Legal Issues Journal 7(1) 2019, pages 53-95, © The UK Law and Society Association

GENETIC DATA MISUSE: RISK TO FUNDAMENTAL HUMAN RIGHTS IN DEVELOPED ECONOMIES

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Summary. The unprecedented and growing amount of predictive information we can draw from an individual's genetic data poses serious threats to fundamental human rights for a number of reasons. Large-scale whole genome sequencing and data sharing, enabled by technological advancements, are ongoing internationally. The extent of data availability and genetic data being the 'gold mines' of the 21st century has led to large-scale data breaches being regular and unavoidable. The traditional protective measure – anonymisation of data – is ineffective in preventing re-identification of individuals. Moreover, genetic data are useful for more than a generation. Therefore, once information is extracted from genetic data and is in possession of potential misusers, even the discarding of sequenced genomes does not protect individuals from the numerous potential misuses of genetic information. Protection provided by the law is either non-existent or scattered across a number of legislations even in countries with recently updated laws, with fundamental rights being under threat. This threat is particularly imminent in developed economies, as genomic testing is becoming common and genomic medicine a reality. To protect individuals, societies must enact specific laws to regulate existing and anticipated uses of genetic information.

INTRODUCTION

Genomic data present an enormous resource for improving peoples' lives, including health (Green et al., 2011; Manolio et al., 2015), educa-

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tion (Kovas et al., 2015; Kovas, Malykh, & Gaysina, 2016) and justice (Selita, 2018). The value of genomic data is also recognised by the commercial world, such as pharmaceutical, insurance, marketing, and data processing businesses. Moreover, genetic data can become a resource for policing and military (Mehlman and Li, 2014). This makes genomic data amongst the most valuable data sources – the goldmines of today's advanced economies, "exploitable raw materials, which can be put to use for a variety of purposes beyond those for which they were originally collected" (Nuffield Council on Bioethics, 2015), para 9).

The current value of the Genomic data market is difficult to evaluate, but several indicators already suggest that it is high and growing. For example, direct-to-consumer genetic testing market has almost trebled in value in 4 years (Statista, n.d.). Another indicator is the current value of other data. For example, in the EU the value of the data market was more than €285 billion in 2015 and is expected to increase to €739 billion by 2020 (4% of the GDP) (EC, 2014a); and the value of the Internet of Things (objects that connect and exchange data) alone is expected to rise to as much as $11.1 trillion per year in 2025 (Manyika et al., 2015).

Research has begun to address the risks of misusing of genetic data (Botkin et al., 2015; Dedrickson, 2017; Nordberg et al., 2018), such as issues of privacy, including electronic health records (Kulynych and Greely, 2017; Naveed et al., 2014); genetic tests in clinical setting (Heeney, Hawkins, de Vries, Boddington, & Kaye, 2011; Kulynych & Greely, 2017; Naveed et al., 2014); identification of individuals from anonymised data (Gymrek et al., 2013); and data processing and sharing (Heeney et al., 2011).

This paper assesses the existing fundamental rights' protection from misuses of genetic information in developed economies, focusing on the UK, EU, and the USA. Paradoxically, it is in the developed economies that threats to fundamental rights are particularly pertinent because genetic testing is used increasingly in medical settings, for family planning and personal interest (e.g., ancestry testing); and because direct-to-consumer genetic sequencing is increasingly more available. The paper concludes with recommendations for legislative updates and policy changes.

FIVE REASONS WHY THE USE OF GENETIC DATA THREATEN FUNDAMENTAL RIGHTS IN DEVELOPED ECONOMIES

1. Genomic information can be used to predict traits.

The human genome (sequenced DNA) is the text of life, an incredibly long sequence of approximately 3 billion pairs of letters (nucleotides). The sequenced DNA of an individual provides information about present and future traits (e.g. health status, educational performance). The precision of information from sequenced DNA is likely to become far greater than that offered by family history, such as illness or talent running across generations. Family history is not individual-specific and cannot account for genetic differences within families.

It is now well-established that genes play a significant role in most traits (Plomin et al., 2016). For example, a meta-analysis of 17,804 traits from 2,748 publications including 14,558,903 twin pairs showed that across all traits, genes account for an average of 49 % of the differences in traits (Polderman et al., 2015). Another meta-analysis showed that 66 % of individual differences in educational achievement and up to 80 % of differences in intelligence among adults are explained by differences in people's genomes (de Zeeuw et al., 2015; Nature Editorial, 2016; Plomin and Deary, 2015).

Research has also shown that multiple genes contribute to every trait. The effect of each genetic variant is usually minimal, making the linking of genes to traits a slow and expensive process. Despite this, enormous progress has been achieved in recent years. For example, several recent studies have found hundreds of genetic variants linked to educational attainment (e.g., Okbay et al., 2016), aggressive behaviour (Zhang-James et al., 2018); depression (Howard et al., 2018); intelligence (Davies et al., 2018; Hill et al., 2018; Sniekers et al., 2017); and antisocial behaviour (Wertz et al., 2018b). DNA variants already discovered explain significant amounts of variability in traits. For example, 10% of individual differences in exam results at age 16 could be explained by DNA in a UK study (Selzam et al., 2017). This means that the power to diagnose or predict illnesses and other human traits is still quite low, but is continuously increasing. For some rare disorders, genetic variants have been found that present extremely high risk to carriers. For example, carriers of the BRCA1 mutation have around 80 percent risk of developing breast cancer, as opposed to the average 12-18 percent (Mavaddat et al., 2013).

Precision in genetic prediction and diagnosis is likely to grow fast. In 2003 the sequencing of the human genome took ten years of multinational efforts at a cost of 2.7 billion USD (NIH, 2016). Only 12 years later,

this cost dropped to around 4,000 USD; and a few months later, to around 1,500 USD. At the time of writing, a new technology has been announced that completes a standard human whole genome sequencing data analysis in less than 40 minutes (Goyal et al., 2017); and a private company, is currently offering it for 399 USD (Dante Labs, n.d.). Moreover, most whole genome sequencing projects already combine genetic, medical and lifestyle data, creating what is known as geno-phenobanks – a powerful resource for the prediction of traits.

Information obtained from DNA extends beyond specific traits to other life outcomes. For example, genes linked to intellectual potential, are relevant to education, occupation, mental and physical health, longevity, and behavioural problems, including crime (Plomin and Deary, 2015; Wertz et al., 2018b, 2018a). Such predictions can be invaluable for prevention and early interventions, but also present risks for discrimination. The following sections overview these risks in relation to children's rights, employment, surveillance, insurance, and issues of agency and free will.

Children's rights

Children lack the capacity to decide whether to undergo DNA testing. However, this decision has the potential to change the course of their lives and the lives of their children. In developed countries, all newborns undergo a heal prick blood extraction (from the early 1960s in the US (Suter, 2014)), which is analysed for a number of known genetic mutations, with the aim to alleviate or manage serious genetic disorders. Because early diagnosis has immense benefits, newborn screening is forecasted to move towards routine whole-genome sequencing in the near future (Collins, 2014). However, this prospect poses a wealth of unresolved issues. One issue is whether such testing is cost-effective, especially since its clinical utility is currently low, as current understanding of biological pathways underlying many illnesses remains unclear (Friedman et al., 2017).

Another major issue relates to informed consent. Who should have the right to consent to sequencing and what expertise/knowledge should those consenting (e.g., parents, doctors) possess? In relation to genomic data, the general public's ability to evaluate the implications of consenting is limited. Informed consent requires genetic knowledge, which is currently poor even amongst the well-educated (Chapman et al., 2018). Moreover, for consent to be informed, people must have all the information on the possible use of their data, which is usually not the case. For example, the US Department of Health has been found to keep newborns' blood samples collected for genetic screening (3.9 million children tested annually) (Kelly et al., 2016); and have allowed outside or-

ganisations to use these samples for research, without parents' permission (Leagle, 2011).

Another issue is where and how the genotyping information is kept, once DNA has been sequenced. A single genome represents approximately 725 megabytes of data, which will need to be stored (and presumably backed up) and can be used throughout the individual's life and beyond. Who will be responsible for the safety and privacy of these data? Will doctors, parents and individuals themselves hold a copy?

Another major problem is that it is impossible to foresee all the future risks at the time when genetic data are collected (McGuire and Beskow, 2010). For example, parents may make poor decisions based on an incorrect or incomplete understanding of genetic information, such as interpreting probabilistic information as deterministic. They may enrol children in specialised schools or medical programmes, or contribute to 'self-fulfilling prophesies', whereby a belief that some ability or skill is impossible to achieve may lead to avoiding certain activities, changes in people's attitudes and lost motivation and deferred time and effort investment.

Schools can also misapply genetic information due to poor understanding of genetic effects – genetic education having only recently been introduced, and only in health care (NHS UK, n.d.). For example, schools may stream individuals on the basis of potential performance. This raises ethical concerns because it is currently unclear how such streaming will benefit or harm individuals. Some research on existing practices of streaming children based on actual performance suggested that streaming in education disadvantages many students (Bohan, n.d.; Johnston and Wildy, 2016). Cases of discrimination based on a lack of understanding of genetic information have already occurred. For example, a school in California expelled a boy because he has a genetic predisposition to cystic fibrosis (Live Science, 2012).

Genetic information can be used to implement early interventions for potential health or behavioural problems. Research has suggested that interventions are most successful when they start early. For example, intervention for the prevention of persistent offending is recommended to commence in preschool or even prenatally (Tremblay, 2006). However, early interventions based on probabilistic information also present risks.

Employment

The battle for talent is likely to lead to employers using genetic information for headhunting, such as long-term targeted messaging and selecting personnel based on genetic data. This may have both positive and negative consequences. The recruitment process may be simplified and made more reliable than current recruitment processes, widely accepted for being unreliable (Oh et al., 2013; Peck and Levashina, 2017). On the

other hand, as genetic information is probabilistic, genetic employment selection will lead to missed opportunities for both individuals and employers.

There are already concrete plans to use genetic information in employment selection and employee development. For example, recommendations have already been made to the US military to employ genomic technologies to enhance health, readiness, and performance of military personnel and to determine genetic makeup for traits/phenotype of special relevance to military performance, including physical and mental performance; responses to battlefield stress; the ability to tolerate difficult conditions ('The $100 Genome: Implications for the Department of Defence' Report (The MITRE Corporation, 2010)).

State surveillance

State surveillance on the basis of 'family trees' – although unreliable in relation to an individual – is already being practised in a number of countries, with genetic-based databases including 1000s of children too (Reuters, 2013; Stallard, n.d.). In the genomic era, predictive genetic information can be used to identify individuals for surveillance. For example, antisocial behaviour is highly heritable and is linked to many negative life outcomes, including crime (Moffitt, 1993; Viding et al., 2008). Therefore, surveillance of people with a genetic propensity for antisocial behaviour could be deemed a justifiable crime-prevention measure, especially considering decreasing surveillance costs – digital mass surveillance now being wide-spread in developed economies. However, this presents significant risks for people's rights. As behaviours result from both genetic and environmental factors, genetic information will always remain probabilistic. In this context, how much genetic risk will constitute as sufficient to justify pre-emptive measures? Would surveillance be allowed if the risk of an individual committing a crime is 50%, 70% or 90%, or will it be prohibited?

Insurance

Insurance relies on risk assessment, as well as money collected from healthier people covering the costs of people with more health problems. Access to genetic information would enable insurance corporations to assess risk significantly more precisely, allowing for tailoring premiums to risk. Genetic data can be combined with other types of big data, such as phenotypic (lifestyle, habits, mobile phone, email, credit card, and health data) and circumstance/environment data (e.g. postcode, shopping patterns, and other indicators of childhood and adulthood socioeconomic status). Such combined use of data will make the already powerful pre-

diction even more precise, as it taps into complex processes of gene-environment co-action (Barsky and Gaysina, 2016).

The current trend in wealthy economies, including the UK and the US, is decreasing social provisions, with more people turning to private insurance (Barnett and Berchick, 2017; Collinson, 2017). At the same time, the prevalence of many health problems remains high. For example, one in two people suffer from mental health problems at some point in life (OECD, 2014). Depression alone has been reported to account for a large proportion of days off work (12.5 million working days lost due to depression in the UK in 2016/17 (HSE, 2017)); and is predicted to be the number 1 cause of time off work by 2020 (Kessler and Bromet, 2013; Munce et al., 2007; Reddy, 2010). Illnesses are also often undiagnosed. For example, approximately 50% of depression cases are undiagnosed in wealthy countries (Mental Health Foundation, 2016). Information on mental health predisposition of an individual is invaluable for insurers. In the absence of a diagnosis, insurers can use genetic information to estimate risks of developing or having health problems and determine premiums accordingly.

The implications of such use will differ across individuals. For example, those whose genetic code shows propensities for health risks would be affected negatively, whereas those who show a propensity for minimal health risks - positively. Therefore, countries need to develop policies to buffer this inequality.

Influences on decisions and behaviour

Genetic information can be used to influence individuals in many other aspects of life, including their voting decisions; consumer choice; as well as inspiring conflict. This can be done through targeted advertising on different media platforms and by other means. In addition, individuals themselves may seek genetic information about themselves and make decisions based on this information regarding partner choice, family planning and lifestyle (e.g. (BBC, 2015)). This is problematic in the context of inadequate knowledge and misleading information provided by companies, such as 23andme, that provide genetic testing for multifactorial conditions (Tandy-Connor et al., 2018).

2. Everyone will be affected

Benefits of genetic testing, such as prevention of serious diseases, are enormous and may outweigh potential risks associated with using genetic information. In order to benefit from genomic science, people would need to have their genomes sequenced. Genomes of millions of people have already been sequenced as part of ongoing large-scale whole-

genome sequencing projects, including 2 million people's - by Astra-Zeneca (Ledford, 2016); 1 million people – by NIH; 5 million Genomes Project in the UK (Gilchrist, n.d.); and Million Veteran Program (MVP) (Gaziano et al., 2016) (see a detailed list in (Molnár-Gábor et al., 2017).

