

New Genetics and Society

Critical Studies of Contemporary Biosciences

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/cngs20>

Consensus too soon: judges' and lawyers' views on genetic information use

Fatos Selita, Robert Chapman, Yulia Kovas, Vanessa Smereczynska, Maxim Likhhanov & Teemu Toivainen

To cite this article: Fatos Selita, Robert Chapman, Yulia Kovas, Vanessa Smereczynska, Maxim Likhhanov & Teemu Toivainen (2023) Consensus too soon: judges' and lawyers' views on genetic information use, *New Genetics and Society*, 42:1, e2197583, DOI: [10.1080/14636778.2023.2197583](https://doi.org/10.1080/14636778.2023.2197583)

To link to this article: <https://doi.org/10.1080/14636778.2023.2197583>



© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



[View supplementary material](#)



Published online: 13 Apr 2023.



[Submit your article to this journal](#)



Article views: 22



[View related articles](#)



[View Crossmark data](#)



Consensus too soon: judges' and lawyers' views on genetic information use

Fatos Selita ^{a*}, Robert Chapman ^a, Yulia Kovas ^a,
Vanessa Smereczynska^a, Maxim Likhanov ^b and Teemu Toivainen ^a

^a*Department of Psychology, Goldsmiths University of London, London, UK;* ^b*State Key Laboratory of Cognitive Neuroscience and Learning, Beijing Normal University, Beijing, People's Republic of China*

(Received 28 July 2022; final version received 28 March 2023)

Timely effective regulation of genetic advances presents a challenge for justice systems. We used a 51-item battery to examine views on major genetics-related issues of those at the forefront of regulating this area – Supreme Court judges ($N = 73$). We also compared their views with those of other justice stakeholders ($N = 210$) from the same country (Romania). Judges showed greater endorsement and less variability in views on the use of genetic data and technologies than the other groups. The agreement among the judges was strikingly strong for some controversial issues, including gene editing; patenting of genetic findings; and the State using genetic information for crime prevention. Judges and other lawyers recognized the need for amending the relevant laws. Without appropriate regulation, genetic science has a risk of propelling inequality rather than fulfilling its promise to improve people's lives.

Keywords: Judges' opinions; lawyers' opinions; genomic era laws; genetic data misuse; genetic discrimination; gene editing; gene-base crime prevention

Introduction

We live in an era of increasing applications of genetic information in all spheres of life, including health, prediction of traits, improvement of traits, lifestyle, family planning, ancestry, sports, and marriage. Due to unique features of genetic data, their misuses can harm an individual and their biological relatives throughout life (Selita 2019). A person's genetic code does not change throughout their life. Therefore, once an individual's DNA is sequenced and this sequence is digitally stored, information that can be extracted from this sequence expands continuously. This is because Genome-Wide Association and other studies identify involvement of more and more DNA polymorphisms in different human traits, including risk taking, educational attainment and antisocial behavior (Wertz *et al.* 2018; Lee

*Corresponding author. Email: fatos.selita@gold.ac.uk

et al. 2018; Clifton *et al.* 2018) . Moreover, genetic privacy is difficult to protect because anonymization of data does not prevent reidentification of an individual (see e.g. [Clayton *et al.* 2019; Gymrek *et al.* 2013; Rocher, Hendrickx, and de Montjoye 2019]).

The law mostly lags behind in addressing applications of genetic advancements, such as gene-based selection, prediction and intervention; and gene editing. Some jurisdictions with advanced genetic science have passed genetic-specific laws such as the Genetic Information Non-discrimination Act (GINA) 2008 in the USA; and the Genetic Non-discrimination Act 2017 in Canada. However, even these laws provide only limited protection from misuses of information extracted from sequenced data (Clayton *et al.* 2019; Furrow *et al.* 2013; Karelin, Matsepuro, and Selita 2018; Rothstein 2009; Selita 2020; Hammond 2020; Impact Ethics 2020; Rothstein 2009; Chapman *et al.* 2020). as For example, GINA does not allow employers to seek genetic information from employees, but permit employers to request employees' genetic information for the purposes of voluntary wellness programs – opening the door for potential misuse (Selita 2019; Rothstein 2009). In addition, recent major legislation on data protection, such as the EU's General Data Protection Regulation (GDPR), improve data protection in general, but cannot effectively protect against misuses of genetic data. For example, a recent review identified three key reasons why the GDPR does not provide effective protection of genetic data: (1) it serves two conflicting purposes: making data accessible (e.g. for research), and making data inaccessible (to protect data and privacy); (2) it does not account for the special characteristics of genetic data; and (3) the data protection law is difficult to enforce (Selita 2019).

Until laws are amended, the role of judiciaries in regulating the use of genetic information and application of genetic advances will be manifold. Judges will, for example, preside over cases that involve uses of genetic information. Such cases have already been reported in many countries, including 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). Judges' decisions in such cases will not only affect specific outcomes but will also impact the development of relevant laws. In addition, as judges influence policy development more broadly, their views may influence what societal measures are developed in response to genetic advances.

It is, therefore, important to find out the views of this group of stakeholders, as well as to provide a platform for the judiciary within and between countries to share their views and initiate important discussions. However, very little is known to date about judges' and lawyers' attitudes and views on key areas of genetic applications: genetic testing; gene editing (engineering); and using genetic information for selection (e.g. in education or employment), prediction (e.g. for early interventions, therapy), and crime prevention (e.g. gene based surveillance). In the following sections, we describe these areas, as well as the results of the few available studies.

Genetic testing

Genetic testing, both privately and state-organized, is now becoming increasingly common. 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 many cases, these sequenced data are used beyond the initial purpose of the testing. For example, 50,000 blood samples, collected as part of newborn screening for known genetic mutations in the State of Minnesota, were found to have been shared with private companies and used for research, including new test development (Bearder v. State 2011).

The limited research available on uptake of genetic testing has shown that it varies across contexts. For example, one study in the United States found that only 11% of participants were willing to provide DNA for a research database, when they were not rewarded (Briscoe *et al.* 2020). The same study found that around 50% were willing to donate their DNA for payment. The uptake is relatively high for predictive testing for diseases, especially for preventable conditions. For example, in one study, 39% of Belgian participants were willing to learn about their genetic predisposition to diseases, and almost 50% were interested in getting tested for treatable or preventable diseases (Chokoshvili *et al.* 2017). In another study, 85% of participants in Russia were willing to undergo testing for preventable genetic conditions, or to improve an individual's treatment options (Makeeva *et al.* 2010). The uptake is also quite high for family planning. For example, the study in Belgium found that around 50% of participants were interested in genetic testing as a preconception screening for recessive disorders and around 60% were interested in prenatal genetic screening (Chokoshvili *et al.* 2017). Studies also show that people's willingness to have a genetic test changes as to the level of known familial disease risk (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]). Views of key justice stakeholders – the judiciary – on genetic testing have been largely unexplored.

Gene editing

Gene editing techniques, such as CRISPR-Cas9 (clustered regularly interspaced short palindromic repeat nuclease system), allow a living organism's genome to be altered at precise loci in the DNA sequence (Cai *et al.* 2015; Kang *et al.* 2017; Jinek *et al.* 2012; Whitworth *et al.* 2014; Doudna and Sternberg 2017). These fast-developing technologies have already led to significant developments in medicine and biology, with the first clinical trials on human cells underway in many countries (Cyranoski 2016; Frangoul *et al.* 2021; Gillmore *et al.* 2021; Kang *et al.* 2017; Lu *et al.* 2020; Memi, Ntokou, and Papangeli 2018). Given the potential of gene editing to treat and even eradicate debilitating diseases, research on gene editing is proliferating in many countries (Liang *et al.* 2015).

Currently, 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. A more controversial use of gene editing is editing germline cells (sperm or egg cells; embryos; and reproductive stem cells). Engineering of germline cells can lead to permanent alterations of the human genetic pool, as these gene “edits” can be inherited by children (Knopik *et al.* 2017).

Moreover, gene editing may become widely used in assisted reproductive procedures for “editing” physical and behavioral characteristics of future children at the pre-implantation stage – creating “designer babies” (Nuffield Council on Bioethics 2018). Such possibilities are no longer theoretical, exemplified by a case of gene editing in human embryos in 2018 (Begley 2018; Cohen 2019; Critchley *et al.* 2019; J. Doudna 2019; Regalado 2019a, 2019b).

Views of genetic professionals and scientific bodies point to the likely applications of gene editing in the near future. For example, the latest reports by the UK Nuffield Council on bioethics and the U.S. 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). Recent studies also found that 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). Views among non-experts on this matter are divided, but overall people express greater support for gene editing in cases of debilitating diseases than other applications (Bosley *et al.* 2015; Funk and Hefferon 2018; Gaskell *et al.* 2017; McCaughey *et al.* 2016; Scheufele *et al.* 2017; Weisberg, Badgio, and Chatterjee 2017).

Despite many potential benefits of gene editing, it also presents risks of potentially irreversible damage to an organism, and of changes to the population genetic pool. Many of the long-term consequences of gene editing are currently poorly defined and understood. Moreover, gene editing presents potential risk to society and societal organization, for example through unequal access to the benefits of gene editing, leading to worsening of already wide social disparities.

Many countries have begun to put in place specific gene editing standards, regulations and legislation to limit the use of gene editing and related research, both for somatic and germline cells (Government Office for Science 2022). The WHO’s Expert Advisory Committee reported that regulatory authorities in all countries *should* not allow any further work in this area until gene editing implications have been properly considered (WHO 2021). Fair and effective regulation has been described as a condition for application of gene editing in medical and other contexts (Baltimore *et al.* 2015; National Academy of Sciences *et al.* 2017; Taguchi *et al.* 2019). As the judiciary and other lawyers are key workforces in the process of regulating genetic advances, it is particularly important to explore their views and attitudes on gene editing.

