2019; Selzam et al. 2017). Many gene- and other DNA variants have already been linked to various traits, such as psychiatric disorders; criminal behaviour; physical illness; learning disabilities; educational attainment; health variables; downward or upward social mobility; aggressive behaviour; intelligence; and depression (Belsky et al. 2018; Davies et al. 2018; W. D. Hill et al. 2018; Howard et al. 2018; Okbay et al. 2016; Rimfeld et al. 2016; Snickers et al. 2017; Wertz et al. 2018). For example, polygenic scores identified up to 2016 predicted around 9% of the variation in academic achievement at age 16

(accounting for 15% of the heritable variance) (Selzam et al. 2017). Additionally, for some rare disorders many genetic variants that present an extremely high risk to carriers have been found. For example, carriers of the BRCA1 mutation have an around 80 percent risk of developing breast cancer, as opposed to the average risk which is 12-18 percent (Mavaddat et al. 2013). These developments mean that prediction in the Genomic Era is unlike any prediction societies have experienced before – because it is individual-specific and also informative about genetic differences within families.

Moreover, the power of prediction is growing at an unprecedented speed. Only recently, in 2003, it took 10 years of work from over 2,000 researchers around the world and 2.7 billion USD, to sequence one genome (NIH, US 2016). Only 12 years later, this cost dropped to around 4,000 USD. A few months later, the cost dropped to around 1,500 USD, and more recently, private companies are offering genome sequencing for 399 USD (Dante Labs n.d.). This cost is around 30 million times cheaper than it was in 2003, and the costs are likely to continue declining, as technologies advance.

There are four other reasons for why the precision of prediction is likely to grow and gene-based prediction is likely to proliferate:

1) *Scale of studies.* The precision of prediction from sequenced DNA depends on the scale of such studies. Now that sequencing is much faster and cheaper than ever before, studies have increased in scale. The genomes of millions of people have already been sequenced (Gaziano et al. 2016; Gilchrist n.d.; Ledford 2016; Molnár-Gábor et al. 2017). Some countries have sequenced the genetic data of entire populations (e.g. Iceland) and other countries have similar plans (Brown 2018; Yirka and Xpress 2011). In addition, international consortia have emerged to pool resources for gene discovery, including the International Cancer Genome Consortium (ICGC) (Hudson et al. 2010; Stein et al. 2015; The UK10K Consortium. 2015); and the Global Genomic Medicine Collaborative (G2MC n.d.). This growth in the magnitude of studies means that the progress in DNA prediction will likely be faster than ever before.

2) *Advances in technology.* Progress in prediction has grown alongside progress in technology. Technological progress in this field is perhaps the fastest ever witnessed. For example, new technology enables the genotyping of hundreds of thousands of DNA variants simultaneously. Microarrays can also be used to evaluate epigenetic processes across the genome simultaneously. New technologies are on the horizon and are claimed to sequence a complete human genome in less than 1 hour (Goyal et al. 2017; Lightbody et al. 2019; Nurk et al. 2022).

3) *Geno-phenobanks.* Large data pools already combine genetic data from whole genome sequencing projects with medical and lifestyle data – creating what is known as geno-phenobanks. Cross-analysing of these data pools constitutes a powerful resource for increasing the precision of the prediction of traits.

4) *Understanding of gene-environment co-action.* Our growing understanding of complex processes of gene-environment co-action (Barsky and Gaysina 2016) also helps to improve precision in prediction. Prediction is more precise with assessment of the interaction between genes and environment for a specific person or group. The greater our understanding of gene-environment co-action is, the greater the precision of prediction. A better understanding of the gene-environment processes is made possible through the availability of data from sources such as hospitals, bank cards, mobile phones, shopping, gym memberships, online media, phone

calls, emails, state managed CCTVs and AI Google – which are sufficient to build a clear picture on individuals’ behaviour and lifestyle (Executive Office of the President 2014a).

Overall, the growing precision in prediction is a powerful tool in societies’ hands – with positive and negative implications.

## **Benefits and risks of the Power of Prediction**

### **Benefits**

Prediction is an attractive power for societies. For example, prediction has been used to guide surveillance – for crime prevention; to guide targeted prophylactic screening – for public health; and to determine health insurance premiums (via family history disclosure and medical history (Brayne 2020; House of Lords, UK n.d.; Piza et al. 2019).

The powerful and increasingly accessible genetic prediction makes genetic data an enormous resource for improving peoples’ lives, including their health (Green et al. 2011; Manolio et al. 2015), education (Kovas et al., 2015; Kovas, Malykh, & Gaysina, 2016) and justice (Kovas and Selita 2021a; Selita 2018a). As genetic effects on traits can change via changing the environment, gene-based prediction can be particularly beneficial (see Publication 2), for example through early intervention.

### **Risks**

The risks presented by this power stretch across different aspects of life, including:

**Children’s rights.** All newborns in developed countries have for decades been tested for specific known mutations (from early 1960s in the US (Suter 2014)). It is forecasted that in the near future everyone's genome will be sequenced at birth (Collins 2014)). However, the life-long and intergenerational risks associated with genome sequencing, are beyond a child's control. Parents' or societies' decisions to sequence a child's genome has the potential to change the course of their lives and the lives of their children. Moreover, large-scale misuses of children's genetic data have been reported. For example, DNA samples collected by hospitals at birth to test for known mutations have been shared over the years with private corporations (Kelly et al. 2016) (Leagle 2011).

Other risks include schools and police mis-applying genetic information to stream individuals on the basis of potential performance or to place children under surveillance. For example, State surveillance of children based on their ethnicity (e.g. of Roma) have been documented in Sweden and Italy (Marinaro 2009; Reuters 2013; Stallard n.d.). Parents may also take decisions based on an incorrect or incomplete understanding of genetic information, such as interpreting probabilistic information as deterministic. For example, parents may enroll children in specialised schools or medical programmes based on genetic information, which may not end up being necessary or suitable for that child.

Yet, parents lack genetic literacy to evaluate benefits and risks as genetic knowledge is poor even amongst the well-educated (R. Chapman et al. 2019). Furthermore, the complexity and diversity of topics within the field and fast-pace of developments mean that there is sometimes

confusion even amongst those who work or study in the field of genetics, such as misconceptions around heritability (Madrid-Valero et al. 2021).

**State surveillance.** The current and growing power of prediction (e.g. for antisocial behaviour/crime) (Moffitt 1993; Viding et al. 2008) can make gene-based State surveillance seem a justifiable crime-prevention measure. However, it presents serious risks for all individuals, including those whose predicted traits would have never expressed. The very categorisation of individuals into 'high risk' and 'low risk' is problematic. It is currently unresolved as to when, if ever, gene-based surveillance can be justifiable. For example, what level of risk will be deemed appropriate for surveillance to be justified and will the risk be estimated on a combination of genetic and other personal factors?

**Health insurance.** For insurance providers, the power of prediction presents an enormous resource. This has been acknowledged by the insurance industry. For example, the Association of British Insurers (ABI) and the UK Government have agreed that “unless otherwise agreed, insurance companies should have access to all relevant information to enable them to assess the price risk fairly in the interest of all their customers” (HM Government 2014; UK Department of Health 2022). The industry depends on moneys collected from the more healthy (lower health risk) to cover the costs of those less healthy (higher health risks). This means that if people have access to increasingly precise information on their genetic predispositions and have to disclose these risks to insurance providers, people with greater estimated risks will be disadvantaged. Moreover, the line between diagnosed and undiagnosed (predicted) conditions may become increasingly blurred, with regulation urgently required of how this will be evaluated. At the same time, the situation, where individuals have access to their genetic risks, and private insurers do not (known as anti-selection or adverse selection), is identified as a threat for the industry (The Economist 2017). These challenges are reflected in the growing research in this field, e.g. (C. R. Chapman et al. 2020; Pugh 2021). Engagement of key legal stakeholders is urgently needed in order to develop alternative insurance provisions that will work to protect both individuals and insurance providers.

**Employment.** Considering that talent is necessary in a competitive business world, the power of prediction becomes highly desirable for businesses. Selection on ‘markers of success’ is a booming industry that uses past achievement and behaviour, current cognitive ability, physical build (e.g. for sports) and personality characteristics – to evaluate one’s potential for future success in a particular field. It is only a matter of time before genetic markers are added to this list. Plans have been reported to use gene-based prediction by the military – to determine genetic makeup for traits/phenotype of special relevance to military performance, including physical and mental performance; responses to battlefield stress; and the ability to tolerate difficult conditions (see ‘The \$100 Genome: Implications for the Department of Defense’ Report (The MITRE Corporation 2010)). Considering, genetic information is probabilistic, gene-based employment selection would lead to missed opportunities for both individuals and employers. Moreover, gene-based job selection carries other risks of discrimination, via selecting staff with reduced risk of depression and other conditions.

**Manipulation and influences on decisions.** People’s data are widely used to influence their decisions. For example, politicians use information about voters for targeted manipulations (Burkell and Regan 2019; Hern 2018). Data collected through various data-gathering approaches are used to manipulate peoples’ purchasing behaviour – via targeted advertising or trend setting, e.g. (Kant 2021). The power of genetic prediction may also be used

to influence people's decisions across life aspects, including in purchasing of medication, consumer choices, voting and inspiring conflict.

**Entrenching Prejudice.** Gene information may be used to entrench existing racial and other prejudices. Discrimination based on hypothesised biological differences between groups has led to numerous catastrophes: see for example (Selita, Willers, et al. 2020) for an in-depth assessment), including the following well known genocides: the murder of up to 1.5 million Armenians in 1915; of around 6 million Jews and hundreds of thousands of Roma in the Second World War; and more recently (1992-95), of around 250,000 Bosnians (Derderian 2005; Paulsson 2011; ushmm.org n.d.). Hypothesised biological differences have also been used as a justification for the centuries-long segregation of black people; the persistent discrimination of minority ethnic groups; and the group and class discrimination through eugenic practices against groups considered genetically inferior, targeting immigrants, minorities and poor people (Andrews et al. 2015; Bouche and Rivard 2014; Daniel J. Kevles 1985; Kevles 1999; Lombardo 2011; UNICEF 2017). The millions of forced sterilisations were conducted in the name of 'improving race' and alleviating the 'burden' that the poor, disabled and mentally ill 'impose' on society. Such discrimination continues, as evidenced, for example, in recent reports of sterilisations of inmates as recently as 2010 in the State of California (Johnson 2013). There are risks that genetic information will lead to neo-eugenics (Epstein 2003; Somsen 2009), and will continue to be misused to promote 'race' discrimination – despite the fact that latest genetic findings go against biological 'justifications' for 'race' discrimination.

**Psychological harm.** Beyond intentional misuses of our genetic information by others, it can be misused by ourselves, especially if our interpretations are misinformed. For example, knowledge of the future (e.g. results of direct-to-consumer (DTC) genetic testing), can have significant impact on our lives. We may decide not to pursue a chosen career; develop anxiety about the future or redefine our past in a negative way (Kovas and Selita 2021b). The misinterpretation of information may also contribute to 'self-fulfilling prophecies' – e.g. via believing that some ability or skill is impossible to achieve and so avoiding certain activities.

To sum up, the power of genetic prediction presents challenges for societies, that need to be addressed in order for societies to maximise benefits and minimise risks.

## The Power of Environmental Engineering

The Power of Environmental Engineering allows societies to change genetic effects on traits/life outcomes, without the need to edit the DNA code. This power is enabled by our understanding of gene-environment co-action; for example, that genes express differently in different environmental conditions and that people with different gene variants respond differently to the same environments. This means that environments can be used to suppress or enhance traits via the altering of genetic effects.

Making environments more suitable to individual propensities and needs is an important societal challenge. Despite many years of social engineering (e.g. social mobility enhancing efforts, compulsory secondary education, wide access to educational resources), variation in human traits remains vast. For example, results from longitudinal large international studies show children differ greatly in their academic achievement within all countries. The Programme for International Student Assessment (PISA) study showed that students' performance in mathematics at age 15 varies more within a country than between countries

(OECD, 2013). Within a country, the gap between the highest- and the lowest-achieving students was over 300 points, the average score in OECD countries being around 500 points. This difference is enormous, as performance gap of about 70 score points represents a large difference in the skills and knowledge, the equivalent of about two years of schooling in a typical OECD country (OECD, 2013). The results also suggested that, although most of the variability overlaps across countries, there are also significant differences across countries, especially in the proportion of students achieving low and high scores (OECD, 2014).

In the Genomic Era, in addition to understanding that the nature of traits is polygenic and polyenvironmental, it has been established that genetic and environmental factors interplay. One way in which this interplay can manifest is in the amount of variance in human traits explained by genetic differences in particular environments (heritability). Heritability is a widely used term, but is still commonly misunderstood (Kovas & Malykh, 2016). For example, people may erroneously believe that heritability relates to a specific person – so that if heritability of a trait (e.g. academic achievement) is 60% it means that 60% of an individual's academic achievement is determined by the person's genes. In reality, it means that 60% of the differences among people in this trait are explained by their genetic differences (see Kovas & Malykh, 2016 for a detailed explanation). Heritability of a trait within a population can be estimated (quantified) by using different methods – one of the most common being the study of monozygotic (MZ) and dizygotic (DZ) twins. Another quantitative method is Genomewide Complex Trait Analysis (GCTA), which estimates heritability directly by comparing DNA and trait similarities of unrelated individuals (Plomin & Deary, 2014).

Biologically, heritability reflects all the differences in the structure of the DNA that exists among humans. Research shows, that around 1% of the human DNA sequence is different among people, with the rest of the sequence being identical for all. Although this is a small proportion of the genome sequence, it represents millions of DNA variants, each potentially contributing to the observed differences among people. Moreover, recent research suggests that we may be even more different from each other genetically, with each person's DNA containing many rare or completely new (De novo) mutations. A large study with 10,000 sequenced genomes found that each person's DNA contains an average of 8,579 novel genetic variants (Telenti et al., 2016).

Moreover, genetic variability is further exacerbated by epigenetic processes that affect how genes work. Genes constitute around 2% of the total DNA sequence and are referred to as coding DNA, because the information contained in genes is used by the cell to synthesise proteins. Children inherit approximately 23,000 pairs of genes from their parents, but the way these genes express depend on the environment. Experiences leave a chemical 'signature' on genes that determines whether and how the genes are expressed. These processes are referred to as epigenetic; and collectively, these chemical signatures are called the epigenome.

Effects of experiences and environments on gene function impact early brain development, as most human genes are expressed in the brain (Negi and Guda 2017). Experiences trigger signals between neurons, which respond by producing gene regulatory proteins. These proteins move to the nucleus of the neural cell, where they either attract or repel enzymes that can attach them to the genes. Positive experiences, such as exposure to rich learning opportunities, and negative influences, such as psychological stress, poor quality of nutrition, pollution or other toxins, can change the chemistry of genes in brain cells (Murgatroyd and Spengler 2011). Such epigenetic changes can be temporary or permanent.

Overall, today it is clear that heritability is not static and fixed, but refers to the genetic contribution to differences among people within a *particular population*, at a *particular time*. In other words, genetic factors can explain a different proportion of individual differences in different populations (even if the overall amount of trait variability is similar). This, in turn, means that through environmental interventions it may be possible to suppress or enhance the genetic effects related to a trait (to change heritability of that trait). For this, we need a good understanding of the interplay between *environments* and *genetic effects* in a particular population or group. The following section summarises our current understanding of the interplay between environments and heritability (covered in Publication 2).

## **The interplay between environments and heritability**

The assessment of the interplay between environments and heritability is difficult because it requires comparing data within and across populations or groups. For example, we know that *between population* variability could arise from differences in allelic frequencies (e.g. how common a particular gene variant is) and from differences in environmental circumstances (e.g. how common alcohol consumption is) across populations. *Within population* differences are also a product of both genetic and environmental factors. In fact, much research has shown that most genetic variability is present within any ethnic group or geographically defined population; and only a small proportion of genetic variation can be assigned to differences among the groups (Bulatao et al. 2004; Jorde and Wooding 2004; Witherspoon et al. 2007). Environmental provisions also vary greatly within and between populations. Recently, assessment of the interplay between environments and heritability has been made possible by the greater availability of:

1. A wealth of findings on variability of life outcomes within and across populations;
2. Sufficient studies on heritability (the genetic component) of this variability – within and across populations; and
3. The vast number of findings on the impact of specific environmental conditions on life outcomes. One such measurable source of environmental impact is inequality.

In the following section, the interplay between inequality and heritability is analysed as a model of heritability-environment interplay. The focus on this environmental condition is justified because inequality is well studied, and societies potentially have greater control over inequality than over poverty, which is another well-studied environment that can significantly suppress positive genetic effects through epigenetic processes.

### **Inequality–Heritability interplay**

Inequality in a population can be expressed as a Gini index which represents income or wealth distribution among all people, irrespective of the wealth of a country. Inequality plays a major role in creating *environmental disparities* in our societies with serious impact on life outcomes, such as health, education, mortality from infancy, life expectancy, mental illness, obesity, educational attainment and achievement, teenage birth rates and social mobility (Ansell 2017; Bischoff and Reardon 2013; Carter and Reardon 2014; County Health Rankings and Roadmaps 2015; Duncan and Murnane 2011, 2016; Kawachi and Kennedy 1997; Logan 2014; Marmot et al. 1978, 1984; Pickett and Wilkinson 2015; Reardon 2011; Rowlingson 2011; Ryan and Adams 1998; R. G. Wilkinson and Pickett 2009; Richard G. Wilkinson and Pickett 2006).

For example, in relation to education, inequality has been found to activate numerous long-term biological processes that affect children directly and through their parents – leading to a range of psychological and health-related outcomes (Braveman and Gottlieb 2014; County Health Rankings and Roadmaps 2015; Duncan and Murnane 2016; Johnson et al. 2015; Kaplan et al. 1988; Pinto et al. 2008; Ryan and Adams 1998; Singer and Ryff 2001; R. Wilkinson et al. 2003; R. G. Wilkinson and Pickett 2009; Richard G. Wilkinson and Marmot 2003; Richard G. Wilkinson and Pickett 2011). These processes include provoking pro-inflammatory cytokine production (Kiecolt-Glaser et al. 2010); and chronic inflammation (e.g. (Ford et al. 2006; Gianaros et al. 2013; Loucks et al. 2006). Research identified that in developed countries, children in more unequal societies are on average more likely to: be overweight and experience more mental health problems; experience more bullying and victimisation; become teenage parents; leave education after compulsory attendance; have on average lower achievement (Bischoff and Reardon 2013; Duncan and Murnane 2011; Pickett and Wilkinson 2007, 2015; Reardon 2011; Ryan and Adams 1998; UNICEF Office of Research 2016; R. G. Wilkinson and Pickett 2009, 2009).

To understand the interplay between inequality and heritability (Gene-Gini interplay), an important question to address is whether the vast variability observed in children’s academic achievement within each population is explained to a different extent by genetic and environmental factors in different populations. For example, if two countries show comparable variances but differ in average performance, variability in one country may be largely due to environmental disparities, whereas in the other – due to genetic variability (free from environmental limitations).

A review of educationally relevant behavioural genetic studies and meta-analyses suggests evidence for the Gene-Gini interplay – the effect of inequality (through epigenetic processes) on heritability of educational attainment and achievement in a population (Publication 2). For example, when comparing heritability of educational achievement across wealthy countries, it is lower in countries with high inequality (Gini), and higher in countries with low inequality. In fact, the strength of heritability can be viewed as a measure of environmental equality in the population. Inequality affects heritability through environmental disparities it creates. First, the strength of genetic contribution to differences among people in a population depends on environmental conditions (this can be seen in significant statistical interaction). Second, environmental conditions may enhance or suppress genetic effects in an individual (causal mechanism).

Inequality can affect heritability in education via a number of processes. For example, people’s experience of inequality, such as feelings of injustice, unfairness and envy – may lead to elevated stress. In turn, this may trigger cascading negative biological reactions, such as inflammatory and other pathways which impact the structural integrity of brain networks (Gianaros et al. 2013). Through these processes, an individual’s developmental trajectory can diverge from that enabled by their genetic propensities – for example suppressing genetic predispositions for advanced reading ability through neurodevelopmental processes affecting brain structure and function.

Genetic effects (heritability) may be weaker in disadvantaged environments, as such conditions lack ‘food’ (educational opportunity, resources, encouragement, choice of activities) for children’s genetic ‘appetite’ for learning. In other words, genetically influenced potentials for adaptive functioning may be expressed to a greater extent in enriched environments: see

(Tucker-Drob and Bates 2016) for more detail on the Scarr-Rowe hypothesis of Gene by SES interaction).

Research has identified that once children are out of low income environments, every incremental increase in household income is associated with superior child development outcomes; and that there is no point above which high income ceases to benefit children's development (Phipps & Lethbridge, 2008).

Inequality, beyond poverty, during childhood (early environment) can also affect later development through epigenetic regulation (e.g. Meaney, 2010). Several studies that assessed this impact have drawn a number of important conclusions:

- That negative life events in early childhood can affect the expression of genes involved in immune functioning (Bick et al., 2012).
- That there are differences in the expression of genes involved in inflammation and anti-inflammation between those who grew up in low and middle income families (Miller & Chen, 2007).
- That socioeconomic disadvantage is linked to the increased expression of inflammatory molecules and proteins, transcriptional changes in genes and intracellular signaling cascades promoting systemic inflammation (Gianaros et al. 2013).
- That effects can emerge pre-birth and affect the entire path of development. For example, mother's stress and anxiety during pregnancy can suppress or enhance genetic expression in the mother and her developing baby, e.g. reviewed in (Coussons-Read et al. 2007; Kovas et al. 2016). Some of the epigenetic changes have also been found to be transmitted across generations (Heijmans et al. 2008; Kim et al. 2010).