The number of individuals with sequenced genomes will continue to grow. Existing large genetic data banks, with un-sequenced data, are also growing fast. Some of these contain samples from virtually entire national populations (UNESCO, 2003). State-organised genetic services are growing, such as the Nation-wide Genomic Medicine Service recently rolled out in the UK. Direct to consumer genetic testing services, with online genomic databases, are also growing fast (Mukherjee et al., 2017). These private companies are authorised to provide genetic health risk tests for multifactorial conditions. For example, 23andme has been given such authorisation by the US Food and Drug Agency. Private companies are also accumulating large amounts of genetic information. For example, AncestryDNA has collected over 7 million DNA samples (ancestry.co.uk), and 23andme has collected over 2 million samples (23andme.com).

3. Genetic information privacy cannot be ensured in the genomic era

In recent years, data protection has received significant attention. Much effort is dedicated to finding ways to protect individuals' privacy in the digital information era, and it is becoming clear that full protection of digital information is not possible (see Existing laws section below). Genomic data, which provide detailed information on all traits, pose an even greater threat to privacy than other types of data for the following reasons.

De-identification (anonymisation) of genomic data does not protect privacy

Genetic information is unique to every individual and is detailed enough to re-identify an individual, despite anonymisation (e.g., (Erlich and Narayanan, 2014; Gymrek et al., 2013; Nuffield Council on Bioethics, 2015). For example, it was demonstrated that nearly 50 people (including DNA donors and their relatives) could be re-identified, using the anonymised data from combined dataset from 1000 Genomes project and Y-chromosome databases which included last names (Hayden, 2013). Another research group showed that it is possible to link sequenced data to individuals - using a technique that relies entirely on free, publicly accessible, Internet resources (Gymrek et al., 2013).

Identification is also made easier by other types of big data, such as credit card data (e.g. shopping and travel trends); mobile phone data (e.g.

health and activity apps); and email data. Big data, through data fusion techniques, can lead to 'mosaic effect', whereby datasets that do not include personal identifiers enable a clear picture of who an individual is and what he or she likes (Executive Office of the President, 2014).

Moreover, it is impossible to retrieve, or make private again, or monitor uses of genomic data that were once publicly released (Heeney et al., 2011). Individuals can request that their names and other identifying information are removed from databases, but anonymised data, such as sequenced DNA, remain as part of large-scale anonymised databases.

Data sharing has dramatically increased in recent years

Large-scale data sharing is common. For example, in the EU, in 2013, there were around 3,500 organisations across a broad range of industries that were Safe Harbor-certified for cross-continental data transfer (Mcbride et al., 2013). In the UK, the National Health Service shared medical data of 1.6 million patients with Google, as part of a data-sharing agreement (Fenton, 2016). Petabytes (1 petabyte = 1015 bytes) are shared as part of on-going large-scale genomic data projects, such as the multinational (17 countries) project of the International Cancer Genome Consortium (ICGC) (Stein et al., 2015; The International Cancer Genome Consortium et al., 2010; The UK10K Consortium et al., 2015). Genomic and pharmacogenomic science efforts have become increasingly more global. For example, at the 2014 Global Leaders in Genomic Medicine Summit, a Global Genomic Medicine Collaborative (G2MC) was formed to join efforts in the implementation of genomic medicine in clinical care (G2MC, n.d.). Genomic biobanks are established as national and international common pool resources (Winickoff, 2007).

There is also a policy push for greater data sharing. For example, the EU has plans to make data freely available for research within EU, with researchers encouraged to deposit their datasets into open access repositories (EC, n.d.). The European Commission, emphasising the significant economic value of data, has proposed a number of policy and legislative initiatives to create a common European data space and enable secondary use of existing data (EC, 2018). The EU has also created the European Open Science Cloud (EOSC) so that all researchers in Europe have open access to interdisciplinary data (EC, 2017a). Similarly, in the UK, the Health and Social Care Act 2012 enabled the Health and Social Care Information Centre (HSCIC) to collect and share confidential information from health records via the "care.data" service - for the benefit of research inside and outside the NHS. Within two years (by July 2014), 40 million patients had an electronic summary care record, with doctors, nurses and community pharmacies having access to it by 2018.

Although such data sharing enables faster progress, it makes it more difficult to prevent data breaches; or to calculate and access compensa-

tion for damages caused from breaches (see *Data protection and privacy* section below).

Diverse cloud platforms are becoming increasingly more common

Cloud computing enables exceptionally fast processing. Exabytes (exabyte = quintillion = 1018 bytes) of data can, for example, be moved to Amazon cloud in a matter of weeks (Amazon Web Services, 2016), when only two petabytes (roughly 500,000 DVDs-worth) would take more than 15 months to transfer using a standard university internet (Hon and Millard, 2012; Stein et al., 2015). Cloud computing provides an excellent platform for integration of genetic, clinical and lifestyle data; and allow for researchers to use as much data and space (computers) as needed, and to control them from their own computers, paying only for the computing time (Molnár-Gábor et al., 2017). For these reasons, cloud computing is used increasingly in genomic research projects (Langmead and Nellore, 2018). Examples include the PCAWG international project that involves whole genomes of over 2000 patients with cancer (Campbell et al., 2017; Stein et al., 2015); and the Cancer Genomics Cloud (CGC) of the National Cancer Institute (Lau et al., 2017).

Using cloud technologies for genomic research, however, raises concerns, as it makes it difficult for individuals to locate the origin of data breaches. Moreover, establishing jurisdiction in such data breach disputes is problematic.

Information extracted from genomic data has life-long and increasing value

DNA code does not change over an individual's lifetime. Therefore, once genetic risk for a particular trait (e.g. cancer) is established, that information remains valid throughout the life of the person. Even if the sequencing data are then destroyed, the knowledge already gained can be used to cause harm. Moreover, due to the familial nature of the data (family members are more similar genetically), genetic information can also be used to discriminate relatives, including across generations. For example, in relation to Huntington's disease (HD), if one parent has HD, the child of that parent has a 50% risk of inheriting HD (see (Chapman et al., In Press) for facts on HD). The disease usually develops later in life, but the known parental risk is highly informative for all biological relatives – irrespective of their age. Moreover, risks to individuals stemming from misuse of sequenced data increase in parallel with progress in the understanding of the genomic code. Similar to the gradual and patchy process of extracting meaning from a text written in an unknown ancient language, DNA sequencing is being deciphered gradually, providing new

meanings every day. Therefore, breaches of today can be used to harm individuals during their lifetime.

Large-scale data breaches are common

Over a billion data breaches have been reported to take place annually (Gemalto, 2016; Kessler and Bromet, 2013; Munce et al., 2007; Ponemon Institute, 2017; Reddy, 2010), including hacks to highly secure organisations, such the US Department of Defence (Shanker and Bumiller, 2011). Cyber attacks, which together with hacks make around 47% of breaches (Ponemon Institute, 2017), have increased by as much as 81% in one year; and hacking incidents are reported to have exposed over 200 million identities in one year (Wood et al., 2012). For example, in 2017, the world experienced the WannaCry attack, which affected over 150 countries (Fung, 2017). In the UK, the Information Commission and police have uncovered evidence of "a pervasive and widespread 'industry' devoted to the illegal buying and selling of confidential personal information" (ICO, 2006), p3.

Data breaches in health care are common. For example, in around four years, 1,419 large-scale health data breaches (each affecting at least 500 people) have been reported to the US Department of Health and Human Services (Ornstein, 2015). In the UK, a recent NHS data breach involved around 500,000 medically sensitive documents (results of blood tests, biopsies and cancer and other screening) (Merrick, 2017). In addition, unsanctioned use of data can be viewed as data breaches, even when data are used for research purposes such as that of newborns' blood samples by the US Department of Health.

Lack of compliance in security measures exacerbates the problem of data breaches. For example, only a small proportion of health care providers reported complying with the HIPAA security rule (Having and Davis, 2005; Rinker, 2013). In the EU, a study revealed that the national data protection authorities in 11 (of 27) member states were unable to carry out their tasks due to lack of financial and human resources (Kuner, 2011).

The current situation can be likened to a river spilling over its banks – with streams of precious information on individuals, including highly sensitive genetic information, flowing thorough poorly designed unattended channels. The current laws, which impose only fines, are insufficient to deter big corporations from reckless and deliberate breaches (e.g. (US Department of Justice, 2017, 2012), which make a significant proportion of data breaches (Ponemon Institute, 2017).

4. Genomic editing may redefine our nature

We can now modify the genome of living humans using gene editing methods, including CRISPR (clusters of regularly interspaced short palindromic repeats (Dolgin, 2017). These methods have potential, to cure certain disorders and cancers, including those that have no current treatment options (Nordberg et al., 2018). With a one-time procedure, gene editing can turn a disease-causing mutation into a healthy version of the gene. The new CRISPR editing systems no longer require cutting through the DNA (cutting anything out or putting anything in), but instead rewrite individual genetic bases/letters (A, T, C, G) (Crossley, 2018; Dolgin, 2017). In vitro gene editing trials in humans have been carried out since 2009 (Le Page, 2017; NIH, 2016), including on reproductive cells (Liang et al., 2015). First in vivo gene editing (inside the human body) to successfully treat a disease has been reported in 2017 in the US (Ma et al., 2017). Gene editing has the potential to alleviate suffering of millions of people worldwide affected by over 10,000 identified monogenic inherited disorders (Ma et al., 2017).

It is unlikely that CRISPR method will be applied to most complex polygenic traits, such as intelligence (Liang et al., 2015). The factors that preclude such use include: the complexity of multiple gene systems (polygenicity and epistasis) interacting with multiple environments; pleiotropic effects (one gene influencing many traits); and antagonistic pleiotropy (one gene influencing different traits in different directions – positively, neutrally and negatively) (Cheng et al., 2015). However, CRISPR has surpassed all science fiction predictions, and therefore new understanding may bring new methods of gene editing.

Progress in gene editing also makes it a powerful tool which can be misused, unless properly regulated. Unregulated editing of the human germline (cells that are relevant for reproduction) might create unwanted or harmful inheritable genetic changes, affecting the whole population's genetic pool. In the globalised world, one population's change will spread to other populations. Although unwanted intergenerational changes are reversible in principle, multi-jurisdiction enforcement is unlikely to be possible. Currently, different jurisdictions regulate germline editing differently, with some prohibiting it, some having ambiguous regulation and some allowing it (Araki and Ishii, 2014; Nordberg et al., 2018).

Moreover, if gene editing is ever applied to polygenic traits, this can also lead to injustices. For example, gene enhancement/biohacking is likely to be widely used, including for intelligence, sports performance and defence. Non-genetic bio-enhancement is already widely used. For example, it is reported that the US Department of Defence (DOD) designed and implemented force-wide, mandatory Anthrax Vaccine Immunization Program (AVIP), despite potential side effects and ineffective-

ness against weaponised anthrax on the battlefield (US House of Representatives, 2000). A head of the US Intelligence has compared the power of gene editing with that of a weapon of mass destruction and has warned of risks of its use in creating harmful biological agents or products (Nature Editorial, 2016).

Despite obvious concerns, the rules on allowing gene editing on humans are relaxing. In 2015, when British scientists first sought permission to edit human embryos in vitro – in vivo editing was out of the question (Sample, 2015). Just three years later, in vivo gene editing is becoming a reality. Unless we have a one-government world (advocated by many, including Albert Einstein (Lu, 2016)), it will be increasingly difficult to protect human rights from gene editing misuse.

5. Lawyers and legislators do not have the necessary understanding of genetic information

Unlike most fundamental rights, such as the right to life and freedom from torture, any decision-making on genetic information requires a substantial degree of technical expertise. This includes knowledge about the pleiotropic nature of genes; polyfactorial nature of traits; and factors affecting epigenetic regulation (Plomin et al., 2016). Genetic knowledge, being the literacy of the 21 century, is important for all people (Chapman et al., 2018) and is crucial to lawyers and judges.

Unless complexities of the origins of human traits are accounted for, decisions are likely to be wrong. For example, for any decision involving human behaviour, it is essential to understand that genetic effects can be stronger or weaker in different circumstances. A genetic risk for developing a particular trait (e.g. aggression), may be suppressed in certain environments, but enhanced in other environments, including those outside peoples' control, such as inequality, with potential cross-generational impact (Selita and Kovas, 2018). It is also essential to know that genes contribute to both stability and change of a particular behaviour (Kovas et al., 2007). Genetic knowledge it is also essential to enable progress with updating legislation and policy, to protect people and implement findings. For example, lack of expertise and training programs in genetics is reported to be one of the main barriers to global implementation of genomic medicine worldwide (Manolio et al., 2015). Currently, lawyers have no training in genetics, and their knowledge comes mainly from the media, which often misreports genetic findings (Selita et al., 2015).

CURRENT LEGAL PROTECTION AGAINST MISUSE OF GENETIC DATA/INFORMATION

Most current laws have been drafted at the time when genetic knowledge was much less advanced, and genetic information was far less informative than it is today. Most current legislation, therefore, is not designed to prevent genetic discrimination in the genomic era. This section assesses legal protection of individuals related to data protection/privacy and health insurance discrimination – the two areas with most developed laws in the EU and US jurisdictions. The section also evaluates whether there are sufficient safeguards to minimise breaches; and whether the law provides accessible remedies for losses suffered as a result of breaches or misuses of information.

DATA PROTECTION AND PRIVACY

This section focuses on protection in the EU, where laws in this area are most developed. The *right to protection of data* is recognised as a fundamental right. For example, the General Data Protection Regulation 2016 (GDPR) of the European Union, states in the preamble that "The protection of natural persons in relation to the processing of personal data is a fundamental right". Article 8(1) of the Charter of Fundamental Rights of the European Union (the 'Charter') and Article 16(1) of the Treaty on the Functioning of the European Union (TFEU) provide that "everyone has the right to the protection of personal data concerning him or her." *The right to privacy* is also long recognised as a fundamental right, including in the Universal Declaration of Human Rights 1948 (Article 12), the European Convention of Human Rights 1953 (Article 8) and the European Charter of Fundamental Rights 2000 (Article 7). In relation to genomic data, the two rights are interdependent. The right to privacy cannot exist unless genomic data are protected, and therefore the two rights can be referred to interchangeably.