Use of genetic data / information

Beyond editing the genome, genetic information can be used to “engineer” environments, adapting them to individuals’ characteristics. Such “environmental engineering” may become an important mechanism of personalization. In medicine, this includes selecting treatments based on genotypes (Abad *et al.* 2018), and providing more regular checks and prophylactic medicine for people at greater genetic risk. In education, preventative or remedial interventions may be provided to those at genetic risk for learning problems (Selzam *et al.* 2017). In sports, “suitability screening” may be used to advise people – for example, those with high risk of sudden death syndrome, against entering competitive sports. More broadly, genetic information may be used for life design/career planning based on evaluation of genetic potential for success in particular areas (Hill 2009).

Genetic information can further be used to enhance prediction: for health insurance; and selection for specialized schools, competitive sports, jobs, matchmaking, and other areas. Prediction and selection are now a booming industry that relies on such markers of future success as past achievement and behavior, cognitive skills, particular physical build (for sports), and personality characteristics. It is only a matter of time before genetic markers are added to this list. For monogenic traits, prediction is already relatively easy. For polygenic traits (influenced by few or many genes), prediction is getting more precise as genetic science progresses (Lloyd-Jones *et al.* 2019; Selzam *et al.* 2017).

Several recent studies have explored people’s attitudes towards the use of genetic information (Chapman *et al.* 2018; Haga *et al.* 2013; Saastamoinen *et al.* 2020; Selita, Chapman, and Kovas 2019). The results of these studies show 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. It is important to explore whether a similarly wide variety of views exist among the judiciary and other justice stakeholders on the use of genetic information.

Amending relevant laws

Amending laws is generally a long process, where lawyers are key contributors, including in the drafting of Bills and influencing overall regulation. Therefore, judges’ and other lawyers’ views on genetics related issues may influence the laws that are ultimately passed by Congressional or Parliament members.

Moreover, as genetic science is developing at an unprecedented speed, there is a growing risk that the law will lag too far behind and will miss the “sensitive period” for updates. In psychology, a sensitive period is a time in a person’s development when the effects of experience are particularly strong; so that if the relevant experience does not occur during this time, development may be negatively affected (e.g. (Knudsen 2004)). Using this analogy, we

suggest that the “sensitive period” for developing genetics related regulation is the next few years. If it is missed, societies will have to deal with a flood of negative consequences, including judges being faced with deciding cases for which there are no sufficiently developed laws. It is therefore important to evaluate views of key justice stakeholders on the urgency of amending relevant laws.

The present study

The present study addresses four core limitations of the previous research. 1. Low participation rates (e.g. 4% of the judges who were contacted participated in research [Berryessa 2016]). 2. Focus on single or small number of issues, usually asking judges to apply current laws to hypothetical scenarios, rather than judges’ views on how genetics data should be used, or if laws should be updated. 3. Lack of direct comparisons between judges and other groups. Such comparisons are needed to establish the extent to which judges’ and lawyers’ views are representative of the broader population. 4. Focus on Western samples (e.g. US, Germany [Berryessa 2016; Fuss, Dressing, and Briken 2015]). Genetic issues, dilemmas and controversies cannot be confined within one country – they are global and affect all people. There may also be hidden concerns or barriers to amending laws that are jurisdiction-specific, and these can be identified through cross-cultural comparisons. It is therefore important to examine the views of stakeholders in different countries.

The present study uses a targeted data collection, designed to achieve a good participation rate. The study is the first to explore opinions on a comprehensive set of issues. Participants responded to 51 items exploring their opinions and attitudes towards genetics and its applications across different contexts, including genetic testing, gene editing, use of genetic information, and the amending of relevant laws. The study also compares the views of Supreme Court judges with those of other lawyers and non-lawyers from the same jurisdiction.

The study is the first to explore the views of judges on genetics related issues in an Eastern European country (Romania). Romania is a civil law jurisdiction, where 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, in both civil and common law jurisdictions, supreme court judges’ views and attitudes provide an important insight into future directions in the regulation of genetic advances. The Supreme Court of Romania – The High Court of Cassation and Justice – is the highest court in the country, and therefore 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 2022).

Methods

The study was approved by the Goldsmiths Department of Psychology Ethics Committee (PSY10102016). Data were collected via an online survey (iGLAS) using Qualtrics software. Informed consent is imbedded at the beginning of the survey. Participants were provided a link to the study and completed the questionnaire when they wished. Participants could skip any items and discontinue at any time.

Participants

The total sample included 283 participants, and was composed of three groups: Supreme Court judges ($N = 73$); lawyers ($N = 94$); and non-lawyers ($N = 116$). Descriptives for these groups can be found in Table 1.

All participants were educated (attended secondary school) and resided in Romania. Participants had to be at least 18 years of age ($M = 42.08$, $SD = 11.09$) to participate.

Data were collected as part of a large study conducted concurrently in 9 languages, including Romanian. The iGLAS survey (described below) collects extensive demographic information, which allows for exploration of knowledge and attitudes in different groups, stratified for example by country, occupation, and education. The study also uses targeted collection opportunities, such as assessing specific cohorts of students or representative samples of professionals. This approach was taken in the present study, collecting data from a sample of Romanian Supreme Court judges – the highest court 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.

The samples of lawyers and non-lawyers were drawn from the general iGLAS on-line collection taking place over three months at approximately the same time. All participants who identified themselves as educated and resident in Romania were selected and split into two groups: Lawyers (identifying themselves as either lawyers, barristers, or solicitors); and Non-lawyers.

Measures and procedure

The International Genetic Literacy and Attitudes Survey (iGLAS), used to collect the data, is a dynamic instrument which is currently in its 10th edition. This

Table 1. Gender and age descriptives per group.

Group	Male	Female	Undisclosed	Non-binary	Age		
					Mean	SD	Range
Judge	27 (37.0%)	44 (60.3%)	1 (1.4%)	1 (1.4%)	48.50	6.87	34–66
Lawyer	37 (39.4%)	57 (60.6%)	0 (0.0%)	0 (0.0%)	45.23	6.75	21–62
Non-lawyer	38 (32.8%)	77 (66.4%)	1 (0.9%)	0 (0.0%)	35.61	12.57	18–62

instrument was first created and validated in English (Chapman *et al.* 2017), and is adapted to other languages reflecting the international composition and collaboration of the research team. To date, more than 14,000 participants from different countries completed the survey.

iGLAS in Romanian language was created by following the usual translation and back-translation procedure; and was additionally checked by a team of experts and piloted with a small sample of participants. Translation documentation is available from the authors. The survey takes approximately 15–20 min to complete.

This study analyzes 51 items grouped into the following four themes:

1. genetic testing – 25 items, including 16 on Likert scales (SOM Table 1);
2. gene editing – 3 items, all on Likert scales (SOM Table 2);
3. the use of genetic data/information – 12 items, all on Likert scales (SOM Table 3);
4. insufficient regulation and amending of relevant laws – 11 items, including 5 on Likert scales (SOM Table 4).

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 for different analyses as participants could skip any items they did not wish to answer. Data screening was applied – retaining only data from participants with at least 70% completion of the survey.

Response options

36 of the 51 items were presented on 7-point scales, of which 23 items had the following response options: 1 = strongly disagree; 2 = disagree; 3 = somewhat disagree; 4 = neither agree nor disagree; 5 = somewhat agree; 6 = agree; 7 = strongly agree; and 13 items had the response options: 1 = very unlikely; 2 = unlikely; 3 = somewhat unlikely; 4 = undecided; 5 = somewhat likely; 6 = likely; 7 = very likely.

15 of the 51 items had categorical responses, with participants only being able to select one of them. 9 of these were a group of genetic testing concerns, with participants selecting each concern that applied to them (Figure 1).

Analyses

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

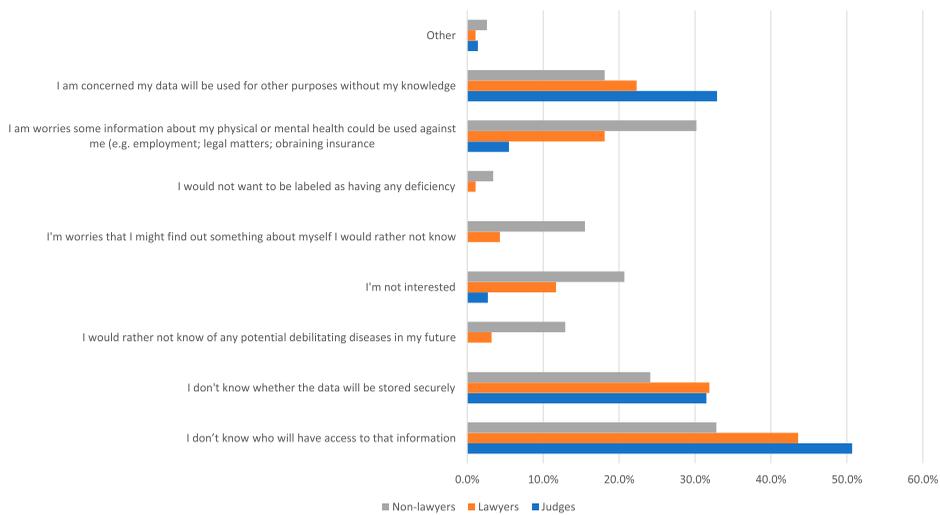


Figure 1. In deciding on whether to take a genetic test, which of the considerations below apply to you? Note. Judges $N = 73$, Lawyers $N = 94$, Non-lawyers $N = 116$. The bars represent the percentages responding “yes, this consideration applies to me.”

on Likert scale = .001). Inferential statistics for comparisons of all groups are available from the authors on request.

Post-hoc data collection

In order to better understand participants’ responses to one of the questions and to inform further research, we conducted a small post-hoc study, approximately one year from the initial data collection (following data analyses). Participants were an opportunistic sample of 5 lawyers and 5 judges in Romania. The participants were provided with the study information and consent information. After consent was given, participants were asked to provide their views on the following item. The session was not audio or video recorded, but detailed notes were made during the session.

The question (Item 31) explored participants’ views on the use of genetic information for crime prevention: “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): Yes/No/I don’t know.” The main analysis (reported below) showed high endorsement of such use. Without further information it is difficult to ascertain what specific measures participants had in mind, in addition or instead of the provided example (surveillance). In the post-hoc study we asked participants to answer this question without providing any examples and invited them to elaborate on specific measures, asking: “What kind of measures did you think the State can take in this context?”

