Genomics Beyond Health

Report Overview

Foresight

How would you feel if your genomic information made your car insurance more expensive?

If you could find out whether your child was likely to excel at sport or academic pursuits, would you?

Should criminal sentencing account for a person's genomic predispositions?

These are just some of the questions that we might face in the not-too-distant future as genomic science provides us with more and more information about the human genome, and the role it plays in influencing our traits and behaviours.

A person's genomic information - their unique deoxyribonucleic acid (DNA) sequence - can already be used to make some medical diagnoses and personalise their treatment. But we are also beginning to understand how the genome can influence people's traits and behaviours *beyond* health.

There is already evidence that non-health traits such as risk taking, educational attainment, and substance abuse are influenced by the genome. As we understand more about how genes influence traits, we may be better able to predict how likely and to what extent someone will develop these traits from their genomic sequence.

This raises several important questions. How might this information be used? What could this mean for our society? And how might policy across departments need to adapt? Will we need more regulation? How will we manage the ethical questions raised, address the risk of discrimination, and the potential threats to privacy?

While some of the potential uses of genomics may not be realised in the short or even medium-term, people are already exploring new ways to use genomic information today. This means that now is the time to anticipate how genomics might be used in the future. We should also consider the impact that genomic services might have if they are offered to the public before the science is truly ready. This will allow us to properly consider the opportunities and risks that these new applications of genomics may represent, and to identify actions we can take in response.

The *Genomics Beyond Health* report, published by the Government Chief Scientific Adviser and the Government Office for Science, explores these potential futures in more detail. The report introduces genomics for the non-specialist, investigates how the science is developing, and tries to consider the implications across a variety of sectors. The report looks at what is possible now, what might be possible in the future, and explores where the capabilities of genomics are potentially being oversold. Our findings are summarised in this overview, but the full report is publicly available on the Government Office for Science website.

What is genomics?

Humans have long been fascinated by our genetics, and the role they play in making us who we are. We are eager to understand how hereditary factors influence our physical features, health, personalities, characteristics, and skills, as well as how they interact with environmental influences.

Genomics is the study of an organism's genome – their entire DNA sequence, and how all our genes work together in our biological system. In the 20th century, studies on the genome were often limited to the observation of twins to explore the role of genetics vs. environment in physical and behavioural characteristics (or 'nature vs. nurture'). However, the mid 2000s marked the first publication of the human genome and the development of faster and cheaper genomic technologies.

£4 billion
13 years
Cost and time it took to draft sequence the first human genome.
Cost adjusted for inflation.

These technologies meant that researchers could finally investigate the genetic code directly, and at a fraction of the time and cost as was previously possible. Sequencing the whole human genome, which once took years and cost billions of pounds, now takes **less than a day** and costs about **£800**[1]. Researchers can now analyse the genomes of hundreds of individuals or draw on biobanks containing the genomic information of many thousands more. As a result, genomic data is being accumulated in vast quantities for research use.

Until now, genomics has mostly been utilised within **healthcare and medical research**. For example, identifying the presence of a faulty gene variant, such as the BRCA1 variant that is associated with breast cancer. This can allow earlier preventative treatment that would not be possible without genomic knowledge. However, as our understanding of genomics grows, it's becoming clear that the influences of the genome extend well beyond health and disease.

What is DNA?

The quest to understand our genetic makeup has taken huge steps forward over the past 20 years. We are beginning to understand the genome's structure and function, but there is a lot left to learn.

We have known since the 1950's that our **DNA sequence is a code**, and this code contains the instruction for our cells on how to make proteins. Each gene corresponds to a different protein, and the proteins that are made give rise to an organism's **traits** (such as eye colour, or flower size). DNA can influence traits through a variety of mechanisms; a single gene might determine a trait (like ABO blood group), several genes may work together synergistically (as seen with height

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[1] National Human Genome Research Institute (2020) DNA Sequencing Costs: Data from the NHGRI Genome Sequencing Program (GSP). Accessed 17 June 2021.

and skin pigmentation), or some genes may override one another, masking the influence of others (like baldness and hair colour).

3.2 billion

Approx. number of letters (bases) in the human genome.

Most traits are influenced by many (likely thousands) of different segments of DNA working together. But **mutations to our DNA** can cause the proteins to change – this might then cause the trait to change. This is the primary driving force behind biological variability, diversity, and disease. Mutations can confer advantages or disadvantages to an individual, a neutral change, or they may have no effect at all. They can be passed down through families or occur from the point of conception. However, if they occur during adulthood, this generally limits their effects to the individual rather than their offspring.