The recently enacted GDPR, which regulates the processing of personal data, increases penalties and administrative fines for breaches to up to 20 million Euros or 4% of the total annual turnover in the preceding financial year, whichever is higher (Articles 83 and 84). It also includes remedies for non-material damages (Article 82). Individuals can file their complaints through a national data protection authority (Art 71(1) GDPR); and have a right to seek compensation from a data controller or processor for breaches of the Regulation (Art 82 and 79, GDPR). For example, in the UK, until the transitionary time post-Brexit has ended (currently set for 31 December 2019), complaints are to be brought to the

Information Commissioner's Office (ICO) (s 214, DPA 2018). The ICO is to respond within three months of the complaint, either with a decision or with information on the progress. The ICO has investigative powers and may apply to a judge for a warrant to enter and search the premises (s 154, DPA 2018); and may also issue a penalty notice (ss 155-159, DPA 2018) – a civil matter which may be enforced through the civil courts (para 9, Schedule 16, DPA 2018). Three key shortfalls in the relevant law, including the GDPR, are outlined below.

The law on data protection and privacy is a servant of two masters

The GDPR and other data protection and privacy legislations, are passed with the aim to: (1) make data accessible (e.g. for research) and (2) make data inaccessible (protect data and privacy) - favouring the first. This can be seen from considerations by a number of Government bodies, prior to the passing of the law, on the trade-offs between benefits of data accessibility and individuals' privacy – which have tilted towards data accessibility legislative framework (EC, 2017b, 2014b; Executive Office of the President, 2014; HM Government, 2013; US National Intelligence Council, 2012). The GDPR has as one of the three main objectives to prohibit restriction of the free movement of personal data within the Union (Article 1). It also lists a significant number of exceptions, when processing of personal data is to prevail over privacy (Article 9). These include circumstances when processing is "necessary for achieving purposes in the public interest, scientific or historical research purposes" – a test which can be easily satisfied in relation to use of genetic data because they are a vital resource for medical and other research.

The Regulation also allows for data sharing with a third country or organisation which does *not* provide the required adequate safeguard in circumstances when "the requirements in this Regulation relating to transfers subject to appropriate safeguards, including binding corporate rules, and derogations for specific situations are fulfilled" (Recital 107 of the GDPR). The language used allows for significant discretion.

Moreover, Regulations are secondary legislations, while EU Treaties are primary legislation (European Union, web). The GDPR, therefore, needs to be interpreted and applied in conjunction with the Treaties, which favour freedom of research. For example, the Treaty on European Union and the Treaty on the Functioning of the European Union states that the Union "shall promote scientific and technological advance" (Article 3). Similarly, Article 13 of the Charter of Fundamental Rights of the European Union states that "The arts and scientific research shall be free of constraint". Considering there is, in general, a negative correlation between making data accessible and privacy, the legal protection of personal data and privacy is hindered.

Another weakness of the GDPR is that, with regard to the processing of genetic, biometric and health data, it allows Member States to "maintain or introduce further conditions, including limitations" (Article 9) to the GDPR. For example, in the UK, the Data Protection Act 2018 gives the power to the Secretary of State to make provisions, including transitional, transitory, amending and repealing (see Provision 213); and the protection of privacy is limited by a number of legislations. The Health Service (Control of Patient Information) Regulations 2002, require that in England and Wales, data be disclosed without patient consent for purposes, such as: to diagnose risks to public health; recognise trends in such risks; control and prevent the spread of risks; and monitor and manage the delivery, efficacy and safety of immunisation programmes (Article 3(a). Under the 2002 Regulations, as well as under section 251 of NHS Act 2006, the common law duties (e.g. confidentiality) may also be set aside. In addition, the law requires diagnostic laboratories to provide positive diagnostic test results on specified diseases to Public Health England - see (Taylor, 2015). The Health and Social Care (Safety and Quality) Act 2015 has introduced a duty for health and social care providers to share confidential patient information, where they consider the disclosure to be in their patient's best interest (Article 3). Moreover, under the Police and Criminal Evidence Act 1984, a judge may order that the police have access to medical records for the purpose of a criminal investigation. Overall, the power given to States to alter the law creates uncertainty and may interfere with both purposes of the Regulation because it can limit data sharing across jurisdictions and protection of individuals (Molnár-Gábor et al., 2017; Nature Editorial, 2018).

The law does not account for the special characteristics of genetic data

To protect individuals' privacy in the genomic era, the law needs to account for six key characteristics of genetic data. First, individuals are unlikely to know that their data have been breached. As discussed above, genomic data are often stored and shared globally in clouds or other digital platforms, and laws regulating cloud computing have gaps and weaknesses (Robinson, N. et al., 2011). Second, once an individual knows of the breach, it is difficult for them to assess whether they have suffered damage as a result. Damages resulting from the breach depend on the individual's genetic makeup. For example, for a person whose genomic code shows a high propensity for illness or aggression may suffer discrimination, including in insurance and pre-emptive surveillance. On the other hand, a person with a genetic propensity for good health or high intelligence may actually benefit from the breach. Third, a breach of an individual's data has the potential to harm biological family members

(Chapman et al., In Press). The law does not clarify the legal rights of family members. In additions, it does not clarify obligations of data processors and family members towards other family members. For example, should a person or medical centre release genetic risk information to family members?

Fourth, now that genetic data are collected in a range of contexts (e.g. medical, direct to consumer testing, contribution to research, and law enforcement bio-banks), it is impossible for people to determine the origin of the breach of their genomic data. Fifth, it is difficult to assess the extent to which damages originate from genomic data alone or from the linked and cross-analysed additional big data (e.g., medical, lifestyle, etc.). Sixth, damages stemming from genomic data breaches are almost impossible to quantify because they can manifest in different contexts, including in insurance, education, employment and state surveillance; and they can accumulate over the life course of a person, and affect relatives, including future generations.

Data protection and privacy laws are difficult to enforce

To date, there has been minimal enforcement of data protection and privacy laws in the EU, UK and the US (e.g. (EC, 2003; ICO, 2018; Leagle, 2011). Very few of the numerous discovered violations result in penalties (Ornstein, 2015). Moreover, the existing laws do not provide for imprisonment for criminal data breaches (e.g. GDPR; UK DPA 2018). Case law regarding international data flow and data protection has been described as inadequate in the EU and the US (Kulynych and Greely, 2017; Svantesson, 2010), with few successful enforcements (Hon, 2017). The imposed penalties are usually relatively small, even post GDPR. For example, a UK medical centre was fined £35,000 for leaving highly sensitive data of patients in an empty unsecured building for 18 months; and a government enforcement institution was fined £80,000 for sending a bulk email that identified victims of child abuse (ICO, 2018).

Protection of genetic privacy and protection from genetic discrimination also require enforcement of individuals' right to access their personal data processed by data controllers – so that people can know when their data are being misused. This is a well-established right, but it is difficult to enforce. For example, from our independent assessment, different institutions, including UK Law Enforcement Agency/police, and Inns of Court (that admit barristers), deny individuals' requests to access data held on them through imposing conditions which are impossible to satisfy. These conditions include requiring individuals to provide: details of specific information the individual wished to access; details of data to be rectified; and addresses (with evidence) for ten years. Applied to the ge-

netic data, it would be particularly difficult for individuals to specify exactly what data about them is kept by data-controllers.

Enforcement is similarly minimal in relation to transfers of data (e.g. (Hon, 2017)). Currently, for transfers outside the EU, the transferor must ensure that the transferee and its jurisdiction provide an 'adequate level of protection' of data. The minimal enforcement against the 'many unauthorised and possibly illegal transfers' is recognised by European Commissioner (EC) itself (EC, 2003). Similarly, in the US, already over 15 years ago the then US Secretary of Health and Human Services, Donna Shalala, warned that "Every day, our private health information is being shared with fewer safeguards than our video store records." (Andrews, 2001) p. 140. Recognition of the minimal protection, however, takes a long time before it leads to action. For example, it took until 2015 for the European Court of Justice to find invalid EC's decision that the US ensured an adequate level of protection for EU citizens' data (EUR-Lex, 2015). The updated EU-US data transfer guidelines, the EU–US Privacy Shield (EC, 2016), have also been criticised by data protection experts (see (Molnár-Gábor et al., 2017)).

The minimal enforcement may also be supported by the confusing and sometimes surprising interpretation of the law. For example, in the UK, in relation to the ownership of health data, the UK Department of Health states that "it is not the information contained on the records that has an owner, but the paper or files the information is on", and, as a result, "Legal ownership of health records resides with the organisation that owns the paper or database on which the record is stored." (see Government response DE00000700509 at (UK Department of Health, 2012). This is inconsistent with the well-established law regulating medical data. The European Court of Human Rights states that "Personal information relating to a patient undoubtedly belongs to his or her private life." (see for example (ECHR, 2008), para 35); and that "the protection of personal data, not least medical data, is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life"; that respecting the confidentiality of health data "is a vital principle in the legal systems of all the Contracting Parties to the Convention"; that without such protection, "those in need of medical assistance may be deterred from revealing such information …, thereby endangering their own health and, in the case of transmissible diseases, that of the community."; and that the "domestic law must therefore afford appropriate safeguards…" (ECHR, 1997) para 95).

The interpretation of the law has not improved post-GDPR. For example, in a key post-GDPR case, the judges of the UK Court of Appeal showed a strong disagreement in a matter of data protection law that is well-established in Treaties, GDPR and domestic laws (BAILII, 2018). The issue before the Court was that of a patient's access to personal data

processed by public authorities. In the US, the situation is similar. For example, the Department of Health (and two state courts) interpreted the Genetic Privacy Act of Minnesota to allow them to use, store, and disseminate hundreds of thousands of blood samples of newborns without parents' consent and violating the Act – interpretation which the Supreme Court found troubling (Leagle, 2011).

Enforcement is further affected by costs of litigation – identified as a key barrier in general data protection issues in the EU (EU Agency for Fundamental Rights, 2014). The costs in genomic-related litigation are likely to be high, because of the technical nature of genetic information and because it requires the input of multiple experts to assess, prove and quantify damages. This will also deter people from bringing claims on the fear of facing legal costs of the breaching organisation. In a recent UK case, for example, the individual whose distressing health data had been breached due to the medical centre's negligence (who sought removal of this information from records), was ordered to pay the legal costs of the data breaching organisation (Ramesh and Dinsdale, 2013). In relation to genomic data, the controllers are often major corporations, with the resources and motivation to fight legal actions, generally in order to prevent disadvantageous precedent (European Union, 2013).

The lack of protection to privacy and personal data in the current (genomic) era, may lead to a chain reaction of threats to related human rights, including the child's rights and the right to non-discrimination (freedom from discrimination). Although these risks are becoming more and more recognised (Andrews et al., 2015; Kovas and Selita, 2014; Nuffield Council on Bioethics, 2015; Relman, 2010), the relevant legislation might take a long time to be updated (e.g. in around 10 years on average in the UK and the US). In the meantime, immediate action is needed to provide all stakeholders with transparent information as to the degree of protection provided by the law. Currently, misleading promises are given to people, such as the statement by Genomics England addressed to parents of children with cancer (or suspected cancer): "No-one can access the data without asking us first…" (Department of Health, UK, n.d.).

GENETIC DISCRIMINATION

Specific laws protecting against genetic discrimination, with a focus on insurance and employment, have already been passed in some countries. These include the Genetic Information Non-discrimination Act 2008 (GINA) in the US; and the Genetic Non-Discrimination Act 2017 in Canada. Some international instruments, such as the European Convention on Human Rights and Biomedicine 1997 (Biomedicine Convention)

and the Charter of Fundamental Rights of the EU (the Charter), also aim to prevent discrimination on ‘genetic heritage’ (Biomedicine Convention, Article 11) and ‘genetic features’ (the Charter, Article 21). However, the party countries may denounce the Biomedicine Convention at any time (Article 37), and the Charter applies only within the EU. Moreover, the existing laws cover some genetically influenced characteristics but do not deal with the wealth of information that can be extracted from whole genome sequencing data. This section assesses the existing protection against genetic discrimination in health insurance, focusing on the US, as a jurisdiction with one of the earliest and most advanced specific legislations in this area. The section also includes a comparative overview of the protection in the UK.

In the US, protection of individuals from genetic discrimination in health insurance is covered by a number of legislations, including the Employee Retirement Income Security Act 1974 (ERISA); Health Insurance Portability and Accountability Act 1996 (HIPAA); the Affordable Care Act 2009 (ACA); and the Genetic Information Non-discrimination Act 2008 (GINA). A large proportion (55.7%) of privately insured US population (67.5%) are insured through the employment-based group coverage; 37.3 per cent - through government coverage, and the remaining 8.8 % - are uninsured (Barnett and Berchick, 2017).

Group health plans are regulated by HIPAA, which prohibits discrimination on the basis of any health information or considering pre-existing conditions for individual employees moving from one job to another (Edemekong and Haydel, 2018). However, HIPAA allows a group health plan to charge all members of a group higher premiums on the basis of an individual’s genetic information (Congressional Research Service, 2008). This pushes employers to learn about any genetic propensities and conditions of employees and prospective employees. GINA does not allow employers to seek this information from employees, but permits employers to request employees' genetic information for the purposes of voluntary wellness programs – creating a loophole in the law. This directly contradicts the public opinion: before GINA was passed, a poll of 4834 Americans showed that most people were against employers (92%) and health insurers (80%) having access to an individual's genetic information (Baruch and Hudson, 2008). Voluntary wellness programs entail collecting employees' biometric data (e.g. weight, blood pressure, cholesterol levels) and are typically run by third-party companies (US NIH, 2017). Although employees can refuse to give genetic information, the scheme provides benefits for participation (discounts on health insurance) and penalties (insurance cost increase) for non-participation. The conflicting provisions in HIPAA and GINA, lead to people surrendering some of their rights, in order to access benefits and avoid penalties.

Unlike HIPAA and GINA, the ACA, which provides similar protection to groups and individuals, does not allow for coverage to be refused and also prohibits adjustment of premiums on medical conditions and genetic information (included as health information) (Article 1201). The notion of 'actuarial fairness' – premiums based on the estimated likelihood of needing medical care – is also prohibited. However, ACA allows 50% premium enhancement for tobacco use, as well as for geographic area of residence and age (CMS, 2013; Department of Health and Human Services, 2013a) – creating another loophole. For example, geographic locations can be correlated with genetic information, such as higher rates of mutations in BRCA1 and BRCA2 genes, associated with cancer in some populations (Furrow et al., 2013) ch. 16. Behaviours, such as smoking, are also correlated with genetic information (Davies and Soundy, 2009; Loukola et al., 2014). Moreover, insurers are known to use all loopholes to increase profits. For example, in one case insurers deprived the insured of pay for treatment of breast-ovarian carcinoma syndrome on the excuse that it is not an illness, but a genetically based condition (Court Listener, 1994)).