We report the results of the post-hoc study together with the main results for this item. Verbatim transcriptions of the responses are available from the authors.

Results

The judges' participation rate was 91%: out of 80 judges approached, 73 provided full data – capturing almost 70% of all Supreme court judges in Romania.

The results are organized by the four themes. For the items presented to participants on Likert scales, detailed results are reported in SOM in four tables. Each table gives the item description, response options, N of participants, as well as the mean, standard deviation, and frequency responses for each group (Judges, Lawyers, Non-lawyers). Any items where non-lawyers and/or lawyers differed significantly from judges are indicated with an asterisk (*).

To simplify the discussion, in this section we refer to Likert scores of 1–3 as negative endorsement, 4 as a neutral endorsement, and 5–7 as a positive endorsement. Heatmapping has been applied to the frequency responses to aid visual inspection. Cells with darker shading represented higher values.

Genetic testing

Using 25 items we assessed participants' willingness to have their genome sequenced (undergo genetic testing) in different scenarios. In addition, we assessed their concerns and considerations around genetic testing, as well as more general attitudes to using scientific advances for improving people's lives. 16 of these (Items 1–16) were presented on Likert scales and can be found in SOM Table 1. The remaining 9 items are presented in [Figure 1](#) (below).

100% of the judges were willing to undergo genetic testing when it allowed for improved treatment (Item 1). Willingness to undergo genetic testing (Item 2) differed, depending on whether family history of severe disease was absent (no relatives with a particular disease) –48%; moderate (some relatives with a particular disease) –94.5%; or definite (a clear pattern of a particular disease among first- and second-degree relatives) - 98.6%.

A smaller proportion of lawyers and non-lawyers were willing to have their genome sequenced across the scenarios: 90.5% and 68.4%, respectively were willing to undergo genetic testing when it allowed for improved treatment (Item 1); 10.9% and 21.9% if they had *no history* of severe disease in their family (Item 2); 64.1% and 46.1% when *moderate history* (Item 3); 84.1% and 51.6% when a *definite history* (Item 4) of severe disease in their family. The responses ranged from strongly disagree to strongly agree.

Group comparisons showed that the average agreement for genetic testing for treatment and research was significantly higher for judges than for non-lawyers. For family history items, judges were significantly more likely than lawyers and non-lawyers to consider genomic sequencing in all cases.

We then explored participants' willingness to seek to improve wellbeing via different means: genetic testing with a private company; counseling support; advice of a psychic; courses in mindfulness and self-awareness; religious guidance; self-help literature; and alternative medicine (such as homeopathy) – rather than seeking treatment from conventional medicine (Items 5–11). Judges' willingness to seek to improve wellbeing varied across different methods, with 97.2% being willing to seek to improve wellbeing through genetic testing via a private company – similarly high as other methods such as counseling (89.1%), mindfulness and self-awareness courses (98.6%); self-help literature (98.6%); and alternative medicine, such as homeopathy (83.5%). In contrast, none opted for advice from a psychic; and only 4.8% opted for religious guidance.

A lower proportion of lawyers (53.9%) and non-lawyers (42.8%) were willing to seek to improve wellbeing through genetic testing with a private company – with similar proportions opting for counseling support; courses in mindfulness and self-awareness; self-help literature; and alternative medicine. These groups were more likely than judges to opt for advice from a psychic (15.3% of lawyers and 27.8% of non-lawyers); and religious guidance (7.9% of lawyers and 24.5% of non-lawyers).

Group comparisons showed that for 5 out of 6 measures, the average endorsement of judges was significantly greater than that of lawyers and non-lawyers. For religious guidance, judges and lawyers differed significantly from non-lawyers but not from each other.

We further evaluated participants' views on genetic testing for research. 100% of the judges were willing to donate DNA for research (Item 12), despite the fact that 93.2% also expressed that they do not trust research institutions as they may misuse participants' genetic data (Item 14). Fewer lawyers (83%) and non-lawyers (63.1%) than judges were willing to donate DNA for research, despite the fact that their trust in research institutions was greater than that of the judges'. 70.3% of lawyers and 47.8% of non-lawyers thought that research institutions may misuse participants' genetic data.

Scientific development was viewed as essential for improving people's lives (Item 13) by the majority of participants in each group: judges (100%), lawyers (96.8%), and non-lawyers (88.7%).

We also tested participants' concerns (Items 15-16) associated with genetic testing. Across the three groups – judges, lawyers and non-lawyers – 15%, 26.6%, and 28%, respectively thought that establishing genetic influences on mental health problems increases stigma for people with conditions such as depression, schizophrenia, and bi-polar disorder; and 4.1%, 22.6%, and 43%, respectively felt suspicious about there being hidden political/economic agenda behind genetic studies. For these items we saw the whole range of variability in responses: substantial proportions of participants agreeing and disagreeing.

Additionally, we explored what participants consider relevant when deciding whether to take a genetic test (see [Figure 1](#)). Participants could select none, some or all of 9 considerations. The top three concerns across all three groups were not knowing who will have access to their genetic information; that data would not be stored securely; and that data would be used for other purposes without their permission. The results also showed some group differences in the pattern of responses. More non-lawyers (12.9%) than lawyers (3.2%) and judges (0%) worried about knowing something about themselves they would rather not know. The pattern was similar for two other concerns: 30.2% of non-lawyers, 18.1% of lawyers and 5.5% of judges worried that information about their physical or mental health could be used against them (e.g. employment; legal matters; obtaining insurance); and 12.9% of non-lawyers, 3.2% of lawyers and 0% of judges worried about learning of a potential future debilitating disease. Very few ($N = 5$) participants chose the “other” option and none offered any further information when prompted as part of the survey.

We further created a variable – “overall worry” in relation to genetic testing, based on the number of endorsed worries. Out of the 9 response options, 2 were excluded (“I am not interested” and “other”). The resulting variable ranged between 0 and 7 – indicating how many worries each participant endorsed. 15.2% of all participants reported no concerns. Three quarters (74.9%) reported 1 or 2 concerns. 9.9% reported between 3 and 6 concerns. No participants selected all 7 options. No significant differences in the mean “overall worry” scores were found between judges ($M = 1.21$, $SD = 0.55$), lawyers ($M = 1.24$, $SD = 0.85$) and non-lawyers ($M = 1.37$, $SD = 1.43$).

Gene editing

Using three items, we assessed participants’ views on whether societies should use gene editing in healthcare and to improve themselves and their children; and on safety of consuming genetically modified (GMO) food (Items 17-19). The three items were presented on Likert scales (see SOM Table 2).

Almost all of the judges (98.6%, only one judge undecided) agreed with using genetic manipulation/gene editing for prevention and treatment of disease; and that people should be allowed to opt for gene editing in order to improve themselves/their children. The range of responses was greater for the other two groups: 89.4% of lawyers and 72.1% of non-lawyers agreed with gene editing for prevention and treatment of disease; and 85.1% of lawyers and 56.1% of non-lawyers agreed with use of gene editing to improve oneself/one’s children. The average endorsement was significantly greater for judges than for the other two groups.

In contrast, none of the judges agreed that it is perfectly safe to consume genetically modified (GMO) food. Variability in responses was greater for lawyers and non-lawyers, but the means were similarly low for all three groups (around 2.5).

Use of genetic data / information

12 items assessed participants' views on the use of genetic data in different life aspects (Items 22-31, SOM Table 3).

We first assessed participants' views on the usefulness of knowledge about genetic and environmental effects for personalizing education (Items 20-21). 100% of the judges agreed that understanding of both genetic and environmental factors can help personalize education. 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.

We then assessed participants' views on whether genetic information should be used to adapt environments to people's needs, for example through individualized health advice (Item 22). 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.

Further, we collected judges' and lawyers' views on whether employers, schools, and insurers should be allowed to use genetic data for hiring, admissions, and issuing of health and/or life insurance respectively. No data on these items were collected from non-lawyers. 84.7% of the judges and 73.4% of the lawyers disagreed with employers being allowed to use genetic data for hiring; 80.6% of the judges and 73.1% of the lawyers disagreed with schools being allowed to use genetic data for admissions; and 83.3% of the judges and 73.4% of the lawyers disagreed with insurance companies being allowed to request genetic data prior to issuing health and/or life insurance. Another item (Item 26) on insurance explicitly stated that the insurance industry would be disadvantaged if people do and insurers do not have access to genetic data. Most judges (84.9%) and lawyers (59.4%) still disagreed with insurance companies having access to genetic data.

We further explored judges' and lawyers' views on how the insurance industry can be organized in the genomic era (Items 27-30). 22.2% of the judges and 23.7% of the lawyers thought governments should provide health insurance to people considering age only; 31.5% and 40.7% – considering medical records, but not genetic data; 50.7% and 59.3% – equally, not considering age, genetic data, medical records or lifestyle; and 58.9% and 53.4% – without consideration of medical records or genetic data (but considering other factors such as lifestyle). Responses regarding all four alternatives were similarly varied for judges and lawyers. Overall, participants preferred that governments provide equal insurance to all people without considering personal data (means 4.3–4.6) over insurance provision based on personal data, including genetics (means 3.2–3.7).

Finally, we assessed judges' and lawyers' views on use of genetic information for crime prevention. 98.6% of the judges and 84.1% of the lawyers thought the

State should use genetic information on propensity for violence for prevention of crime (e.g. through surveillance). The average endorsement of the judges was significantly higher than that of the lawyers. The judges' almost unanimous agreement on this controversial issue was unexpected. We therefore decided to conduct a post-hoc study to obtain further insights. We asked 10 participants (5 judges and 5 lawyers) to complete this item – this time removing the example “e.g. through surveillance” – and to provide free text comments on what specific measures they think the State could take in this context. These results are presented in SOM Table 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: (1) genetic testing by the State violates everyone's privacy and can open the door to total control; (2) that only some of the people who show propensity for violence actually develop criminal behavior; and (3) that social factors outweigh genetics.

Insufficient regulation and amending of relevant laws

11 items assessed participants' views related to amending of laws (9 of these were presented only to lawyers and judges).