On the other hand, some of the negative genetic effects can be reduced by greater equality (as measured by the income Gini and the associated educational investment gap (Magnuson and Waldfogel 2008; Piketty and Saez 2003; Reardon 2011)). For example, more equal educational provisions, such as compulsory secondary education, can suppress the negative effects of genetic propensities on educational attainment (years in education) and associated outcomes. The requirement that students continue education until a certain age (e.g. 18 in the UK) overrides genetic contributions towards dropping out of school, meaning that genes cannot explain the variance in whether a person progresses to higher education and for how long.

These examples of Gene-Gini interplay demonstrate that environments may be engineered to change genetic effects. However, the power of changing genetic effects through environments (environmental engineering) may bring both, benefits and risks for people and societies.

## **Benefits and Risks of the Power of Environmental Engineering**

Environmental engineering (altering behaviour through environments) has always been extensively used by humans, for example educational outcomes have been changed via educational policies. In the Genomic Era, environmental engineering is an even more powerful tool if it is based on understanding of gene-environment co-action.

## Benefits

In a positive sense, the Power of Environmental Engineering allows individuals and societies to extract the most from our genetic propensities in five broad ways.

- 1) This power is a mechanism of personalisation across aspects of life – such as education, health and life-style. It may enhance the positive expression for desired traits (e.g. strong academic performance, motivation), and suppress undesired traits (e.g. aggression) through early intervention. Personalisation can include the use of genetic information to apply medical screening and treatments (Abad et al. 2018; Virolainen et al. 2022); taking preventative or remedial measures for those at genetic risk for learning problems (Selzam et al. 2017); and more broadly, using genetic potential for success in particular areas for life design/career planning (K. Hill 2009).
- 2) The power of environmental engineering allows us to assess whether variability in a particular trait in a particular population is largely due to environmental or genetic disparities (free from environmental limitations). For example, after environmental disparities are reduced, the remaining large variability in traits (e.g. educational outcomes) has been shown to be largely driven by genetic differences (Schwabe et al. 2017). In other words, environmental engineering in the Genomic Era can act on testable alterations to the heritability of traits in a group or population.
- 3) This power allows us to assess whether the environments we are creating are suppressing or enhancing our genetic potential and to act accordingly. For example, studies can assess the impact of population-wide social measures on our genetic potential (Stienstra et al. 2022).
- 4) Understanding the power of environmental engineering to help societies move further way from deterministic views often held about genetic effects, and in particular for when judging the behaviour of others (attribution errors).
- 5) Better understanding of the origins of behaviour (a prerequisite to effective environmental engineering), may also help societies to move away from a blame and praise culture. For example, at present, blaming (or praising) teachers, students and parents for children's outcomes is deeply engrained in our culture, both in terms of our attitudes and formal league tables of students, classes and schools (J. Rothstein 2016).

## Risks

The power of environmental engineering can also be used negatively in three broad ways.

- 1) Personalisation (attempts) may lead to suppression of traits that would benefit people (e.g. academic performance), and to enhancement of undesired traits (e.g. aggressiveness).
- 2) Interventions that have positive intentions may actually lead to harm, for example if they are not individualised enough or if they are premature or based on imprecise information.
- 3) It can be used by authorities to manipulate opinions or actions through instilling fear in society in a more controlled way than in the pre-Genomic Era. For example, harmful negative attitudes can be 'engineered' towards a select group, creating the belief that a select group is the

cause of certain undesirable outcomes. This in turn is a mechanism creating conflict among groups/populations.

Overall, the power of environmental engineering in the Genomic Era is one of the most important powers societies have ever possessed. If used in an ethical way, it has potential to improve life for all at a pace not previously possible – including through enhanced education, health and happiness. However, it also presents significant challenges for societies.

## The Power of Genetic Engineering

For the first time in recorded history, our power has advanced to editing our ancient text of life – DNA. Gene editing technologies, such as CRISPR-Cas9, have already been used to modify the genome at precise loci in the DNA sequence in living humans (Cai et al. 2015; Dolgin 2017; Doudna and Sternberg 2017; Kang et al. 2017; M et al. 2012; Whitworth et al. 2014); as well as in the germline – creating so called 'designer babies' (Begley 2018; Cohen 2019; Critchley et al. 2019; Le Page 2017; Liang et al. 2015; Ma et al. 2017; NIH, US 2016; Nuffield Council on Bioethics 2018; Regalado 2019a, 2019b). Genetic engineering (gene editing) is an immense new power that has the potential to change all aspects of our lives.

Currently, the use of gene editing is mostly limited to somatic cells (the majority of cells) that are not passed on to future generations. In these cases, 'editing', such as correcting a mutation that causes a monogenic disease, is confined to a specific person. In contrast, editing germline cells (sperm or egg cells; embryos; and reproductive stem cells) transcends an individual as these cells are carried forward to future generations. Germline editing is currently controversial, because it can lead to a permanent alterations of the human gene pool (Knopik et al. 2017).

Despite controversies, the use of gene editing is likely to grow, as it presents enormous business and medical opportunities. In fact, the rules on allowing gene editing in humans have recently been relaxing. In 2015, when British scientists first sought permission to edit human embryos in vitro, in vivo editing was out of the question (Sample 2015). Just 3 years later, in vivo gene editing was becoming a reality. Unless we have a one-government world (advocated by many, including Albert Einstein (Lu 2016)), it will be increasingly difficult to protect human rights from gene editing misuse. The majority of genetic professionals predict that germline gene engineering *will* be applied in clinical settings in the near future (Armsby et al. 2019; Taguchi et al. 2019). The UK Nuffield Council on bioethics, and the US National Academies of Sciences, Engineering, and Medicine (NASEM), suggest that gene engineering in embryos would be acceptable if used in critical conditions and in the best interest of the child (National Academy of Sciences et al. 2017; Nuffield Council on Bioethics 2018).

The regulation of this power is problematic. Many countries have begun to put in place regulation for gene editing, such as to limit the use of gene editing and related research, both for somatic and germline cells (Government Office for Science 2022). However, regulations in one country do not protect from misuses in another. In the globalised world, one population's change will spread to other populations. Multi-jurisdiction enforcement is unlikely to be possible for many reasons, including due to the principles of sovereignty. Currently, jurisdictions regulate germline editing differently, with some prohibiting it, some having ambiguous regulation and some allowing it (Araki and Ishii 2014; Nordberg et al. 2018).

# Benefits and risks of the power of intervention through gene editing

## Benefits

Gene editing is already used to cure disorders, and has the potential to cure illnesses that have no other current treatment options (Nordberg et al. 2018). With a one-time procedure, gene editing can change a disease-causing mutation into a healthy version of the gene. In the nearer future, it is predicted to help over 10,000 identified monogenic disorders (Ma et al. 2017).

In addition, gene editing can be used to enhance traits. For example, recommendations have already been made to the US military to employ genomic technologies to enhance health, readiness and performance of military personnel ('The \$100 Genome: Implications for the Department of Defense Report' (The MITRE Corporation 2010)).

Another potential (but controversial) benefit is the use of gene editing at the pre-implantation stage during assisted reproductive procedures for 'editing' physical and behavioural characteristics of children (Nuffield Council on Bioethics 2018).

## Risks

Risks associated with the power of intervention through gene editing are serious (Doudna and Sternberg 2017). For example, the then head of the US Intelligence has compared the power of gene editing with that of a weapon of mass destruction, and has warned of far-reaching implications from its deliberate or unintentional misuse (Nature Editorial 2016b). The complexity of gene editing means that unforeseen harm can be caused to the organism. Moreover, the damage can potentially be irreversible, with many consequences currently unknown. Gene editing can also change the population genetic pool. For example, unregulated editing of the human germline (cells that are relevant for reproduction) might create unwanted or harmful inheritable genetic changes, affecting the whole population's genetic pool.

In addition, mutations harmful for one trait, can have protective effect for other traits – a phenomenon known as antagonistic (negative) pleiotropy (Austad and Hoffman 2018; Byars et al. 2017). One example of antagonistic pleiotropy, found in an East Asian population, is a genetic variant which has a protective effect against heart disease but contributes to the risk of developing macular degeneration and blindness (Cheng et al. 2015).

Gene editing can also worsen the already wide social disparities, for example through unequal access to the benefits of gene editing. If gene editing is ever applied to polygenic traits, this can also lead to injustices. For example, gene enhancement (a form of biohacking) may be widely used, including for intelligence, sport performance and within the military. Non-genetic bio enhancement is already widely used. For example, it is reported that the US Department of Defense designed and implemented force-wide, mandatory Anthrax Vaccine Immunization Program (AVIP), despite the fact that it was designed for a different purpose, was not proven to be safe and was ineffective against weaponized anthrax on the battlefield (Nass 2002; US House of Representatives 2000).

## Urgency of regulation

In evaluating the urgency of regulating the use of the three powers reviewed above, it is important to take into consideration the following four key realities related to genetic data.

**1) Privacy challenges.** The unique DNA code of each individual means that genetic information privacy cannot be ensured in the Genomic Era. For example, De-identification (anonymisation) of genomic data does not fully protect privacy, as sequenced data can be linked to individuals using free, publicly accessible, Internet resources (Erlich and Narayanan 2014; Gymrek et al. 2013; Hayden 2013; Nuffield Council on Bioethics 2015). Identification is also made easier by other types of big data. In fact, anonymised Big data (without genetic data), through data fusion techniques, enable a clear picture of an individual and their tastes (Executive Office of the President 2014b). The predictive power makes genomic data the goldmines of today's advanced economies – “exploitable raw materials, which can be put to use for a variety of purposes beyond those for which they were originally collected” (Nuffield Council on Bioethics 2015), para 9).

The economic value is also one reason for large scale data sharing which makes private information accessible from any part of the world that has Internet connection. Data driven economies and scientific progress relying on the availability of large data sets, has made large-scale data sharing inevitable. Data are shared internationally in State-State, State-Private and Private-Private transactions (EC 2017, 2018). For example, in 2013 there were around 3,500 organizations in the EU that were Safe Harbor-certified for cross-continental data transfer (Mcbride et al. 2013). In the UK, medical data of 40 million patients were made available electronically to a range of stakeholders, and such data were also reported to be shared with private organisations, such as Google (Hodson 2016). From the moment genomic data are publicly released (via a breach or intentionally), it is impossible to retrieve, make private again, or monitor uses (Heeney et al. 2011). Moreover, the storing of data in diverse cloud platforms, makes enforcing of data protection more difficult. It is a serious challenge to locate the origin of data breaches and establish jurisdiction in data breach disputes. Therefore, engagement of the key stakeholders is required to find solutions for the multiple difficulties with data protection in the Genomic Era.

**2) Wide reach.** Genetic prediction already affects millions of people and soon everyone is likely to be affected. This is because one needs to have their own genome sequenced in order to access benefits of genetic science, such as better health. Moreover, genetic data banks are already large and growing fast, with some data banks containing samples from virtually entire national populations from as early as 2003 (UNESCO 2003). Genetic data are collected as part of State-organised genetic services, such as the Nation-wide Genomic Medicine Service (UK) and as part of Direct to Consumer genetic testing services (Mukherjee et al. 2017). Private companies are also being authorised to provide genetic health risk tests for multifactorial conditions. In addition, it is forecasted that soon everyone's DNA will be sequenced at birth, with for example, newborns in virtually all European countries already tested for several known genetic conditions (Friedman et al. 2017; Loeber et al. 2021).

At the same time, large-scale data breaches are common. Over a billion data breaches have been reported to take place annually (Cyentia Institute 2016; Kessler and Bromet 2013; Munce et al. 2007; Ponemon Institute 2017; Reddy 2010), including hacks to highly secure organisations, such the US Department of Defense (Shanker and Bumiller 2011). Cyberattacks,

which together with hacks make around 47% of breaches (Ponemon Institute 2017), have been reported to increase by as much as 81% in one year; and hacking incidents have been reported to have exposed over 200 million identities in one year (Wood et al. 2012). For example, in 2017, the world experienced the WannaCry attack, which affected over 150 countries (Fung 2017). In the UK, the Information Commission and police have uncovered evidence of “a pervasive and widespread ‘industry’ devoted to the illegal buying and selling of confidential personal information” (ICO 2006), p3. Data breaches in health care are also common. For example, in around 4 years, 1,419 large-scale health data breaches (each affecting at least 500 people) have been reported to the US Department of Health and Human Services (Ornstein 2015). In the UK, a recent NHS data breach involved around 500,000 medically sensitive documents (results of blood tests, biopsies and cancer and other screening) (Merrick 2017). In addition, unsanctioned use of data, can be viewed as data breaches, even when data are used for research purposes such as that of newborns’ blood samples by the US Department of Health (Suter 2014).

Lack of compliance in security measures exacerbates the problem of data breaches. For example, in a US study, healthcare providers self-evaluated their compliance with the security rule of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), with only 17% of the respondents reporting full security compliance (Having and Davis 2005; Rinker 2013). In the EU, a study revealed that the national data protection authorities in 11 (of 27) member states were unable to carry out their tasks due to lack of financial and human resources (Kuner 2011). The current situation can be likened to a river overflowing its banks – with streams of precious information on individuals, including highly sensitive genetic information, flowing through unattended channels.

**3) Long-term reach.** Genetic information extracted from DNA today, can be used to harm individuals and their relatives throughout their lifetime and across generations (Publication 1). The DNA code does not change over an individual’s lifetime. Moreover, the more science progresses, the more valuable the previously sequenced data becomes, including to those who wish to misuse the data for gain. Similar to the gradual and patchy process of extracting meaning from a text written in an unknown ancient language, the human DNA sequence is being deciphered gradually, providing new meanings every day. Even if the sequenced data are destroyed, the knowledge already gained can be used to cause harm, including to family members who have not consented to genetic testing. Therefore, data breaches of today, when laws do not provide sufficient protection, can be used to harm individuals at a later time in life.

**4) Insufficient regulation.** Current laws are not designed to offer protection from misuses of sequenced genetic data. Relevant laws in place were largely designed prior to genome sequencing, and so are not designed to protect from misuses of sequenced data, including in jurisdictions with advanced genetic science such as the US, UK and Russia (Clayton et al. 2019; Furrow et al. 2013; Karelin et al. 2018; M. A. Rothstein 2009; Selita 2020). The few genetics-related laws that have been passed in some countries, such as the Genetic Information Non-discrimination Act (GINA) 2008 in the US; and the Genetic Non-discrimination Act 2017 in Canada – provide limited protection (Hammond 2020; Impact Ethics 2020; M. A. Rothstein 2009). Recent major legislation on data protection, such as the EU’s General Data Protection Regulation of 2016 (GDPR) serve two competing interests – data sharing and data protection – making it impossible to effectively protect against misuses of genetic data (Publication 1). Moreover, the current laws impose nothing more than fines for data breaches, which is insufficient to deter big corporations from reckless and deliberate breaches (e.g. (US

Department of Justice 2012, 2017). Such breaches have been reported to make-up a significant proportion of all data breaches (Ponemon Institute 2017).

To sum up, the scope and benefits of the application of the three powers (prediction, environmental engineering and genetic engineering) in different contexts will depend on whether fair and effective regulation can be achieved (Baltimore et al. 2015; National Academy of Sciences et al. 2017; Taguchi et al. 2019). Part II examines societal readiness for achieving such regulation and for a successful adaptation to the Genomic Era.

## Part II

# Adapting to the Genomic Era: readiness of individuals and societies<sup>3,4,5</sup>

Genetic advances have multisector and global implications. Individuals are increasingly confronted with genetics-related complex questions in multiple contexts, such as *whether to*: have their child's genome sequenced; undergo a genetic test with national health services or private companies; seek help with interpreting genetic testing results; purchase genetic-based interventions for serious illnesses; give permission to disclose genetic risks to family members; use genetic information for major decisions such as partner selection, career planning and life design more broadly; use their children's genetic information to direct children's education and hobbies (see Publications 3, 4, 5).

At a societal level, we need to decide on matters such as *whether to allow*: insurance companies to use genetic information; the State to use genetic information for immigration decisions; the State and private companies to use genetic information in recruitment and promotion ubiquitously or in specific contexts (e.g. military; professional sports); financial institutions to use genetic information for determining access to loans; general use of genetic advances in economic policy and education. In justice contexts, societies need to decide *whether to*: allow the State to use genetic information for crime prevention; allow the Courts to use genetic information in sentencing; give weight (and how much) to genetic information in legal proceedings; and use new findings about human behaviour to update criminal justice systems' assumptions and expectations, such as those related to free will and punishment.

Each of these questions is inherently multifaceted, incorporating economic, social (e.g. utilitarian), political (e.g. democratic), philosophical (e.g. moral) and psychological (e.g. understanding, values, biases) dimensions. Success of human adaptation to the new world of the Genomic Era will depend on individual and societal decisions made by people living today.

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<sup>3</sup> Fatos Selita\*, Vanessa Smereczynska, Robert Chapman, Teemu Toivainen, Yulia Kovas. 2020. Judging in the Genomic era: judges' genetic knowledge, confidence and need for training. *European Journal of Human Genetics*. doi: 10.1038/s41431-020-0650-8

\* Corresponding author.

<sup>4</sup> Fatos Selita\*, Robert Chapman And Yulia Kovas. 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).

\* Corresponding author.

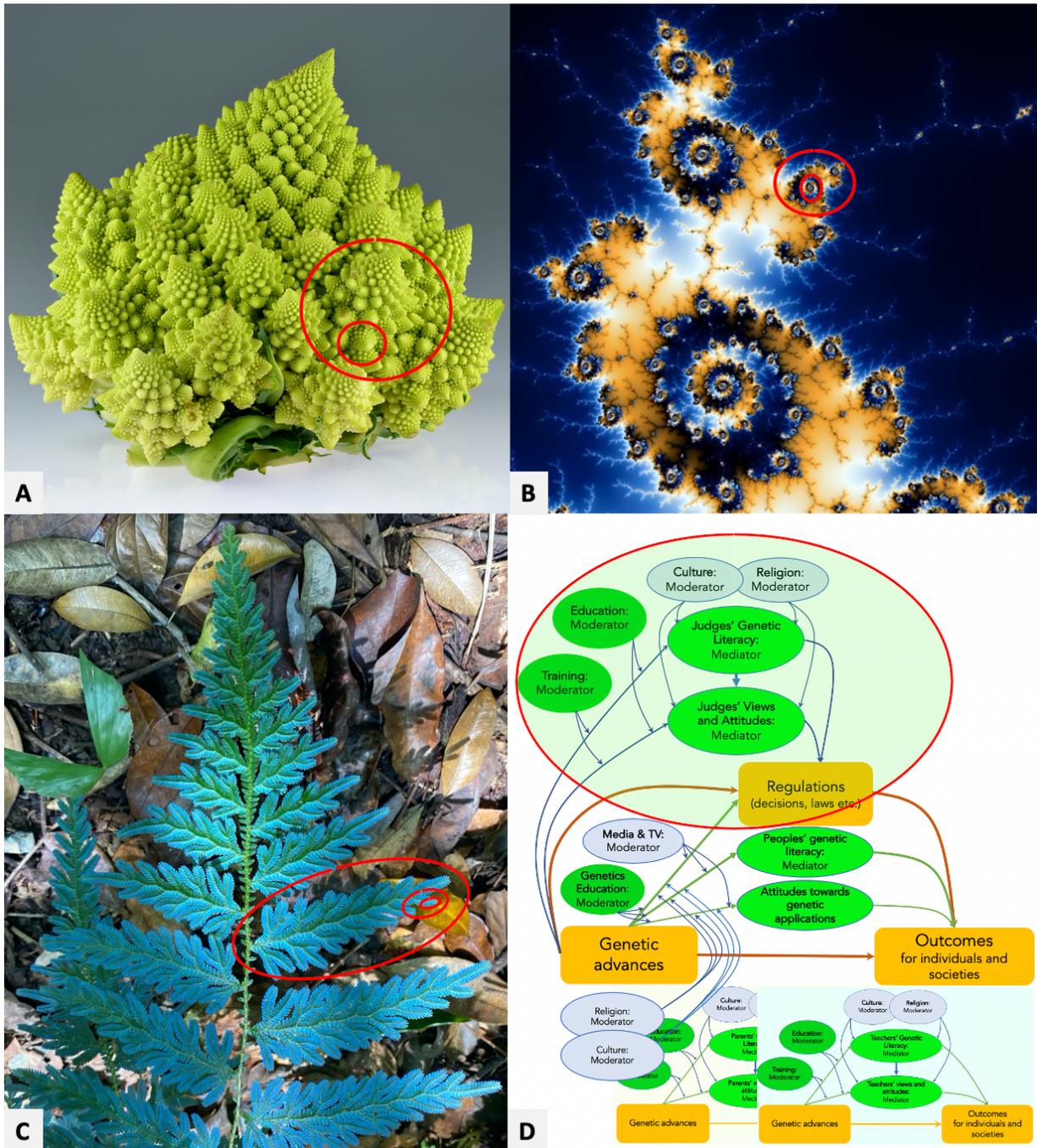
<sup>5</sup> Fatos Selita\*, Robert Chapman, Yulia Kovas, Vanessa Smereczynska, Maxim Likhanov and Teemu Toivainen. 2023. Consensus too soon: judges' and lawyers' views on genetic information use. *New Genetics and Society*. doi: 10.1080/14636778.2023.2197583

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## The path from genetic advances to outcomes

The path from genetic advances to outcomes for people and societies is a complex system of co-influencing elements. The system includes direct influences of one element (e.g. availability of genetic testing) on another (decision to undergo genetic testing), as well influences that are mediated and moderated by multiple other elements (e.g. genetic literacy, regulation of application of advances, personality characteristics, values, cultural norms etc.). In Figure 1 this system is likened to a Mandelbrot set – a set of complex numbers demonstrating how complexity can be created from simple rules via multiple iterations of progressively finer recursive elements (See further detail in Figure 1). The process of adaptation to the Genomic Era involves multiple quasi-similar processes. It is difficult to imagine that we will ever be able to capture all of the elements or their interactions. However, focusing on several specific elements and understanding their interrelations, may help identify important points in the system at which interventions may be most successful. The present thesis focuses on several subsystems within the Genomic Era system, aiming to identify several points at which interventions (informational, educational, policy) will lead to favourable outcomes (e.g. prevention of genetic information misuse and abuse).