The variability of traits can also be influenced by **epigenetic mechanisms**. These can control whether genes are switched on or off. Unlike genetic mutations, they are **reversible and partly influenced by our environment**. This means that understanding the cause of a trait is not a simple study of what genetic sequence influences each trait. It is necessary to consider genetics within a wider context, with an appreciation of the networks and interactions across the whole genome, and the role of the environment.

Genomic technologies

Genomic technologies can be used to determine someone's genetic sequence. These techniques are now used widely in many research studies and are increasingly offered by commercial companies for the purposes of health or ancestry analysis. The methods by which a company or study will determine someone's genetic sequence varies, but until recently most have used a technique called **DNA microarray**. Microarrays measure **sections of a person's genome** rather than reading the entire sequence. Historically, microarrays have been easier, quicker, and cheaper to use than other methods, but their use comes with some limitations.

Once data has been accumulated, it can be studied at scale through a **genome wide association study** (or GWAS). These studies look for gene variants which are associated with a specific trait. However, to date, even the largest studies have only been able to identify **a fraction** of the genetic effects behind many traits compared to what we expect from twin studies. The inability to identify all the relevant genetic markers for a trait is known as the **"missing heritability"** problem[2]. However, the power of GWAS to identify relevant gene variants **improves with the addition of more data**, so the missing heritability problem may be solved as increasing amounts of genomic data are collected.

[2] Young, A (2019) Solving the missing heritability problem. PLoS Genetics, 15(6), DOI: 10.1371/journal.pgen.1008222

Furthermore, as costs continue to fall and the technology continues to improve, more researchers are using a technique called **whole genome sequencing** instead of microarrays. This reads the whole genomic sequence directly rather than parts of it. Sequencing can overcome many of the limitations associated with microarrays, so the data obtained is richer and more informative. This data also helps to reduce the missing heritability problem, and this means that **we are beginning to understand more about which genes work together to influence a trait**.

97.7%
Decrease in cost to sequence a human genome since 2010.
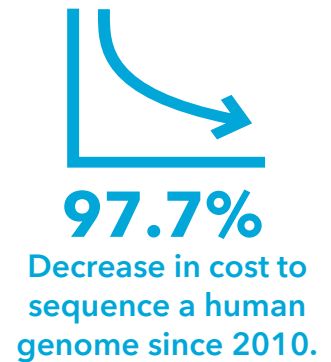
Similarly, the massive collection of whole genome sequences now planned for healthcare purposes will provide a much richer and more powerful research dataset. This will benefit those studying both health and non-health traits.

As we develop an understanding of how genes influence traits, we can better predict how different genes may act together on a specific trait. This is done by combining estimated effects from multiple genes into a single measure of genetic liability, known as **polygenic scoring**. Polygenic scores tend to provide more accurate predictions for how likely an individual is to develop a trait than are possible from individual genetic markers.

Polygenic scores are now becoming popular in health research, with the objective of one day using them to guide clinical interventions at an individual level. However, polygenic scores are constrained by GWAS and as such **many do not yet predict their target trait very accurately**, with a polygenic score for height only achieving a predictive accuracy of 25%[3]. This means that for some traits they may be less accurate to other diagnostic methods, such as a blood test or MRI scan. Nevertheless, as genomic data improves, so should the accuracy of polygenic scores. In the future, polygenic scoring could provide clinical risk information far earlier than is possible with traditional diagnostic tools, and they may also be used to predict non-health traits in the same way.

0.3%
Proportion of GWAS which have been based on data from people of African ancestry.

But as with any methodology, there are limitations. The key limitation of a GWAS is the diversity of the data it uses, which has not reflected the diversity of the general population. Research has shown that as much as **83% of GWAS have been conducted on cohorts entirely of European ancestry**[4]. This is clearly problematic because it means that a GWAS may only be relevant for a select population. Developing and using predictive tests based on findings from population biased GWAS may therefore be discriminatory to those outside the GWAS population.