We first assessed views on whether the existing laws are sufficient to protect individuals from misuses of genetic data by: (1) selective/private schools (e.g. for admission); (2) insurance companies; and (3) employers (e.g. for hiring or firing purposes). Over 80% of the judges and over 70% of the lawyers thought that (in their country) laws in place do not provide sufficient protection to individuals against misuses of genetic data in all three cases (Items 32-34; SOM Table 4). The average responses to these items did not differ significantly between judges and lawyers.

We further asked judges and lawyers when laws related to genetics should be updated, namely: data protection and privacy laws; discrimination laws (e.g. education, health benefits, race); insurance laws; and employment laws (see Table 2). There was a strong agreement among the judges and lawyers that laws covering all four areas should be updated now (asap). 89% of the judges and 81.4% of the lawyers thought that updating of data protection laws was urgent; and a slightly lower proportions of participants (70–78%) viewed as urgent updating of laws concerning genetic discrimination, insurance, and employment.

Two vignettes explored judges' and lawyers' views on who would be liable for harm resulting from misuses of genetic data. Vignette 1 (see Table 3) described a hypothetical court case for compensation, where untraceable use of genetic data by the insurance provider has made health insurance inaccessible, with serious consequences for the individual. Data had been previously breached by the National Health Service (NHS). 42.5% of judges and 33% of lawyers found the

Table 2. Responses to items about the need to amend relevant laws.

From a DNA sample taken at birth we already can predict, with a degree of probability, future behavior, 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?

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%

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%

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%

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%

Government responsible for not having updated laws in time – when it became apparent that genetic sequencing was becoming a routine – and decided that the Government is to pay compensation for the suffered loss. Around 50% of the judges and lawyers found the NHS responsible for the loss, deciding that the NHS is to pay compensation. Few judges (6.8%) and lawyers (13.8%) thought that compensation should be paid by the insurance company or by no one.

Vignette 2 (see Table 4) described a hypothetical case where employers were headhunting using genetic data they had obtained through untraceable sources.

Table 3. Vignette 1: 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%

The data had been breached prior to the updating of laws which provide greater protection. 63% of the judges and 43.6% of the lawyers found the Government liable for not updating laws in time to prevent genetic data breaches; and 37%

Table 4. Vignette 2: 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%

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.

Further, we asked the judges and lawyers whether genetic findings should be patented, considering that many people contribute data for research, but may not benefit from the findings due to the high costs (Item 35; SOM Table 4). 100% of the judges and 95% of the lawyers endorsed patenting genetic findings by companies.

We also asked judges and lawyers whether, to provide justice, the justice system should accommodate the wide variability among people, including in terms of ability, personality and level of education (Item 36 SOM Table 4). 100% of judges and 96.6% of lawyers agreed that, to provide justice for all, the legal system should accommodate the variability of the population it represents, including in terms of procedure and resources.

Discussion

The study is the most comprehensive and representative to date to investigate opinions of judges on the use of genetic information and application of genetic advances. The study assessed opinions of the judges of the Supreme Court - and compared them with opinions of lawyers and non-lawyers from the same country (Romania). The opinions of the Supreme Court judges are particularly informative as this group consists of some of the most experienced judges. The issues examined in this study are not limited to any one jurisdiction, but are universally pressing.

The results were mostly similar for judges, lawyers and non-lawyers, but some interesting group differences emerged. 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. The judges also tended to show stronger agreement (smaller standard deviation) in all their responses when compared to both lawyers and non-lawyers.

Below we discuss the results for the 4 broad themes explored in this study.

Genetic testing

All of the judges were willing to undergo genetic testing when it allowed for improved treatment. Genetic testing received similar endorsement as counseling, courses in mindfulness and self-awareness, self-help literature and alternative medicine (which may include a range of measures, such as herbal teas and healthy foods). This pattern of results suggests that the judges view genetic testing as one of the elements in a system of wellbeing measures. Other lawyers and non-lawyers were also mostly willing to undergo genetic testing for improved treatment, although their responses were more varied, and the average willingness

was lower. The willingness of lawyers (5.7 out of 7 on a Likert scale) and non-lawyers (5.1) in our study were very similar to those reported in a large international general population sample (5.6) (N~4300; Likhonov *et al.* 2023).

The judges also almost unanimously endorsed genetic testing in the case of definite and clear family history of disease. This strong endorsement stands out from the other two groups and from other unselected samples. Previous research has shown 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 (Chapman *et al.* 2018).

All participants in our study indicated that they would be more likely to have their genome sequenced in the case of *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 (affected relatives having the disease variant of the gene), 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 in cases where no family risks are known, opting for other types of genotyping in other cases.

The judges also showed unanimous willingness to provide a DNA sample (have genetic testing) for research, even though almost all of them expressed concerns about potential misuse of genetic data by institutions. The other two groups showed more variability in willingness to provide DNA for research, with lower average willingness (5.6 for lawyers and 4.7 for non-lawyers) – very similar to that reported in an international general population sample (5.2) (N~4300; Likhonov *et al.* 2023). The willingness of many participants to give DNA for research is consistent with the finding that most participants also viewed science as essential for improving people's lives.

The present study showed that potential benefits of genetic testing seem to outweigh risk considerations, such as data protection. The number of concerns endorsed by participants was low and did not differ between the judges and the other two groups. There were some interesting differences between the judges and the other groups in *what* risks they deemed unimportant. Most of the judges did not select risks of stigmatization, discrimination, and psychological effects of finding out risk information – all important and currently unresolved issues. These concerns were identified by more participants in the other two groups, particularly by non-lawyers. This is consistent with results from an unselected international sample (Likhonov *et al.* 2023) that showed that substantial proportions of participants were concerned about their data being misused and about learning some information regarding their health that they would rather not know.

Previous research has found that genetic information, when incorrectly interpreted, may lead to stigmatization because many people are affected by essentialist biases. These biases include beliefs in immutability (e.g. genetic influences cannot be changed); discreteness (genetic risk is either present or not); inherence and uniformity (e.g. people who share genetic aetiology are similar or essentially the same); invariance (e.g. related behavioral characteristics will always be demonstrated); and informativeness (that knowing a genetic risk has a strong predictive power) (Berryessa 2019). Given these and other biases and low genetic literacy (Chapman *et al.* 2019; Selita *et al.* 2020), genetic information may be used against people, for example if it is viewed immutable in criminal trials. Our 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 2021b).

Gene editing

An unexpectedly high degree of agreement among the judges emerged for the controversial issue of gene editing. Almost all the judges agreed with using genetic manipulation/gene editing for the prevention and treatment of disease. Almost all the judges also agreed that people should be allowed to opt for gene editing so that people can improve themselves or their children. Such strong endorsement of genetic engineering for “improvement” of traits is striking. In fact, endorsement of both items was significantly lower in the other two groups, with a full range of responses observed.

Further research is needed to understand this pattern of responses. For example, it is possible that judges are prepared to endorse genetic 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 own traits and traits of children could be different if these were presented in separate items.

The strong endorsement of gene editing in humans in this study contrasted sharply with the participants’ attitude to GMO. Most participants did not view consuming GMO as safe. This pattern of results is interesting, because much research has demonstrated safety of GMO foods (Bawa and Anilakumar 2013; Gbashi *et al.* 2021; Teferra 2021), whereas long-term consequences of genetically modifying humans are currently unknown. We are conducting further research into sources of such views.

Use of genetic data / information

Overall, participants showed strong support for uses of genetic information in some contexts and low support in other contexts.

Endorsement was high for using genetic information to adapt environments to people's needs, for example through individualized health advice. Such uses of genetics are growing, for example for selecting appropriate medication based on genotypes, or receiving more frequent screening for people at genetic risk for certain conditions (Forgetta *et al.* 2020; Meisel *et al.* 2015; NHS, UK 2017; Thomas *et al.* 2021). However, wide implementation of gene-based advice remains controversial, with many currently unresolved ethical, economic and practical issues (Godard *et al.* 2003). For example, gene-based treatments may be prohibitively expensive, further exacerbating inequalities in access to medical care. An extreme but telling example of this is a \$3.5-million, one-time gene therapy treatment that was recently approved by the US Food and Drug Administration (FDA) (Naddaf 2022). In addition, results of genetic testing are relevant to family members, and it is unresolved whether family members should be informed of the identified risks (Chapman *et al.* 2018). Moreover, as genetic literacy is generally low (Chapman *et al.* 2019), gene-based advice may be incorrectly interpreted which, as discussed above, may trigger a cascade of psychological and behavioral changes that may amount to "self-fulfilling prophecy" (Kovas and Selita 2021a).

Adapting environments to people's needs based on genetic information in non-medical contexts may be even more controversial as it may lead to discrimination. For example, controversies exist in regards to using genetic information of individuals in education, including for tracking and streaming; early diagnostics and prevention of perceptual and learning deficits; and early identification of talent (Larsen, Little, and Byrne 2022).

In our study, most judges and other lawyers disagreed with allowing employers and schools to use people's genetic information. Participants were more supportive of gaining greater understanding of genetic and environmental influences in order to help personalize education. This pattern of responses highlights the great challenge facing education: to use the emergent knowledge about gene-environment processes in ways that provide nuanced personalized support to each learner rather than segregate and stigmatize people (Butterworth and Kovas 2013; Thomas *et al.* 2015).

The judges were almost unanimous in endorsing the State's use of genetic information on propensity for violence for prevention of crime. The lawyers also showed overall endorsement for this use, although their responses were more varied. The example provided to participants was "crime prevention through surveillance." Surveillance based on genetic information would violate human rights. It is therefore surprising to see such a level of endorsement for gene-based surveillance by legal professionals. It is possible that the participants viewed gene-based methods as more reliable than many other controversial methods such as parole decisions based on machine learning algorithms (Larson *et al.* 2016; Shah, Bhagat, and Shah 2021); and keeping records of children from certain ethnic groups in the form of genealogical trees showing blood inter-relationships (so called lineage databases) (Ghosh 2013). However, given the probabilistic nature

of genetic influences, gene-based selection for surveillance would never be precise or reliable.