Figure 1. Illustrations of the Mandelbrot set, exhibiting progressively ever-finer recursive (defined in terms of itself) detail at increasing magnifications.



*Note.* Outside the field of mathematics, the Mandelbrot set is used as an example of a complex structure arising as a result of simple rules. The Mandelbrot set is quasi self-similar: small slightly different versions of itself are found under magnification. Panel D is a model of a system with multiple subsystems via which genetic advances will influence people’s lives in the Genomic Era, including literacy and attitudes of judges, teachers and parents, with multiple other systems implied but not presented in the Figure. The circled element is a subsystem that focuses on judges, and is magnified and discussed in Figure 3.

Figure 2 presents a snapshot of the complex model – illustrating several core subsystems of mediators and moderators of the links between genetic advances and their consequences for people’s everyday life.

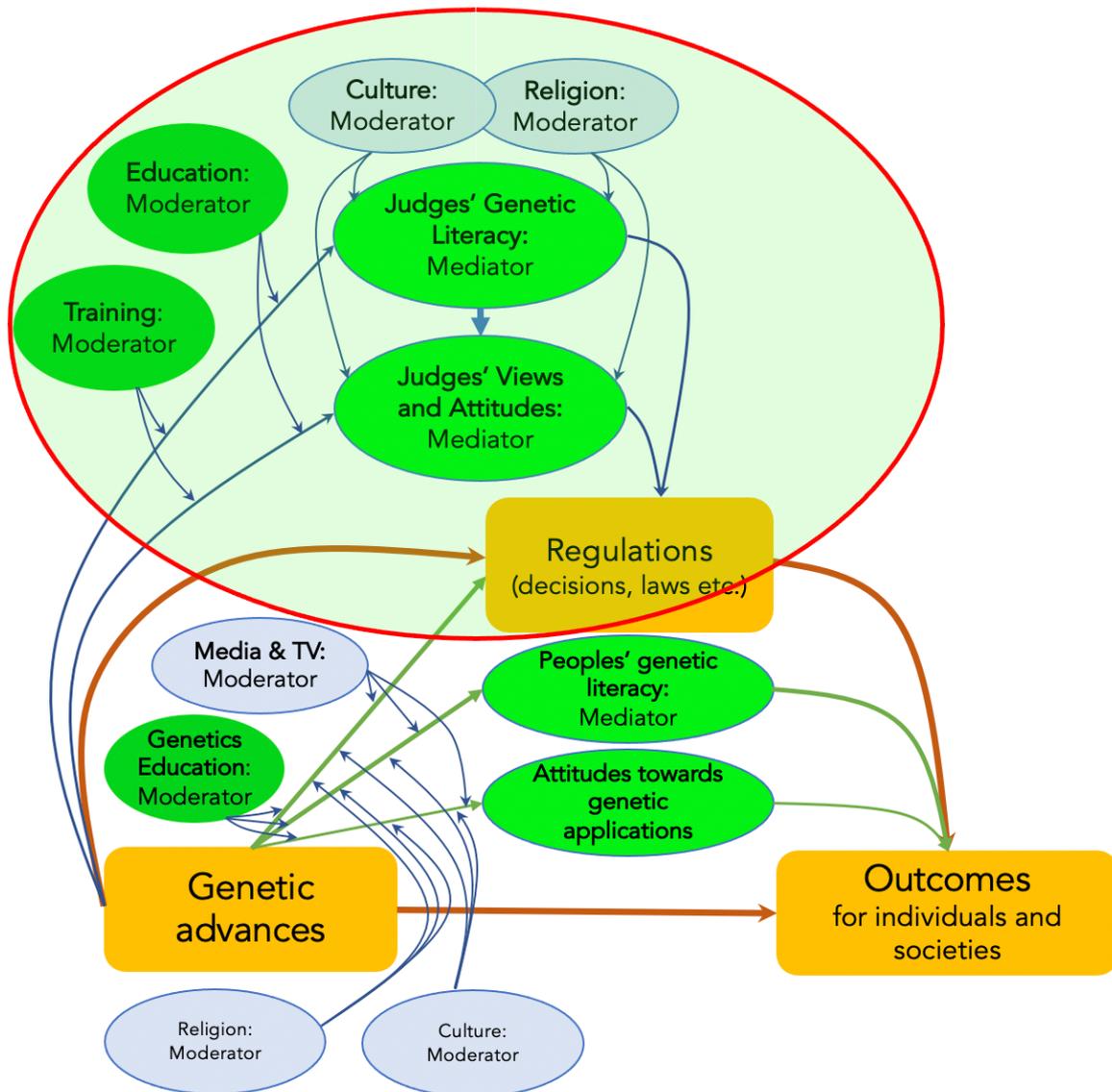
At the societal level, these subsystems include:

- education and curriculum – preschool, school, higher education and professional training (what, when and how people learn about genetics)
- societal regulation (e.g. which laws and policies have been/will be adopted and why)
- societal set-ups (e.g. inequality in access to genetic advances, education and support with interpreting genetic results or with understanding implications of genetic information)
- **genetic knowledge and attitudes of key stakeholders, such as lawyers and judges – the workforce at the forefront of regulation of genetic information use (the focus of this thesis)**
- cultural norms and values (e.g. religious beliefs, utilitarian values)

At the individual level, these subsystems include:

- understanding of genetics (genetic literacy)
- genetics related personal views, attitudes and values (what one thinks about genetics and why)
- existential beliefs (e.g. what genetic findings mean for one’s sense of control, agency, will and meaning)

Figure 2. A system of multiple mediated and moderated processes via which genetic advances will influence people's lives in the Genomic Era.



*Note.* The circled element is the system that includes Judges' genetic literacy and attitudes as mediators between genetic advances and outcomes. Genetic literacy and views are also themselves outcomes of mediated and moderated processes, such as education, culture and media.

## Judges' and lawyers' genetic literacy and attitudes as mediators between genetic advances and their outcomes

The judiciary and lawyers play a 'steering' role in the development of the law for novel matters, including through first cases (especially in common law jurisdictions such as the UK, where case law is a source of law); the drafting of Bills; and knowledge exchange through their professional bodies, such as the Inns of Court and the Law Societies/Associations. Until relevant laws are developed and updated, the judiciary will play a manifold role in regulating the use of genetic information and the application of genetic advances. Judges will, for example, decide upon how to respond to new genetics-related issues and will scrutinise controversial applications as they arise.

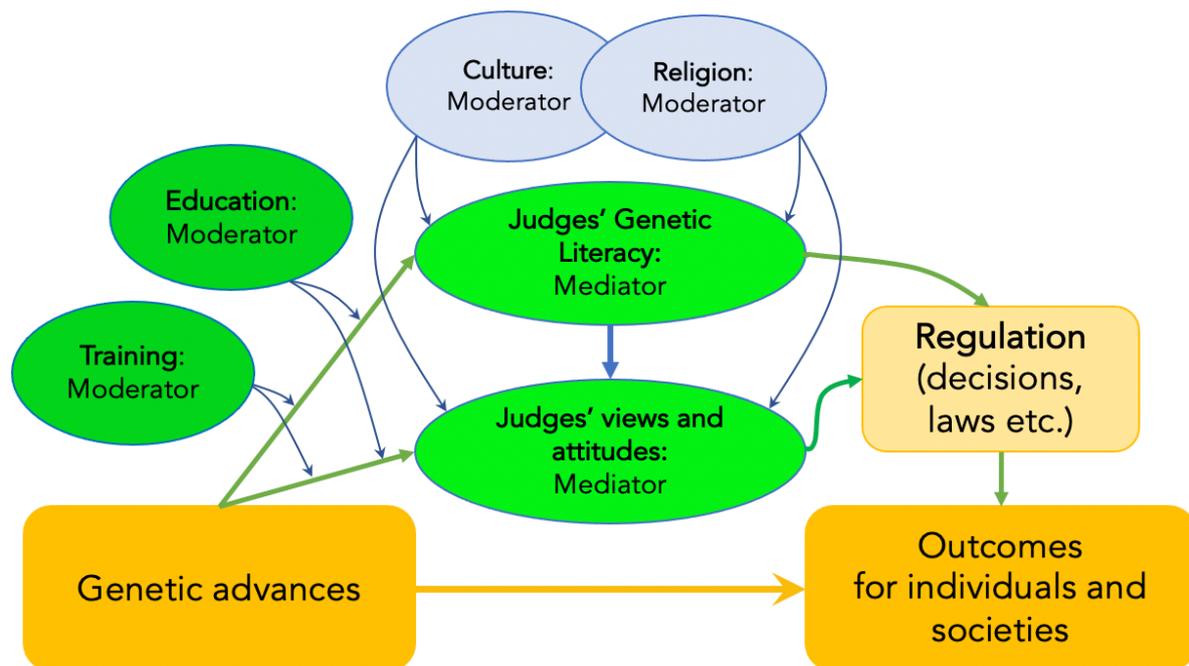
An increasing number of cases involve genetic information, including cases arising in the US (Denno 2011; Farahany 2015); England and Wales (Catley and Claydon 2015); Italy (Forzano et al. 2010); and the Netherlands (de Kogel and Westgeest 2015). Decisions on these first cases set precedent, and by doing so, influence the development of the law. Therefore, judges impact the development of laws and other societal measures needed for the Genomic Era.

Reliable decisions on genetics-related matters are not possible unless the decision-makers understand what the findings mean. The usual procedure of relying on expert evidence in complex cases is not realistic for Genomic Era matters for two key reasons. First, genetic findings are complex, and so it is not generally possible to understand them adequately in the short space of time the judge (or a committee) has with an expert witness. Second, even if genetic findings were not difficult to understand, new genetic advances affect many areas of justice, including all criminal justice matters, insurance, discrimination and education – making expert evidence not a viable option. This is because expert evidence is costly and experts are scarce.

All this means that decisions by judges and lawyers are the primary mediators of how people will be affected by genetic advances. In other words, in the current circumstances, where laws and societal structures are yet to be designed for the Genomic Era, we depend on the *readiness* of judges and lawyers to avert negative outcomes through regulation (downstream methods). Two of the components of such readiness are: 1) sufficient level of **genetic literacy**; and 2) informed, unbiased and **realistic attitudes towards the application of genetic advances**. Judges' and lawyers' genetic literacy and attitudes towards the application of genetic advances will be reflected in the decisions they make about specific cases, in policy and laws that will be developed, and in the application of these laws in practice. Therefore, genetic knowledge and attitudes of these key stakeholders are powerful mediators of the effects of genetic advances on people's lives.

Figure 3 describes this system of interrelated elements. For example, genetic literacy may be affected by attitudes towards genetics and, in turn, judges' attitudes may be affected by their genetic literacy. Education (e.g. at school and via genetic modules included in judges' professional training) can moderate the links, for example affecting how judges view the genetic advances. The links may also be moderated by cultural, including religious, values and norms. The following sections explore several parts of this system by providing first empirical insights into Judges' genetic knowledge and attitudes.

Figure 3. Judges' genetic literacy and attitudes as a moderated mediation between genetic advances and their outcomes.



Note: This subsystem is the focus of the thesis. Judges' and other lawyers' genetic knowledge and attitudes are studied, as they are among the most important mediators between genetic advances and their applications for individuals and societies. These mediators may be moderated by education/professional training available to the legal workforce. A myriad of other potential processes are likely at play. For example, judges' attitudes may moderate the impact of their genetic literacy on their decisions; or judges' genetic literacy training may moderate the mediated link between genetic advances and their regulation via judges' attitudes towards them.

The following sections present: a new empirical study of genetic literacy of judges, other lawyers and non-lawyers (*Genetic Literacy* study, Publication 3); and 2 studies of views and attitudes on genetics held by judges, other lawyers and non-lawyers (*Views 1* and *Views 2* studies, Publications 4 and 5).

All three studies were approved by the Goldsmiths Department of Psychology Ethics Committee. Data were collected via Qualtrics software. Informed consent was gathered before the beginning of the survey. Participants were provided a link to the study and could complete the questionnaire when they wished, as well as skip any items and discontinue at any time.

### ***Genetic Literacy Study***

Having *genetically-literate citizens* is the most potent element of a society's readiness for the Genomic Era. Genetic literacy can empower people with tools for reliable assessment of genetics' implications; and can enable meaningful discussion and debates – necessary for the development of balanced regulation. Therefore, achieving adequate genetic literacy is a major challenge of the 21<sup>st</sup> century (Asbury et al. 2022; R. Chapman et al. 2019).

The findings from several recent studies on Genetic literacy of the general population show that levels of genetic knowledge are generally low, even among the well-educated (Bowling et al. 2008; R. Chapman et al. 2019; Lanie et al. 2004; Miller et al. 2006; Shaw et al. 2008). For example, in one study, even though questions were designed to evaluate a basic and functional level of genetic knowledge, only 1.2% of 5,404 participants answered all questions correctly (R. Chapman et al. 2019).

The complexity and rapid advancements of genetic science means that raising the level of the genetic literacy of the population will take a large orchestrated effort, including adapting school curricula; training an educational workforce that is comfortable with teaching these complex matters; developing effective ways of public engagement and media coverage of genetics; and setting up institutions to support people in understanding consumer genetics outputs.

As acquiring better genetic literacy for all citizens is a slow process, some more immediate societal interventions are also required. One of the most promising directions is to ensure good genetic literacy of key stakeholders – judiciary and other lawyers – who play a key role in the development of regulation. Currently, little is known about these stakeholders’ genetic knowledge.

If judges’ genetic knowledge is similarly insufficient to that of the general population, their decisions in cases involving the evaluation of genetic advancements, including privacy, crime, discrimination, insurance and education – may have negative impact on individuals and society. This is because deciding on applications of genetic advances requires knowledge of fundamental genetic concepts. For example, to get a meaningful picture of the implications of genetic discoveries for criminal justice, one would need to have a grasp of multiple issues including: what genes are and what their functions are; what the genome is; how many genes there are and what proportion of the genome they constitute; how genes link to traits; how many unknown polymorphisms are likely to contribute to criminal behaviour and how many polymorphisms have been linked to it to date; that genes that are involved in one trait (e.g. criminality) also contribute to other traits (e.g. cognition, personality and mental health characteristics); how genes express in different environments; and how genetics is relevant to how we make decisions (e.g. at the molecular or psychological levels).

Even outside the highly technical and rapidly developing areas, mistakes in decisions are common. For example, the UK Court of Appeal – a court where cases are usually heard by three highly qualified judges, has been found to have issued unlawful sentences which were 'not only of inappropriate severity (excessive or unduly lenient) but cases in which the type of sentence imposed was simply wrong in law' for 36% of 262 randomly selected cases (UK Law Commission 2018). A potential reason identified for this is that sentencing judges have to contend with more than 1,300 pages of law filled with outdated and inaccessible language. Such decision errors in applying criminal sentencing laws which have been developing for centuries, indicate that decision errors in cases concerning regulation of genetic advances are likely to be even more common, especially since the related laws, including case law, are undeveloped.

This study (Publication 3) is the first to explore the genetic literacy of the judiciary and to compare it with that of other legal professionals and of non-lawyers. The study was conducted with Supreme Court judges – the High Court of Cassation and Justice of Romania – which is the highest court in the country. Romania has a legal system based on Roman law (as do most countries) – a civil law jurisdiction. This means that case law (law developed by the courts through judgements) is normally not a source of law. This contrasts with common law

jurisdictions (e.g. the UK), where case law is also a source of law. However, the Supreme Court of Romania, being the highest court in the country, is the only judicial institution with the power to ensure the uniform interpretation and application of the law by other courts in the country. Moreover, judgments by the Supreme Court are reported to be an unquestionable secondary source of law (European e-Justice Portal n.d.). Therefore, the results from the study provide insights for both, civil law and common law jurisdictions.

## Method

### Participants

The sample was a representative group of 73 judges of the Supreme Court, 94 lawyers and 116 non-lawyers from the same country – Romania. The age for the three groups was: judges: mean age = 48.5, range = 34-66; lawyers: mean age = 45.2, range = 21-62; and non-lawyers: mean age = 33.6, range = 18-62. The judges sample had a participation rate of 91% (of those approached) and captured almost 70% of all Supreme Court judges in Romania. The collection was carried out with the help of a Supreme Court judge, who provided general information about the study to their colleagues. No incentives were offered to participants beyond their contribution to research and the learning experience embedded in the questionnaire (e.g. the Instrument provides explanations of genetic concepts). Participants completed the questionnaire on their own when they wished. Participants could skip any items and discontinue at any time.

The samples of lawyers and non-lawyers were drawn from the database of the International Genetic Literacy and Attitudes Survey (iGLAS) study (R. Chapman et al. 2017), based on the following criteria: 1) completed the iGLAS within the three months of the judges' data collection; 2) identified themselves as having obtained secondary education in Romania; and 3) were currently resident in Romania. This sample was then split into two groups: Lawyers and Non-lawyers.

### Measures and Procedure

The data were collected using the International Genetic Literacy and Attitudes Survey (iGLAS) – a validated instrument (R. Chapman et al. 2017) developed by a team of researchers, including the author of this thesis. This instrument has been used internationally to tap into readiness of individuals and societies for the Genomic Era (R. Chapman et al. 2019; Likhanov et al. In review; Selita et al. 2019; Yoshida et al. 2023). The iGLAS has been implemented in 9 languages using standard translation and back-translation procedures. The iGLAS collects extensive demographic information, which allows for exploration of knowledge and attitudes in different groups, stratified for example by country, occupation and education. In addition to the ongoing main data collection, the research team uses targeted collection opportunities, such as specific cohorts of students or representative samples of professionals. This approach was taken in the present study to collect data from judges.

The genetic literacy section of the iGLAS includes 25 items tapping into a wide range of fundamental genetic concepts needed for those living in the Genomic Era (R. Chapman et al. 2017; Selita, Smereczynska, et al. 2020). Of these, 17 items (see Table 2) were formatted in various ways: yes/no, Likert scales, dropdowns and multiple choice. Correct answers for these 17 items were summed to give total genetic knowledge (GK) scores for each participant. The

remaining 8 items (see Table 4) assessed knowledge of heritability of 8 complex traits, with participants rating genetic influence on a scale of 0–100 (zero to full genetic influence). In addition to genetic literacy, the study also assessed confidence in genetic knowledge, as well as whether judges thought information about gene-environment processes should be included in judges’ training.

## Results and Discussion

### Genetic knowledge

The results (presented in Table 1) showed that the judges’ average genetic knowledge (73% correct responses) was relatively good, but given that items had 2 and 4 response options, between 50% and 25% of the items could be answered correctly just by chance. Empirical studies have shown that the multiple-choice format significantly increases the chances of correct responses, even from people with minimal knowledge (Royal and Stockdale 2017). Moreover, items included in the iGLAS assess fundamental genetic concepts, that are needed for people without genetic training to be able to understand implications of genetics for their lives. In fact, only scores close to 100% correct would indicate good genetic literacy, because good literacy reflects a coherent system of knowledge, rather than knowledge of unrelated facts.

Table 1. Overall average genetic knowledge and confidence for the judges, lawyers and non-lawyers.

<b>Average Genetic Knowledge (0-1)</b>					
<b>Group</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>N</b>	<b>Min</b>	<b>Max</b>
Judges	.73	.11	73	.29	.94
Lawyers	.66	.17	94	.12	1.00
Non-lawyers	.61	.21	116	.24	.94
Total	.66	.18	274	.12	1.00

<b>How confident are you in your genetic knowledge? (0-1)</b>					
<b>Group</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>N</b>	<b>Min</b>	<b>Max</b>
Judges	.55	.10	72	.30	.76
Lawyers	.50	.19	93	.00	.92
Non-lawyers	.41	.23	115	.00	1.00
Total	.48	.20	280	.00	1.00

*Note:* Genetic knowledge scores are based on each participant’s total correct score divided by the total items (17), and so are analogous to percentage correct scores (e.g. .73 = 73% correct). Confidence in genetic knowledge was measured on a scale of 0 – 100, rescaled in this table to 0-1, so that figures can be easily compared with average genetic knowledge scores. Percentages are not presented in this table so that means and standard deviations can be more easily considered together.

The results of an ANCOVA showed that the judges’ overall GK (73%) was significantly higher than that of lawyers (66%) and non-lawyers (61%), after controlling for age and education level  $F(2,269) = 5.24, p = 0.006$  (Partial Eta Squared = 0.037). The judges’ greater knowledge was not related to differences across the groups in terms of education,  $F(1,269) = 0.50, p = 0.481$  ( $\eta^2 = 0.002$ ). However, their greater knowledge was partially related to age,  $F(1,269) = 4.18, p = 0.042$  ( $\eta^2 = 0.015$ ), with older participants scoring on average higher. The judges also showed a significantly narrower distribution of scores than the other two groups (Levene’s test =  $F(2,271) = 18.75, p < 0.001$ ).

To provide a broader context, the overall genetic knowledge scores of the Romanian participants were additionally compared to the results previously reported in a large (N = 5404) international general sample (R. Chapman et al. 2019), co-conducted by the author of this thesis. In this study, 88% of all respondents indicated that they had completed or were working towards university degree-level qualifications. The study found an average genetic literacy of 65.5%, which is comparable to that of lawyers (66%) and non-lawyers (61%), and lower than that of the judges' (73%) in the Romanian study – although formal comparisons were not performed. This pattern of results suggests that the results are overall similar in different groups of well-educated people.