Despite limitations, ACA provides greater protection than the other Acts. However, the ACA has recently suffered some damage from Tax Cuts and Jobs Act of 2017. As a result, from 2019 there will no longer be a penalty for not having health insurance (Edemekong & Haydel, 2018) - the penalty clause that ensures sharing of the costs (with the healthy people also taking health insurance). ACA has faced other threats, including recently proposed amendments that would jeopardise legal protection for millions of people (Alonso-Zaldivar, 2018; California Healthline, 2018; KHN, 2018). Although these have failed so far, (e.g. Kaplan & Sullivan, 2017), the future of ACA remains unclear.

In relation to private insurance outside employment, GINA, which updates ERISA, HIPAA and the Internal Revenue Code, prohibits most health plans from using or disclosing genetic information for underwriting purposes (Department of Health and Human Services, 2013b). GINA, does not, however, prohibit such use for insurance covering life, long-term care, or disability. Moreover, GINA is designed to protect only asymptomatic individuals. This means that if a person develops a condition, the insurance company can refuse to renew the policy at the annual renewal date, and the law allows this in virtually every state (Rothstein, 2009). It is clear from these and other co-existing Acts that the law offers only limited protection of individuals in the US see ("History of EBSA and ERISA" 2016) (and (Furrow et al., 2013) for more information on insurance law in the US).

The situation is similar in the UK, where the Association of British Insurers (ABI) and the Government have entered into an agreement, Concordat and Moratorium on Genetics and Insurance ('Concordat') to:

a) abide by a policy framework for co-operation that provides that insurers' use of genetic information is transparent, fair and subject to regular reviews; and b) remain committed to the voluntary Moratorium on insurers' use of predictive genetic test results until 1 November 2019 (HM Government, 2014), p.1). The Concordat does not prohibit the use of genetic information in health insurance. On the contrary, it emphasises that ABI and the Government agree 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". Moreover, the Concordat has as one of the main aims protecting insurers' right of equal access to information about risks.

Under the Concordat, insurers can ask for genetic test results that confirm diagnoses of ill health. Moreover, the Moratorium only covers tests used to predict future illness. The clause protecting individuals from discrimination on genetic information has no legal power because it is merely a recommendation. It states that 'Insurers should not treat customers who have an adverse predictive genetic test result less favourably than others without justification'. The words 'should' and 'without justification' show that there is no obligation and that a justification would suffice to exonerate liability. Moreover, there are exceptions, including monogenic diseases, late-onset, and of high genetic risk of developing the disorder. The limited protection offered by the Concordat is further reduced by suggesting that applicants may disclose a positive result from a predictive genetic test if they wish the result to be considered in the underwriting decision (p 4). This creates a situation where, if people do not disclose, it may be assumed that they are withholding genetic risk information. Recent legislation on health insurance, the Consumer Insurance (Disclosure and Representations) Act 2012 (CIDRA), does not deal with genetic discrimination.

In practice, if one wishes to obtain health insurance in the UK, it is not clear whether one can keep private genetic information without jeopardising the right to recovering health costs. For example, the multinational insurance corporation AVIVA plc states that they do not cover treatment of any pre-existing condition, or any related conditions if the person applying for health insurance has "symptoms of, diagnostic tests for, medication for, treatment for, or advice about, that condition in the five years before you joined the policy" (AVIVA Plc, 2018). It is unclear whether all genetic risks will be considered in these circumstances as 'pre-existing conditions". Moreover, the law does not clarify the meaning of genetic terms, such as 'genetic condition', 'genetic trait' and 'genetic disease'. Furthermore, if one has their genome sequenced, it is likely that they would seek advice about the results (e.g. a mutation related to health risk). There is also an additional risk of being accused of having knowledge of a pre-existing condition on the basis of having genome se-

quenced, even though the person may not have been given or understood the related health implications. In the 'Full Medical Underwriting' section, in addition to asking about health, AVIVA states that, "if we need to, we may ask your permission to get more details from your doctor". If one denies access, one may be considered to conceal risk information.

These uncertainties are likely to affect millions of people because, whilst currently in the UK there is free health care, the system is gradually changing, increasingly charging for more services (Donnelly, 2018; Smith and Dexter, n.d.). Doctors and nurses have described some of the current charges as a "deliberate cruelty" of the Government (Bulman, 2017). Hospitals are also advertising quick access at any time to paying patients, which is likely to affect other patients' access, including making referrals less accessible.

Overall, in both the US and the UK, protection is limited even in the areas with most developed laws. To date, legislators internationally have not passed even basic specific legislation (with few exceptions such in the US and Canada). The primary justification proposed for not updating legal protection is the lack of need for such updates. For example, relevant authorities in the UK (the House of Lords Science and Technology Committee) have concluded that there is no sufficient evidence of there being legal implications (Department of Health and Social Care, 2009). The very few existing genomic specific legislations are incomplete, and laws protecting people are scattered. In the US, for example, more than 1,000 laws and resolutions were enacted between 2015 and 2018 in relation to health insurance and access to it (The Health Innovations Database, n.d.). This makes it difficult for lawyers and almost impossible for members of the public to know what rights to seek and how. There is, therefore, a clear need for urgent action by governments.

RECOMMENDATIONS

Genetic knowledge is the most powerful tool humanity has to improve the quality of life, but it can also be used to violate human rights. To protect fundamental human rights in the genomic era governments can quickly implement a number of cost-effective measures, including:

Organize interdisciplinary teams to draft specific legislations

Interdisciplinary teams, including specialists in genetics, law and digital processing, must be formed to work on updating laws. There are already a number of interdisciplinary groups that work on these issues, such as the Working Group on Legal, Ethical and Societal Implication of Genet-

ics (LESIG) (TAGC, n.d.) at The Accessible Genetics Consortium (TAGC, n.d.) and The Ethical, Legal and Social Implications (ELSI) Research Program (NIH, US, n.d.). However, due to the scale of implications, Governments should coordinate this work - to enable fast legislative updates.

Consolidate and extend the existing protection

The new legislation should aim to bring together the current scattered protection, to make protection accessible to people. This can be done by passing specific legislation which regulates the use of genetic information across all relevant areas and incorporating the current protection.

Introduce effective penalties

The law needs to set strict penalties in order to minimise data hacks and fraudulent and negligent data breaches. This can be done by imposing appropriate fines and prison sentences for such breaches. Imposing imprisonment, instead of only fines, will reduce the significant revenue from fines (e.g. in 2014 alone, the US Department of Justice recovered $2.3 billion for prosecutions of health care fraud (Gosfield, 2015)). However, this measure will provide better protection of people's rights and will reduce the impact of injustices on individuals.

Train relevant stakeholders on basic genetic findings

Introduce genomic education for lawyers and judges as part of their professional development programmes. Modules on genetics should also be taught as part of the law degrees. Introducing such education would have a positive effect on improving decision-making (e.g. criminal behaviour, lie detecting) and overall justice.

Beyond these relatively simple steps, other measures will require more significant societal changes. For example, some areas, such as health care insurance, cannot be properly regulated by simply updating legislation. It is not possible to arrange for a fair, fully private, health insurance system, because insurance companies rely on risk assessment and need payments from the healthy to cover expenses. Therefore, to provide a fair system for all, governments will need to either provide health care insurance to all people, without considering any medical and genetics data; or make insurance mandatory, and cover the costs in part through public funds for those who cannot afford it – as is the case in Netherlands and Switzerland (Furrow et al., 2013).

Genomic research has brought humans closer to understanding human behaviour. The prediction precision for disorders, diseases, and other traits is increasing fast – enabling a powerful tool for both improving quality of life and harming individuals. This powerful tool cannot be regulated by stopping progress in genetic research - restricting it in one jurisdiction would not prevent other (possibly more permissive) jurisdictions from pursuing this research (Bosley et al., 2015)). Therefore, societies need to do everything in their power to regulate the use of this powerful tool. Action is needed now before it becomes practically impossible to protect people's rights.

REFERENCES

Alonso-Zaldivar, R., 2018. Worker Protections Seen at Risk in Trump Health Care Shift. US News World Rep.

Amazon Web Services, 2016. AWS Snowmobile – Move Exabytes of Data to the Cloud in Weeks [WWW Document]. Amaz. Web Serv. URL https://aws.amazon.com/blogs/aws/aws-snowmobile-move-exabytes-of-data-to-the-cloud-in-weeks/ (accessed 9.28.18).

Andrews, L.B., 2001. Future Perfect: Confronting Decisions About Genetics. Columbia University Press.

Andrews, L.B., Mehlman, M.J., Rothstein, M.A., 2015. Genetics: Ethics, Law and Policy, 4th Edition. ed. West Academic.

Araki, M., Ishii, T., 2014. International regulatory landscape and integration of corrective genome editing into in vitro fertilization. Reprod. Biol. Endocrinol. 12, 108. https://doi.org/10.1186/1477-7827-12-108

AVIVA Plc, 2018. Private Health Insurance [WWW Document]. AVIVA Health Insur. URL https://www.aviva.co.uk/health/health-products/private-health-insurance/ (accessed 9.28.18).

BAILII, 2018. B v The General Medical Council.

Barnes, J.C., Beaver, K.M., Boutwell, B.B., 2011. Examining the Genetic Underpinnings to Moffitt's Developmental Taxonomy: A Behavioral Genetic Analysis*. Criminology 49, 923–954. https://doi.org/10.1111/j.1745-9125.2011.00243.x

Barnett, J.C., Berchick, E.R., 2017. Health Insurance Coverage in the United States: 2016.

Barsky, P., Gaysina, D., 2016. Gene-Environment Interplay and Individual Differences in Psychological Traits, in: Kovas, Y., Malykh, S., Gaysina, D. (Eds.), Behavioural Genetics for Education. Palgrave Macmillan UK, London, pp. 24–41. https://doi.org/10.1057/9781137437327_2

Baruch, S., Hudson, K., 2008. Civilian and Military Genetics: Nondiscrimination Policy in a Post-GINA World. Am. J. Hum. Genet. 83, 435–444. https://doi.org/10.1016/j.ajhg.2008.09.003

BBC, 2015. Genetic tests scupper Saudi weddings. BBC.

Bohan, C., n.d. 'Streaming' in schools is bad for students – ESRI [WWW Document]. TheJournal.ie. URL http://jrnl.ie/303960 (accessed 9.2.18).

Bosley, K.S., Botchan, M., Bredenoord, A.L., Carroll, D., Charo, R.A., Charpentier, E., Cohen, R., Corn, J., Doudna, J., Feng, G., Greely, H.T., Isasi, R., Ji, W., Kim, J.-S., Knoppers, B., Lanphier, E., Li, J., Lovell-Badge, R., Martin, G.S., Moreno, J., Naldini, L., Pera, M., Perry, A.C., Venter, J.C., Zhang, F., Zhou, Q., 2015. CRISPR germline engineering—the community speaks. Nat. Biotechnol. https://doi.org/10.1038/nbt.3227

Botkin, J.R., Belmont, J.W., Berg, J.S., Berkman, B.E., Bombard, Y., Holm, I.A., Levy, H.P., Ormond, K.E., Saal, H.M., Spinner, N.B., Wilfond, B.S., McInerney, J.D., 2015. Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents. Am. J. Hum. Genet. 97, 6–21. https://doi.org/10.1016/j.ajhg.2015.05.022

Bulman, M., 2017. Doctors and nurses accuse Government of 'deliberate cruelty' as upfront NHS charging and ID checks come into force. The Independent.

California Healthline, 2018. Even If You Get Insurance Through Work, Trump Administration's Pre-Existing Conditions Decision Could Still Effect You. Calif. Heal.

Campbell, P.J., Getz, G., Stuart, J.M., Korbel, J.O., Stein, L.D., Net, -ICGC/TCGA Pan-Cancer Analysis of Whole Genomes, 2017. Pan-cancer analysis of whole genomes. bioRxiv 162784. https://doi.org/10.1101/162784

Chapman, R., Likhanov, M., Selita, F., Zakharov, I., Smith-Woolley, E., Kovas, Y., 2018. New literacy challenge for the twenty-first century: genetic knowledge is poor even among well educated. J. Community Genet. https://doi.org/10.1007/s12687-018-0363-7

Chapman, R., Selita, F., Devereux, J., Nanu, V., Smereczynska, V., Matsepuro, D., Kovas, Y., In Press. To tell or not to tell? Ethics and law of disclosing health-related genetic information to family members. Eur. Proc. Soc. Behav. Sci.

Cheng, C.-Y., Yamashiro, K., Jia Chen, L., Ahn, J., Huang, Lulin, Huang, Lvzhen, Cheung, C.M.G., Miyake, M., Cackett, P.D., Yeo, I.Y., Laude, A., Mathur, R., Pang, J., Sim, K.S., Koh, A.H., Chen, P., Lee, S.Y., Wong, D., Chan, C.M., Loh, B.K., Sun, Y., Davila, S., Nakata, I., Nakanishi, H., Akagi-Kurashige, Y., Gotoh, N., Tsujikawa, A., Matsuda, F., Mori, K., Yoneya, S., Sakurada, Y., Iijima, H., Iida, T., Honda,

S., Lai, T.Y.Y., Tam, P.O.S., Chen, H., Tang, S., Ding, X., Wen, F., Lu, F., Zhang, X., Shi, Y., Zhao, P., Zhao, B., Sang, J., Gong, B., Dorajoo, R., Yuan, J.-M., Koh, W.-P., van Dam, R.M., Friedlander, Y., Lin, Y., Hibberd, M.L., Foo, J.N., Wang, N., Wong, C.H., Tan, G.S., Park, S.J., Bhargava, M., Gopal, L., Naing, T., Liao, J., Guan Ong, P., Mitchell, P., Zhou, P., Xie, X., Liang, J., Mei, J., Jin, X., Saw, S.-M., Ozaki, M., Mizoguchi, T., Kurimoto, Y., Woo, S.J., Chung, H., Yu, H.-G., Shin, J.Y., Park, D.H., Kim, I.T., Chang, W., Sagong, M., Lee, S.-J., Kim, H.W., Lee, J.E., Li, Y., Liu, J., Teo, Y.Y., Heng, C.K., Lim, T.H., Yang, S.-K., Song, K., Vithana, E.N., Aung, T., Bei, J.X., Zeng, Y.X., Tai, E.S., Li, X.X., Yang, Z., Park, K.-H., Pang, C.P., Yoshimura, N., Yin Wong, T., Khor, C.C., 2015. New loci and coding variants confer risk for age-related macular degeneration in East Asians. Nat. Commun. 6, 6063.