It is also possible that the participants were not endorsing gene-based surveillance, but had in mind other ways of using genetic information for crime prevention. The results of our post-hoc qualitative study showed that participants endorsed measures such as early identification and implementation of targeted educational interventions, rather than State surveillance. However, such educational interventions, although they appear to benefit individuals and society, can also lead to stigmatization and discrimination from early childhood. Similar issues are posed by mandated psychological interventions and other treatments (e.g. (Hachtel, Vogel, and Huber 2019)).

Contrasting with the high endorsement for gene-based crime prevention, most participants were opposed to insurance companies having access to genetic information, even in circumstances when people themselves have their health-related genetic information. The judges' views could mean that they do not believe that those already disadvantaged with higher genetic risks should be further disadvantaged by having restricted access to healthcare via insurance.

However, this situation may pose risks for the private insurance industry, because it depends on moneys collected from the more healthy (lower health risk) to cover the costs of those less healthy (higher health risks). The situation, where individuals have access to their genetic risks, and private insurers do not (known as anti-selection or adverse selection), is recognized as a threat for the industry (The Economist 2022), although it remains unclear how widespread this problem may become (Pugh 2021). In the light of the high and increasing level of genetic prediction, basing eligibility or premiums on genetic information, is clearly important for private insurers (Chapman *et al.* 2020). 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 issue of insurers' access to predictive genetic information has received much attention - with a range of proposals being put forward since the completion of the human genome project (Rothstein 2009; Furrow *et al.* 2013; Selita 2020; Pugh 2021; Rodriguez-Rincon *et al.* 2022; Chapman *et al.* 2020). To-date, different countries have adopted different rules regarding use of genetic information in health insurance, with some European countries prohibiting taking into account genetic test results to determine the cost of obtaining insurance (Pugh 2021). In other countries, e.g. the UK, limited use of genetic test results is allowed.

In our study we explored participants' views on alternative insurance provision models. Many participants endorsed insurance provision by the State (irrespective of genetic make-up), but opinions were mixed on factors that should be considered in determining insurance premiums. The responses for each option ranged across

the entire scale. For example, 28.8% *strongly* agreed and 13.7% *strongly* disagreed that insurance should be provided equally, not considering age, genetic data, medical records or lifestyle.

Overall, our results highlight that, to prevent harmful applications of genetic information, societies need to take essential precautions. Potential uses of genetic information need to be continuously critically examined in a cross disciplinary framework; and there needs to be open debates 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.

Insufficient regulation and amending of the relevant laws

Most of the judges and lawyers expressed the view that laws in place do not provide sufficient protection from misuses of genetic data by schools, employers, and insurance companies. The majority of the judges and lawyers also agreed that the relevant laws should be updated now (as soon as possible). These views are justified given the high likelihood of misuses and that people cannot protect their genetic data because data breaches are now unpreventable and common (Selita 2020).

The participants also endorsed making the justice system more accessible to accommodate the large variability in population, including through updating dispute resolution procedures and resource allocation. These results are consistent with previous research that also found similar endorsement by lawyers (Selita, Chapman, and Kovas 2019). The views are also in line with the widely exposed inaccessibility to justice for most people (Moorhead *et al.* 2005; Selita 2018; The Lord Chief Justice 2015; Trinder *et al.* 2014).

The results further show that regulation of genetic findings present challenges. For example, the participants' views differed significantly on who was liable for damages caused due to misuse of genetic data – those who had breached the data, those who misused them, or the Government for not having updated laws timely to prevent breaches. In one of the case scenarios, the national health services had breached the data, when data protection laws were not sufficiently effective. These data were then used by insurance providers to determine risk and premiums. Views were split as to who is liable: the NHS being found liable by 48–50%, the government by 33–43% and the insurance company by 7–14%.

The views were similarly divided on who would be liable if employers used genetic information from undisclosed sources for personnel selection: the employers (37–54%), and the government (44–63%). 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 disagreement. 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). It is indisputable that privacy of genetic information cannot be fully protected, as even anonymized genetic data can be used to identify individuals (Gymrek *et al.* 2013). Therefore, the need for developing effective regulation of genetic information use is evident.

Beyond liability issues, another area of concern, that produced interesting results, is patenting of genetic findings. 100% of the judges and lawyers endorsed patenting 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. Indeed, patenting of findings may be inevitable and some battles in this area have been 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, banned by the US Supreme Court in 2013 and then sought to be overturned by law in Congress; and patenting gene based treatments (Andrews, Mehlman, and Rothstein 2015; Kesselheim *et al.* 2013; Ledford 2021; Servick 2019; YourGenome.org 2022).

However, commercial interests should not overshadow the main aims of genetic science - to prevent and cure diseases, and to improve quality of life for all. Genetic discoveries rely on contribution of genetic, medical and lifestyle data from millions of people. Acknowledging this, it should be at the forefront of societal efforts to ensure equal access to benefits of this science. Cross-disciplinary efforts are essential to develop 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 COVID-19 pandemic regarding costs of protective equipment, vaccines, and treatments, profits made by different providers and inequalities in access.

Limitations and conclusions

This study explored the views of participants from a civil law jurisdiction. More research is needed to investigate whether the current results apply to other countries, especially those with common law systems (Hay 2001; Tetley 1999). For example, the need for amending laws may be more pressing in countries with a legal system based on Roman law (civil law jurisdiction). 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 for amending laws may be greater in common law countries. 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.

In addition, attitudes towards controversial issues, such as gene editing, may vary as to cultural norms, religious beliefs, availability of information and other factors. However, there is some indication that the results of this study are broadly

generalizable, as results were similar in a large international general population sample – for the items that were common for the two studies (Likhanov *et al.* 2023). Therefore, opinions on these matters of legal professionals in one jurisdiction can inform those in other countries, regardless of type of legal system in place.

The study showed that judges, lawyers, and non-lawyers see potential in genetic science to improve people's lives, but also show awareness of problems and urgent need for amending laws. Judges, compared to the other groups, focused more on the benefits that can be gained from genetic science than on potential societal risks of genetics applications. They 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. Previous research found that even highly educated people, including judges, have significant gaps in their understanding of key genetic concepts (Selita *et al.* 2020).

As some of the results were particularly surprising (e.g. high endorsement of gene-based crime prevention), we considered a possibility of a framing effect. For example, phrasing of the item as “the state should use this information” rather than “the state should not use this information” may have had some effect. However, another item, using identical phrasing “Insurance companies should be allowed” generated a high degree of disagreement. Overall, it is unlikely that phrasing of the questions could have significantly affected the views of these professionals. In our previous work, we showed no effect of phrasing on how deterministic participants' views of genetics were (Gallop *et al.* 2017). Moreover, the formulations of the questions chosen for this study reflect real world practice, where issues are not uniformly presented.

To conclude, the present study highlights the need for more in-depth research, public discussion, as well as cross-disciplinary assessment of the use and regulation of genetic information. Moreover, as issues related to using genetic information transcend borders and affect all people, these discussions and assessments need to become international.

Availability of data and material

All data are available upon request from the corresponding author (fatos.selita@gold.ac.uk).

Compliance with ethics guidelines

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all participants for being included in the study.

Declarations

We are grateful to all participants for taking time from their busy schedules to complete a lengthy survey and to provide additional comments. Their contribution is invaluable for development of justice in this complex area.

Disclosure statement

No potential conflict of interest was reported by the author(s).

ORCID

Fatos Selita  <http://orcid.org/0000-0003-1843-7908>

Robert Chapman  <http://orcid.org/0000-0002-1696-1514>

Yulia Kovas  <http://orcid.org/0000-0001-9633-6374>

Maxim Likhonov  <http://orcid.org/0000-0001-6003-741X>

Teemu Toivainen  <http://orcid.org/0000-0002-8770-3635>

References

- Abad, A., E. Martínez-Balibrea, J. M. Viéitez, V. Alonso-Orduña, P. García Alfonso, J. L. Manzano, B. Massutí, et al. 2018. "Genotype-Based Selection of Treatment of Patients with Advanced Colorectal Cancer (SETICC): A Pharmacogenetic-Based Randomized Phase II Trial." *Annals of Oncology* 29 (2): 439–444. doi:10.1093/annonc/mdx737.
- Andrews, Lori B., Maxwell J. Mehlman, and Mark A Rothstein, eds. 2015. *Genetics: Ethics, Law and Policy*. 4th ed. West Academic. <https://faculty.westacademic.com/Book/Detail?id = 31475>.
- Armsby, Alyssa J., Yvonne Bombard, Nanibaa' A. Garrison, Bonnie L. Halpern-Felsher, and Kelly E. Ormond. 2019. "Attitudes of Members of Genetics Professional Societies Toward Human Gene Editing." *The CRISPR Journal* 2 (5): 331–339. doi:10.1089/crispr.2019.0020.
- Baltimore, David, Paul Berg, Michael Botchan, Dana Carroll, R. Alta Charo, George Church, Jacob E. Corn, et al. 2015. "A Prudent Path Forward for Genomic Engineering and Germline Gene Modification." *Science* 348 (6230): 36–38. doi:10.1126/science.aab1028.
- Bawa, A. S., and K. R. Anilakumar. 2013. "Genetically Modified Foods: Safety, Risks and Public Concerns—A Review." *Journal of Food Science and Technology* 50 (6): 1035–1046. doi:10.1007/s13197-012-0899-1.
- Bearder v. State. 2011. JUSTIA. Minnesota Supreme Court.
- Begley, Sharon. 2018. "Amid Uproar, Chinese Scientist Defends Creating Gene-Edited Babies." *STAT*, November 28. <https://www.statnews.com/2018/11/28/chinese-scientist-defends-creating-gene-edited-babies/>.
- Berryessa, Colleen M. 2016. "Judges' Views on Evidence of Genetic Contributions to Mental Disorders in Court." *The Journal of Forensic Psychiatry & Psychology* 27 (4): 586–600. doi:10.1080/14789949.2016.1173718.
- Berryessa, Colleen M. 2019. "Judicial Stereotyping Associated with Genetic Essentialist Biases Toward Mental Disorders and Potential Negative Effects on Sentencing." *Law & Society Review* 53 (1): 202–238. doi:10.1111/lasr.12382.
- Bosley, Katrine S., Michael Botchan, Annelien L. Bredenoord, Dana Carroll, R. Alta Charo, Emmanuelle Charpentier, Ron Cohen, et al. 2015, May. "CRISPR Germline Engineering—The Community Speaks." *Nature Biotechnology*. doi:10.1038/nbt.3227.