[3] Yengo, L (2018) Meta-analysis of genome-wide association studies for height and body mass index in ~700000 individuals of European ancestry. Human Molecular Genetics, 27(20), DOI: 10.1093/hmg/ddy271
[4] Mills, M (2019) A scientometric review of genome-wide association studies. Communications Biology, 2(9), DOI: 10.1038/s42003-018-0261-x

For non-health traits, predictions from polygenic scores are currently less informative compared to non-genomic information that is already available. For example, a polygenic score for predicting educational attainment (currently one of the best performing polygenic scores available) is less informative than a simple measure of parental education[5]. The predictive power of polygenic scores will inevitably increase with larger, more diverse studies, and studies based on whole genome sequencing data.
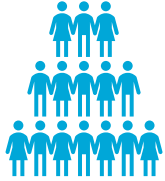
The current uses of genomics:
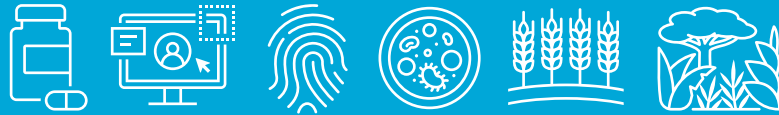
Health:

Genomic research has focused heavily on the genomics of health and disease, helping to identify sections of the genome that influence disease risk. Our knowledge about the role of genomics differs across diseases. For some diseases that are caused by a single gene, such as Huntington's, we can accurately predict an individual's likelihood of developing the disease from their genomic data. For diseases that are caused by many genes in combination with environmental exposures, such as coronary heart disease, genomic prediction is far less accurate. Generally, the more complex a disease or trait is, the more difficult it is to understand and predict accurately. However, predictive accuracy is improving as study cohorts become larger and more diverse.

The UK is at the forefront of health genomics research. We have already developed large scale infrastructure in genomic technologies, research databases, and computational power. The UK has contributed widely to global genomic knowledge, particularly during the COVID-19 pandemic, where we have led efforts to sequence the genome of the SARS-CoV-2 virus and its emerging variants.

Genome UK is the UK's ambitious genomic healthcare strategy[6], which will see the NHS integrate genomic sequencing into routine clinical care to diagnose rare diseases, cancer, or infectious disease. It will also lead to a **massive increase in the number of human genomes available for research**. This should allow for wider studies and will unlock further applications for genomics. As a world leader in the development of genomic data and infrastructure, the UK could lead internationally on the ethics and regulation of genomic science.

1,000,000 by 2024
Whole genome sequencing target of GMS and UK Biobank.

[5] Morris, T (2020) Can education be personalised using pupils' genetic data? eLife, 9, DOI: 10.7554/eLife.49962
[6] DHSC, BEIS, OLS, and Lord Bethell of Romford (2020) Genome UK: the future of healthcare. Accessed 17 June 2021.

Direct-to-consumer testing:

Direct-to-consumer (DTC) genetic testing kits are marketed and sold directly to consumers without the involvement of a healthcare provider. A swab of saliva is sent off for analysis, providing the consumer with personalised health or ancestry analysis in just a few weeks. This market is growing rapidly, and tens of millions of consumers across the world have submitted DNA samples for commercial sequencing, to gain insights into their health, ancestry, and genetic predisposition to traits.

While rapidly growing in popularity[7], there are some risks associated with DTC testing. The accuracy of some genomic-based insights which underpin direct- to-consumer services can be very low. The tests may also impact an individual's privacy, through data sharing, identifiability of relatives, and potential lapses in cybersecurity protocols. Customers may not fully understand these issues when they engage with a DTC testing company.

$2.7 billion by 2025
Predicted growth of the global DTC testing market (USD).

DTC genomic tests for non-medical traits are also largely unregulated. They fall beyond the scope of legislation covering medical genomic tests, relying instead on voluntary self-regulation by the test providers. Many of these companies are also based outside of the UK and are not subject to UK regulation.

Forensics:

DNA sequences are uniquely powerful in forensic science for the identification of unknown individuals. Basic DNA analysis has been widely used since the invention of DNA fingerprinting in 1984, and the UK's National DNA Database (NDNAD) holds profiles of 5.7 million individuals and 631,000 crime scene records[8]. The database may only be used for the detection or prevention of crime, or to identify bodies following deaths from natural disasters.

DNA fingerprinting counts the number of repeated sequences in pre-determined short tandem repeat (STR) areas of the genome to differentiate between individuals, rather than matching the sequences directly. This allows suspects to be matched to samples taken from crime scenes. The forensic DNA profile used by police in England and Wales, DNA-17, uses 16 different STR areas (or loci) for comparison. This means that the probability of two full DNA profiles from unrelated individuals matching by chance is around one in a billion.