CMS, 2013. Overview: Final Rule for Health Insurance Market Reforms.

Collins, F.S., 2014. Francis Collins Says Medicine in the Future Will Be Tailored to Your Genes. Wall Str. J.

Collinson, P., 2017. Private health insurance sales surge amid NHS crisis. The Guardian.

Congressional Research Service, 2008. Genetic Discrimination: Overview of the Issue and Proposed Legislation.

Court Listener, 1994. Katskee v. Blue Cross/Blue Shield.

Crossley, M., 2018. What is CRISPR gene editing, and how does it work? The Conversation.

Dante Labs, n.d. Whole Genome Sequencing (WGS) - Full DNA analysis for Rare Diseases [WWW Document]. Dante Labs. URL https://www.dantelabs.com/products/whole-genome-sequencing (accessed 9.25.18).

Davies, G., Lam, M., Harris, S.E., Trampush, J.W., Luciano, M., Hill, W.D., Hagenaars, S.P., Ritchie, S.J., Marioni, R.E., Fawns-Ritchie, C., Liewald, D.C.M., Okely, J.A., Ahola-Olli, A.V., Barnes, C.L.K., Bertram, L., Bis, J.C., Burdick, K.E., Christoforou, A., DeRosse, P., Djurovic, S., Espeseth, T., Giakoumaki, S., Giddaluru, S., Gustavson, D.E., Hayward, C., Hofer, E., Ikram, M.A., Karlsson, R., Knowles, E., Lahti, J., Leber, M., Li, S., Mather, K.A., Melle, I., Morris, D., Oldmeadow, C., Palviainen, T., Payton, A., Pazoki, R., Petrovic, K., Reynolds, C.A., Sargurupremraj, M., Scholz, M., Smith, J.A., Smith, A.V., Terzikhan, N., Thalamuthu, A., Trompet, S., Lee, S.J. van der, Ware, E.B., Windham, B.G., Wright, M.J., Yang, J., Yu, J., Ames, D., Amin, N., Amouyel, P., Andreassen, O.A., Armstrong, N.J., Assareh, A.A., Attia, J.R., Attix, D., Avramopoulos, D., Bennett, D.A., Böhmer, A.C., Boyle, P.A., Brodaty, H., Campbell, H., Cannon, T.D., Cirulli, E.T., Congdon, E., Conley, E.D., Corley, J., Cox, S.R., Dale, A.M., Dehghan, A., Dick, D., Dickinson, D., Eriksson, J.G., Evangelou, E.,

Faul, J.D., Ford, I., Freimer, N.A., Gao, H., Giegling, I., Gillespie, N.A., Gordon, S.D., Gottesman, R.F., Griswold, M.E., Gudnason, V., Harris, T.B., Hartmann, A.M., Hatzimanolis, A., Heiss, G., Holliday, E.G., Joshi, P.K., Kähönen, M., Kardia, S.L.R., Karlsson, I., Kleineidam, L., Knopman, D.S., Kochan, N.A., Konte, B., Kwok, J.B., Hellard, S.L., Lee, T., Lehtimäki, T., Li, S.-C., Liu, T., Koini, M., London, E., Longstreth, W.T., Lopez, O.L., Loukola, A., Luck, T., Lundervold, A.J., Lundquist, A., Lyytikäinen, L.-P., Martin, N.G., Montgomery, G.W., Murray, A.D., Need, A.C., Noordam, R., Nyberg, L., Ollier, W., Papenberg, G., Pattie, A., Polasek, O., Poldrack, R.A., Psaty, B.M., Reppermund, S., Riedel-Heller, S.G., Rose, R.J., Rotter, J.I., Roussos, P., Rovio, S.P., Saba, Y., Sabb, F.W., Sachdev, P.S., Satizabal, C.L., Schmid, M., Scott, R.J., Scult, M.A., Simino, J., Slagboom, P.E., Smyrnis, N., Soumaré, A., Stefanis, N.C., Stott, D.J., Straub, R.E., Sundet, K., Taylor, A.M., Taylor, K.D., Tzoulaki, I., Tzourio, C., Uitterlinden, A., Vitart, V., Voineskos, A.N., Kaprio, J., Wagner, M., Wagner, H., Weinhold, L., Wen, K.H., Widen, E., Yang, Q., Zhao, W., Adams, H.H.H., Arking, D.E., Bilder, R.M., Bitsios, P., Boerwinkle, E., Chiba-Falek, O., Corvin, A., Jager, P.L.D., Debette, S., Donohoe, G., Elliott, P., Fitzpatrick, A.L., Gill, M., Glahn, D.C., Hägg, S., Hansell, N.K., Hariri, A.R., Ikram, M.K., Jukema, J.W., Vuoksimaa, E., Keller, M.C., Kremen, W.S., Launer, L., Lindenberger, U., Palotie, A., Pedersen, N.L., Pendleton, N., Porteous, D.J., Räikkönen, K., Raitakari, O.T., Ramirez, A., Reinvang, I., Rudan, I., Rujescu, D., Schmidt, R., Schmidt, H., Schofield, P.W., Schofield, P.R., Starr, J.M., Steen, V.M., Trollor, J.N., Turner, S.T., Duijn, C.M.V., Villringer, A., Weinberger, D.R., Weir, D.R., Wilson, J.F., Malhotra, A., McIntosh, A.M., Gale, C.R., Seshadri, S., Mosley, T.H., Bressler, J., Lencz, T., Deary, I.J., 2018. Study of 300,486 individuals identifies 148 independent genetic loci influencing general cognitive function. Nat. Commun. 9, 2098. https://doi.org/10.1038/s41467-018-04362-x

Davies, G.E., Soundy, T.J., 2009. The genetics of smoking and nicotine addiction. S. D. Med. J. S. D. State Med. Assoc. Spec No, 43–49.

de Zeeuw, E.L., de Geus, E.J.C., Boomsma, D.I., 2015. Meta-analysis of twin studies highlights the importance of genetic variation in primary school educational achievement. Trends Neurosci. Educ. 4, 69–76. https://doi.org/10.1016/j.tine.2015.06.001

Dedrickson, K., 2017. Universal DNA databases: a way to improve privacy? J. Law Biosci. 4, 637–647. https://doi.org/10.1093/jlb/lsx041

Department of Health and Human Services, 2013a. Patient Protection and Affordable Care Act; Health Insurance Market Rules; Rate Review; Final Rule.

Department of Health and Human Services, 2013b. HIPAA Final Rule.

Department of Health and Social Care, 2009. Government response to the House of Lords Science and Technology Committee inquiry into genomic medicine.
Department of Health, UK, n.d. Genomics England [WWW Document]. Genomics Engl. URL https://www.genomicsengland.co.uk/ (accessed 9.27.18).
Dolgin, E., 2017. CRISPR hacks enable pinpoint repairs to genome. Nat. News 550, 439. https://doi.org/10.1038/550439a
Donnelly, L., 2018. Patients should be charged for GP and hospital visits to fund NHS, leading doctors say. The Telegraph.
EC, 2018. Towards a common European data space.
EC, 2017a. European Open Science Cloud (EOSC) [WWW Document]. URL https://ec.europa.eu/research/openscience/index.cfm?pg=open-science-cloud (accessed 9.26.18).
EC, 2017b. Enter the Data Economy: EU Policies for a Thriving Data Ecosystem.
EC, 2016. Guide to the EU-U.S. Privacy Shield (Text).
EC, 2014a. Elements of the European data economy strategy [WWW Document]. Eur. Comm. URL https://ec.europa.eu/digital-single-market/en/towards-thriving-data-driven-economy (accessed 9.25.18).
EC, 2014b. Communication from the Commission on data-driven economy (No. COM(2014)442 final).
EC, 2003. Report from the Commission - First Report on the implementation of the Data Protection Directive (95/46/EC).
EC, n.d. Horizon 2020 [WWW Document]. Horiz. 2020. URL http://ec.europa.eu/programmes/horizon2020/en/ (accessed 9.26.18).
ECHR, 2008. I v. FINLAND.
ECHR, 1997. Z v. FINLAND.
Edemekong, P.F., Haydel, M.J., 2018. Health Insurance Portability and Accountability Act (HIPAA), in: StatPearls. StatPearls Publishing, Treasure Island (FL).
Erlich, Y., Narayanan, A., 2014. Routes for breaching and protecting genetic privacy. Nat. Rev. Genet. 15, 409–421. https://doi.org/10.1038/nrg3723
EU Agency for Fundamental Rights, 2014. Access to data protection remedies in EU Member States.
EUR-Lex, 2015. Maximillian Schrems v Data Protection Commissioner.
European Union, 2013. Comparative study on different approaches to new privacy challenges, in particular in the light of technological developments. (Website).
Executive Office of the President, 2014. Big Data: Seizing Opportunities, Preserving Values. Createspace Independent Pub.
Fenton, S., 2016. The NHS is sharing the medical records of 1.6 million patients with Google [WWW Document]. The Independent. URL

http://www.independent.co.uk/life-style/health-and-families/health-news/nhs-google-medical-records-data-sharing-16-million-a7011891.html (accessed 9.26.18).

Friedman, J.M., Cornel, M.C., Goldenberg, A.J., Lister, K.J., Sénécal, K., Vears, D.F., Friedman, J.M., Cornel, M.C., Al-Thihli, K., Borry, P., Flannery, D., Goldenberg, A., Junker, A., Kingsmore, S., Laing, N.G., Scott, E., Wonkam, A., Knoppers, B., the Global Alliance for Genomics and Health Regulatory and Ethics Working Group Paediatric Task Team, 2017. Genomic newborn screening: public health policy considerations and recommendations. BMC Med. Genomics 10, 9. https://doi.org/10.1186/s12920-017-0247-4

Fung, B., 2017. How to protect yourself from the global ransomware attack. Wash. Post.

Furrow, B., Greaney, T., Johnson, S., Stoltzfus, T.J., Schwartz, R.L., 2013. Health Law, Cases, Materials and Problems, 7th Edition. ed. West Academic Publishing.

G2MC, n.d. Improving the implementation of: Global Genomic Medicine [WWW Document]. URL https://g2mc.org/ (accessed 9.26.18).

Gale, W.G., Gelfond, H., Krupkin, A., Mazur, M.J., Toder, E., 2018. EFFECTS OF THE TAX CUTS AND JOBS ACT: A PRELIMINARY ANALYSIS 51.

Gaziano, J.M., Concato, J., Brophy, M., Fiore, L., Pyarajan, S., Breeling, J., Whitbourne, S., Deen, J., Shannon, C., Humphries, D., Guarino, P., Aslan, M., Anderson, D., LaFleur, R., Hammond, T., Schaa, K., Moser, J., Huang, G., Muralidhar, S., Przygodzki, R., O'Leary, T.J., 2016. Million Veteran Program: A mega-biobank to study genetic influences on health and disease. J. Clin. Epidemiol. 70, 214–223. https://doi.org/10.1016/j.jclinepi.2015.09.016

Gemalto, 2016. Mining for Database Gold: Findings from 2016 Breach Level Index. Cybersecurity Res. Publ. Libr.

Gilchrist, R., n.d. UK plans to sequence 5 million genomes in 5 years - BioNews [WWW Document]. URL https://www.bionews.org.uk/page_138891 (accessed 10.28.18).

Glied, S., 2018. Implications of the 2017 Tax Cuts and Jobs Act for Public Health. Am. J. Public Health 108, 734–736. https://doi.org/10.2105/AJPH.2018.304388

Gosfield, A.G., 2015. Health Law Handbook, 27th ed. Thompson Reuters.

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

Green, E.D., Guyer, M.S., Institute, N.H.G.R., 2011. Charting a course for genomic medicine from base pairs to bedside. Nature 470, 204–213. https://doi.org/10.1038/nature09764

Gymrek, M., McGuire, A.L., Golan, D., Halperin, E., Erlich, Y., 2013. Identifying Personal Genomes by Surname Inference. Science 339, 321–324. https://doi.org/10.1126/science.1229566

Having, K., Davis, D.C., 2005. HIPAA Compliance in U.S. Hospitals: A Self-Report of Progress Toward the Security Rule. Perspect. Health Inf. Manag. AHIMA Am. Health Inf. Manag. Assoc. 2.

Hayden, E.C., 2013. Privacy protections: The genome hacker. Nat. News 497, 172. https://doi.org/10.1038/497172a

Heeney, C., Hawkins, N., de Vries, J., Boddington, P., Kaye, J., 2011. Assessing the privacy risks of data sharing in genomics. Public Health Genomics 14, 17–25. https://doi.org/10.1159/000294150

Hill, W.D., Marioni, R.E., Maghzian, O., Ritchie, S.J., Hagenaars, S.P., McIntosh, A.M., Gale, C.R., Davies, G., Deary, I.J., 2018. A combined analysis of genetically correlated traits identifies 187 loci and a role for neurogenesis and myelination in intelligence. Mol. Psychiatry 1. https://doi.org/10.1038/s41380-017-0001-5

HM Government, 2014. Concordat and Moratorium on Genetics and Insurance.

HM Government, 2013. UK data capability strategy: seizing the data opportunity.

Hon, W.K., 2017. Data Localization Laws and Policy. Ch 6: Compliance and Enforcement.

Hon, W.K., Millard, C., 2012. Cloud Computing vs. Traditional Outsourcing – Key Differences.

Howard, D.M., Adams, M.J., Shirali, M., Clarke, T.-K., Marioni, R.E., Davies, G., Coleman, J.R.I., Alloza, C., Shen, X., Barbu, M.C., Wigmore, E.M., Gibson, J., Hagenaars, S.P., Lewis, C.M., Ward, J., Smith, D.J., Sullivan, P.F., Haley, C.S., Breen, G., Deary, I.J., McIntosh, A.M., 2018. Genome-wide association study of depression phenotypes in UK Biobank identifies variants in excitatory synaptic pathways. Nat. Commun. 9, 1470. https://doi.org/10.1038/s41467-018-03819-3

HSE, 2017. Work-related Stress, Depression or Anxiety Statistics in Great Britain 2017.