### *Analyses of individual items*

The judges' knowledge was uneven across different aspects of genetic literacy. As can be seen in Table 2, for some items, more judges than lawyers and non-lawyers selected the correct responses; and for other items, the reverse was true. Below, some of the items are analysed, providing rationale for their inclusion and implications of the observed pattern of results.

In addition, frequencies of correct responses for each item in the current study were compared between the Judges' group and the previously reported results from the unselected sample described above (R. Chapman et al. 2019). These results are summarized in Table 3. For 12 out of the 17 items, more judges provided correct responses – showing better knowledge than that of the international sample. However, for 5 of the items, the judges' knowledge was similar or lower than that of unselected participants. Again, no formal comparisons were conducted across the two studies, and more research is needed to evaluate whether these observed differences are consistent.

Chi-square analyses were conducted to compare frequencies of correct responses across the three groups. The results of the Chi-square tests can be found in Publication 3. In the subsections below, comparisons are described **as significant** if the p-value associated with the difference in frequency between any two groups was  $<.05$ .

Table 2. Number of participants (and proportions) for each of the multiple-choice response option in the 17 genetic knowledge items.

Item	N participants (%participants)			
1. What is a genome?				
	A sex chromosome	<b>The entire sequence of an individual's DNA</b>	All the genes in DNA	Gene expression
Judges	0 (0)	<b>29 (39.7)</b>	44 (60.3)	0 (0)
Lawyers	0 (0)	<b>75 (79.8)</b>	18 (19.1)	1 (1.1)
Non-lawyers	4 (3.4)	<b>78 (67.2)</b>	27 (23.3)	7 (6)
2. Which of the following 4 letter groups represent the base units of DNA?				
	GHPO	HTPR	<b>GCTA</b>	LFWE
Judges	7 (9.6)	12 (16.4)	<b>42 (57.5)</b>	12 (16.4)

Lawyers	15 (16.3)	14 (15.2)	<b>53 (57.6)</b>	10 (10.9)
Non-lawyers	11 (10.1)	11 (10.1)	<b>80 (73.4)</b>	7 (6.4)

3. How many copies of each gene do we have in each cell?

	1 copy	<b>2 copies</b>	23 copies	5 copies
Judges	0 (0)	<b>71 (97.3)</b>	2 (2.7)	0 (0)
Lawyers	8 (8.5)	<b>74 (78.7)</b>	12 (12.8)	0 (0)
Non-lawyers	22 (19.3)	<b>67 (58.8)</b>	22 (19.3)	3 (2.6)

4. All humans differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?

	75%	<b>50%</b>	0.01%	99.90%
Judges	2 (2.8)	<b>65 (90.3)</b>	1 (1.4)	4 (5.6)
Lawyers	6 (6.5)	<b>58 (62.4)</b>	1 (1.1)	28 (30.1)
Non-lawyers	16 (13.8)	<b>75 (64.7)</b>	11 (9.5)	14 (12.1)

5. What is the main function of all genes?

	<b>Storing information for protein synthesis</b>	To provide energy to the cell	To clear out waste from the cell	To repair damage to a cell
Judges	<b>18 (24.7)</b>	36 (49.3)	8 (11)	11 (15.1)
Lawyers	<b>49 (52.7)</b>	33 (35.5)	4 (4.3)	7 (7.5)
Non-lawyers	<b>77 (67.5)</b>	16 (14.0)	5 (4.4)	16 (14.0)

6. On average, how much of their total DNA is the same in two people selected at random?

	Less 50%	75%	90%	<b>More than 99%</b>
Judges	35 (47.9)	6 (8.2)	4 (5.5)	<b>28 (38.4)</b>
Lawyers	33 (35.5)	9 (9.7)	12 (12.9)	<b>39 (41.9)</b>
Non-lawyers	46 (39.7)	5 (4.3)	7 (6.0)	<b>58 (50.0)</b>

7. Genetic contribution to the risk for developing Schizophrenia comes from:

	One gene	<b>Many genes</b>
Judges	9 (12.5)	<b>63 (87.5)</b>
Lawyers	24 (26.4)	<b>67 (73.6)</b>
Non-lawyers	46 (39.7)	<b>70 (60.3)</b>

8. In humans, DNA is packaged into how many pairs of chromosomes?

	<b>23 pairs</b>	48 pairs	10 pairs	27 pairs
Judges	<b>69 (94.5)</b>	2 (2.7)	1 (1.4)	1 (1.4)
Lawyers	<b>85 (90.4)</b>	7 (7.4)	2 (2.1)	0 (0.0)
Non-lawyers	<b>99 (87.6)</b>	12 (10.6)	2 (1.8)	0 (0.0)

9. An Epigenetic change is:

	<b>A change in gene expression</b>	A change of the genetic code itself	A process by which human beings can consciously change their DNA	Gene splicing
Judges	<b>47 (65.3)</b>	13 (18.1)	3 (4.2)	9 (12.5)
Lawyers	<b>45 (47.9)</b>	28 (29.8)	11 (11.7)	10 (10.6)
Non-lawyers	<b>60 (52.2)</b>	25 (21.7)	19 (16.5)	11 (9.6)

10. Approximately how many genes does the human DNA code contain?

	2,000	1 million	3 billion	<b>20,000</b>
Judges	4 (5.5)	2 (2.7)	1 (1.4)	<b>66 (90.4)</b>
Lawyers	12 (12.8)	15 (16.0)	10 (10.6)	<b>57 (60.6)</b>
Non-lawyers	12 (10.5)	21 (18.4)	15 (13.2)	<b>66 (57.9)</b>

11. Genetic contribution to the risk for developing Autism comes from:

	One gene	<b>Many genes</b>
Judges	2 (2.8)	<b>70 (97.2)</b>
Lawyers	23 (24.7)	<b>70 (75.3)</b>
Non-lawyers	64 (55.7)	<b>51 (44.3)</b>

12. What are polymorphisms?

	Building blocks of the DNA	Proteins found in the brain	<b>Points of genetic variation</b>	Deoxyribonucleic Acid
Judges	10 (13.9)	4 (5.6)	<b>56 (77.8)</b>	2 (2.8)
Lawyers	21 (22.6)	4 (4.3)	<b>66 (71)</b>	2 (2.2)
Non-lawyers	25 (21.7)	7 (6.1)	<b>79 (68.7)</b>	4 (3.5)

13. The DNA sequence in two different cells, for example a neuron and a liver cell, of one person, is:

	Entirely different	About 50% the same	More than 90% the same	<b>100% identical</b>
Judges	1 (1.4)	0 (0.0)	1 (1.4)	<b>70 (97.2)</b>
Lawyers	7 (7.4)	5 (5.3)	13 (13.8)	<b>69 (73.4)</b>
Non-lawyers	16 (13.8)	18 (15.5)	23 (19.8)	<b>59 (50.9)</b>

14. "Non-coding" DNA describes DNA that:

	Is removed when passed from parent to offspring	<b>Does not lead to the production of proteins</b>	Is non-human DNA	Is not composed of nucleotides
Judges	22 (30.1)	<b>21 (28.8)</b>	19 (26)	11 (15.1)
Lawyers	27 (29.3)	<b>37 (40.2)</b>	13 (14.1)	15 (16.3)
Non-lawyers	24 (21.2)	<b>53 (46.9)</b>	19 (16.8)	17 (15.0)

15. Genetic modification is:

	Selective breeding	Genetic engineering	<b>Both of the above</b>	Neither of the above
Judges	5 (6.8)	8 (11.0)	<b>54 (74)</b>	6 (8.2)
Lawyers	19 (20.4)	31 (33.3)	<b>36 (38.7)</b>	7 (7.5)
Non-lawyers	22 (19.1)	50 (43.5)	<b>40 (34.8)</b>	3 (2.6)

16. Can we fully predict a person's behaviour from examining their DNA sequence?

	Yes	<b>No</b>
Judges	3 (4.1)	<b>70 (95.9)</b>
Lawyers	16 (17.0)	<b>78 (83.0)</b>
Non-lawyers	17 (14.8)	<b>98 (85.2)</b>

17. At present in many countries, new born infants are tested for certain genetic traits

	TRUE	FALSE
Judges	<b>70 (95.9)</b>	3 (4.1)
Lawyers	<b>88 (93.6)</b>	6 (6.4)
Non-lawyers	<b>97 (83.6)</b>	19 (16.4)

*Note.* The numbers represent N of participants choosing each response option. Proportions (%) of participants choosing each option are presented in brackets. **Correct responses are highlighted in bold.** The darker the shading – the higher proportion of participants selecting that response. Formatting is applied across all items to aid visual inspection of both inter and intra comparisons.

Table 3. Frequencies of correct responses to each item from the present study and from a larger non-targeted collection of the iGLAS.

Question (choose from four options)	Non-targeted sample <sup>1</sup> % correct	Judges % correct	Difference
1. What is a genome?	53	40	-13
2. Which of the following 4 letter groups represent the base units of DNA?	76	57	-19
3. How many copies of each gene do we have in each autosome cell?	46	97	+51
4. All humans differ in the amount of DNA they share. How much of this differing DNA do siblings usually share?	31	90	+59
5. What is the main function of all genes?	99	25	-74
6. On average, how much of their total DNA is the same in two people selected at random?	31	38	+7
7. Genetic contribution to the risk for developing Schizophrenia comes from: choose from two options	67	88	+21
8. In humans, DNA is packaged into how many pairs of chromosomes?	82	95	+13
9. An Epigenetic change is: choose from four options	72	65	-7
10. Approximately how many genes does the human DNA code contain?	45	90	+45
11. Genetic contribution to the risk for developing Autism comes from:	68	97	+29
12. What are polymorphisms?	75	78	+3
13. The DNA sequence in two different cells, for example a neuron and a heart cell, of one person, is:	74	97	+23
14. Non-coding DNA describes DNA that...	78	29	-49
15. Can dog breeding be considered a form of gene engineering?	65	74	+9
16. Can we fully predict a person's behaviour from examining their DNA sequence?	63	96	+33
17. At present in many countries, new born infants are tested for certain genetic traits.	83	94	+11

<sup>1</sup>Non-targeted general sample (N = 5404) reported in Chapman et al. 2019. The *Difference* score indicates how much smaller or greater the proportion of correct responses is for the judges group in the present study in comparison with the non-targeted sample reported in Chapman et al. A negative difference score reflects poorer knowledge for judges vs the non-targeted sample.

**What is a genome? (Item 1, Table 2)** The human genome was first sequenced at the beginning of the 21<sup>st</sup> century, over 20 years ago. Genomic data present a wide range of implications for justice. Genome sequencing is now common, is predicted to soon become routine, and some healthcare providers have been offering it as part of routine clinical care since 2018 (Geisinger Health 2018; Pillar et al. 2014). Understanding the difference between genes and genome is important, for example, for decisions to undergo genetic testing or interpreting the results of such testing. In sentencing, equating ‘predictive’ information from single genes vs. polygenic risk scores vs. epigenetic profiles may lead to giving an inappropriate weight to information. Therefore, an inability to recognise the correct answer to this item indicates poor basic knowledge.

In our study, only 39.7% of the judges answered this question correctly; the majority (60.30%) selected an incorrect answer: ‘all the genes in DNA’. The responses for this item were significantly better for lawyers (74.8%) and non-lawyers (67.2%). It could be that many judges know the meaning of ‘ome’ (all) and therefore selected this option.

**On average, how much of their total DNA is the same in two people selected at random? (Item 6, Table 2)** Knowledge of how similar or different people are genetically is needed to evaluate the precision of the predictive use of genetic information; to plan environmental engineering; as well as for combatting discrimination. One of the response options provided for this item was ‘that we share less than 50% of the total DNA with other people’ (which is similar to what we share with bananas). If one believes that people are so different genetically, they may view individuals from different groups as being alien; especially if one is also prone to deterministic and essentialist biases. Such misconceptions can provide illusory (but incorrect) scientific backing to long-held discriminatory beliefs.

Only 38% of the judges selected the correct answer – that on average more than 99% of the total DNA is the same in two people selected at random. 48% selected an incorrect response of ‘less than 50%’. The judges’ response rates for this item were similar to those of lawyers (41.4%) and non-lawyers (50%). These results suggest that many judges and lawyers do not distinguish between ‘total DNA’ and ‘variable/differing/segregating’ DNA – the portion (less than 1%) of the total DNA that differs across people.

**What is the main function of all genes? (Item 5, Table 2)** Knowing the main function of genes is crucial for many decisions related to genetics and behaviour in general. For example, knowing that the main function of the genes is to code for protein (storing information for protein synthesis) enables further understanding of the biological underpinnings of human behaviour. For example, this knowledge is a prerequisite to having some idea of the role genes play in our decision making (e.g. our control over behaviour). Genes code for a variety of different proteins; variability in our genetic code translates into which proteins are coded in different people; and this in turn may affect the molecular structures in brain synapses that play a key role in the communication between synapses (decoding the electrical and chemical signals); and ultimately to our thinking (Grant 2019). Lack of this knowledge among judges and lawyers could potentially contribute to various misconceptions around the issue of ‘free will’ in the justice system (Kovas and Selita 2021a).

The results showed that fewer than 25% of the judges answered correctly that the main function of all genes is storing information for protein synthesis. Almost 50% chose the incorrect answer ‘To provide energy to the cell’. A significantly greater proportion of lawyers (52.7%) and non-lawyers (67.5%) than of judges chose the correct response for this item. This pattern of

responses may be a result of the lawyers and nonlawyers having on average completed education more recently – their age being on average younger. For example, the way ‘genome’ was explained 30-40 years ago would be different (e.g. genes are important, the rest of the DNA is ‘junk’) from the way it is viewed more recently (both coding (genes) and non-coding (the rest of the DNA) are functional).

**What is an epigenetic change? (Item 9, Table 2)** A good grasp of this concept is needed for understanding the origins of individual differences in traits; and about environmental effects on gene expression. For example, physical and psychological stressors (e.g. prison environment) lead to a cascade of biological processes, such as stress-induced DNA methylation, which in turn may lead to numerous negative health and behavioural outcomes (Bainomugisa and Mehta 2022). The conceptual understanding of epigenetics is also crucial for evaluating the probabilistic power of genetic prediction, because environments may alter genetic effects. Moreover, epigenetics has direct relevance to determinism: if genetic effects can be modified by environments, true determinism is not possible.

The study showed that 65.3% of the judges knew that an epigenetic change is a change in gene expression. A slightly (but significantly) smaller proportion of lawyers (47.9%) and non-lawyers (52.2%) than judges chose the correct response for this item.

Six of the items (two discussed below) resulted in particularly high accuracy (>90%) in judges – higher than in other lawyers and non-lawyers.

**Is the DNA sequence in two different cells, for example a neuron and a heart cell, of one person, the same or different? (Item 13, Table 2)** The incorrect belief that the DNA sequence in two different cells is different may cause problems. For example, one would not understand some privacy-related issues, including that reidentification on DNA code is made possible as cells in different organs have the same DNA code. Lack of this knowledge may also lead to an underestimation of risks linked to misuses of genetic information. Once a person’s DNA from any cell is sequenced, it presents a life-long wealth of information about that person, including the possibility of precise identification, behavioural risk information and much more (Selita, 2019a). In addition, one would not understand the relevance of genomic sequencing based on cells from one tissue or organ (e.g. saliva) – for all traits, beyond the original purpose of the analyses. Furthermore, without understanding that DNA is the same in different cells of the body, it would be difficult to understand pleiotropy – for example that genetic mutations affecting one organ/trait may also affect other organs/traits. One may also not understand that the same DNA in different cells is expressed differently through epigenetic mechanisms.

The results showed that almost all the judges (97.2%) answered this question correctly. A significantly smaller proportion of lawyers (52.7%) and non-lawyers (67.5%) chose the correct response for this item. It is possible that more judges than lawyers and non-lawyers were able to arrive at the correct answer through general reasoning: if a genome can be extracted from saliva and be informative on ancestry, illness and much more, it follows that DNA is the same in different tissues. The greater reasoning ability could reflect greater education, age, experience and general cognitive ability – among other factors.

**Can we fully predict a person's behaviour from examining their DNA sequence? (Item 16, Table 2)** This knowledge is needed when assessing the power of prediction, such as for insurance, surveillance, or in sentencing. It is also essential to understand this to avoid

having deterministic views, which would have serious implications for justice across different areas. In this study, most judges (95.9%) correctly identified that we cannot predict a person’s behaviour from examining their DNA sequence. Significantly more judges provided a correct response than lawyers (83%) and non-lawyers (85.2%).

The study also evaluated, for 8 complex traits, participants’ estimates of heritability – the proportion of differences in a trait among people within a population or group which are explained by their genetic differences (Visscher et al. 2008).

The results (presented in Table 4) show that the judges were overall relatively accurate in estimating the heritability of these traits, providing similar average estimates to those reported in reputable genetic studies (see Note to Table 4). The average estimates were also overall accurate for the other two groups, with a tendency to underestimate heritability for some traits (e.g. height; weight). The judges’ average estimates in this study were also overall similar to those reported in other iGLAS samples (R. Chapman et al. 2019).

However, the range of the heritability estimates was wide for all groups (Table 4). For judges, the lowest heritability estimates were from 14 to 57 for the 8 traits, whereas for lawyers they ranged from 0 to 6 and for non-lawyers from 0 to 2. The upper limit was from 81 to 100 for judges, and 100 for the other groups. This pattern of results suggests that participants’ relatively accurate average estimates mask many extremely inaccurate estimates, with judges overall providing a more reasonable range of answers.

Table 4. Estimates of genetic influences (heritability) for 8 complex traits for the three groups.

On a scale of 0-100 how important are genetic differences between people in explaining individual differences in the following traits						
<b>Heritability from studies<sup>1</sup></b>	<b>Group</b>	<b>N</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>Min</b>	<b>Max</b>
Height (70)	Judges	72	76.28	8.63	57	92
	Lawyers	94	67.27	18.83	6	100
	Non-lawyers	114	59.94	25.96	0	100
Weight (66)	Judges	73	75.49	10.61	34	94
	Lawyers	94	64.26	21.15	2	100
	Non-lawyers	111	53.74	25.99	0	100
IQ (50)	Judges	73	62.71	14.33	28	93
	Lawyers	94	61.3	19.59	6	100
	Non-lawyers	113	62.84	25.04	2	100
Eye colour (82)	Judges	73	76.9	14.8	14	98
	Lawyers	93	71.06	18.41	6	100
	Non-lawyers	112	67.91	23.77	1	100
Clinical depression (42)	Judges	73	54.45	13.19	27	100
	Lawyers	93	46.47	20.3	2	100
	Non-lawyers	106	47.76	25.22	0	100
Motivation (40)	Judges	73	51.11	12.35	29	81
	Lawyers	94	43.44	20.91	2	100
	Non-lawyers	109	46.86	27.5	0	100
School achievement (57)	Judges	73	49.93	13.49	25	89
	Lawyers	94	47	20.59	2	100

	Non-lawyers	107	46.32	26.06	0	100
	Judges	73	68.63	13.78	37	93
Sexual orientation (37)	Lawyers	93	52.32	22.67	0	100
	Non-lawyers	101	46.31	29.37	0	100

*Note:* <sup>1</sup>Average heritability as estimated in reputable genetic studies: eye colour (Larsson et al. 2011); height (Jelenkovic et al. 2016); weight (Liu et al. 2015); school achievement (Rimfeld et al. 2015); IQ (Kovas et al. 2013); clinical depression (Lohoff 2010); motivation (Kovas et al. 2015); sexual orientation (LeVay 2016).

Overall, the results of the judges' genetic literacy demonstrate that even the most highly educated people, at the top of their profession, lack essential genetic knowledge. This is of course not surprising, as genetic science is rapidly developing, amassing vast amounts of complex, and continuously updated, information.

### Confidence in knowledge

The average judges' confidence in their genetic knowledge was 55.6 out of 100, ranging from 30 to 76 (see Table 1). This was higher than that of lawyers (50/100) and non-lawyers (41/100); and also higher than the confidence level (35.9 out of 100) found in a group of undergraduate Psychology students in the UK (N = 153) (Gallop et al. 2017). The ANCOVA on genetic knowledge confidence, indicated significant group differences between the judges, lawyers and non-lawyers when controlling for education level and age ( $F(2,266) = 6.39, p = .002, \eta^2 = .046$ ). Age did not have a significant effect on confidence ( $F(1,266) = 1.55, p = .215, \eta^2 = .006$ ). Education level also did not have a significant effect ( $F(1,266) = .201, p = .654, \eta^2 = .001$ ). Levene's test indicated unequal variances ( $F(2,268) = 19.73, p < .001$ ), with judges showing a narrower distribution than the other two groups.

The higher level of confidence for judges was expected, as their knowledge was also higher than that of the other groups. However, the correlations between knowledge and confidence for judges ( $r = .43, N = 72, p < .001$ ); and lawyers ( $r = .34, N = 93, p < .001$ ) were only moderate; and the correlation was not significant for non-lawyers ( $r = .12, N = 115, p = .206$ ). This suggests that people, including judges, are not precise in estimating their own genetic knowledge. For example, many judges whose knowledge was high did not consider themselves to be particularly knowledgeable, and some of those whose knowledge was very poor considered themselves to be highly knowledgeable.

### Embracing of the need for training

The study also explored whether the judges felt that information on gene-environment processes should be covered in judges' training. Training of judges in different jurisdictions is somewhat different, and so the training would be implemented in different ways. For example, in Romania, where judges are initially trained by the National Institute of Magistracy (European Justice, EU n.d.), the training can be included in its curriculum. In other jurisdictions, like the UK, the training can be implemented as part of continuous professional development; and preferably earlier, as part of the legal training.