- Briscoe, Forrest, Ifeoma Ajunwa, Allison Gaddis, and Jennifer McCormick. 2020. "Evolving Public Views on the Value of One's DNA and Expectations for Genomic Database Governance: Results from a National Survey." *PLOS ONE* 15 (3): Public Library of Science: e0229044. doi:10.1371/journal.pone.0229044.
- Brown, Kristen V. 2018. "Dubai Plans to DNA Test All 3 Million of Its Residents." *Gizmodo*. <https://gizmodo.com/dubai-plans-to-dna-test-all-3-million-of-its-residents-1823393276>.
- Butterworth, Brian, and Yulia Kovas. 2013. "Understanding Neurocognitive Developmental Disorders Can Improve Education for All." *Science* 340 (6130): 300–305. doi:10.1126/science.1231022.
- Cai, Yupeng, Li Chen, Xiujie Liu, Shi Sun, Cunxiang Wu, Bingjun Jiang, Tianfu Han, and Wensheng Hou. 2015. "CRISPR/Cas9-Mediated Genome Editing in Soybean Hairy Roots." *PLOS ONE* 10 (8): Public Library of Science: e0136064. doi:10.1371/journal.pone.0136064.
- Carrington, Damian, and Damian Carrington Environment editor. 2022. "UK Government Sued Over "Pie-in-the-Sky" Net-Zero Climate Strategy." *The Guardian*, January 12, sec. Environment. <https://www.theguardian.com/environment/2022/jan/12/net-zero-climate-strategy-uk-government-sued>.
- Catley, Paul, and Lisa Claydon. 2015, July. "The Use of Neuroscientific Evidence in the Courtroom by Those Accused of Criminal Offenses in England and Wales." *Journal of Law and the Biosciences*: lsv025. doi:10.1093/jlb/lsv025.
- Chapman, Robert, Johanna Devereux, Victoria Nanau, Vanessa Smereczynska, Daria Matsepuro, and Fatos Selita. 2018. "To Tell or Not to Tell: The Ethics and Law of Disclosing Health-Related Genetic Information to Family Members." *Psychology in Russia: State of the Art* 11 (4): 68–78. doi:10.11621/pir.2018.0405.
- Chapman, Robert, Maxim Likhonov, Fatos Selita, Emily Smith-Woolley, and Yulia Kovas. 2017. "Genetic Literacy And Attitudes Survey (Iglas): International Population-Wide Assessment Instrument." *The European Proceedings of Social & Behavioural Sciences*, 45–66. doi:10.15405/epsbs.2017.12.6.
- Chapman, Robert, Maxim Likhonov, Fatos Selita, Ilya Zakharov, Emily Smith-Woolley, and Yulia Kovas. 2019. "New Literacy Challenge for the Twenty-First Century: Genetic Knowledge Is Poor Even among Well Educated." *Journal of Community Genetics* 10 (1): 73–84. doi:10.1007/s12687-018-0363-7.
- Chapman, Carolyn Riley, Kripa Sanjay Mehta, Brendan Parent, and Arthur L Caplan. 2020. "Genetic Discrimination: Emerging Ethical Challenges in the Context of Advancing Technology." *Journal of Law and the Biosciences* 7 (1): lsz016. doi:10.1093/jlb/lsz016.
- Chokoshvili, Davit, Carmen Belmans, Roxanne Poncellet, Sofie Sanders, Deborah Vaes, Danya Vears, Sandra Janssens, Isabelle Huys, and Pascal Borry. 2017. "Public Views on Genetics and Genetic Testing: A Survey of the General Public in Belgium." *Genetic Testing and Molecular Biomarkers* 21 (3): 195–201. doi:10.1089/gtmb.2016.0418.
- Clayton, Ellen Wright, Barbara J Evans, James W Hazel, and Mark A Rothstein. 2019. "The Law of Genetic Privacy: Applications, Implications, and Limitations." *Journal of Law and the Biosciences* 6 (1): 1–36. doi:10.1093/jlb/lasz007.
- Clifton, Emma A. D., John R. B. Perry, Fumiaki Imamura, Luca A. Lotta, Soren Brage, Nita G. Forouhi, Simon J. Griffin, Nicholas J. Wareham, Ken K. Ong, and Felix R. Day. 2018. "Genome-Wide Association Study for Risk Taking Propensity Indicates Shared Pathways with Body Mass Index." *Communications Biology* 1 (1): Nature Publishing Group: 1–10. doi:10.1038/s42003-018-0042-6.
- Cohen, Jon. 2019. "The Untold Story of the 'Circle of Trust' Behind the World's First Gene-Edited Babies." August 1. <https://www.science.org/content/article/untold-story-circle-trust-behind-world-s-first-gene-edited-babies>.

- Critchley, Christine, Dianne Nicol, Gordana Bruce, Jarrod Walshe, Tamara Treleaven, and Bernard Tuch. 2019. "Predicting Public Attitudes Toward Gene Editing of Germlines: The Impact of Moral and Hereditary Concern in Human and Animal Applications." *Frontiers in Genetics* 9 (January): 704. doi:10.3389/fgene.2018.00704.
- Cyranoski, David. 2016. "CRISPR Gene-Editing Tested in a Person for the First Time." *Nature* 539 (7630): 479–479. doi:10.1038/nature.2016.20988.
- de Kogel, C. H., and E. J. M. C. Westgeest. 2015, June. "Neuroscientific and Behavioral Genetic Information in Criminal Cases in the Netherlands." *Journal of Law and the Biosciences*: lsv024. doi:10.1093/jlb/lsv024.
- Denno, Deborah W. 2011. "Courts' Increasing Consideration of Behavioral Genetics Evidence in Criminal Cases: Results of a Longitudinal Study." *Michigan State Law Review* 2011: 967–1047. <https://ssrn.com/abstract=20655>.
- Doudna, Jennifer. 2019. "He Jiankui: The 100 Most Influential People of 2019." *TIME*, April 18. <https://time.com/collection/100-most-influential-people-2019/5567707/he-jiankui/>.
- Doudna, Jennifer A., and Samuel H. Sternberg. 2017. *A Crack in Creation: Gene Editing and the Unthinkable Power to Control Evolution*. Boston: Houghton Mifflin Harcourt Publishers.
- The Economist. 2022. "Genetic Testing Threatens the Insurance Industry." Accessed December 15. <https://www.economist.com/finance-and-economics/2017/08/03/genetic-testing-threatens-the-insurance-industry>.
- European e-Justice Portal. 2022. "European E-Justice Portal - National Legislation." Accessed December 14. https://e-justice.europa.eu/6/EN/national_legislation?ROMANIA&member=1.
- Farahany, Nita A. 2015. "Neuroscience and Behavioral Genetics in US Criminal Law: An Empirical Analysis." *Journal of Law and the Biosciences* 2 (3): 485–509. doi:10.1093/jlb/lsv059.
- Forgetta, Vincenzo, Julian Keller-Baruch, Marie Forest, Audrey Durand, Sahir Bhatnagar, John P. Kemp, Maria Nethander, et al. 2020. "Development of a Polygenic Risk Score to Improve Screening for Fracture Risk: A Genetic Risk Prediction Study. Edited by Christelle Nguyen." *PLOS Medicine* 17 (7): e1003152. doi:10.1371/journal.pmed.1003152.
- Forzano, Francesca, Pascal Borry, Anne Cambon-Thomsen, Shirley V. Hodgson, Aad Tibben, Petrus de Vries, Carla van El, and Martina Cornel. 2010. "Italian Appeal Court: A Genetic Predisposition to Commit Murder?" *European Journal of Human Genetics* 18 (5): 519–521. doi:10.1038/ejhg.2010.31.
- Frangoul, Haydar, David Altshuler, M. Domenica Cappellini, Yi-Shan Chen, Jennifer Domm, Brenda K. Eustace, Juergen Foell, et al. 2021. "CRISPR-Cas9 Gene Editing for Sickle Cell Disease and β -Thalassemia." *New England Journal of Medicine* 384 (3): 252–260. doi:10.1056/NEJMoa2031054.
- Funk, Cary, and Meg Hefferon. 2018. "Public Views of Gene Editing for Babies Depend on How It Would Be Used." *Pew Research Center Science & Society*, July. <https://www.pewresearch.org/science/2018/07/26/public-views-of-gene-editing-for-babies-depend-on-how-it-would-be-used/>.
- Furrow, Barry, Thomas Greaney, Sandra Johnson, Timothy J. Stoltzfus, and Robert L. Schwartz. 2013. *Health Law, Cases, Materials and Problems*. 7th ed. West Academic Publishing. <https://faculty.westacademic.com/Book/Detail?id=2028>.
- Fuss, Johannes, Harald Dressing, and Peer Briken. 2015. "Neurogenetic Evidence in the Courtroom: A Randomised Controlled Trial with German Judges." *Journal of Medical Genetics* 52 (11): 730–737. doi:10.1136/jmedgenet-2015-103284.
- Gallo, Lucy, Robert Chapman, Fatos Selita, and Yulia Kovas. 2017. "Effects of Education and Media Framing on Genetic Knowledge and Attitudes." *The European Proceedings of Social & Behavioural Sciences* 33 (13): 121–141. doi:10.15405/epsbs.2017.12.13.