ICO, 2018. Enforcement action [WWW Document]. ICO. URL https://ico.org.uk/action-weve-taken/enforcement/ (accessed 9.27.18).

ICO, 2006. What price privacy? The unlawful trade in confidential personal information.

Johnston, O., Wildy, H., 2016. The effects of streaming in the secondary school on learning outcomes for Australian students – A review of the international literature. Aust. J. Educ. 60, 42–59. https://doi.org/10.1177/0004944115626522

Kaplan, T., Sullivan, E., 2017. Health Care Vote: Senate Rejects Repeal Without Replace. N. Y. Times.

Kelly, N., Makarem, D.C., Wasserstein, M.P., 2016. Screening of Newborns for Disorders with High Benefit-Risk Ratios Should Be Mandatory. J. Law. Med. Ethics 44, 231–240. https://doi.org/10.1177/1073110516654133

Kessler, R.C., Bromet, E.J., 2013. The Epidemiology of Depression Across Cultures. Annu. Rev. Public Health 34, 119–138. https://doi.org/10.1146/annurev-publhealth-031912-114409

KHN, 2018. Even If You Get Insurance Through Work, Trump Administration's Pre-Existing Conditions Decision Could Still Effect You. Kais. Health News.

Kovas, P.Y., Selita, F., 2014. Applying genetic discoveries to education 3.

Kovas, Y., Garon-Carrier, G., Boivin, M., Petrill, S.A., Plomin, R., Malykh, S.B., Spinath, F., Murayama, K., Ando, J., Bogdanova, O.Y., Brendgen, M., Dionne, G., Forget-Dubois, N., Galajinsky, E.V., Gottschling, J., Guay, F., Lemelin, J.-P., Logan, J.A.R., Yamagata, S., Shikishima, C., Spinath, B., Thompson, L.A., Tikhomirova, T.N., Tosto, M.G., Tremblay, R., Vitaro, F., 2015. Why children differ in motivation to learn: Insights from over 13,000 twins from 6 countries. Personal. Individ. Differ. 80, 51–63. https://doi.org/10.1016/j.paid.2015.02.006

Kovas, Y., Haworth, C.M.A., Dale, P.S., Plomin, R., 2007. The genetic and environmental origins of learning abilities and disabilities in the early school years. Monogr. Soc. Res. Child Dev. 72, vii, 1–144. https://doi.org/10.1111/j.1540-5834.2007.00439.x

Kovas, Y., Malykh, S., Gaysina, D. (Eds.), 2016. Behavioural Genetics for Education. Palgrave Macmillan UK, London. https://doi.org/10.1057/9781137437327

Kulynych, J., Greely, H.T., 2017. Clinical genomics, big data, and electronic medical records: reconciling patient rights with research when privacy and science collide. J. Law Biosci. 4, 94–132. https://doi.org/10.1093/jlb/lsw061

Kuner, C., 2011. Regulation of Transborder Data Flows under Data Protection and Privacy Law. https://doi.org/10.1787/5kg0s2fk315f-en

Langmead, B., Nellore, A., 2018. Cloud computing for genomic data analysis and collaboration. Nat. Rev. Genet. 19, 208–219. https://doi.org/10.1038/nrg.2017.113

Lau, J.W., Lehnert, E., Sethi, A., Malhotra, R., Kaushik, G., Onder, Z., Groves-Kirkby, N., Mihajlovic, A., DiGiovanna, J., Srdic, M., Bajcic, D., Radenkovic, J., Mladenovic, V., Krstanovic, D., Arsenijevic, V., Klisic, D., Mitrovic, M., Bogicevic, I., Kural, D., Davis-Dusenbery, B., 2017. The Cancer Genomics Cloud: Collaborative, Reproducible, and Democratized—A New Paradigm in Large-Scale Computational

Research. Cancer Res. 77, e3–e6. https://doi.org/10.1158/0008-5472.CAN-17-0387
Le Page, M., 2017. Boom in human gene editing as 20 CRISPR trials gear up. New Sci.
Leagle, 2011. Bearder v. State, Leagle.
Ledford, H., 2016. AstraZeneca launches project to sequence 2 million genomes. Nat. News 532, 427. https://doi.org/10.1038/nature.2016.19797
Liang, P., Xu, Y., Zhang, X., Ding, C., Huang, R., Zhang, Z., Lv, J., Xie, X., Chen, Y., Li, Y., Sun, Y., Bai, Y., Songyang, Z., Ma, W., Zhou, C., Huang, J., 2015. CRISPR/Cas9-mediated gene editing in human tripronuclear zygotes. Protein Cell 6, 363–372. https://doi.org/10.1007/s13238-015-0153-5
Live Science, 2012. Should Boy's Genes Get Him Kicked Out of School? [WWW Document]. URL https://www.livescience.com/24112-cystic-fibrosis-genes-school.html (accessed 9.25.18).
Loukola, A., Hällfors, J., Korhonen, T., Kaprio, J., 2014. Genetics and smoking. Curr. Addict. Rep. 1, 75–82. https://doi.org/10.1007/s40429-013-0006-3
Lu, C., 2016. World Government, in: Zalta, E.N. (Ed.), The Stanford Encyclopedia of Philosophy. Metaphysics Research Lab, Stanford University.
Ma, H., Marti-Gutierrez, N., Park, S.-W., Wu, J., Lee, Y., Suzuki, K., Koski, A., Ji, D., Hayama, T., Ahmed, R., Darby, H., Dyken, C.V., Li, Y., Kang, E., Park, A.-R., Kim, D., Kim, S.-T., Gong, J., Gu, Y., Xu, X., Battaglia, D., Krieg, S.A., Lee, D.M., Wu, D.H., Wolf, D.P., Heitner, S.B., Belmonte, J.C.I., Amato, P., Kim, J.-S., Kaul, S., Mitalipov, S., 2017. Correction of a pathogenic gene mutation in human embryos. Nature 548, 413–419. https://doi.org/10.1038/nature23305
Manolio, T.A., Abramowicz, M., Al-Mulla, F., Anderson, W., Balling, R., Berger, A.C., Bleyl, S., Chakravarti, A., Chantratita, W., Chisholm, R.L., Dissanayake, V.H.W., Dunn, M., Dzau, V.J., Han, B.-G., Hubbard, T., Kolbe, A., Korf, B., Kubo, M., Lasko, P., Leego, E., Mahasirimongkol, S., Majumdar, P.P., Matthijs, G., McLeod, H.L., Metspalu, A., Meulien, P., Miyano, S., Naparstek, Y., O'Rourke, P.P., Patrinos, G.P., Rehm, H.L., Relling, M.V., Rennert, G., Rodriguez, L.L., Roden, D.M., Shuldiner, A.R., Sinha, S., Tan, P., Ulfendahl, M., Ward, R., Williams, M.S., Wong, J.E.L., Green, E.D., Ginsburg, G.S., 2015. Global implementation of genomic medicine: We are not alone. Sci. Transl. Med. 7, 290ps13-290ps13. https://doi.org/10.1126/scitranslmed.aab0194
Manyika, J., Chui, M., Bisson, P., Woetzel, J., Dobbs, R., Bughin, J., Aharon, D., 2015. Unlocking the potential of the Internet of Things.

Mavaddat, N., Peock, S., Frost, D., Ellis, S., Platte, R., Fineberg, E., Evans, D.G., Izatt, L., Eeles, R.A., Adlard, J., Davidson, R., Eccles, D., Cole, T., Cook, J., Brewer, C., Tischkowitz, M., Douglas, F., Hodgson, S., Walker, L., Porteous, M.E., Morrison, P.J., Side, L.E., Kennedy, M.J., Houghton, C., Donaldson, A., Rogers, M.T., Dorkins, H., Miedzybrodzka, Z., Gregory, H., Eason, J., Barwell, J., McCann, E., Murray, A., Antoniou, A.C., Easton, D.F., 2013. Cancer Risks for BRCA1 and BRCA2 Mutation Carriers: Results From Prospective Analysis of EMBRACE. JNCI J. Natl. Cancer Inst. 105, 812–822. https://doi.org/10.1093/jnci/djt095

Mcbride, N., Sotto, L.J., Treacy, B., Llp, W., 2013. Privacy & Data Security: The Future of the US-EU Safe Harbor 5.

McGuire, A.L., Beskow, L.M., 2010. Informed Consent in Genomics and Genetic Research. Annu. Rev. Genomics Hum. Genet. 11, 361–381. https://doi.org/10.1146/annurev-genom-082509-141711

Mehlman, M.J., Li, T.Y., 2014. Ethical, legal, social, and policy issues in the use of genomic technology by the U.S. Military. J. Law Biosci. 1, 244–280. https://doi.org/10.1093/jlb/lsu021

Mental Health Foundation, 2016. Fundamental Facts about mental health 2016. Mental Health Foundation: London.

Merrick, R., 2017. GPs urgently examine 173 cases of patients who may have been harmed after massive NHS data loss.

Moffitt, T.E., 1993. Adolescence-limited and life-course-persistent antisocial behavior: a developmental taxonomy. Psychol. Rev. 100, 674–701.

Molnár-Gábor, F., Lueck, R., Yakneen, S., Korbel, J.O., 2017. Computing patient data in the cloud: practical and legal considerations for genetics and genomics research in Europe and internationally. Genome Med. 9, 58. https://doi.org/10.1186/s13073-017-0449-6

Mukherjee, S., Stamatis, D., Bertsch, J., Ovchinnikova, G., Verezemska, O., Isbandi, M., Thomas, A.D., Ali, R., Sharma, K., Kyrpides, N.C., Reddy, T.B.K., 2017. Genomes OnLine Database (GOLD) v.6: data updates and feature enhancements. Nucleic Acids Res. 45, D446–D456. https://doi.org/10.1093/nar/gkw992

Munce, S.E.P., Stansfeld, S.A., Blackmore, E.R., Stewart, D.E., 2007. The role of depression and chronic pain conditions in absenteeism: results from a national epidemiologic survey. J. Occup. Environ. Med. 49, 1206–1211. https://doi.org/10.1097/JOM.0b013e318157f0ba

Nature Editorial, 2018. Science needs clarity on Europe's data-protection law. Nature. https://doi.org/10.1038/d41586-018-05220-y

Nature Editorial, 2016. Gene intelligence. Nat. News 531, 140. https://doi.org/10.1038/531140a

Naveed, M., Ayday, E., Clayton, E.W., Fellay, J., Gunter, C.A., Hubaux, J.-P., Malin, B.A., Wang, X., 2014. Privacy in the Genomic Era. ArXiv14051891 Cs.

NHS UK, n.d. Genomics Education Programme [WWW Document]. URL https://www.genomicseducation.hee.nhs.uk/ (accessed 9.23.18).

NIH, 2016. An Overview of the Human Genome Project [WWW Document]. Natl. Hum. Genome Res. Inst. NHGRI. URL https://www.genome.gov/12011238/an-overview-of-the-human-genome-project/ (accessed 9.25.18).

NIH, US, n.d. The ELSI Research Program [WWW Document]. Natl. Hum. Genome Res. Inst. NHGRI. URL https://www.genome.gov/10001618/the-elsi-research-program/ (accessed 9.27.18).

Nordberg, A., Minssen, T., Holm, S., Horst, M., Mortensen, K., Møller, B.L., 2018. Cutting edges and weaving threads in the gene editing (Я)evolution: reconciling scientific progress with legal, ethical, and social concerns. J. Law Biosci. 5, 35–83. https://doi.org/10.1093/jlb/lsx043

Nuffield Council on Bioethics, 2015. Biological and health data [WWW Document]. Nuffield Bioeth. URL http://nuffieldbioethics.org/project/biological-health-data (accessed 9.25.18).

OECD, 2014. Making Mental Health Count, Mental Health and Work. OECD Publishing. https://doi.org/10.1787/9789264124523-en

Oh, I.-S., Postlethwaite, B.E., Schmidt, F.L., 2013. Rethinking the Validity of Interviews for Employment Decision Making: Implications of Recent Developments in Meta-Analysis. Social Science Research Network, Rochester, NY.

Okbay, A., Beauchamp, J.P., Fontana, M.A., Lee, J.J., Pers, T.H., Rietveld, C.A., Turley, P., Chen, G.-B., Emilsson, V., Meddens, S.F.W., Oskarsson, S., Pickrell, J.K., Thom, K., Timshel, P., Vlaming, R. de, Abdellaoui, A., Ahluwalia, T.S., Bacelis, J., Baumbach, C., Bjornsdottir, G., Brandsma, J.H., Concas, M.P., Derringer, J., Furlotte, N.A., Galesloot, T.E., Girotto, G., Gupta, R., Hall, L.M., Harris, S.E., Hofer, E., Horikoshi, M., Huffman, J.E., Kaasik, K., Kalafati, I.P., Karlsson, R., Kong, A., Lahti, J., Lee, S.J. van der, deLeeuw, C., Lind, P.A., Lindgren, K.-O., Liu, T., Mangino, M., Marten, J., Mihailov, E., Miller, M.B., Most, P.J. van der, Oldmeadow, C., Payton, A., Pervjakova, N., Peyrot, W.J., Qian, Y., Raitakari, O., Rueedi, R., Salvi, E., Schmidt, B., Schraut, K.E., Shi, J., Smith, A.V., Poot, R.A., Pourcain, B.S., Teumer, A., Thorleifsson, G., Verweij, N., Vuckovic, D., Wellmann, J., Westra, H.-J., Yang, Jingyun, Zhao, W., Zhu, Z., Alizadeh, B.Z., Amin, N., Bakshi, A., Baumeister, S.E., Biino, G., Bønnelykke, K., Boyle, P.A., Campbell, H., Cappuccio, F.P., Davies, G., Neve, J.-E.D., Deloukas, P., Demuth, I., Ding, J., Eibich, P., Eisele, L., Eklund, N., Evans, D.M., Faul, J.D., Feitosa, M.F., Forstner, A.J., Gandin, I.,