The results showed that 100% of the judges agreed that information on gene-environment processes should be included in judges' training. This endorsement by the judges attests to their recognition of the importance of such knowledge.

## ***Views and Attitudes Studies***

The second major mediator of the effects of genetic advances on people's lives is the key stakeholders' attitudes towards genetic advances. Such attitudes are only partly related to genetic literacy and the associations appear to be complex. For example, higher genetic knowledge was found to be associated with more uncertainty about the impact of genetic testing on a person's future (Haga et al. 2013). In other studies, higher levels of genetic knowledge was associated with more favourable attitudes towards genetic testing (Calsbeek et al. 2007a; Morren et al. 2007a). Yet, other studies did not find such an association (Aro et al. 1997; Henneman et al. 2006).

Beyond literacy, many other phenomena are linked to attitudes, including values (e.g. valuing meritocracy), beliefs (e.g. believing that in the 'just world' people get what they deserve) and biases (e.g. essentialist or deterministic views) (Haga et al. 2013; "Just-world hypothesis" n.d.). Biases may stem from: the way in which information is perceived, analysed and interpreted; individual characteristics of decision-makers (e.g. their experience, personality, working environment); and the cognitive architecture of the human brain (Dror 2020).

A wealth of research has shown how biases affect decisions (Berthet 2022; Dror 2020; Petersen 2013), including those of judges (e.g. (Bystranowski et al. 2021)). Recent research has begun to look into how judges are influenced by genetic information and by their own views on genetics (Aspinwall et al. 2012; Cheung and Heine 2015; Fuss et al. 2015). For example, one study explored through phone interviews how knowledge of genetic influences on mental disorders would affect judges' views on sentencing. The study used a sample of 59 Pennsylvania State Court judges (response rate of 7.4%). The judges were asked to describe their thoughts about sentencing in cases where (a) the offender had mental disorders and (b) the offender's mental disorder was known to be genetically influenced (Berryessa 2019). The qualitative analyses showed that a high proportion of judges held essentialist beliefs (e.g. that traits are genetically determined; people with similar genetics are inherently the same; a person's genetics cannot be changed, etc.); as well as stigmatisation biases associated with such beliefs (e.g. that a person with genetic risk poses a threat to society). The study also suggested that sentencing partly depended on factors such as the judges' personal experiences with genetics and with mental disorders. Overall, the results of the scarce previous research suggest that genetic information can affect the views of judges, and that these effects may differ as a function of multiple factors, such as held beliefs, knowledge and experience with genetics; and jurisdiction.

Previous research with the judiciary has a number of limitations. First, the studies did not specifically evaluate judges' knowledge of genetics. Second, the studies addressed what judges would do in a scenario under the current laws, procedure and guidance; rather than judges' views on how genetic information and advances should be used in court and other contexts. Third, most previous research focused on mental disorders, specifically psychopathy - a disorder characterised by reduced emotional responses, empathy, remorse and control over behaviour - commonly associated with a great deal of stigma. Fifth, the research has potential

representativeness limitations, as participation rates were either very low, or unknown. This could have impacted results, as, for example, participants may have had a particular interest in issues related to the sentencing of people with psychopathy. Sixth, previous studies explored judges' views only in a few jurisdictions (e.g. US, Germany) and more research is needed to understand whether judiciaries' attitudes differ across countries and jurisdictions. Finally, previous research used single items or very few items to assess judges' views and attitudes, and mostly employed qualitative analyses which, although provides some in-depth insights from individuals, does not allow for data collection from many participants on many variables, and does not allow for formal group comparisons.

The two studies, reported in the following sections, extend previous research, by conducting multi-item and multi-sample empirical investigations into people's genetic *views and attitudes*. The quantitative approach allows for direct comparisons between knowledge and views of judges, other lawyers and unselected samples. Previous research with unselected samples showed a wide variability in views, from full endorsement of using genetic information in a wide variety of contexts to serious concerns and rejection of such use, especially predictively (R. Chapman et al. 2018; Haga et al. 2013; Saastamoinen et al. 2020; Selita et al. 2019).

Using the International Genetic Literacy and Attitudes Survey (iGLAS), the two studies assessed people's views and attitudes on key areas of genetic applications, such as genetic testing, gene editing (engineering), using genetic information in different contexts (e.g. selection in education or employment, early interventions, crime prevention); as well as on whether the current laws are sufficient; and whether there is a need for amending laws and, if so, when.

In order to streamline the presentation of key findings, the results from the two studies – the *Views 1* and *Views 2* studies – are discussed in the same Results section, organised thematically. For simplicity of presentation, for items presented on 7-point Likert scales, responses have been grouped into 3 categories as follows: Disagree (strongly disagree, disagree and somewhat disagree), Agree (strongly agree, agree and somewhat agree) and Neither agree nor disagree; and Unlikely (very unlikely, unlikely and somewhat unlikely), Likely (very likely, likely and somewhat likely) and Undecided.

## Method

### Participants (*Views 1* study)

The Study reports finding from two opportunistic international samples – an unselected general sample and a sample of lawyers and law students – from the same iGLAS database. Participants were recruited through social media, Reddit Ask Me Anything (AMA) and by email. Data were collected online, therefore all participants were computer literate and had access to the internet. Most (88%) of all respondents indicated that they had completed or were working towards university degree-level qualifications. The number of participants varied across different analyses, as not all participants answered all questions.

**General Sample:** A total of 13,356 participants initiated the survey. After data cleaning and removing of outliers, the sample included 10,090 participants. Data cleaning involved retaining only data from participants who completed at least 70% of the survey. The criteria for outliers were: participants with an age above 3 interquartile ranges from the mean (between age 97 and 116). The mean age was 30.16, SD = 11.21, range 18–80. Of these, 3,643 (36.1%) were male;

6,105 (60.5%) were female; 63 (0.6%) were non-binary; 69 (0.7%) preferred not to say; and 210 (2.1%) participants skipped the gender item.

Law sample: From its 4<sup>th</sup> version (collections from 17/08/2017 onwards), the iGLAS included additional items specifically for legal professionals and law students – implemented via adaptive branching. In total, 486 participants completed these additional law items. 217 were law students (age mean (M) = 22.40, SD = 4.13, range 18–54); 224 were law professionals (age M = 44.4, SD = 9.39, range 18–66); and 45 participants reported that they were both working in a legal profession and studying law (age M = 22.98; SD = 2.82; range 18–31). For the purposes of this study, these three samples were grouped together. The gender distribution of the law sample was very similar to the whole sample: 169 (36.1%) were male; 309 (62.1%) were female; 1 (0.4%) was non-binary; and 2 (1.5%) preferred not to say.

It was decided not to perform formal comparisons among the sub-samples within the law sample or between the law sample and the large unselected sample, because of small or unequal sample sizes and because participants were from a range of countries (the samples not being targeted collections).

### Measures (Views 1 study)

This study uses 8 opinion items from the iGLAS to assess views and attitudes tapping into the following issues:

- The link between genetic influences on behaviour and ‘free will’.
- Existence of ‘genetic disadvantage’ (similar to ‘environmental disadvantage’).
- Whether genetic disadvantage should be taken into account in criminal sentencing and, if yes, how.
- Whether societies should make provisions to buffer the effects of genetic disadvantage.
- Whether the State should use genetic information for crime prevention.

The number of participants differed across the items because four items were only presented to participants who identified either as lawyers and/or law students – using adaptive branching; and the collection took place over several months, during which some items were removed and some were added. Seven items were measured on a 7-point Likert scale, from strongly disagree to strongly agree. The exact items and participant numbers for Items 1–7 are presented in Table 5. The 8th item was a vignette for which participants selected one of the four response options (see Table 14).

### Participants (Views 2 study)

Data were collected from the same samples as described in the *Genetic Literacy* study above: 73 Supreme Court judges; 94 lawyers and 116 non-lawyers from the same country, Romania. The study compared views of judges with those of lawyers and non-lawyers.

### Measures (Views 2 study)

This study used 51 items from the iGLAS to collect views, opinions and attitudes on: genetic testing (25 items, 16 of which were rated using 7 point Likert scales); gene editing (3 items, all rated using Likert scales); the use of genetic data/information (12 items, all rated using Likert

scales); insufficient regulation and amending of relevant laws (11 items, of which 5 were rated using Likert scales). The full list of items, response options and other details can be found in the Supplementary Online Materials (SOM) of Publications 5.

Of the 51 items, 11 were presented only to participants who identified themselves as either judge or lawyer, using adaptive branching. The number of responses varied slightly for different analyses as participants could skip any items they did not wish to answer. The following major themes were explored:

### **Genetic Testing**

- Are people willing to undergo genetic testing using private companies?
- Should we use genetic testing to improve treatment?
- Can genetic testing results lead to increased stigma in those with mental health problems (depression, schizophrenia, bi-polar disorder etc.)?

### **Use of the Power of Prediction**

- Should employers be allowed to use genetic data for hiring?
- Should schools be allowed to use genetic data for admissions?
- Should insurance companies be allowed to request genetic data prior to issuing health and/or life insurance?
- Should insurers be allowed access to genetic data of those applying for insurance in cases where access by public but not by insurers would likely disadvantage insurers (e.g. payouts surpassing collected premiums)?
- Should the State use genetic information on propensity for violence for the prevention of crime (e.g. through surveillance)?

### **Use of the Power of Environmental Engineering**

- Can an understanding of how genes influence academic achievement help to personalise education?
- Can an understanding of how environments influence academic achievement help to personalise education?
- Should we use genetic information to adapt environments to people's needs, for example through individualised health advice?

### **Use of the Power of Gene Engineering /Editing**

- Should gene editing be allowed for the prevention and treatment of disease?
- Should gene editing be allowed for people to improve themselves and/or their children?

### **Current Effectiveness of Regulation of the Genetic Powers**

- Are current laws sufficient to protect individuals from misuses of the powers of genetic advances by:
  - Selective/private schools (e.g. for admission).
  - Insurance companies (for health insurance provision).
  - Employers (e.g. for hiring or firing purposes).

### **Whose duty is it to update laws and who should compensate victims for damages**

- If people cannot access health care via insurance due to breaches of genetic data which took place when laws were not updated, who should pay compensation?
- If employers are headhunting using genetic data obtained through untraceable sources, following data breaches that took place prior to the updating of laws - who is liable?

### **When and how to adapt, e.g. update laws and provide insurance**

- When should laws on genetics-related data protection and privacy, discrimination and insurance be updated?

- In the light of new knowledge on populations variability, do we need to accommodate this variability to provide justice?
- How should health insurance be provided in the Genomic Era?
- Should we allow the patenting of genetic findings, restricting access to benefits, and under which circumstances?

## Results and Discussion

Complete results from the *Views 1* and *Views 2* studies can be found in Publications 4 and 5, respectively. Here, some of the most important results for each theme are described and discussed in turn. Most results come from the *Views 2* study – the most comprehensive study of genetics-related attitudes to date, which also compared the results from judges, other lawyers and non-lawyers. Means, Standard Deviations and frequency responses from the *Views 2* study can be found in SOM of Publication 5. Group comparisons were made using ANOVAs and post-hoc analyses. Where groups were non-homogenous (as per Levene’s test), Welch’s ANOVA and Games-Howell post-hoc analyses were conducted. Post-hoc analyses are only reported where the overall ANOVA was significant. **A p of <.001 was set to reduce Type 1 errors which may arise from multiple comparisons (.05/36 measures on Likert scale = .001).**

The results were mostly similar for judges, lawyers and non-lawyers, but some interesting group differences emerged. In particular, the judges tended to have decisive opinions even on controversial issues (rarely judges opted for the ‘undecided’ option). There were significant average differences between the judges and at least one of the other two groups for 21 of the 36 matters assessed on a 1-7 scale (details provided below). The judges also tended to show stronger agreement (there was a smaller standard deviation) in their responses when compared to lawyers and non-lawyers on most items.

The following sections discuss the results of selected items. Results from the *Views 2* study are supplemented with results from *Views 1* study for overlapping items.

## Views on Genetic Testing

Genetic testing presents a number of concerns primarily because of the enormous power of prediction and the potential for large-scale breaches of genetic data. However, genetic testing is needed for prediction, intervention and scientific progress. Therefore, it is important to understand key justice stakeholders' views and attitudes towards genetic testing and related matters.

Some of the items (25) were used to assess judges’, lawyers’ and non-lawyers’ views and attitudes on a range of testing-related issues, including: willingness to undergo genetic testing in different scenarios, willingness to have their own genome sequenced, perceptions of associated risks of stigma, and whether willingness to have genetic testing is related to views on how safe genetic data are perceived to be. Responses to 16 of these items were on Likert scales (see Items 1-16 in SOM Table 1 Publication 5). The frequency of responses for each item by group can be found in SOM Table 1 of Publication 5.

Table 5 presents Means (SDs) for 16 items from the *Views 2* study by group (judges, lawyers and non-lawyers from Romania). The means indicate participants responses to how likely (0 – very unlikely; 7 – highly likely) they were to endorse particular uses of genetics. The table also presents the results of statistical group means comparisons; as well as variance comparisons.

Table 5. Means (Standard Deviations) for the 16 items on a 7 point Likert scales related to genetic testing (the *Views 2* study).

<b>Item</b>	<b>Group</b>	<b>Mean (SD)</b>	
1. If genetic testing allowed you to have improved treatment (for example, medication with fewer side effects) how likely would you be to take the test? <sup>1</sup>	Judges	6.22 (0.54)	
	Lawyers	5.69 (1.24)	
	Non-lawyers	5.13 (1.55)*	
2 - 4. In each of the scenarios below, please indicate how likely you would be to take up the offer to have your genome sequenced? <sup>1</sup>	If there were NO history of severe disease in your family	Judges	4.12 (1.33)
		Lawyers	2.68 (1.42)*
		Non-lawyers	3.23 (1.56)*
	If there was a MODERATE history of severe disease in your family <sup>+</sup>	Judges	5.99 (0.94)
		Lawyers	4.64 (1.47)*
		Non-lawyers	4.13 (1.77)*
	If there was a DEFINITE AND CLEAR history of severe disease in your family <sup>+</sup>	Judges	6.73 (0.61)
		Lawyers	5.89 (1.65)*
		Non-lawyers	4.92 (1.94)*
5 – 10. How likely would you be to pursue one of the following? <sup>1</sup>	Counselling support <sup>+</sup>	Judges	5.52 (0.97)
		Lawyers	4.30 (1.74)*
		Non-lawyers	4.13 (1.94)*
	Advice of a psychic <sup>+</sup>	Judges	1.18 (0.56)
		Lawyers	2.38 (1.80)*
		Non-lawyers	3.35 (1.76)*

Genetic testing through a private company <sup>+</sup>	Judges	5.85 (0.84)
	Lawyers	4.11 (1.98)*
	Non-lawyers	3.93 (1.88)*
Course in mindfulness and self-awareness <sup>+</sup>	Judges	5.93 (0.73)
	Lawyers	4.74 (1.99)*
	Non-lawyers	4.42 (1.90)*
Religious guidance <sup>+</sup>	Judges	1.74 (1.25)
	Lawyers	1.99 (1.42)
	Non-lawyers	3.46 (1.69)*
Self-help literature <sup>+</sup>	Judges	6.26 (0.65)
	Lawyers	4.92 (2.12)*
	Non-lawyers	4.80 (1.78)*
11. When you get ill, how likely are you to turn to alternative medicine (such as homeopathy) rather than seeking treatment from conventional medicine? <sup>1+</sup>	Judges	5.4 (1.22)
	Lawyers	4.78 (1.53)
	Non-lawyers	4.49 (1.82)*
12. How likely would you be to give a sample of your DNA for scientific research if your data are stored anonymously? <sup>1+</sup>	Judges	6.4 (0.55)
	Lawyers	5.55 (1.26)*
	Non-lawyers	4.73 (1.85)*
13. Scientific development is essential for improving people's lives <sup>2+</sup>	Judges	6.58 (0.55)
	Lawyers	6.22 (1.00)*
	Non-lawyers	5.84 (1.18)*
14. I do not trust research institutions in my country because they might misuse data obtained from participants <sup>2+</sup>	Judges	5.14 (0.61)
	Lawyers	4.64 (1.22)
	Non-lawyers	4.38 (1.44)*
15. Studies showing genetic influences on mental health problems (depression, schizophrenia, bi-polar disorder etc.) lead to increased stigma for people with those conditions: <sup>2</sup>	Judges	3.01 (1.46)
	Lawyers	3.54 (1.49)
	Non-lawyers	3.75 (1.50)

	Judges	2.75 (1.04)
16. I feel suspicious about genetic studies; hidden political/economic agendas may be behind them <sup>2+</sup>	Lawyers	3.34 (1.36)
	Non-lawyers	3.99 (1.69)*

*Note:* \*Items with significant differences between judges and other groups at  $p < .001$ ; +Items with non-homogenous variation (as indicated by Levene's test); N/A marks the items where information from non-lawyers was not collected. <sup>1</sup>Very unlikely (1), unlikely (2), somewhat unlikely (3), undecided (4), somewhat likely (5), likely (6), very likely (7). <sup>2</sup>Strongly disagree (1), disagree (2), somewhat disagree (3), neither agree nor disagree (4), somewhat agree (5), agree (6), strongly agree (7).

**How likely would you be to take a genetic test, if it allowed you to have improved treatment? (Item 1, Table 5)** All (100%) of the judges were willing to undergo genetic testing when it allowed for improved treatment. A substantial proportion of lawyers (90.5%) and non-lawyers (68.4%) were also willing to undergo such testing. Previous research has also shown variable, but relatively high, uptake for genetic testing in medical contexts. For example, one previous iGLAS study showed that 90% of participants from general populations in the UK, the US and Russia expressed willingness to undergo genetic testing for improved treatment (R. Chapman et al. 2019). Similar results were found in another study, with 85% of 2,000 respondents from a Russian urban population expressing positivity towards undergoing predictive genetic testing for preventable health conditions (Makeeva et al. 2010). In another study with Belgian participants, around 50% were interested in getting tested for treatable or preventable diseases, 50% – in genetic testing as a preconception screening for recessive disorders and around 60% – in prenatal genetic screening (Chokoshvili et al. 2017). People's willingness to have a genetic test has also been found to change alongside knowledge about the level of known familial disease risk, as shown in (R. Chapman et al. 2019). Moreover, people are less willing to undergo DNA testing when their trust in private companies, government and research institutions is low (e.g. (Milne et al. 2019).

**How likely would you be to take up the offer to have your genome sequenced, if (Items 2, 3 and 4, Table 5):**

- **there was NO history of severe disease in your family?**
- **there was a MODERATE history of severe disease in your family?**
- **there was a DEFINITE AND CLEAR history of severe disease in your family?**

Judges showed a similar level of willingness for whole genome sequencing as for genetic testing. This willingness differed, depending on whether family history of severe disease was absent (48%), moderate (94.5%) or definite (98.6%). A smaller proportion of lawyers and non-lawyers were willing to have their genome sequenced across the scenarios, namely 10.9% and 21.9% respectively if they had *no history* of severe disease in their family (Item 2); 64.1% and 46.1% when there was a *moderate history* (Item 3); 84.1% and 51.6% when there was a *definite history* (Item 4) of severe disease in their family. The responses ranged from strongly disagree to strongly agree.

The judges' almost unanimous endorsement of genome sequencing in the case of definite and clear family history of disease stands in contrast to the other two groups and from the rest of the population. Previous research has shown a very wide variability in people's readiness to find out their status for conditions for which no treatment is currently available. For example, many

people whose parents have Huntington's disease choose not to undergo predictive testing (R. Chapman et al. 2018).

On average, judges, lawyers and non-lawyers indicated that they would be more likely to have their genome sequenced in the case of a *definite* or *moderate* history of severe disease in their family than in the case of *no* history of severe disease in the family. This pattern of results suggests that many participants may not be aware of the distinction between 'genome sequencing' and other 'genetic testing'. For many genetic conditions with high penetrance (high likelihood that a person who has a certain disease-causing genetic mutation will show signs and symptoms of the disease) – testing for just one or few specific genes is sufficient (e.g. BRCA 1 and 2 for breast cancer; or huntingtin (HTT) gene for Huntington's disease). In contrast, screening for many DNA makers is required for polygenic illnesses (Yanes et al. 2020). Therefore, it may be more advantageous to undergo DNA sequencing (rather than genotyping of only some genetic markers) in cases where no family risks are known.

**Do you trust research institutions to not misuse data obtained from participants?**

**(Item 14, Table 5)** The majority (93.2%) of the judges expressed that they do not trust research institutions as they may misuse genetic data. Interestingly, this mistrust in research institutions did not correspond to their willingness to undergo genetic testing and have their genome sequenced. This contrasts with previous research with unselected samples showing less willingness to undergo DNA testing when trust in private companies, government and research institutions is low (e.g. (Milne et al. 2019). In the *Views 1* study, a smaller proportion of lawyers (70.3 %) and of the general sample (47.8%) did not trust research institutions to not misuse their data. The difference among the groups may be due to judges' greater familiarity with the commercial value of data and related misuses.

**How likely would you be to give a sample of your DNA for scientific research if your data were stored anonymously? (Item 12, Table 5)** Fewer lawyers (83%) and non-lawyers (63.1%) than judges (100%) were willing to donate DNA for research, despite the fact that their trust in research institutions was greater than that of the judges'. These results suggest that people's attitudes towards genetic testing (and genetics more broadly) may not be consistent at a first glance, but may represent some coherent and currently poorly understood system of knowledge, values and other elements.