- Gaskell, George, Imre Bard, Agnes Allansdottir, Rui Vieira da Cunha, Peter Eduard, Juergen Hampel, Elisabeth Hildt, et al. 2017. "Public Views on Gene Editing and Its Uses." *Nature Biotechnology* 35 (11): 1021–1023. doi:10.1038/nbt.3958.
- Gbashi, Sefater, Oluwafemi Adebo, Janet Adeyinka Adebisi, Sarem Targuma, Shandry Tebele, Oluwaseun Mary Areo, Bunmi Olopade, Julianah Olayemi Odukoya, and Patrick Njobeh. 2021. "Food Safety, Food Security and Genetically Modified Organisms in Africa: A Current Perspective." *Biotechnology and Genetic Engineering Reviews* 37 (1): 30–63. doi:10.1080/02648725.2021.1940735.
- Ghosh, Palash. 2013. "Swedish Police Keep Secret Files on Roma (Gypsy) People: Fighting Crime Or Ethnic Profiling?" *International Business Times*, December 4. <https://www.ibtimes.com/swedish-police-keep-secret-files-roma-gypsy-people-fighting-crime-or-ethnic-profiling-1495498>.
- Gillmore, Julian D., Ed Gane, Jorg Taubel, Justin Kao, Marianna Fontana, Michael L. Maitland, Jessica Seitzer, et al. 2021. "CRISPR-Cas9 In Vivo Gene Editing for Transthyretin Amyloidosis." *New England Journal of Medicine* 385 (6): 493–502. doi:10.1056/NEJMoa2107454.
- Godard, Béatrice, Leo ten Kate, Gerry Evers-Kiebooms, and Ségolène Aymé. 2003. "Population Genetic Screening Programmes: Principles, Techniques, Practices, and Policies." *European Journal of Human Genetics* 11 (S2): S49–S87. doi:10.1038/sj.ejhg.5201113.
- Government Office for Science. 2022. "Genomics Beyond Health." <https://www.gov.uk/government/publications/genomics-beyond-health>.
- Gymrek, Melissa, Amy L. McGuire, David Golan, Eran Halperin, and Yaniv Erlich. 2013. "Identifying Personal Genomes by Surname Inference." *Science* 339 (6117): 321–324. doi:10.1126/science.1229566.
- Hachtel, Henning, Tobias Vogel, and Christian G. Huber. 2019. "Mandated Treatment and Its Impact on Therapeutic Process and Outcome Factors." *Frontiers in Psychiatry* 10 (April): 219. doi:10.3389/fpsy.2019.00219.
- Haga, Susanne B., William T. Barry, Rachel Mills, Geoffrey S. Ginsburg, Laura Svetkey, Jennifer Sullivan, and Huntington F. Willard. 2013. "Public Knowledge of and Attitudes Toward Genetics and Genetic Testing." *Genetic Testing and Molecular Biomarkers* 17 (4): 327–335. doi:10.1089/gtmb.2012.0350.
- Hammond, Kathleen. 2020. "Unnecessary and Redundant? Evaluating Canada's Genetic Non-Discrimination Act, 2017." *Canadian Bar Review* 98 (3): 480. <https://canlii.ca/t/07h>.
- Hay, P. 2001. "Civil Law." In *International Encyclopedia of the Social & Behavioral Sciences*, 1865–1869. Elsevier. doi:10.1016/B0-08-043076-7/02767-4.
- Hill, Kim. 2009. "Genetic Testing in the Employment Application Process." *Senior Honors Theses & Projects*, January. <https://commons.emich.edu/honors/125>.
- HM Government. 2014. *Concordat and Moratorium on Genetics and Insurance*.
- Impact Ethics. 2020. "Genetic Discrimination: Provincial & Territorial Laws Needed." *Impact Ethics*, December 16. <https://impactethics.ca/2020/12/16/genetic-discrimination-provincial-territorial-laws-needed/>.
- Jinek, M., K. Chylinski, I. Fonfara, M. Hauer, Doudna Ja, and E. Charpentier. 2012. "A Programmable Dual-RNA-Guided DNA Endonuclease in Adaptive Bacterial Immunity." *Science (New York, N.Y.)* 337 (6096): Science. doi:10.1126/science.1225829.
- Kang, Xiang Jin, Chiong Isabella Noelle Caparas, Boon Seng Soh, and Yong Fan. 2017. "Addressing Challenges in the Clinical Applications Associated with CRISPR/Cas9 Technology and Ethical Questions to Prevent Its Misuse." *Protein & Cell* 8 (11): 791–795. doi:10.1007/s13238-017-0477-4.
- Karelin, Dmitry V., Daria Matsepuro, and Fatos Selita. 2018. "Criminal Legal Protection of Genetic Data of the Person: To Statement of a Problem." *Vestnik Tomskogo Gosudarstvennogo Universiteta. Pravo* 29 (September): 79–90. doi:10.17223/22253513/29/7.

- Kesselheim, Aaron S., Robert M. Cook-Deegan, David E. Winickoff, and Michelle M. Mello. 2013. "Gene Patenting—The Supreme Court Finally Speaks." *The New England Journal of Medicine* 369 (9): 869–875. doi:10.1056/NEJMHle1308199.
- Knopik, Valerie S., Jenae M. Neiderhiser, J. C. DeFries, and Robert Plomin. 2017. *Behavioral Genetics*. Seventh ed. New York: Worth Publishers, Macmillan Learning.
- Knudsen, Eric I. 2004. "Sensitive Periods in the Development of the Brain and Behavior." *Journal of Cognitive Neuroscience* 16 (8): 1412–1425. doi:10.1162/0898929042304796.
- Kovas, Yulia, and Fatos Selita. 2021a. *Oedipus Rex in the Genomic Era: Human Behaviour, Law and Society*. Palgrave Macmillan UK. <https://link.springer.com/book/10.1057978-1-349-96048-4>.
- Kovas, Yulia, and Fatos Selita. 2021b. "Prophesied Future and Redefined Past in the Genomic Era." In *Oedipus Rex in the Genomic Era*, edited by Yulia Kovas and Fatos Selita, 73–110. London: Palgrave Macmillan UK. doi:10.1057/978-1-349-96048-4_4.
- Larsen, Sally A., Callie W. Little, and Brian Byrne. 2022, February. "Teaching the Teachers the Genetics of Learning: An Application of the Mixed Blessings Model." *Mind, Brain, and Education: mbe.12315*. doi:10.1111/mbe.12315.
- Larson, Jeff, Surya Mattu, Lauren Kirchner, and Julia Angwin. 2016. "How We Analyzed the COMPAS Recidivism Algorithm." https://www.propublica.org/article/how-we-analyzed-the-compas-recidivism-algorithm?token=EnKCO7S5tur0EVV_U9AOINE-b5icIEOw.
- Ledford, Heidi. 2021. "Inside the Lawsuit That Ended US Gene Patenting." *Nature* 598 (7882): 561–562. doi:10.1038/d41586-021-02905-9.
- Lee, James J., Robbee Wedow, Aysu Okbay, Edward Kong, Omeed Maghizian, Meghan Zacher, Tuan Anh Nguyen-Viet, et al. 2018. "Gene Discovery and Polygenic Prediction from a Genome-Wide Association Study of Educational Attainment in 1.1 Million Individuals." *Nature Genetics* 50 (8): 1112–1121. doi:10.1038/s41588-018-0147-3.
- Liang, Puping, Yanwen Xu, Xiya Zhang, Chenhui Ding, Rui Huang, Zhen Zhang, Jie Lv, et al. 2015. "CRISPR/Cas9-Mediated Gene Editing in Human Triprenuclear Zygotes." *Protein & Cell* 6 (5): 363–372. doi:10.1007/s13238-015-0153-5.
- Likhanov, Maxi, Ilya Zakharov, Adeyemi A. Awofala, Olusegun E. Ogundele, Fatos Selita, Yulia Kovas, and Robert Chapman. 2023. "Attitudes Towards Genetic Testing: The Role of Genetic Literacy, Motivated Cognition, and Socio-demographic Characteristics." In review.
- Lloyd-Jones, Luke R., Jian Zeng, Julia Sidorenko, Loïc Yengo, Gerhard Moser, Kathryn E. Kemper, Huanwei Wang, et al. 2019. "Improved Polygenic Prediction by Bayesian Multiple Regression on Summary Statistics." *Nature Communications* 10 (1): 5086. doi:10.1038/s41467-019-12653-0.
- The Lord Chief Justice. 2015. "The Lord Chief Justice's Report 2015." Judiciary of England and Wales. https://www.judiciary.uk/wp-content/uploads/2016/01/lcj_report_2015-final.pdf.
- Lu, You, Jianxin Xue, Tao Deng, Xiaojuan Zhou, Kun Yu, Lei Deng, Meijuan Huang, et al. 2020. "Safety and Feasibility of CRISPR-Edited T Cells in Patients with Refractory Non-Small-Cell Lung Cancer." *Nature Medicine* 26 (5): 732–740. doi:10.1038/s41591-020-0840-5.
- Makeeva, Oksana A., Valentina V. Markova, Allen D. Roses, and Valery P. Puzyrev. 2010. "An Epidemiologic-Based Survey of Public Attitudes Towards Predictive Genetic Testing in Russia." *Personalized Medicine* 7 (3): 291–300. doi:10.2217/pme.10.23.
- McCaughy, Tristan, Paul G. Sanfilippo, George E.C. Gooden, David M. Budden, Li Fan, Eva Fenwick, Gwyneth Rees, et al. 2016. "A Global Social Media Survey of Attitudes to Human Genome Editing." *Cell Stem Cell* 18 (5): 569–572. doi:10.1016/j.stem.2016.04.011.
- Meisel, Susanne F., Nora Pashayan, Belinda Rahman, Lucy Side, Lindsay Fraser, Sue Gessler, Anne Lancelley, and Jane Wardle. 2015. "Adjusting the Frequency of Mammography Screening on the Basis of Genetic Risk: Attitudes among Women in the UK." *The Breast* 24 (3): 237–241. doi:10.1016/j.breast.2015.02.001.