Gunnarsson, B., Halldórsson, B.V., Harris, T.B., Heath, A.C., Hocking, L.J., Holliday, E.G., Homuth, G., Horan, M.A., Hottenga, J.-J., Jager, P.L. de, Joshi, P.K., Jugessur, A., Kaakinen, M.A., Kähönen, M., Kanoni, S., Keltigangas-Järvinen, L., Kiemeney, L.A.L.M., Kolcic, I., Koskinen, S., Kraja, A.T., Kroh, M., Kutalik, Z., Latvala, A., Launer, L.J., Lebreton, M.P., Levinson, D.F., Lichtenstein, P., Lichtner, P., Liewald, D.C.M., Study, L.C., Loukola, A., Madden, P.A., Mägi, R., Mäki-Opas, T., Marioni, R.E., Marques-Vidal, P., Meddens, G.A., McMahon, G., Meisinger, C., Meitinger, T., Milaneschi, Y., Milani, L., Montgomery, G.W., Myhre, R., Nelson, C.P., Nyholt, D.R., Ollier, W.E.R., Palotie, A., Paternoster, L., Pedersen, N.L., Petrovic, K.E., Porteous, D.J., Räikkönen, K., Ring, S.M., Robino, A., Rostapshova, O., Rudan, I., Rustichini, A., Salomaa, V., Sanders, A.R., Sarin, A.-P., Schmidt, H., Scott, R.J., Smith, B.H., Smith, J.A., Staessen, J.A., Steinhagen-Thiessen, E., Strauch, K., Terracciano, A., Tobin, M.D., Ulivi, S., Vaccargiu, S., Quaye, L., Rooij, F.J.A. van, Venturini, C., Vinkhuyzen, A.A.E., Völker, U., Völzke, H., Vonk, J.M., Vozzi, D., Waage, J., Ware, E.B., Willemsen, G., Attia, J.R., Bennett, D.A., Berger, K., Bertram, L., Bisgaard, H., Boomsma, D.I., Borecki, I.B., Bültmann, U., Chabris, C.F., Cucca, F., Cusi, D., Deary, I.J., Dedoussis, G.V., Duijn, C.M. van, Eriksson, J.G., Franke, B., Franke, L., Gasparini, P., Gejman, P.V., Gieger, C., Grabe, H.-J., Gratten, J., Groenen, P.J.F., Gudnason, V., Harst, P. van der, Hayward, C., Hinds, D.A., Hoffmann, W., Hyppönen, E., Iacono, W.G., Jacobsson, B., Järvelin, M.-R., Jöckel, K.-H., Kaprio, J., Kardia, S.L.R., Lehtimäki, T., Lehrer, S.F., Magnusson, P.K.E., Martin, N.G., McGue, M., Metspalu, A., Pendleton, N., Penninx, B.W.J.H., Perola, M., Pirastu, N., Pirastu, M., Polasek, O., Posthuma, D., Power, C., Province, M.A., Samani, N.J., Schlessinger, D., Schmidt, R., Sørensen, T.I.A., Spector, T.D., Stefansson, K., Thorsteinsdottir, U., Thurik, A.R., Timpson, N.J., Tiemeier, H., Tung, J.Y., Uitterlinden, A.G., Vitart, V., Vollenweider, P., Weir, D.R., Wilson, J.F., Wright, A.F., Conley, D.C., Krueger, R.F., Smith, G.D., Hofman, A., Laibson, D.I., Medland, S.E., Meyer, M.N., Yang, Jian, Johannesson, M., Visscher, P.M., Esko, T., Koellinger, P.D., Cesarini, D., Benjamin, D.J., 2016. Genome-wide association study identifies 74 loci associated with educational attainment. Nature 533, 539–542. https://doi.org/10.1038/nature17671

Ornstein, C., 2015. Fines Remain Rare Even As Health Data Breaches Multiply [WWW Document]. ProPublica. URL https://www.propublica.org/article/fines-remain-rare-even-as-health-data-breaches-multiply (accessed 9.26.18).

Peck, J.A., Levashina, J., 2017. Impression Management and Interview and Job Performance Ratings: A Meta-Analysis of Research Design

with Tactics in Mind. Front. Psychol. 8. https://doi.org/10.3389/fpsyg.2017.00201
Plomin, R., Deary, I.J., 2015. Genetics and intelligence differences: five special findings. Mol. Psychiatry 20, 98–108. https://doi.org/10.1038/mp.2014.105
Plomin, R., DeFries, J.C., Knopik, V.S., Neiderhiser, J.M., 2016. Top 10 Replicated Findings from Behavioral Genetics. Perspect. Psychol. Sci. J. Assoc. Psychol. Sci. 11, 3–23. https://doi.org/10.1177/1745691615617439
Polderman, T.J.C., Benyamin, B., Leeuw, C.A. de, Sullivan, P.F., Bochoven, A. van, Visscher, P.M., Posthuma, D., 2015. Meta-analysis of the heritability of human traits based on fifty years of twin studies. Nat. Genet. 47, 702–709. https://doi.org/10.1038/ng.3285
Ponemon Institute, 2017. Data Protection Risks & Regulations in the Global Economy.
Ramesh, R., Dinsdale, P., 2013. Patient lost £18,000 legal battle over GP medical records. The Guardian.
Reddy, M.S., 2010. Depression: The Disorder and the Burden. Indian J. Psychol. Med. 32, 1–2. https://doi.org/10.4103/0253-7176.70510
Relman, D.A., 2010. The biological century: coming to terms with risk in the life sciences. Nat. Immunol. https://doi.org/10.1038/ni0410-275
Reuters, 2013. Police database of Roma stirs outrage in Sweden. Reuters.
Rinker, V., 2013. HIPAA Privacy, Security and Breach Notification Audits. Presented at the 2013 NIST / OCR Security Rule Conference, US Department of Health and Human Services.
Rothstein, M.A., 2009. Gina's Beauty is Only Skin Deep.
Sample, I., 2015. UK scientists seek permission to genetically modify human embryos. The Guardian.
Selita, F., 2018. Unrepresented Litigants in Modern Courts – Ordeal by Combat 35.
Selita, F., Chapman, R., Rimfeld, K., Kovas, Y., 2015. Save Science from Fiction.
Selita, F., Kovas, Y., 2018. GENES AND GINI: WHAT INEQUALITY MEANS FOR HERITABILITY. J. Biosoc. Sci. 1–30. https://doi.org/10.1017/S0021932017000645
Selzam, S., Krapohl, E., Stumm, S. von, O'Reilly, P.F., Rimfeld, K., Kovas, Y., Dale, P.S., Lee, J.J., Plomin, R., 2017. Predicting educational achievement from DNA. Mol. Psychiatry 22, 267–272. https://doi.org/10.1038/mp.2016.107
Shanker, T., Bumiller, E., 2011. Hackers Gained Access to Important Files, Pentagon Says. N. Y. Times.
Smith, J., Dexter, E., n.d. Implications of upfront charging for NHS care: a threat to health and human rights. J. Public Health. https://doi.org/10.1093/pubmed/fdy050

Sniekers, S., Stringer, S., Watanabe, K., Jansen, P.R., Coleman, J.R.I., Krapohl, E., Taskesen, E., Hammerschlag, A.R., Okbay, A., Zabaneh, D., Amin, N., Breen, G., Cesarini, D., Chabris, C.F., Iacono, W.G., Ikram, M.A., Johannesson, M., Koellinger, P., Lee, J.J., Magnusson, P.K.E., McGue, M., Miller, M.B., Ollier, W.E.R., Payton, A., Pendleton, N., Plomin, R., Rietveld, C.A., Tiemeier, H., Duijn, C.M. van, Posthuma, D., 2017. Genome-wide association meta-analysis of 78,308 individuals identifies new loci and genes influencing human intelligence. Nat. Genet. 49, 1107–1112. https://doi.org/10.1038/ng.3869

Soini, S., 2012. Genetic testing legislation in Western Europe—a fluctuating regulatory target. J. Community Genet. 3, 143–153. https://doi.org/10.1007/s12687-012-0078-0

Stallard, M., n.d. DNA sequencing is inadvertently exacerbating social biases and inequalities [WWW Document]. The Conversation. URL http://theconversation.com/dna-sequencing-is-inadvertently-exacerbating-social-biases-and-inequalities-103869 (accessed 10.28.18).

Statista, n.d. Direct-to-consumer genetic testing market size worldwide 2014-2022 [WWW Document]. Statista. URL https://www.statista.com/statistics/792022/global-direct-to-consumer-genetic-testing-market-size/ (accessed 9.2.18).

Stein, L.D., Knoppers, B.M., Campbell, P., Getz, G., Korbel, J.O., 2015. Data analysis: Create a cloud commons. Nat. News 523, 149. https://doi.org/10.1038/523149a

Suter, S., 2014. Did You Give the Government Your Baby's DNA? Rethinking Consent in Newborn Screening. Minn. J. Law Sci. Technol. 15, 729.

Svantesson, D.J.B., 2010. A Legal Method for Solving Issues of Internet Regulation; Applied to the Regulation of Cross-Border Privacy Issues (Working Paper).

TAGC, n.d. LESIG Working Group [WWW Document]. tagc.world. URL http://tagc.world/lesig/ (accessed 9.27.18a).

TAGC, n.d. The Accessible Genetics Consortium [WWW Document]. URL tagc.world (accessed 9.27.18b).

Tandy-Connor, S., Guiltinan, J., Krempely, K., LaDuca, H., Reineke, P., Gutierrez, S., Gray, P., Davis, B.T., 2018. False-positive results released by direct-to-consumer genetic tests highlight the importance of clinical confirmation testing for appropriate patient care. Genet. Med. https://doi.org/10.1038/gim.2018.38

Taylor, M.J., 2015. Legal Bases for Disclosing Confidential Patient Information for Public Health: Distinguishing Between Health Protection and Health Improvement. Med. Law Rev. 23, 348–374. https://doi.org/10.1093/medlaw/fwv018

The Health Innovations Database, n.d. Health Reform and State Health Legislative Initiatives [WWW Document]. Natl. Conf. State Legis. URL http://www.ncsl.org/research/health.aspx (accessed 9.25.18).

The International Cancer Genome Consortium, Hudson (Chairperson), T.J., Anderson, W., Aretz, A., Barker, A.D., Bell, C., Bernabé, R.R., Bhan, M.K., Calvo, F., Eerola, I., Gerhard, D.S., Guttmacher, A., Guyer, M., Hemsley, F.M., Jennings, J.L., Kerr, D., Klatt, P., Kolar, P., Kusuda, J., Lane, D.P., Laplace, F., Lu, Y., Nettekoven, G., Ozenberger, B., Peterson, J., Rao, T.S., Remacle, J., Schafer, A.J., Shibata, T., Stratton, M.R., Vockley, J.G., Watanabe, K., Yang, H., Yuen, M.M.F., Knoppers (Leader), B.M., Bobrow, M., Cambon-Thomsen, A., Dressler, L.G., Dyke, S.O.M., Joly, Y., Kato, K., Kennedy, K.L., Nicolás, P., Parker, M.J., Rial-Sebbag, E., Romeo-Casabona, C.M., Shaw, K.M., Wallace, S., Wiesner, G.L., Zeps, N., Lichter (Leader), P., Biankin, A.V., Chabannon, C., Chin, L., Clément, B., de Alava, E., Degos, F., Ferguson, M.L., Geary, P., Hayes, D.N., Hudson, T.J., Johns, A.L., Kasprzyk, A., Nakagawa, H., Penny, R., Piris, M.A., Sarin, R., Scarpa, A., Shibata, T., van de Vijver, M., Futreal (Leader), P.A., Aburatani, H., Bayés, M., Bowtell, D.D.L., Campbell, P.J., Estivill, X., Gerhard, D.S., Grimmond, S.M., Gut, I., Hirst, M., López-Otín, C., Majumder, P., Marra, M., McPherson, J.D., Nakagawa, H., Ning, Z., Puente, X.S., Ruan, Y., Shibata, T., Stratton, M.R., Stunnenberg, H.G., Swerdlow, H., Velculescu, V.E., Wilson, R.K., Xue, H.H., Yang, L., Spellman (Leader), P.T., Bader, G.D., Boutros, P.C., Campbell, P.J., Flicek, P., Getz, G., Guigó, R., Guo, G., Haussler, D., Heath, S., Hubbard, T.J., Jiang, T., Jones, S.M., Li, Q., López-Bigas, N., Luo, R., Muthuswamy, L., Francis Ouellette, B.F., Pearson, J.V., Puente, X.S., Quesada, V., Raphael, B.J., Sander, C., Shibata, T., Speed, T.P., Stein, L.D., Stuart, J.M., Teague, J.W., Totoki, Y., Tsunoda, T., Valencia, A., Wheeler, D.A., Wu, H., Zhao, S., Zhou, G., Stein (Leader), L.D., Guigó, R., Hubbard, T.J., Joly, Y., Jones, S.M., Kasprzyk, A., Lathrop, M., López-Bigas, N., Francis Ouellette, B.F., Spellman, P.T., Teague, J.W., Thomas, G., Valencia, A., Yoshida, T., Kennedy (Leader), K.L., Axton, M., Dyke, S.O.M., Futreal, P.A., Gerhard, D.S., Gunter, C., Guyer, M., Hudson, T.J., McPherson, J.D., Miller, L.J., Ozenberger, B., Shaw, K.M., Kasprzyk (Leader), A., Stein (Leader), L.D., Zhang, J., Haider, S.A., Wang, J., Yung, C.K., Cross, A., Liang, Y., Gnaneshan, S., Guberman, J., Hsu, J., Bobrow (Leader), M., Chalmers, D.R.C., Hasel, K.W., Joly, Y., Kaan, T.S.H., Kennedy, K.L., Knoppers, B.M., Lowrance, W.W., Masui, T., Nicolás, P., Rial-Sebbag, E., Lyman Rodriguez, L., Vergely, C., Yoshida, T., Grimmond (Leader), S.M., Biankin, A.V., Bowtell, D.D.L., Cloonan, N., deFazio, A., Eshleman, J.R., Etemadmoghadam, D., Gardiner, B.A., Kench, J.G., Scarpa, A., Sutherland, R.L., Tempero, M.A., Waddell, N.J., Wil-