**Do studies showing genetic influences on mental health problems (depression, schizophrenia, bi-polar disorder etc.) lead to increased stigma for people with those conditions? (Item 15, Table 5)** Results, showed that across the three groups only 15% (judges), 26.6% (lawyers) and 28% (non-lawyers) thought that this would happen. These results are interesting and require further investigation, as genetic test results confirming mental health risks for such conditions can indeed increase stigma for the individuals tested.

Previous research has found that genetic information, when incorrectly interpreted, may lead to stigma because many people are affected by essentialist biases, such as viewing certain individuals or groups as 'naturally' and 'essentially' distinct (Berryessa, 2019). Given these and other biases and low genetic literacy (R. Chapman et al. 2019; Selita, Smereczynska, et al. 2020), genetic information may be used against people, for example if it is viewed immutable in criminal trials.

There were some interesting differences between the judges and the other groups in terms of *which* risks were deemed unimportant. Most judges did not select risks of stigma, discrimination

and psychological effects of finding out risk information – all important and currently unresolved issues. These concerns were identified by a greater proportion of participants in the other two groups, particularly the non-lawyers.

The study also explored participants’ **willingness to seek to improve wellbeing via genetic testing with a private company (Item 7, Table 5)**. Almost all of the judges (97.2%) and significantly fewer lawyers and non-lawyers were willing to seek to improve wellbeing through genetic testing via a private company.

Overall, the results suggest a need for greater awareness of how genetic testing may lead to positive and negative consequences in different contexts. As genetic testing providers are becoming new ‘oracles’, it is important to evaluate how people will act on their ‘prophecies’ and how the prophecies may become self-fulfilling or self-defeating (Kovas and Selita 2021c).

### Views on the use of the Power of Prediction

Views on the power of prediction were explored in *Views 2* study using 12 items. The group means (SDs) are presented in Table 6. The table also presents the results from statistical means and variance comparisons. As Items 23-31 were not presented to non-lawyers, only judges and other lawyers are compared for these items. The frequency of responses for each item by group can be found in SOM Table 3 of Publication 5.

Table 6: Means (Standard Deviations) for the 12 items related to the use of genetic data /information (the *Views 2* study).

Item	Group	Mean (SD)	N
20. Understanding how genes influence academic achievement can help to personalise education <sup>2+</sup>	Judges	6.51 (0.06)	73
	Lawyers	5.84 (1.14)*	93
	Non-lawyers	5.00 (1.70)*	115
21. Understanding how educational and other environments influence academic achievement, can help to personalise education <sup>2+</sup>	Judges	6.55 (0.53)	73
	Lawyers	5.83 (1.08)*	94
	Non-lawyers	5.53 (1.29)*	114
22. Genetic information should be used to adapt environments to people’s needs, for example through individualized health advice <sup>2+</sup>	Judges	6.40 (0.64)	73
	Lawyers	5.88 (1.06)*	94
	Non-lawyers	5.01 (1.48)*	115
23. Employers should be allowed to use genetic data for hiring <sup>2+</sup>	Judges	2.50 (0.92)	72

		Lawyers	2.69 (1.37)	94
		Non-lawyers	N/A	
24. Schools should be allowed to use genetic data for admissions <sup>2+</sup>		Judges	2.49 (1.20)	72
		Lawyers	2.56 (1.41)	93
		Non-lawyers	N/A	
		Judges	2.71 (0.91)	72
25. Insurance companies should be allowed to request genetic data prior to issuing health and/or life insurance. <sup>2+</sup>		Lawyers	2.84 (1.27)	94
		Non-lawyers	N/A	
		Judges	2.62 (0.91)	73
		Lawyers	3.37 (1.16)	59
26. If people have access to their genetic data, whereas health insurers do not, these insurers are likely to be disadvantaged (e.g. payouts surpassing collected premiums). Insurers should be allowed access to genetic data of those applying for insurance. <sup>2</sup>		Non-lawyers	N/A	
	Considering age only	Judges	3.35 (1.18)	72
		Lawyers	3.17 (1.37)	59
		Non-lawyers	N/A	
27 - 30. In the genomic era (we now live in) governments should provide health insurance to people: <sup>2</sup>	Considering medical records, but not genetic data	Judges	3.85 (1.46)	73
		Lawyers	3.69 (1.56)	59
		Non-lawyers	N/A	
	Equally, not considering age, genetic data, medical records or lifestyle	Judges	4.30 (1.58)	75
Lawyers		4.56 (1.67)	59	
Non-lawyers		N/A		
31. If we find that people with certain genetic mutations have a propensity for violence, the State should use this information for prevention of crime (e.g. through surveillance): <sup>2+</sup> - see also SOM Table 5 for a qualitative follow-up.	Without consideration of medical records or genetic data	Judges	4.55 (1.54)	73
		Lawyers	4.47 (1.59)	59
		Non-lawyers	N/A	
		Judges	6.10 (0.74)	72
	Lawyers	5.49 (1.10)*	94	
	Non-lawyers	N/A		

*Note:* The numbering of the original publication is preserved. \*Items with significant differences between judges and other groups at  $p < .001$ ; +Items with non-homogenous variation (as indicated by Levene's test); N/A marks the items where information from non-lawyers was not collected. <sup>1</sup>Very unlikely (1), unlikely (2), somewhat unlikely (3), undecided (4), somewhat likely (5), likely (6), very likely (7). <sup>2</sup>Strongly disagree (1), disagree (2), somewhat disagree (3), neither agree nor disagree (4), somewhat agree (5), agree (6), strongly agree (7).

**Should employers be allowed to use genetic data for hiring? (Item 23, Table 6)** The majority of the judges (84.7%) and of the lawyers (73.4%) disagreed. Hiring on genetic propensity may indeed be beneficial to employees and employers because it has the potential

to increase performance prediction reliability, enabling employers to better match people to roles that are most suitable for them – increasing productivity and satisfaction. The current alternative – such as considering the curriculum vitae and interview – are known to have limitations. As the battle for talent intensifies, many employers use psychological testing in the hiring process. If genetic testing can be used to supplement other selection tools, employers are likely to turn to it. The results of this study however suggest that most legal professionals are against such use.

**Should schools be allowed to use genetic data for admissions? (Items 24, Table 6)**

The majority of the judges (80.6%) and of the lawyers (73.1%) disagreed with the idea that schools should be allowed to use genetic data for admissions. As with employment, selection is rife in education. If permitted, many educational institutions would likely be willing to supplement their selection methods with genetic testing. However, this study shows that most legal professionals are against such use of genetic testing. This may be a positive result, considering the controversy associated with gene-based selection and the low genetic literacy in the population.

**Should insurance companies be allowed to request genetic data prior to issuing health and/or life insurance? (Item 25, Table 6)** The majority of the judges (83.3%) and of the lawyers (73.4%) disagreed with insurance companies being allowed to request genetic data prior to issuing health and/or life insurance. Only 2.8% of the judges agreed that this should be allowed.

**If people have access to their genetic data, whereas health insurers do not, these insurers are likely to be disadvantaged (e.g. payouts surpassing collected premiums). Insurers should be allowed access to genetic data of those applying for insurance (Item 26, Table 6)** This item explicitly stated that the insurance industry cannot function if people do and insurers do not have access to genetic data. This did not change the judges' and lawyers' views. Only 2.7% of the judges and 11.9% of the lawyers agreed with the idea that insurance companies should have access to genetic data.

These views show that judges understand the associated discrimination risks with the use of genetic data for insurance provision. However, more and more people have access to their genetic data, and the insurance industry depends on money collected from the more healthy (i.e. those with lower health risk) to cover the costs of the less healthy (i.e. those with higher health risks). This means that access to genetic information is important for the insurers, and the insurance industry has highlighted the importance of having access to genetic data. For example, the Association of British Insurers (ABI) and the UK Government have agreed that “unless otherwise agreed, insurance companies should have access to all relevant information to enable them to assess the price risk fairly in the interest of all their customers” (HM Government 2014; UK Department of Health 2022). In the UK, the Government and the ABI have entered into an agreement – known as the Code on Genetic Testing and Insurance (renewed in 2018) – regarding use of genetic data by insurers. This agreement prohibits insurers to require individuals to disclose genetic information for health insurance. However as this Code is merely a voluntary agreement between the ABI and Government, its content is not legally binding (HM Government 2022). As discussed in Part 1 of this thesis (and Publication 1), deciding on whether to allow insurers to request genetic information prior to issuing health and/or life insurance is now a pressing matter for societies. Considering the scale of the industry, as more people have access to their genetic data, it is likely that insurers will too –

unless societies find a different way of providing health insurance, such as subsidising by the State.

**Should insurance in the Genomic Era be provided by the State: (Items 27-30, Table 6; and Table 3, in SOM)**

- **Taking into account only people's age?**
- **Considering medical records, but not genetic data?**
- **Equally, not considering age, genetic data, medical records or lifestyle?**
- **Without consideration of medical records or genetic data?**

Many participants endorsed insurance provision by the State, as follows:

- 58.9% of the judges and 53.4% of the lawyers (the greatest proportion of participants) – thought governments should provide health insurance to people *without consideration of medical records or genetic data* (means 4.55 and 4.47);
- 50.7% and 59.3% (a smaller proportion) – *equally, not considering age, genetic data, medical records or lifestyle* (means 4.3 - 4.6);
- 31.5% and 40.7% (an even smaller proportion) – *considering medical records, but not genetic data* (means 3.9 and 3.7); and
- 22.2% and 23.7% (the smallest proportion) – *considering age only* (means 3.4 and 3.2).

Responses regarding all four alternatives were similarly varied for judges and lawyers. The responses for each option ranged across the entire scale. These results show that finding a suitable solution for provision of health insurance in the Genomic Era presents serious challenges, but there is a majority preference for State-provided insurance that does not consider person-specific information. Informed debates and discussions are essential for effective and reasonable solutions.

**If we find that people with certain genetic mutations have a propensity for violence, should the State use this information for prevention of crime (e.g. through surveillance)? (Item 31, Table 6)** Almost all of the judges (98.6%) and most of the lawyers (84.1%) thought the State should use genetic information in this way. This sharply contrasts with the low endorsement for use of genetic data for insurance provision or using it for selection in educational and employment. The average endorsement of the judges was significantly higher than that of the lawyers.

In a qualitative post-hoc study on this Item with 10 participants (5 judges and 5 lawyers), part of the question ('e.g. through surveillance') was removed. Participants were asked to comment on what specific measures they think the State could take in this context. These results are presented in the SOM Table 5 of Publication 5. Six of the 10 participants endorsed the use of genetic information for crime prevention. The main motive was early identification and implementation of targeted educational interventions. For the four participants who did not agree with gene-based crime prevention, the main three reasons were that: genetic testing by the State violates everyone's privacy and can open the door to total control; that only some of the people who show propensity for violence actually develop criminal behaviour; and that social factors outweigh genetic ones.

The results suggest that it is important for key stakeholders to gain a better understanding of gene-environment processes in order to get a more informed view on gene-based crime prevention. Without this knowledge, the gene-based method can be seen as reliable and more effective than many other controversial methods, such as parole decisions based on machine

learning algorithms (Larson et al. 2016; Shah et al. 2021); and *lineage databases* of children (Ghosh 2013).

In reality, on its own, gene-based selection for surveillance can never be precise or reliable, given the polygenic nature of behaviour and gene-environment interplay. Even if participants were not endorsing gene-based surveillance, and had in mind other ways of using genetic information for crime prevention – such use is controversial. For example, early identification and implementation of targeted educational interventions, although appearing to benefit individuals and society, can also lead to stigma and discrimination from early childhood. Similar issues are posed by mandated psychological interventions and other treatments (e.g. (Hachtel et al. 2019).

This issue was further explored in the *Views 1* study (Publication 4). The law group (the international sample of 473 lawyers and/or law students), used the whole scale of the possible responses, showing wide variability in views. In this study, 47% of the law participants agreed with the State using genetic information for crime prevention (Item 4, Tables 12 and 13). Further research is needed to identify reasons for weaker endorsement of gene-based crime prevention in the *Views 1* study than in the *Views 2* study. Potential explanations may include the inclusion of law students in the *Views 1* study, or differences in such views across countries.

Overall, the results highlight that, to prevent harmful applications of genetic information, societies need to continuously critically examine its use in a cross-disciplinary framework. There is a need for open debates and discussions on these matters. These steps are needed not only to prevent violations of people's rights, but also to help individuals make more informed decisions in dealing with the fast-growing industry of consumer genetics.

## Views on the use of the Power of Environmental Engineering

We have exercised 'environmental engineering' for centuries. Indeed, human traits, including intelligence, academic and occupational achievement, are affected by the environments we create (e.g. parenting and teaching practices, availability of resources). Recent advances in the understanding of epigenetics have brought new insights into the potential of environmental engineering. However, little is known about judges' and lawyers' views on environmental engineering in the Genomic Era – for example whether genetic effects are seen as malleable. In the *Views 2* study, three items (Table 6 and SOM Table 3 in Publication 5) were used to assess the views of judges, lawyers and non-lawyers on the Power of Environmental Engineering in relation to education and health – both being societal priorities.

**Can our understanding of how genes influence academic achievement help to personalise education; and can our understanding of how environments (educational and other) influence academic achievement, help to personalise education? (Items 20 and 21, Table 6)** All (100%) of the judges agreed with both. Views of the lawyers and non-lawyers were more varied on both matters – with, respectively, 93.6% and 92.5% of lawyers and 68.7% and 83.3% of non-lawyers agreeing. Judges' endorsement was significantly greater than that of the other two groups.

These results suggest that legal professionals see potential benefits in increased understanding of genetic and environmental influences on educational processes. However, recent research has demonstrated that partial knowledge may be a mixed-blessing in education (Larsen et al.

2022). Much work is needed to understand how gene-environment information can be brought to educators, parents and students in the most beneficial way.

**Should genetic information be used to adapt environments to people's needs, for example through individualized health advice? (Item 22, Table 6)** All (100%) of the judges agreed. A smaller proportion of lawyers (93.6%) and non-lawyers (69.6%) agreed, showing a greater variability in responses. Judges' endorsement was significantly greater than that of the other two groups.

Such uses of genetics in healthcare are growing, for example for selecting appropriate medication based on genotypes, or receiving more frequent screening for people at a higher genetic risk for certain conditions (Forgetta et al. 2020; Meisel et al. 2015; NHS, UK 2017; C. Thomas et al. 2021). However, wide implementation of gene-based advice remains controversial, due to many currently unresolved concerns (covered in Publications 1-5), including ethical, regulatory, access to benefits, economic/costs, lack of trained staff across sectors (e.g. medical and education) (Alarcón Garavito et al. 2023; Godard et al. 2003). In the field of education, there is also a great challenge to ensure we use the emergent knowledge about gene-environment processes in ways that provide nuanced personalised support to each learner rather than segregate and stigmatise people (Butterworth and Kovas 2013; M. Thomas et al. 2015).

## Views on the Use of the Power of Genetic Engineering

In the *Views 2* study, 3 items explored participants' views on gene editing in different contexts. The results are presented in Table 7.

**Should genetic manipulation, such as gene editing, be allowed for the prevention and treatment of disease? (Item 17, Table 7)** Almost all of the judges (98.6%, only one judge undecided) agreed with using gene editing for prevention and treatment of disease. The range of responses was greater for the other two groups, with 89.4% of lawyers and 72.1% of non-lawyers agreeing. The average endorsement was significantly greater for judges than for the other two groups.

Advancements in this area are moving towards thousands of monogenic diseases being preventable or treatable through gene editing. The high endorsement for this item from judges and other lawyers reflects notable positive implications of gene editing for societies. It is estimated that there are tens of millions of individuals worldwide affected by monogenic diseases, and so gene editing in this area has the potential of improving millions of lives (Konishi and Long 2021). However, many controversial issues need to first be addressed, including equality in access, preimplantation diagnostics and associated decisions, as well as the possibility of altering the genetic pool.

**Should people be allowed to use genetic manipulation, such as gene editing, to improve themselves and/or their children? (Item 18, Table 7)** Almost all of the judges (98.6%, only one judge was undecided) agreed that people should be allowed to opt for gene editing in order to improve themselves/their children. In contrast, 85.1% of lawyers and 56.1% of non-lawyers agreed with such use. The average endorsement was significantly greater for judges than for the other two groups. Such strong endorsement of genetic engineering for the 'improvement' of traits is striking. Further research is needed to understand this pattern of

responses. It is possible that judges are prepared to endorse engineering only for health-related traits (such as cancer influenced by BRCA1 or BRCA2 mutations), rather than traits such as intelligence and athleticism. Additionally, the endorsement of improving one’s own traits and the traits of one’s children could differ if these two questions were presented in separate items. Overall, the results suggest that people may underestimate potential risks of gene editing; and call for training of judges and lawyers in this area.

Table 7. Means (Standard Deviations) and frequency responses for the 3 items related to gene editing (the *Views 2* study).

Item	Group	Mean (SD)	Frequencies (Likert scales 1 = low, 7 = high)						
			1	2	3	4	5	6	7
17. I believe that genetic manipulation, such as gene editing, should be allowed for the prevention and treatment of disease <sup>2+</sup>	Judges	6.27 (0.75)	0 0.0%	0 0.0%	0 0.0%	1 1.4%	10 13.7%	30 41.1%	32 43.8%
	Lawyers	5.70 (1.28)*	1 1.1%	3 3.2%	2 2.1%	4 4.3%	25 26.6%	31 33%	28 29.8%
	Non-lawyers	4.99 (1.59)*	4 3.5%	11 9.6%	5 4.3%	12 10.4%	25 21.7%	46 40.0%	12 10.4%
18. I believe that genetic manipulation, such as gene editing, should be allowed so that people can improve themselves and/or their children <sup>2+</sup>	Judges	6.29 (0.79)	0 0.0%	0 0.0%	0 0.0%	1 1.4%	12 16.4%	25 34.2%	35 47.9%
	Lawyers	5.59 (1.39)*	0 0.0%	7 7.4%	2 2.1%	5 5.3%	21 22.3%	33 35.1%	26 27.7%
	Non-lawyers	4.35 (1.88)*	8 7%	22 19.3%	9 7.9%	11 9.6%	22 19.3%	31 27.2%	11 9.6%

*Note:* N = 73 (judges); N = 94 (lawyers); N = 115 for Item 17 and 114 for Item 18 (non-lawyers). The numbering of the original publication is preserved. The darker the shading - the higher the proportion of participants selecting that response. \*Items with significant differences between judges and other groups at  $p < .001$ ; +Items with non-homogenous variation (as indicated by Levene’s test); N/A marks the items where information from non-lawyers was not collected. <sup>2</sup>Strongly disagree (1), disagree (2), somewhat disagree (3), neither agree nor disagree (4), somewhat agree (5), agree (6), strongly agree (7).

## Views on regulation of genetic powers and implications of genetics for justice

Views in this section include: whether existing laws are sufficient to protect individuals from misuses of genetic data by private schools, insurance companies and employers; who is primarily responsible for updating laws (who should be liable for not updating laws timely); when should the following laws be updated: data protection and privacy laws, discrimination laws (e.g. education, health benefits, race), insurance laws and employment laws; should we allow patenting of genetic findings; whether the legal systems need to take into account findings on population variability (e.g. in terms of ability); whether we should use genetic propensity

information in sentencing and how; what findings on origins of behaviour mean for praise, punishment and free will – the key element of criminal sentencing.

It is the key stakeholders who decide whether we need to update laws, and so their views on these matters are highly informative. The *Views 2* study used 3 items to assess judges' and lawyers' views on the effectiveness of laws in three major areas – admission for education, insurance and employment (Items 32-34, Table 8 and SOM Table 4 in Publication 5).

Table 8. Means (Standard Deviations) and response frequencies for the 5 items related to updating of relevant laws (*Views 2* study).

Item	Group	Mean (SD)	Frequencies (Likert scales 1 = low, 7 = high)							
			1	2	3	4	5	6	7	
32 - 34. Current laws in your country are sufficient to protect individuals from misuses of genetic data by: <sup>2</sup>	Selective/private schools (e.g. for admission) <sup>+</sup>	Judges	2.58 (0.87)	6 8.3 %	29 40.3 %	27 37.5 %	9 12.5 %	1 1.4%	0 0.0%	0 0.0%
		Lawyers	2.81 (1.21)	16 17.2 %	19 20.4 %	33 35.5 %	20 21.5 %	3 3.2%	1 1.1%	1 1.1%
		Non-lawyers	N/A	N/A						
	Insurance companies <sup>+</sup>	Judges	2.64 (0.76)	2 2.8 %	32 44.4 %	28 38.9 %	10 13.9 %	0 0.0%	0 0.0%	0 0.0%
		Lawyers	2.83 (1.10)	13 13.8 %	26 27.7 %	32 34.0%	14 14.9 %	3 3.2%	3 3.2%	3 3.2%
		Non-lawyers	N/A	N/A						
	Employers (e.g. for hiring or firing purposes)	Judges	2.71 (0.83)	5 6.9 %	23 31.9 %	32 44.4 %	12 16.7 %	0 0.0%	0 0.0%	0 0.0%
		Lawyers	2.83 (1.09)	10 10.8 %	25 26.9 %	36 38.7 %	17 18.3 %	3 3.2%	2 2.2%	0 0.0%
		Non-lawyers	N/A	N/A						
35. Genetic findings rely on data from large numbers of people. If companies are allowed to patent findings, then related treatments may become very expensive. Do you agree that companies should be allowed to patent genetic findings? <sup>21+</sup>	Judges	5.82 (0.59)	0 0.0 %	0 0.0%	0 0.0%	0 0.0%	20 27.4 %	46 63.0%	7 9.6%	
	Lawyers	5.63 (0.95)	1 1.7 %	0 0.0%	0 0.0%	2 3.4%	20 33.9 %	29 49.2 %	7 11.9 %	
	Non-lawyers	N/A	N/A							
36. Findings show that within any population	Judges	6.01 (0.49)	0 0.0 %	0 0.0%	0 0.0%	0 0.0%	8 11.0%	56	9	

there is a very large variability among people, including in terms of ability, personality and level of education. To provide justice for all, the legal system should accommodate this variability, including in terms of procedure and resources. For example, providing accessible jargon free information and making court proceedings people friendly. <sup>2</sup>		0.0					76.7	12.3
		%					%	%
	Lawyers	5.76 (0.82)	0 0.0 %	0 0.0%	2 3.4%	0 0.0%	16 27.1 %	33 55.9 %
	Non-lawyers	N/A				N/A		

*Note:* N (Judges) = 72; N (lawyers) = 93-94 for Items 32-34 and 59 for Items 35-36. The numbering of the original publication is preserved. The darker the shading - the higher the proportion of participants selecting that response. \*Items with significant differences between judges and other groups at  $p < .001$ ; +Items with non-homogenous variation (as indicated by Levene's test); N/A marks the items where information from non-lawyers was not collected. <sup>1</sup>Very unlikely (1), unlikely (2), somewhat unlikely (3), undecided (4), somewhat likely (5), likely (6), very likely (7). <sup>2</sup>Strongly disagree (1), disagree (2), somewhat disagree (3), neither agree nor disagree (4), somewhat agree (5), agree (6), strongly agree (7).