- Memi, Fani, Aglaia Ntokou, and Irinna Papangeli. 2018. "CRISPR/Cas9 Gene-Editing: Research Technologies, Clinical Applications and Ethical Considerations." *Seminars in Perinatology* 42 (8): 487–500. doi:10.1053/j.semperi.2018.09.003.
- Milne, Richard, Katherine I. Morley, Heidi Howard, Emilia Niemiec, Dianne Nicol, Christine Critchley, Barbara Prainsack, et al. 2019. "Trust in Genomic Data Sharing among Members of the General Public in the UK, USA, Canada and Australia." *Human Genetics* 138 (11): 1237–1246. doi:10.1007/s00439-019-02062-0.
- Moorhead, Richard, Mark Sefton, Great Britain, and Department for Constitutional Affairs. 2005. *Litigants in Person: Unrepresented Litigants in First Instance Proceedings*. London: DCA Research Unit.
- Naddaf, Miryam. 2022, December. "Researchers Welcome \$3.5-Million Haemophilia Gene Therapy — but Questions Remain." *Nature*: d41586-022-04327–7. doi:10.1038/d41586-022-04327-7.
- National Academy of Sciences, Committee on Human Gene Editing: Scientific, Medical, and Ethical Considerations, National Academy of Medicine, and National Academies of Sciences, Engineering, and Medicine. 2017. *Human Genome Editing: Science, Ethics, and Governance*. Washington, D.C.: National Academies Press. doi:10.17226/24623.
- NHS, UK. 2017. "Predictive Genetic Tests for Cancer Risk Genes." *Nhs.Uk*. October 19. <https://www.nhs.uk/conditions/predictive-genetic-tests-cancer/>.
- Nuffield Council on Bioethics. 2018. "Genome Editing and Human Reproduction." <https://www.nuffieldbioethics.org/publications/genome-editing-and-human-reproduction>.
- Pugh, Jonathan. 2021. "Genetic Information, Insurance and a Pluralistic Approach to Justice." *Journal of Medical Ethics* 47 (7): 473–479. doi:10.1136/medethics-2020-106913.
- Regalado, Antonio. 2019a. "The Scientist Who Created CRISPR Babies is on Time's Most-Influential List—but Not in a Good Way." *MIT Technology Review*, April 18. <https://www.technologyreview.com/2019/04/18/239297/the-scientist-who-created-crispr-babies-is-on-times-most-influential-list-but/>.
- Regalado, Antonio. 2019b. "China's CRISPR Babies: Read Exclusive Excerpts from the Unseen Original Research." *MIT Technology Review*, December 3. <https://www.technologyreview.com/2019/12/03/131752/chinas-crispr-babies-read-exclusive-excerpts-he-jiankui-paper/>.
- Rocher, Luc, Julien M. Hendrickx, and Yves-Alexandre de Montjoye. 2019. "Estimating the Success of Re-Identifications in Incomplete Datasets Using Generative Models." *Nature Communications* 10 (1): 3069. doi:10.1038/s41467-019-10933-3.
- Rodriguez-Rincon, Daniela, Sarah Parkinson, Lucy Hocking, Hamish Evans, Emma Hudson, and Katherine I. Morley. 2022. "Assessing the Impact of Developments in Genetic Testing on Insurers' Risk Exposure." *Rand Health Quarterly* 9 (4): 5. PMID: PMC9519094.
- Rothstein, Mark A. 2009. "Gina's Beauty is Only Skin Deep." April. <https://papers.ssrn.com/abstract=1519975>.
- Saastamoinen, Antti, Virva Hyttinen, Mika Kortelainen, Juho Aaltio, Mari Auranen, Emil Ylikallio, Tuula Lönnqvist, et al. 2020. "Attitudes Towards Genetic Testing and Information: Does Parenthood Shape the Views?" *Journal of Community Genetics* 11 (4): 461–473. doi:10.1007/s12687-020-00462-8.
- Scheufele, Dietram A., Michael A. Xenos, Emily L. Howell, Kathleen M. Rose, Dominique Brosard, and Bruce W. Hardy. 2017. "U.S. Attitudes on Human Genome Editing." *Science* 357 (6351): 553–554. doi:10.1126/science.aan3708.
- Selita, Fatos. 2018. "Unrepresented Litigants in Modern Courts – Ordeal by Combat." *Legal Issues Journal* 6 (1): 1–35. <https://legalissuesjournal.com/10-i11-0118/>.
- Selita, Fatos. 2019. "Genetic Data Misuse: Risk to Fundamental Human Rights in Developed Economies." *Legal Issues Journal* 7 (1): 53–95. doi:10.6084/m9.figshare.11423724.
- Selita, Fatos. 2020. "Justice in the Genomic and Digital Era: A "Different World" Requiring "Different Law"." *Legal Issues Journal* 8 (1). <https://legalissuesjournal.com/10-4i15-0120>.

- Selita, Fatos, 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): 149. doi:10.3390/bs9120149.
- Selita, Fatos, Vanessa Smereczynska, Robert Chapman, Teemu Toivainen, and Yulia Kovas. 2020, May. "Judging in the Genomic Era: Judges' Genetic Knowledge, Confidence and Need for Training." *European Journal of Human Genetics*, 1–9. doi:10.1038/s41431-020-0650-8.
- Selzam, S., E. Krapohl, S. von Stumm, P. F. O'Reilly, K. Rimfeld, Y. Kovas, P. S. Dale, J. J. Lee, and R. Plomin. 2017. "Predicting Educational Achievement from DNA." *Molecular Psychiatry* 22 (2): 267–272. doi:10.1038/mp.2016.107.
- Servick, Kelly. 2019, June. "Controversial U.S. Bill Would Lift Supreme Court Ban on Patenting Human Genes." *Science*. doi:10.1126/science.aay2710.
- Shah, Neil, Nandish Bhagat, and Manan Shah. 2021. "Crime Forecasting: A Machine Learning and Computer Vision Approach to Crime Prediction and Prevention." *Visual Computing for Industry, Biomedicine, and Art* 4 (1): 9. doi:10.1186/s42492-021-00075-z.
- Taguchi, Iku, Takahiro Yamada, Rina Akaishi, Issei Imoto, Kenji Kurosawa, Kaname Nakatani, Fumio Nomura, et al. 2019. "Attitudes of Clinical Geneticists and Certified Genetic Counselors to Genome Editing and Its Clinical Applications: A Nation-Wide Questionnaire Survey in Japan." *Journal of Human Genetics* 64 (9): 945–954. doi:10.1038/s10038-019-0635-z.
- Teferra, Tadesse Fikre. 2021. "Should We Still Worry About the Safety of GMO Foods? Why and Why Not? A Review." *Food Science & Nutrition* 9 (9): 5324–5331. doi:10.1002/fsn3.2499.
- Tetley, W. 1999. "Mixed Jurisdictions: Common Law vs Civil Law (Codified and Uncodified) (Part I)." *Uniform Law Review - Revue de Droit Uniforme* 4 (3): 591–618. doi:10.1093/ulr/4.3.591.
- Thomas, Michael, Yulia Kovas, Emma L. Meaburn, and Andrew Tolmie. 2015. "What Can the Study of Genetics Offer to Educators?" *Mind, Brain, and Education* 9 (2): 72–80. doi:10.1111/mbe.12077.
- Thomas, Chloe, Olena Mandrik, Catherine L. Saunders, Deborah Thompson, Sophie Whyte, Simon Griffin, and Juliet A. Usher-Smith. 2021. "The Costs and Benefits of Risk Stratification for Colorectal Cancer Screening Based on Phenotypic and Genetic Risk: A Health Economic Analysis." *Cancer Prevention Research* 14 (8): 811–822. doi:10.1158/1940-6207.CAPR-20-0620.
- Trinder, Liz, Rosemary Hunter, Emma Hitchings, Joanna Miles, Richard Moorhead, Leanne Smith, Mark Sefton, Victoria Hinchly, Kay Bader, and Julia Pearce. 2014. "Litigants in Person in Private Family Law Cases." November. [https://research-information.bristol.ac.uk/en/publications/litigants-in-person-in-private-family-law-cases\(863ec095-bd56-4e1f-9975-d01cdd7a3aed\)/export.html](https://research-information.bristol.ac.uk/en/publications/litigants-in-person-in-private-family-law-cases(863ec095-bd56-4e1f-9975-d01cdd7a3aed)/export.html).
- UK Department of Health. 2022. "Code on Genetic Testing and Insurance: 3-Year Review 2022." Corporate report. UK. <https://www.gov.uk/government/publications/code-on-genetic-testing-and-insurance-3-year-review-2022/code-on-genetic-testing-and-insurance-3-year-review-2022>.
- Weisberg, Steven M., Daniel Badgio, and Anjan Chatterjee. 2017. "A CRISPR New World: Attitudes in the Public Toward Innovations in Human Genetic Modification." *Frontiers in Public Health* 5 (May): 117. doi:10.3389/fpubh.2017.00117.
- Wertz, J., A. Caspi, D. W. Belsky, A. L. Beckley, L. Arseneault, J. C. Barnes, D. L. Corcoran, et al. 2018. "Genetics and Crime: Integrating New Genomic Discoveries into Psychological Research About Antisocial Behavior." *Psychological Science* 29 (5): 791–803. doi:10.1177/0956797617744542.
- Whitworth, Kristin M., Kiho Lee, Joshua A. Benne, Benjamin P. Beaton, Lee D. Spate, Stephanie L. Murphy, Melissa S. Samuel, et al. 2014. "Use of the CRISPR/Cas9 System to Produce Genetically Engineered Pigs from in Vitro-Derived Oocytes and Embryos." *Biology of Reproduction* 91 (3): 78. doi:10.1095/biolreprod.114.121723.

- WHO. 2021. "WHO Expert Panel Paves Way for Strong International Governance on Human Genome Editing." Accessed December 27. <https://www.who.int/news/item/19-03-2019-who-expert-panel-paves-way-for-strong-international-governance-on-human-genome-editing>.
- Yanes, Tatiane, Mary-Anne Young, Bettina Meiser, and Paul A. James. 2020. "Clinical Applications of Polygenic Breast Cancer Risk: A Critical Review and Perspectives of an Emerging Field." *Breast Cancer Research* 22 (1): 21. doi:10.1186/s13058-020-01260-3.
- Yirka, Bob, and Medical Xpress. 2011. "Small Island Nation to Sequence Genome of Entire Population." *Medical Xpress*. <https://medicalxpress.com/news/2011-10-small-island-nation-sequence-genome.html>.
- YourGenome.org. 2022. "Why Was There a Race to Sequence the Human Genome?" *Yourgenome*. Accessed January 8. <https://www.yourgenome.org/stories/why-was-there-a-race-to-sequence-the-human-genome>.