son, P.J., McPherson (Leader), J.D., Gallinger, S., Tsao, M.-S., Shaw, P.A., Petersen, G.M., Mukhopadhyay, D., Chin, L., DePinho, R.A., Thayer, S., Muthuswamy, L., Shazand, K., Beck, T., Sam, M., Timms, L., Ballin, V., Lu (Leader), Y., Ji, J., Zhang, X., Chen, F., Hu, X., Zhou, G., Yang, Q., Tian, G., Zhang, L., Xing, X., Li, X., Zhu, Z., Yu, Y., Yu, J., Yang, H., Lathrop (Leader), M., Tost, J., Brennan, P., Holcatova, I., Zaridze, D., Brazma, A., Egevad, L., Prokhortchouk, E., Elizabeth Banks, R., Uhlén, M., Cambon-Thomsen, A., Viksna, J., Ponten, F., Skryabin, K., Stratton (Leader), M.R., Futreal, P.A., Birney, E., Borg, A., Børresen-Dale, A.-L., Caldas, C., Foekens, J.A., Martin, S., Reis-Filho, J.S., Richardson, A.L., Sotiriou, C., Stunnenberg, H.G., Thomas, G., van de Vijver, M., van't Veer, L., Calvo (Leader), F., Birnbaum, D., Blanche, H., Boucher, P., Boyault, S., Chabannon, C., Gut, I., Masson-Jacquemier, J.D., Lathrop, M., Pauporté, I., Pivot, X., Vincent-Salomon, A., Tabone, E., Theillet, C., Thomas, G., Tost, J., Treilleux, I., Calvo (Leader), F., Bioulac-Sage, P., Clément, B., Decaens, T., Degos, F., Franco, D., Gut, I., Gut, M., Heath, S., Lathrop, M., Samuel, D., Thomas, G., Zucman-Rossi, J., Lichter (Leader), P., Eils (Leader), R., Brors, B., Korbel, J.O., Korshunov, A., Landgraf, P., Lehrach, H., Pfister, S., Radlwimmer, B., Reifenberger, G., Taylor, M.D., von Kalle, C., Majumder (Leader), P.P., Sarin, R., Rao, T.S., Bhan, M.K., Scarpa (Leader), A., Pederzoli, P., Lawlor, R.T., Delledonne, M., Bardelli, A., Biankin, A.V., Grimmond, S.M., Gress, T., Klimstra, D., Zamboni, G., Shibata (Leader), T., Nakamura, Y., Nakagawa, H., Kusuda, J., Tsunoda, T., Miyano, S., Aburatani, H., Kato, K., Fujimoto, A., Yoshida, T., Campo (Leader), E., López-Otín, C., Estivill, X., Guigó, R., de Sanjosé, S., Piris, M.A., Montserrat, E., González-Díaz, M., Puente, X.S., Jares, P., Valencia, A., Himmelbaue, H., Quesada, V., Bea, S., Stratton (Leader), M.R., Futreal, P.A., Campbell, P.J., Vincent-Salomon, A., Richardson, A.L., Reis-Filho, J.S., van de Vijver, M., Thomas, G., Masson-Jacquemier, J.D., Aparicio, S., Borg, A., Børresen-Dale, A.-L., Caldas, C., Foekens, J.A., Stunnenberg, H.G., van't Veer, L., Easton, D.F., Spellman, P.T., Martin, S., Barker, A.D., Chin, L., Collins, F.S., Compton, C.C., Ferguson, M.L., Gerhard, D.S., Getz, G., Gunter, C., Guttmacher, A., Guyer, M., Hayes, D.N., Lander, E.S., Ozenberger, B., Penny, R., Peterson, J., Sander, C., Shaw, K.M., Speed, T.P., Spellman, P.T., Vockley, J.G., Wheeler, D.A., Wilson, R.K., Hudson (Chairperson), T.J., Chin, L., Knoppers, B.M., Lander, E.S., Lichter, P., Stein, L.D., Stratton, M.R., Anderson, W., Barker, A.D., Bell, C., Bobrow, M., Burke, W., Collins, F.S., Compton, C.C., DePinho, R.A., Easton, D.F., Futreal, P.A., Gerhard, D.S., Green, A.R., Guyer, M., Hamilton, S.R., Hubbard, T.J., Kallioniemi, O.P., Kennedy, K.L., Ley, T.J., Liu, E.T., Lu, Y., Majumder, P., Marra, M., Ozenberger, B., Peterson, J., Schafer, A.J.,

Spellman, P.T., Stunnenberg, H.G., Wainwright, B.J., Wilson, R.K., Yang, H., 2010. International network of cancer genome projects. Nature 464, 993.

The MITRE Corporation, 2010. The $100 Genome: Implications for the DoD.

The UK10K Consortium, Walter, K., Min, J.L., Huang, J., Crooks, L., Memari, Y., McCarthy, S., Perry, J.R.B., Xu, C., Futema, M., Lawson, D., Iotchkova, V., Schiffels, S., Hendricks, A.E., Danecek, P., Li, R., Floyd, J., Wain, L.V., Barroso, I., Humphries, S.E., Hurles, M.E., Zeggini, E., Barrett, J.C., Plagnol, V., Brent Richards, J., Greenwood, C.M.T., Timpson, N.J., Durbin, R., Soranzo, N., Bala, S., Clapham, P., Coates, G., Cox, T., Daly, A., Danecek, P., Du, Y., Durbin, R., Edkins, S., Ellis, P., Flicek, P., Guo, Xiaosen, Guo, Xueqin, Huang, L., Jackson, D.K., Joyce, C., Keane, T., Kolb-Kokocinski, A., Langford, C., Li, Y., Liang, J., Lin, H., Liu, R., Maslen, J., McCarthy (co-chair), S., Muddyman, D., Quail, M.A., Stalker (co-chair), J., Sun, J., Tian, J., Wang, G., Wang, J., Wang, Y., Wong, K., Zhang, P., Barroso, I., Birney, E., Boustred, C., Chen, L., Clement, G., Cocca, M., Danecek, P., Davey Smith, G., Day, I.N.M., Day-Williams, A., Down, T., Dunham, I., Durbin, R., Evans, D.M., Gaunt, T.R., Geihs, M., Greenwood, C.M.T., Hart, D., Hendricks, A.E., Howie, B., Huang, J., Hubbard, T., Hysi, P., Iotchkova, V., Jamshidi, Y., Karczewski, K.J., Kemp, J.P., Lachance, G., Lawson, D., Lek, M., Lopes, M., MacArthur, D.G., Marchini, J., Mangino, M., Mathieson, I., McCarthy, S., Memari, Y., Metrustry, S., Min, J.L., Moayyeri, A., Muddyman, D., Northstone, K., Panoutsopoulou, K., Paternoster, L., Perry, J.R.B., Quaye, L., Brent Richards (co-chair), J., Ring, S., Ritchie, G.R.S., Schiffels, S., Shihab, H.A., Shin, S.-Y., Small, K.S., Soler Artigas, M., Soranzo (co-chair), N., Southam, L., Spector, T.D., St Pourcain, B., Surdulescu, G., Tachmazidou, I., Timpson (co-chair), N.J., Tobin, M.D., Valdes, A.M., Visscher, P.M., Wain, L.V., Walter, K., Ward, K., Wilson, S.G., Wong, K., Yang, J., Zeggini, E., Zhang, F., Zheng, H.-F., Anney, R., Ayub, M., Barrett, J.C., Blackwood, D., Bolton, P.F., Breen, G., Collier, D.A., Craddock, N., Crooks, L., Curran, S., Curtis, D., Durbin, R., Gallagher, L., Geschwind, D., Gurling, H., Holmans, P., Lee, I., Lönnqvist, J., McCarthy, S., McGuffin, P., McIntosh, A.M., McKechanie, A.G., McQuillin, A., Morris, J., Muddyman, D., O'Donovan, M.C., Owen (co-chair), M.J., Palotie (co-chair), A., Parr, J.R., Paunio, T., Pietilainen, O., Rehnström, K., Sharp, S.I., Skuse, D., St Clair, D., Suvisaari, J., Walters, J.T.R., Williams, H.J., Barroso (co-chair), I., Bochukova, E., Bounds, R., Dominiczak, A., Durbin, R., Farooqi (co-chair), I.S., Hendricks, A.E., Keogh, J., Marenne, G., McCarthy, S., Morris, A., Muddyman, D., O'Rahilly, S., Porteous, D.J., Smith, B.H., Tachmazidou, I., Wheeler, E., Zeggini, E., Al Turki, S., Anderson,

C.A., Antony, D., Barroso, I., Beales, P., Bentham, J., Bhattacharya, S., Calissano, M., Carss, K., Chatterjee, K., Cirak, S., Cosgrove, C., Durbin, R., Fitzpatrick (co-chair), D.R., Floyd, J., Reghan Foley, A., Franklin, C.S., Futema, M., Grozeva, D., Humphries, S.E., Hurles (co-chair), M.E., McCarthy, S., Mitchison, H.M., Muddyman, D., Muntoni, F., O'Rahilly, S., Onoufriadis, A., Parker, V., Payne, F., Plagnol, V., Lucy Raymond, F., Roberts, N., Savage, D.B., Scambler, P., Schmidts, M., Schoenmakers, N., Semple, R.K., Serra, E., Spasic-Boskovic, O., Stevens, E., van Kogelenberg, M., Vijayarangakannan, P., Walter, K., Williamson, K.A., Wilson, C., Whyte, T., Ciampi, A., Greenwood (co-chair), C.M.T., Hendricks, A.E., Li, R., Metrustry, S., Oualkacha, K., Tachmazidou, I., Xu, C., Zeggini (co-chair), E., Bobrow, M., Bolton, P.F., Durbin, R., Fitzpatrick, D.R., Griffin, H., Hurles (co-chair), M.E., Kaye (co-chair), J., Kennedy, K., Kent, A., Muddyman, D., Muntoni, F., Lucy Raymond, F., Semple, R.K., Smee, C., Spector, T.D., Timpson, N.J., Charlton, R., Ekong, R., Futema, M., Humphries, S.E., Khawaja, F., Lopes, L.R., Migone, N., Payne, S.J., Plagnol (chair), V., Pollitt, R.C., Povey, S., Ridout, C.K., Robinson, R.L., Scott, R.H., Shaw, A., Syrris, P., Taylor, R., Vandersteen, A.M., Barrett, J.C., Barroso, I., Davey Smith, G., Durbin (chair), R., Farooqi, I.S., Fitzpatrick, D.R., Hurles, M.E., Kaye, J., Kennedy, K., Langford, C., McCarthy, S., Muddyman, D., Owen, M.J., Palotie, A., Brent Richards, J., Soranzo, N., Spector, T.D., Stalker, J., Timpson, N.J., Zeggini, E., Amuzu, A., Pablo Casas, J., Chambers, J.C., Cocca, M., Dedoussis, G., Gambaro, G., Gasparini, P., Gaunt, T.R., Huang, J., Iotchkova, V., Isaacs, A., Johnson, J., Kleber, M.E., Kooner, J.S., Langenberg, C., Luan, J., Malerba, G., März, W., Matchan, A., Min, J.L., Morris, R., Nordestgaard, B.G., Benn, M., Ring, S., Scott, R.A., Soranzo, N., Southam, L., Timpson, N.J., Toniolo, D., Traglia, M., Tybjaerg-Hansen, A., van Duijn, C.M., van Leeuwen, E.M., Varbo, A., Whincup, P., Zaza, G., Zeggini, E., Zhang, W., 2015. The UK10K project identifies rare variants in health and disease. Nature 526, 82.

Tremblay, R.E., 2006. Prevention of Youth Violence: Why not Start at the Beginning? J. Abnorm. Child Psychol. 34, 480–486. https://doi.org/10.1007/s10802-006-9038-7

UK Department of Health, 2012. Ownership of NHS health records [WWW Document]. URL https://www.whatdotheyknow.com/request/115707/response/283144/attach/2/Long%20Email%20Body%2018%2005%202012.html (accessed 9.27.18).

UNESCO, 2003. International Declaration on Human Genetic Data [WWW Document]. URL http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html (accessed 9.25.18).

US Department of Justice, 2017. United States v. GlaxoSmithKline [WWW Document]. URL https://www.justice.gov/usao-ma/united-states-v-glaxosmithkline (accessed 9.28.18).
US Department of Justice, 2012. United States v. GlaxoSmithKline.
US Department of Labor, 2016. History of EBSA and ERISA [WWW Document]. U. S. Dep. Labor. URL https://www.dol.gov/agencies/ebsa/about-ebsa/about-us/history-of-ebsa-and-erisa (accessed 9.24.18).
US House of Representatives, 2000. The Department of Defense Anthrax Vaccine Immunization Program: Unproven Force Protection (legislation). Congress.
US National Intelligence Council, 2012. Global Trends 2030: Alternative Worlds.
US NIH, 2017. GINA and Employee Wellness [WWW Document]. Natl. Hum. Genome Res. Inst. NHGRI. URL https://www.genome.gov/27568501/gina-and-employee-wellness/ (accessed 9.27.18).
Viding, E., Larsson, H., Jones, A.P., 2008. Quantitative genetic studies of antisocial behaviour. Philos. Trans. R. Soc. B Biol. Sci. 363, 2519–2527. https://doi.org/10.1098/rstb.2008.0037
Wertz, J., Agnew-Blais, J., Caspi, A., Danese, A., Fisher, H.L., Goldman-Mellor, S., Moffitt, T.E., Arseneault, L., 2018a. From Childhood Conduct Problems to Poor Functioning at Age 18 Years: Examining Explanations in a Longitudinal Cohort Study. J. Am. Acad. Child Adolesc. Psychiatry 57, 54-60.e4. https://doi.org/10.1016/j.jaac.2017.09.437
Wertz, J., Caspi, A., Belsky, D.W., Beckley, A.L., Arseneault, L., Barnes, J.C., Corcoran, D.L., Hogan, S., Houts, R.M., Morgan, N., Odgers, C.L., Prinz, J.A., Sugden, K., Williams, B.S., Poulton, R., Moffitt, T.E., 2018b. Genetics and Crime: Integrating New Genomic Discoveries Into Psychological Research About Antisocial Behavior. Psychol. Sci. 29, 791–803. https://doi.org/10.1177/0956797617744542
Winickoff, D.E., 2007. Partnership in UK Biobank: A Third Way for Genomic Property? J. Law. Med. Ethics 35, 440–456. https://doi.org/10.1111/j.1748-720X.2007.00166.x
Wood, P., Egan, G., Haley, K., Tran, T.-K., Cox, O., Lau, H., 2012. Internet Security Threat Report.
Zhang-James, Y., Fernàndez-Castillo, N., Hess, J.L., Malki, K., Glatt, S.J., Cormand, B., Faraone, S.V., 2018. An integrated analysis of genes and functional pathways for aggression in human and rodent models. Mol. Psychiatry 1. https://doi.org/10.1038/s41380-018-0068-7