**Are existing laws sufficient to protect individuals from misuses of genetic data by: 1) private schools, for example, for admission; 2) insurance companies; and 3) employers, for example, for hiring or firing purposes? (Items 32-34, Table 8).** Over 80% of the judges and over 70% of the lawyers thought that (in their country) the laws in place do not provide sufficient protection to individuals against misuses of genetic data in all three contexts. The average responses to these items did not differ significantly between judges and lawyers.

The *Views 2* study further explored views on liability for a failure to update laws. Finding out from the judges and lawyers, as to who they think should be liable for compensation when delays in updating of laws have led to harm, provides an indication as to who judges see as having the primary duty for updating laws. It also helps steer jurisprudence in this area (which is undeveloped) as to compensation for such cases.

Two vignettes (Tables 9 and 10) explored judges' and lawyers' views on who would be liable for harm resulting from the misuse of genetic data in two hypothetical cases.

As can be seen from Table 9, in relation to access to health insurance/care, views were split as to who was liable for the damages caused by the misuse of genetic data – those who had breached the data, those who misused them, or the Government for not having updated laws in a timely manner to prevent breaches. Many of the judges (42.5%) and the lawyers (33%) found the Government responsible for not having updated laws in time – when it became apparent that genetic sequencing was becoming routine – and decided that the Government should pay compensation for the suffered loss. Around 50% of the judges and lawyers found that the NHS was responsible for the loss, deciding that the NHS should pay compensation.

Few judges (6.8%) and lawyers (13.8%) thought that compensation should be paid by the insurance company or that it should not be paid at all.

Table 9. Vignette 1 on compensation for genetic data breaches.

It is now 2020. Mary's genome shows that she has a propensity for a particular type of cancer. Due to earlier data breaches by the national health service, Mary's genetic data had fallen into the possession of insurance companies, from untraceable sources. Mary had applied for health insurance, and had received very high quotes (her genetic propensity not given as a reason), which she could not afford. Mary is now ill and facing very high medical bills. Based on this scenario:

Group	The NHS should compensate Mary, because data were in their possession.	The Government should compensate Mary for not having updated the laws when it became apparent that genetic sequencing was becoming a routine for research and other purposes.	The insurance company should compensate Mary even though their claim is that the data were available online.	No one is responsible, because Mary should have opted out of the research programme.
Judges	37 50.7%	31 42.5%	5 6.8%	0 0.0%
Lawyers	45 47.9%	31 33%	13 13.8%	5 5.3%

*Note:* The darker the shading - the higher the proportion of participants selecting that response.

As can be seen from Table 10, in relation to genetics-related employment matters, most of the judges (63%) and many of the lawyers (43.6%) found the Government liable for not updating laws in time to prevent genetic data breaches; and 37% and 54.3% found the employers liable. None of the judges and only 2.1% of the lawyers thought that no-one should be held liable. It is possible that participants would have chosen more than one option if this was allowed. For example, they might have thought that both employers and the Government were liable, or that no-one was liable, as using genetics in this context can benefit both employers and employees via better 'match to the job'. Nevertheless, the pattern of results is clear: people prefer someone to be liable when genetic data are used for hiring without their consent. These results also indicate that most participants place the duty primarily on the Government to take action to prevent misuses of genetic information and advances.

Table 10. Vignette 2, considering who is responsible for breaches of genetic data in employment.

It is 2020\*. It has now become possible to predict (with a much greater degree of certainty) an individual's performance from DNA alone. The laws are now updated, making genetic data breaches a criminal offence. However, numerous genetic data breaches had occurred before laws were updated. Employers, who got hold of the data through unknown sources (due to previous breaches), without declaring the basis of the selection, started headhunting people whose genetic codes showed that they would be better performers. People have an action against:

Group	The employers	The Government for not updating in time the laws to prevent genetic data breaches	No-one, as it is the right of employers to choose the most suitable people for the job	No one, because hiring on genetic data produces similar outcome to hiring on test results and curriculum vitae (CV), and is a more efficient way.
Judges	27 37.0%	46 63.0%	0 0.0%	0 0.0%
Lawyers	51 54.3%	41 43.6%	2 2.1%	0 0.0%

*Note.* The darker the shading - the higher the proportion of participants selecting that response. \*When this item was developed, 2020 was the near future. Today, in 2023, laws are still undeveloped as to genetic data breaches; for example, for breaches of data only fines are imposed, and generally small (e.g. £30,000 for breaches of sensitive data of hundreds of patients) – see Publication 1.

Overall, this pattern of results demonstrates that court decisions in these areas are likely to depend on individual judge's views; and that passing effective laws will be impeded by the high degree of disagreement among legal practitioners and policy makers. If this situation is left unaddressed, it is likely that Governments will face court actions, similar to already occurring actions against the Government for failing to act regarding climate change matters (Carrington and editor 2022).

Views on when to update laws were explored using 4 items in the *Views 2* study (Table 11).

**In the light of current realities with genetic prediction, sequencing and use of data – when should the following laws be updated?**

- **Data protection and privacy laws**
- **Discrimination laws (e.g. education, health benefits, race)**
- **Insurance laws**
- **Employment laws**

As can be seen from Table 11, there was a strong agreement among the judges and lawyers that laws covering all four areas should be updated now (as soon as possible). More judges (89%) and lawyers (81.4%) saw the need to update data protection laws as urgent as compared to the other three areas, with a slightly lower proportions of participants (70-78%) viewing updating laws concerning genetic discrimination, insurance and employment to be urgent. The strong support by judges and lawyers for the need to immediately update laws in these areas further confirms the urgency with which this should happen.

Table 11. Responses to the 4 items about the need to update relevant genetics-related laws (*Views 2* study).

From a DNA sample taken at birth we already can predict, with a degree of probability, future behaviour, such as school performance. The precision of prediction is continuously increasing. Moreover, sequencing is already routinely conducted for medical research and other purposes. When should the following laws be updated accordingly?

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**Data protection and privacy laws**

	Now (asap)	After some cases in these areas have been brought to courts	After we are certain of the scale of the risk	No need to do so as the current laws are sufficient
Judge	65 89%	0 0.0%	8 11%	0 0.0%
Lawyers	48 81.4%	4 6.8%	6 10.2%	1 1.7%

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**Discrimination laws (e.g. education, health benefits, race)**

	Now (asap)	After some cases in these areas have been brought to courts	After we are certain of the scale of the risk	No need to do so as the current laws are sufficient
Judge	57 78.1%	5 6.8%	11 15.1%	0 0.0%
Lawyers	41 69.5%	5 8.5%	11 18.6%	2 3.4%

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**Insurance laws**

	Now (asap)	After some cases in these areas have been brought to courts	After we are certain of the scale of the risk	No need to do so as the current laws are sufficient
Judges	53 72.6%	6 8.2%	14 19.2%	0 0.0%
Lawyers	42 71.2%	6 10.2%	11 18.6%	0 0.0%

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**Employment laws**

	Now (asap)	After some cases in these areas have been brought to courts	After we are certain of the scale of the risk	No need to do so as the current laws are sufficient
Judges	54 74%	5 6.8%	14 19.2%	0 0.0%
Lawyers	40 71.4%	5 8.9%	11 19.6%	0 0.0%

Views on access to genetic advances and to justice in the Genomic Era were explored using 8 items (2 in the *Views 1* study and 6 in the *Views 2* study). Current systems present multiple barriers to accessing justice (e.g. high costs) and a failure to accommodate the large variability of the population in terms of ability, education and other socio-demographic factors (Selita 2018b).

In the *Views 2* study, accessibility of genetic advances was explored with the following item:

**Should patenting of genetic findings by companies be allowed considering it may lead to related treatments becoming inaccessible to most, when genetic findings depend on data from large numbers of people? (Item 35, Table 8).** All (100%) of the judges and the majority (95%) of the lawyers endorsed patenting of genetic findings by companies, *even if* this would lead to related treatments becoming very expensive.

This very high agreement on this controversial issue presumably reflects judges' belief that progress in this area relies on commercial interest, as the research is costly to conduct. Therefore, patenting of findings may be inevitable. However, this may lead to prohibitively high costs of many treatments. For example, a \$3.5-million one-time gene therapy treatment was recently (in Nov 2022) approved by the US Food and Drug Administration (FDA) for the genetic blood-clotting disorder haemophilia B – a treatment that prevents life-threatening bleeding for up to 8 years (Naddaf 2022). It remains to be seen how different healthcare systems will manage access to such costly treatments, and how insurance provision will be regulated for such cases.

The progress in genetic science is largely a product of a multinational effort by thousands of researchers and taxpayers' contributions in several countries. In addition, genetic discoveries are entirely dependent on the availability and processing of genetic, medical and lifestyle data from millions of people – who will potentially not be able to access the benefits of science to which they contributed.

Despite this, commercial companies will make every effort to patent any discoveries, as we witnessed with a number of battles in genetics raging from the start. These include: a race to be the first to sequence the human genome; patenting of naturally occurring segments of human DNA (e.g. gene or protein sequences found in nature), banned by the US Supreme Court in 2013 and then (unsuccessfully) sought to be overturned by law in Congress; and patenting gene based treatments, with numerous treatments patented including in the US and China (Andrews et al. 2015; Kesselheim et al. 2013; Ledford 2021; Servick 2019; YourGenome.org n.d.; Zhou and Wang 2021).

Societies will need to find solutions, so that commercial interests do not overshadow the presumably main aims of genetic science – to prevent and cure diseases and to improve the quality of life for all. Cross-disciplinary efforts are essential for developing new models of fair access, including caps on prices, appropriate taxation on business profits and State subsidies. Perhaps a starting point is to assess what we learned during the COVID-19 pandemic regarding the cost of protective equipment, vaccines, treatments, profits made by different providers and inequalities in access.

Accessibility of justice was explored in both, *Views 1* and *Views 2* studies, with the following item:

**To provide justice for all, in the light of findings on origins of variability within a population, should the legal systems accommodate the large population variability, including in terms of procedure and resources – for example, providing accessible jargon free information and making court proceedings people friendly?** In the *Views 1* study, 71% of the Law sample agreed and only 16% disagreed (Tables 12 and 13). In the *Views 2* study, all (100%) of the judges and almost all (96.6%) of the

lawyers agreed that the legal system should accommodate the variability of the population it represents, including in terms of procedure and resources (**Item 36 Table 8**).

Accommodating population variability, including in terms of ability, personality and level of education – as a prerequisite to providing justice for all – is a concept requiring urgent consideration. Much recent research suggests that this variability is to a large extent outside individuals’ control, which requires reevaluation of many assumptions about freedom of will, blame, praise and punishment (Cashmore 2010; Kovas and Selita 2021a). Judges' and lawyers' confirmation that we should accommodate the variability, is important for the development of jurisprudence in this area, towards more accessible justice.

This issue was also addressed in *Views 1* study using the following 2 items:

**Should we make (legal and policy) provisions to buffer the effects of genetic disadvantage on individuals (e.g. tailored education)? (Item 3, Tables 12 and 13)**

The item was presented to the general sample. Most (65%) agreed and a small proportion (20%) neither agreed nor disagreed.

**Is there genetic disadvantage in the same way as there is socio-economic disadvantage? (Item 2, Tables 12 and 13).** Over half (52%) of participants agreed and 23% neither agreed nor disagreed. The results indicate that many people are not willing to accept that there is genetic disadvantage (in the same way that there is environmental disadvantage).

Table 12. Means (Standard Deviations) and ranges for views on the effectiveness of regulation and broader implications of genetics for justice (*Views 1* study).

No.	Item	N	Mean (SD)	Range
<i>Items presented to the General sample</i>				
1	Genetic influences on our behaviour mean that there is no free will.	4566	2.83 (1.66)	1–7
2	In the same way as there is socio-economic disadvantage, there is genetic disadvantage.	845	4.45 (1.52)	1–7
3	We should make provisions (legal and policy) to buffer the effects of genetic disadvantage on individuals (e.g. tailored education).	848	4.95 (1.46)	1–7
<i>Items presented only to the Law sample</i>				
4	If we find that people with certain genetic mutations have a propensity for violence, the state should use this information for prevention of crime.	473	4.38 (1.83)	1–7
5	According to the latest genetic findings, human behaviours are a product of multiple gene–environment processes, often beyond an individual’s control: This information should be taken into account in deciding the form of sentencing (e.g. compulsory therapy or education, community service, prison sentence).	420	4.47 (1.63)	1–7
6	According to the latest genetic findings, human behaviours are a product of multiple gene–environment processes, often beyond an individual’s control: This information should be taken into account in deciding the length of punishment.	418	4.06 (1.68)	1–7

7	Findings show that within any population there is a very large variability among people, including in terms of ability, personality and level of education. To provide justice for all, the legal system should accommodate this variability, including in terms of procedure and resources. For example, providing accessible jargon free information and making court proceedings people friendly.	426	5.06 (1.53)	1–7
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*Note.* The General sample (N=10,090) included all participants available at the time of analyses; and Law sample (N=486) included those who identified themselves as lawyers and/or law students, whose results are presented separately from the general sample only for the 4 items that were not presented to the general sample. Response options: 1 = strongly disagree; 2 = disagree; 3 = somewhat disagree; 4 = neither agree nor disagree; 5 = somewhat agree; 6 = agree; 7 = strongly agree.

Table 13. Frequencies for the same samples and items as Table 12 for each of the 7 response options for each item (*Views 1* study).

No.	Item (abbreviated descriptions)	Strongly disagree – Strongly agree						
<i>Items presented to the General sample</i>								
1	‘Genetics and free will’	1007 22%	1548 34%	632 14%	545 12%	361 7%	353 8%	120 3%
2	‘Genetic disadvantage’	28 3%	80 10%	109 13%	190 23%	204 24%	174 21%	60 7%
3	‘Buffering against genetic disadvantage’	17 2%	49 6%	60 7%	173 20%	195 23%	243 29%	111 13%
<i>Items presented only to the Law sample</i>								
4	‘Use of genetic information by the State’	45 10%	56 12%	45 10%	61 13%	104 22%	116 25%	46 10%
5	‘Genetic information in sentencing: form’	25 6%	47 11%	39 9%	58 14%	114 27%	118 28%	19 5%
6	‘Genetic information in sentencing: length’	40 10%	60 14%	47 11%	57 14%	123 29%	83 20%	8 2%
7	‘Legal system accommodating variability’	13 3%	27 6%	28 7%	54 13%	90 21%	161 38%	53 12%

*Note.* Darker shading of the cells corresponds to a greater proportion of respondents selecting that specific option on the Likert scale. Response options: 1 = strongly disagree; 2 = disagree; 3 = somewhat disagree; 4 = neither agree nor disagree; 5 = somewhat agree; 6 = agree; 7 = strongly agree.

*Views 1* study also explored views on sentencing. Unlike environmental circumstances of the accused that are often taken into account in sentencing, genetic information is rarely considered. As both environments and genes play a significant role in behaviour, using one and ignoring the other in the justice system is problematic.

The Law Sample provided responses to two items exploring **whether genetic information should be taken into account in criminal sentencing to decide on the form of sentence (e.g. imprisonment, community service); and the length of sentence.** As shown in **Table 13**, 74% of participants agreed with using genetic information to decide on the form of punishment and 51% to decide on the length of the sentence. The responses spanned the entire available range (1-7; **Table 12**). These results demonstrate large variability in views on this matter among lawyers and future lawyers – again highlighting challenges the justice system faces in deciding whether and how to use genetic information in legal contexts.

The *Views 1* study additionally addressed the issue of using genetic information in sentencing with the following vignette:

**Sarah has a particular genetic variant that has been associated with aggression. She is in court being tried for a violent crime. Should knowing about this genetic variation: (see Table 14 for the four response options).** The Vignette was completed by over 10,000 participants in the general sample, as this item was also included in earlier versions of the iGLAS. Halfway through the data collection, one of the response options 'be considered but make no difference to her sentence' was replaced with 'be considered to determine the type of sentence (e.g. mandatory labour, psychological therapy)'. The remaining three response options were the same throughout the collection. This difference in the available response options provided an interesting comparison for the study.

Table 14. Frequencies for each Vignette response option and corresponding proportions of the whole sample (*Views 1* study).

Response options	Frequency	Percent
1.Reduce her sentence	526	5.2
2.Not be taken into consideration	3,554	35.2
3.Increase her sentence	146	1.4
4 <sup>a</sup> .Be considered but make no difference to her sentence	2,974	29.5
4 <sup>b</sup> .Be considered to determine the type of sentence (e.g. mandatory labour, psychological therapy)	2,782	27.6
Total	9,982	98.9
Missing	108	1.1
Total	10,090	100.0

Participants in the earlier and later versions of the iGLAS saw either Response 4<sup>a</sup> or Response 4<sup>b</sup>, respectively.

As can be seen in Table 15, over half of the participants opted for the genetic risk to '*be considered by the court but make no difference to the sentence*', when this option was available – with most of the remaining participants (42%) opting for '*Not be taken into consideration*'. Even more participants (over 60%) opted for genetic information to '*be considered to determine the type of sentence*', when this option was available – with only 28% opting for '*Not be taken into consideration*'. The results show that most participants think that genetic risk is relevant but should not affect the length of sentence.

The vignette data were further analysed splitting the sample into two groups: early iGLAS,  $N = 5,566$  and later iGLAS,  $N = 4,216$ . The two groups had the same three response options, with the 4th response option being different. Table 15 presents frequencies for the two groups. Very few participants chose to 'reduce' the sentence based on this genetic risk (4.9% and 5.7% for earlier and later samples) or to 'increase' it (0.6% and 2.5%).

Table 15. Frequencies (and N) for each of the four response options for earlier and later versions of the iGLAS where option 4 differed (*Views 1* Study).

Response	Earlier iGLAS	Later iGLAS
1.Reduce her sentence	4.9% (275)	5.7% (245)
2.Not be taken into consideration	42% (2,338)	28% (1,200)
3.Increase	0.6% (36)	2.5% (106)
4 <sup>a</sup> Be considered but make no difference to the sentence	52.4% (2,917)	-
4 <sup>b</sup> Be considered to determine the type of sentence (e.g. mandatory labour, psychological therapy)	-	62.1% (2,665)

<sup>a</sup> and <sup>b</sup> – response options presented in earlier and later iGLAS versions, respectively.

These results further suggest that many people believe that it is fair to consider genetic risk in criminal cases, presumably to acknowledge genetic disadvantage as unfair and signifying empathy with the disadvantaged. At the same time, the participants' willingness to use genetic risk to affect the sentence may stem from considerations of public safety. This is consistent with previous research which found harsher sentencing decisions, when genetic aetiology was linked to reoffending or other risks (Cheung and Heine 2015). In the present study, most people were willing to take genetic risk into account to determine the type of punishment when given such an option. This may be because people view this option as fairer (for example, preferring educational or medical interventions to prison sentence). Alternatively, as discussed above, people may think that genetic risk or a combination of different risks reduce one's control and therefore must result in a prison sentence. Further research is needed to investigate these and other possible explanations for the pattern of results whereby genetic information is viewed as more relevant to the type than the length of punishment.

*Views 1* study also investigated views on free will – a core concept that forms the basis for sentencing in the current legal process. There are multiple definitions of free will, with the core assumption that people have control over their behaviour and are responsible for their decisions, actions and the consequences they bring. In criminal justice, 'guilt' is contingent upon whether the criminal act was freely willed.

Participants were asked: **Do genetic influences on our behaviour mean that there is no free will? (Item 1, Tables 12 and 13)** Only 18% agreed. These responses may mean that most participants do not think that genes place significant limitations on free will. However, responses to Items 2, 3, 5 and 6 (Tables 12 and 13) show that many of the same participants also think that both genes and environment have significant impact on human behaviour. In fact, over half of the participants agreed that **there is genetic disadvantage, in the same way as there is environmental disadvantage**, with only about a quarter of participants disagreeing.

These results highlight that the current formulation of free will, as applied in the justice context, is inconsistent with the existence of vast individual differences in many traits that are relevant to behaviour, including in impulse control, cognitive ability, aggressiveness, addiction and other mental health problems. These and many other characteristics, which are a product of complex gene-environment processes, limit the extent to which one's will is free.

The concept of free will is so engrained in people's minds and in the justice system that the words 'free' and 'will' have become inseparably fused. In reality, our will is a complex psychological construct – a product of multitudes of interacted forces and therefore not free (Cashmore 2010; Lavazza 2016); (see also (Kovas and Selita 2021a) for a summary). In fact, people's conceptions of will have always been conflicted. For example, in a paradoxical way, we hold two opposing (or confused) sets of beliefs: we know that behaviour is driven by complex gene-environment interplay and, at the same time, we believe that will has the power to cause or prevent actions, that will is the 'prime mover' and therefore it triumphs over genetic and environmental forces that shape who we are. Similarly, we know from research, that decision activity happens in the brain before we are aware of the decision (Soon et al. 2008) and, at the same time, our consciousness creates an illusion that we make decisions in full awareness (an illusion of free will). In the Genomic Era, societies need to decide on whether human behaviour

realities, including genetic disadvantage and the limitations on the freedom of will, are to be taken into account in criminal sentencing and other contexts.

Finally, *the Views 1* study also examined how different attitudes relate to each other. Table 16 presents the results of the correlational analyses exploring whether people’s views regarding using genetic information in the legal system are consistent across different contexts.

Table 16. Pearson correlations ( $r$ ) between items tapping into different attitudes in the study. Result from same items as in Tables 12 and 13 (*Views 1* study).

Item (abbreviated description)		1	2	3	4	5	6	7	
1	‘Genetics and free will’	$r$	1	0.09**	0.03	0.14**	0.08	0.13**	-0.03
		N	455 6	843	845	472	420	418	425
2	‘Genetic disadvantage’	$r$	1	-0.02	-0.29**	-0.12*	-0.25**	-0.06	
		N	845	844	472	420	418	425	
3	‘Buffering against genetic disadvantage’	$r$	1	0.48**	0.46**	0.43**	0.38**		
		N	848	472	419	417	425		
4	‘Use of genetic information by the State’	$r$	1	0.49**	0.52**	0.29**			
		N	473	419	417	425			
5	‘Genetic information in sentencing: form’	$r$	1	0.58**	0.39**				
		N	420	416	420				
6	‘Genetic information in sentencing: length’	$r$	1	0.32**					
		N	418	418					
7	‘Legal system accommodating variability’	$r$	1						
		N	426						

*Note.* Strength of correlations is indicated using a heat map: darker shades correspond to stronger correlations. N = all participants for whom data for the two items were available. Blue and red shades indicate negative and positive correlations, respectively. Some items have been paraphrased for ease of reference. \*Correlation significant at the  $p = 0.05$  level; \*\*Correlation significant at the  $p = 0.01$  level.

The results suggest that people who agree that ‘We should make provisions (legal and policy) to buffer the effects of genetic disadvantage on individuals’ (Item 3), also tend to think that genetic information should be used in determining the form (Item 5) and length (Item 6) of sentencing, that court procedures should be more people friendly (Item 7) and that the State should use genetic information to prevent crime (Item 4).

The Item ‘*Genetic influences on our behaviour means that there is no free will*’ (Item 1) showed weak/negligible correlations with other items. This is likely because many people who did not agree with this statement nevertheless think that genetic effects are relevant to behaviour. There may also be some overlap between ‘somewhat agree’ and ‘somewhat disagree’ responses. Another item that was only weakly (and negatively) correlated to other items is: ‘*In the same way as there is socio-economic disadvantage, there is genetic disadvantage*’ (Item 2). This may be because of some ambiguity of the statement, as many people may agree that there are both types of disadvantage, but disagree that they are of the same weight in effect. Interestingly, this item showed the strongest negative correlations (-0.29 and -0.25, respectively) with the *State using genetic information* (Item 4) and *genetic information affecting the length of punishment* (Item 6). This might mean that some of the participants who believe that there is genetic disadvantage worry that using genetic information can exacerbate injustice, for example, through gene-based state surveillance or a longer prison sentence.

## Overall conclusions

The results of the *Genetic Literacy* study and the two *Genetic Views* studies reported in this part of the thesis highlight the need for training of key stakeholders. As it stands, their genetic knowledge is uneven and not sufficient for ‘judging in the genomic era’. It is primarily poor for items requiring more than general reasoning, and so particularly for the post-genome sequencing findings. Moreover, participants’ confidence in their genetic knowledge is a poor predictor of their actual knowledge. Judges overall showed stronger agreement (less variability in views) than other lawyers and non-lawyers on how genetic information should be used and by whom, including on controversial matters. Consensus on controversial issues may not be desirable at this stage, particularly given that genetic literacy remains low. The results indicate that training of stakeholders is a crucial step towards becoming ready for the current era – especially considering the gravity of potential harm associated with low genetic literacy among the judiciary. Judges themselves acknowledged the need for such training. In addition, much more societal discussion and debate are needed on many genetics-related issues. These would have the effect of increased interest in knowledge in this area and would bring different perspectives on the issues.

In relation to when and how societies should adapt to the Genomic Era, the results highlight that, an update to the key mediator – regulation (laws) – is urgently required; and that genetic knowledge, especially among the key stakeholders, is essential for a positive and effective mediation of impact of genetic advances on society.

In relation to criminal justice, the results confirmed the expected wide variability in people’s (including lawyers’) views: the whole scale of responses was used by the participants for each of the eight items. Overall views are that there is genetic disadvantage; that we should make provisions (legal and policy) to buffer the effects of genetic disadvantage on individuals; that the State should use genetic information for crime prevention; that genetic information should be taken into account in deciding the form but not length of sentence; and that, to provide justice, the legal system should accommodate the wide variability among people. The research also suggested that erroneous views on heritability and malleability of traits may interfere with justice, for example, if they affect decisions with regards to blame, immutability or risk of recidivism (the tendency to reoffend).

# Part III

## Synthesis and future directions

Parts I and II of this thesis evaluated societies' readiness for the current Genomic era. Part I reviewed recent genetic advances, the powers afforded by these advances and associated benefits and risks for individuals and societies. Part II considered the main mediators and moderators between genetic advances and their outcomes: people's genetic literacy and attitudes. A particular focus of the thesis is on genetic literacy and attitudes of the key stakeholders in the regulation of genetic applications – judges and other lawyers.

This final part presents conclusions drawn from the 5 Publications synthesised in this thesis and provides suggestions for interventions designed to raise genetic literacy of the key stakeholders. This part also summarises limitations of the conducted research and outlines directions for further research and collaborations.

### Societies are not ready for the Genomic Era

One of the key elements of readiness, a genetically literate society, has not yet emerged. A genetically literate society is more likely to enable a balanced regulation in this area. However, achieving genetic literacy in society in itself depends on regulation, such as deciding to include genomics in school and degree curricular. Therefore, regulation is currently the most feasible way to get ready for the Genomic Era. Developing such regulation is not possible unless the key stakeholders involved in the process, such as judges and lawyers, have the required genetic literacy, as well as realistic attitudes of applications of advances.

The two review studies in this thesis (Publications 1 and 2) analysed what living in the Genomic Era means; reviewed the challenges for human rights, equality and wellbeing brought by genetic advances; and showed that the laws and societal structures in place cannot sufficiently protect well-established fundamental rights, such as non-discrimination. The reviews also informed on how the societal structures we create, can interact with our DNA to change genetic effects on traits at a group or population level.

The results from the three empirical studies (Publications 3, 4 and 5) showed that we are not ready for the Genomic Era. For example, key stakeholders lack the genetic knowledge required to build effective regulation. The research showed that judges and other lawyers have striking gaps in their understanding of key genetic concepts. For example, fewer than 40% of the judges knew the main function of genes; what a genome is; and how much of the total DNA is the same in two people selected at random.

The results also showed an interesting pattern of key stakeholders' attitudes towards applications of genetic advances. Almost all judges agreed with using gene editing to improve traits; as well as with the State using genetic information for crime prevention. On the other hand, they were against the use of genetic advances in other areas, such as for health insurance and for selection in employment and education. All judges opted for allowing the patenting of

genetic findings by companies, even though it would reduce accessibility of genetic advances. Although judges, lawyers and non-lawyers see the potential for genetic science to improve people's lives, and show awareness of problems, judges, compared to the other groups, focused more on the benefits that can be gained from genetic science rather than on potential societal risks of genetics applications.

Judges overall showed greater consensus than other lawyers and non-lawyers on how genetic information should be used and by whom, including on controversial matters (e.g. gene editing). At this stage when genetic knowledge is patchy, such high consensus on controversial issues may be premature.

An important finding of the research reported in this thesis is that judges and lawyers showed an awareness of insufficient regulation in this field, and endorsed the urgent need for updating laws. Another important finding is that all judges see a need for training on genetics-related matters.

The research reported in this thesis has a number of limitations. First, judges' opinions were explored only in a civil law jurisdiction (within a legal system based on Roman law). Similar research is needed in jurisdictions with common law systems (e.g. the UK, the US and Australia) to assess whether the current results apply there. For example, the need for updating laws may be more pressing in civil law jurisdictions. This is because, in these jurisdictions all laws are codified and therefore new issues, not covered by legislation, cannot be reliably resolved. On the other hand, the need to update laws may be greater in common law countries, such as UK and the US. In these jurisdictions, in addition to the codified statutes, laws can also be developed by judges (judge-made law), allowing for one individual's views to have a strong impact on society.

Second, attitudes towards controversial issues, such as gene editing, may vary as a function of cultural norms, religious beliefs, the availability of information and other factors. Therefore, it remains to be tested to what extent the opinions on these matters of legal professionals in one country can inform those in other countries. However, the results of participants in Romania were overall similar to those from the large international sample reported in this thesis, and to the results from other samples reported in previous research – suggesting a broader generalisability of the findings.

Third, some items were only presented to law professionals and law students. Future studies need to explore whether lawyers and non-lawyers differ in their considerations of applications of genetic information in the justice system. The available results suggest some differences between law professionals and non-lawyers in variability and average endorsement for many of the issues.

More research is needed to gain a good understanding of genetic literacy and attitudes in different socio-demographic groups, including in groups stratified by education, age and generation, culture and occupation. The majority of participants in the studies reported here indicated that they completed or were working towards university degree-level qualifications.

Further insight is also needed into people's views on the aetiology of behaviour and on whether and how aetiological information should be used in court. The limited research available suggests that people hold diverging views on the implications of genetics to the concepts of free

will, fairness and sentencing (Farahany and Coleman 2006; Gold and Appelbaum 2014; Morse 2011).

## Efforts Towards Genomic Era Readiness

The studies included in this thesis provide a direction as to the most effective steps towards increased readiness. These include: 1) targeted interventions, such as developing the genetic literacy of key stakeholders ; 2) legislation amendments; and 3) updating societal structures.

### Training of stakeholders

Unlike most fundamental rights, such as right to life and freedom from torture, any decision-making on genetic information requires a substantial degree of technical expertise. This includes knowledge about the pleiotropic nature of genes; polyfactorial nature of traits; and factors affecting epigenetic regulation. Genetic literacy of key stakeholders, such as judges and policymakers, is a prerequisite to successful adaptation to the Genomic Era.

The results presented in this thesis demonstrate that, without specific training, even most highly educated people – including those at the top of their profession in law – lack much of the essential genetic knowledge. This is of course expected, as genetic science is rapidly developing and we are amassing vast amounts of complex and continuously updated information. Genetic literacy is not gainable by unstructured learning, such as through media, headlines, or TV programmes. In fact, relying on genetic knowledge from such sources can be harmful. For example, headlines, such as ‘Two genes linked with violent crime’ (BBC 2014), can cause damage through presenting a deterministic view of such traits.

The studies in this thesis identified specific weaknesses in judges’ knowledge, and this information can be used for designing training programmes. The 100% endorsement by the judges of the need for gene-environment training attests to their recognition of the importance of such knowledge. As a priority, as part of professional development programmes, such training should be made available to 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; as well as the judiciary, lawyers and educationalists. By considering this training a priority, bodies responsible for the professional development of key stakeholders, will make a positive difference for millions of people and society in general. Improved genetic literacy of judges and other lawyers would also enable meaningful professional and public discussions. In the longer term, they would also contribute to the narrowing of the huge inequality gap, via pushing for equal access to the benefits of genetic science. It is important that such bodies consider that, due to the complexity of the topic, *usable knowledge of genetic advances and related implications* is unlikely to be achievable in single sessions.

In addition to the proposed professional development training, genetics should be included as part of the curriculum for the training of professionals such as judges, doctors, lawyers, teachers, nurses and psychologists. Introducing such education for key professions would make readiness more realistic. For example, for law professionals, modules on genetics should be taught as part of law degrees. Introducing such education would not only help with developing jurisprudence and laws in this area, but would also have a positive effect on improving decision-making (e.g.

sentencing, considering guilt and considering the reliability of witness statements) and on justice overall. Moreover, including an up-to-date genetics curriculum in the key professionals' training will have a cascading effect, with knowledge reaching children, parents and society at large. Over the past ten years genetics has begun to penetrate University curricula, mostly as specialised modules – in medicine (NHS UK n.d.) and across some social sciences, including degrees in psychology, education, anthropology and economics (Birkbeck University n.d.; Goldsmiths University n.d.; University of York n.d.).

Institutions can also assist with improving genetic knowledge of professionals through cost-free interventions. For example, the Royal Courts and Tribunal Services; School Authorities; and the NHS – can encourage judges, teachers and healthcare professionals to complete anonymised instruments on genetic literacy and opinions which have educational elements. One such instrument is the iGLAS, which, apart from being a research tool, is also an educational resource as it provides correct responses with explanations. The iGLAS, developed with participation of the author of this thesis, is currently available in 9 languages, and has been recognised as having educational impact by educational institutions and professional working groups.

## **Legislation amendments**

Due to the nature of genetic information and technologies, a delayed catching up with regulation will not be effective for controlling harmful applications. For example, decisions related to the predictive use of genetic information can harm individuals throughout their lifetime and across generations. Decisions to edit the germline, could affect society in many ways. For example, a wealthier minority may be able to 'improve' their traits, and the rest of the population may not have this opportunity. Editing the germline may also introduce new effects such as unexpected modifications in non-targeted cells (via pleiotropy). Poorly regulated genetic advances can also lead to growing tension within societies, exacerbating existing inequalities in access to benefits of technological progress (Selita and Kovas 2018). Therefore, societies need to do *everything in their power* to regulate applications of genetic advances before it becomes practically impossible to protect people's rights.

Protecting against large-scale misuses of Genomic Era data/information is difficult to achieve without some compromise on the profitability of the data industry (data processing for commercial gain) and of the legal system. These industries are very large: the data industry is now a primary industry for many advanced economies (see Publication 1); and legal industries are major income generators, for example the UK legal industry is reported to have generated around 32 billion British pounds in 2021 and is forecasted to grow.

Progress towards the Genomic Era readiness would, for example, require that the focus of laws such as GDPR, is on protecting data and privacy rather than on promoting data sharing for a data-driven economy, evident, for example, in the GDPR prohibition of restriction of the free movement of personal data within the European Union (Article 1). Focusing on protecting data and privacy would come at a cost for the data economy, but would also bring major long-term benefits for the society as a whole. Not taking steps of this type would likely increase the tension within societies, further harming social cohesion (e.g. Publication 2 and (County Health Rankings and Roadmaps 2015).

The current scattered (and often inaccessible) protection of rights (Selita 2018b), such as privacy and non-discrimination, would need to be consolidated (rather than adding new legislation to the already immense pool of laws (Law Commission 2018)). The amended legislation must also cover the Genomic Era information and should be made more accessible. Many participants in the studies reported in this thesis strongly agreed that current laws are not sufficient to protect individuals from misuses of genetic data by *selective/private schools (e.g. for admission), insurance companies and employers (e.g. for hiring or firing purposes)*. They also agreed that it is now time to update *data protection and privacy laws; discrimination laws (e.g. those concerning education, health benefits, race); insurance laws; and employment laws*. This would come at some cost to the legal industry in the short term. However, such amendments should bring long term benefits because the industry depends significantly on public trust. If people are not protected from misuses of genetic advances, it is likely that the trust will be reduced, leading to the reduction in the use of the legal services, affecting the size of the industry.

Furthermore, relevant laws need to prevent negative consequences. This will require the introduction of effective penalties in order to minimise data hacks, and fraudulent and negligent data breaches. This can be done by imposing appropriate fines and custodial sentences for genetic data breaches and other data misuses. Imposing imprisonment, instead of only fines, will reduce the significant revenue from fines (e.g. in 2014 alone, the US Department of Justice recovered \$2.3 billion for prosecutions of health care fraud (Gosfield 2015)). However, fines are not effective deterrents, as evident from the existence of “a pervasive and widespread ‘industry’ devoted to the illegal buying and selling of confidential personal information” (ICO 2006), p3. (see also Publication 1 for a summary). Therefore, issuing of custodial sentences for breaches of genetic data is needed.

## Updating Societal Structures

The Genomic Era may lead to restructuring of existing societal provisions, and it is in everyone’s interest that such restructuring is well informed and planned. For example, some areas, such as health care insurance, cannot be properly regulated by simply updating legislation. It is likely not possible to arrange for a fair, fully private, health insurance system, because insurance companies rely on risk assessment and need payments from the healthy to cover the expenses of others.

This means that to protect a large proportion of a population from discrimination, one option is to focus on making social provisions that would render genetic information unusable for harm. For example, instead of preventing insurers from using genetic data, governments will need to either provide health care insurance to all people, without considering any medical and genetic data, for example by covering the costs in part through public funds for those who cannot afford it – as is the case in Netherlands and Switzerland (Furrow et al. 2013). Such options were endorsed by most participants in the research reported in this thesis.

Allowing people, but not private insurers, access to genetic information, will not work. If people have access, so will insurers, because the insurance industry has made its position (e.g. that genetic data are important to them) clear. The situation therefore requires an alternative solution, including in countries with national health-care, where there is a significant gap in access between patients who can pay privately (e.g. with insurance) and those who cannot – even though this access, ironically, is often to the *same* hospitals and professionals. This is the case in the UK, where healthcare is funded mostly through general taxation, but access to care

for those not paying privately has many barriers, including very long waiting times for tests and treatments.

Another societal adaptation is that of creating structures for psychological support to minimise potential harm resulting from what and how genetic testing providers offer to clients (Kovas and Selita 2021c). Genetic testing will almost certainly be used in most areas of life, including personality profiling, intelligence estimation, prediction of academic and occupational success and success in sports and arts. The harms that can result from the related predictions are numerous. For example, research shows that simply receiving genetic information can change people's psychology and physiology (e.g. cardiorespiratory, although it is unclear how long such effects last), with effects of some of these changes being larger than the actual effects of genes (Turnwald et al. 2019).

Informed and planned societal restructuring can only be achieved through combining multidisciplinary expertise. This is because potential uses of genetic information need to be continuously critically examined in a cross-disciplinary framework. Many teams composed of multidisciplinary experts are needed, including members who are trained in all the key fields: genetics, law and societal implications. Examples of such teams include that of the Working Group on Legal, Ethical and Societal Implication of Genetics (LESIG) (TAGC n.d.-a) at The Accessible Genetics Consortium (TAGC n.d.-b); and The Ethical, Legal and Social Implications (ELSI) Research Program (NIH, US n.d.). Due to the scale of implications, Governments should also coordinate this work.

## Final Remarks

Research in genetics has come a long way and has a long way to go. Research on related implications has also progressed, but at a slower rate. The importance of genetic literacy in society has been acknowledged in recent reports, including that by the UK Government Office for Science and that of the Early Intervention Foundation (Asbury et al. 2022; Government Office for Science 2022).

A genetically literate society can better enjoy benefits of genetic advances, including long-term economic benefits – through improved health and educational outcomes; and improved social cohesion – through reducing inequality. For example, increased knowledge in the population can help combat outdated but ingrained views on 'race' and sex, and so help fight discrimination. Increased knowledge can also lead to updating of views on praise and blame and on the freedom of will.

Overall, a desired outcome of the results of the studies reported in this thesis is the promotion of progress towards Genomic Era readiness, including: encouraging the training of judges, lawyers, policymakers, teachers and medical professionals; introducing genetics into educational programmes; and developing policy relevant to this topic. Moreover, as issues related to using genetic information transcend borders and affect all people, these efforts need to become international. The Author (and other members of The Accessible Genetics Consortium) welcomes ideas and proposals for world-wide collaborations.

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<https://doi.org/10.1016/j.gene.2021.145889>

## Appendixes: Publications of the thesis

The following five publication are presented in the same order below.

### **Publication 1: Genes and Human Rights**

Fatos Selita. 2019. Genetic Data Misuse: Risk to Fundamental Human Rights in Developed Economies. *LIJ*, 7 (1). <https://legalissuesjournal.com/10-i13-0119>

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### **Publication 2: Genes and Inequality**

Fatos Selita\* and Yulia Kovas. 2018. Genes and Gini: what heritability means for inequality. *JBS*. 51 (1), 18-47. <https://doi.org/10.1017/S0021932017000645>

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### **Publication 3: Judges' and Lawyers' Genetic Literacy**

Fatos Selita\*, Vanessa Smereczynska, Robert Chapman, Teemu Toivainen and Yulia Kovas. 2020. Judging in the Genomic era: judges' genetic knowledge, confidence and need for training. *European Journal of Human Genetics*. doi: 10.1038/s41431-020-0650-8.

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### **Publication 4: Applying Genetic Information in the Justice System**

Fatos Selita\*, Robert Chapman and Yulia Kovas. 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). doi: 10.3390/bs9120149

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### **Publication 5: Judges' and Lawyers' Views on Applications of Genetics**

Fatos Selita\*, Robert Chapman, Yulia Kovas, Vanessa Smereczynska, Maxim Likhanov and Teemu Toivainen. 2023. Consensus too soon: judges' and lawyers' views on genetic information use. *New Genetics and Society*. doi: 10.1080/14636778.2023.2197583

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