In the future, targeted or full genome sequencing could replace the STR techniques currently in use. This could enable DNA phenotyping (like a 'predictive photofit' image to predict the physical features of an unknown individual) or age prediction, alongside traditional DNA fingerprinting. But expanding the use of DNA

[7] Bergin, J (2020) Direct-to-Consumer Genetic Testing: Global Markets and Technologies. BCC Research. Accessed 18 June 2021.
[8] Home Office (2021) National DNA Database statistics. Accessed 18 June 2021.

in forensics, especially in a genomic capacity, raises issues around surveillance, privacy, and the potential for discrimination against certain groups.

0.78%

Average amount of DNA shared between third cousins.

Large commercial genomic databases may also be used in a forensic capacity. Some DTC companies provide consumers with a copy of their raw genomic data. The consumer may then choose to upload the data to a third-party genomic database for additional health, ancestry, or wellness analysis. US law enforcement agencies have used these databases to identify human remains or criminal suspects through matching samples to distant relatives, which is possible as far as a third cousin match[9,10].

Non-human genomics:

Genomic science isn't an exclusively human science – a point clearly demonstrated by the pivotal role that genomics has played in the response to COVID-19. In many ways, the non-human applications of genomics are even more advanced than the human applications. For example, genomics is often used to inform selective breeding processes in the agricultural sector, the development of genetically edited or modified crops or livestock, environmental monitoring for biological pathogens or indicators of pollutants, species cataloguing, or the modelling of species adaptation in response to climate change. Understanding more about how the genome relates to biological traits may also be used to inform the development of **edited** or **completely synthetic genomes** or biological life forms. These may themselves have a diverse spectrum of uses ranging from biomaterials and biofuels to new types of medicine and biological computers or sensors.

Whilst our report is focussed on human genomics, we also discuss a number of these applications in more detail to illustrate the breadth of scope. However, this is by no means exhaustive, and the range of applications is likely to increase as the science develops.

>90%
percentage of soy, cotton and corn grown in the US (2018) which were genetically modified.

66,000
number of species in the British Isles, which are being sequenced by the Darwin Tree of Life Project.

2045
prediction for when we'll be able to build a full replica human genome synthetically.
Based on current progress.

[9] Resnick, B (2018) How your third cousin's ancestry DNA test could jeopardize your privacy. Vox. Accessed 8 October 2021.
[10] International Society of Genetic Genealogy Wiki (2021) Autosomal DNA statistics. Accessed 8 October 2021.

The future uses of genomics: beyond health

Studies examining the role of genomics in health and disease have generated a wealth of knowledge about the fundamental workings of our genome. The range of fields beyond health, where this knowledge could be applied, is also growing. For example, genomic research into education has provided knowledge of the role that genomics plays in educational outcomes and how people learn.

Like many health traits, non-health traits are usually very complex, being influenced by thousands of genes and an array of environmental factors. This complexity, combined with the infancy of genomic research beyond health, means that **understanding of how genomics applies to non-health fields lags behind its use in health**. In many non-health fields, the operational implications of genomic prediction are also more challenging. For example, as non-health traits are especially complex, accurately predicting them is more difficult compared to traits which are influenced by one or a few genes.

Non-health genomic applications can therefore be grouped into two areas:

  i.   those that are theoretically possible.
  ii.   those that are technically possible, given our current knowledge.

Policymakers and practitioners will need to react to emerging developments in genomic science in two ways. First, to **make the best use of developments in genomics** they will need to address the **technical and ethical issues that they raise**. Second, policymakers will need to consider what **mitigations and support should be in place** to help customers and service providers navigate the genomic marketplace. The DTC genomic testing market is a useful example; it is an international market, mostly governed by voluntary codes, and tests may be offered to customers before they are fully supported by the evidence base, without this being made clear to the customer.

The limitations of the current evidence base should also be acknowledged. The underrepresentation of genomes from people of non-European ancestry in genomic databases impacts the accuracy of predictions that are made to all citizens made using that data. This must be addressed before genomics is used to predict behaviours and prescribe interventions, or we **risk entrenching inequalities in key areas of life**, such as in employment or education.

Regulation on the use of genomic technologies in non-health fields is patchy, and risks being outpaced by advances in the technology. Proactive regulation might prevent genomic technologies from being misused in non-health fields.

Employment:

Genomic tests are currently used in very limited circumstances in employment, such as occasionally in professional sport. However, the rapid development of genomic science could prompt employers to use genomics more widely. This could potentially be in the **selection of workers of optimal health** or **personality** for a role, or to prevent workplace **injury**.

21-51%
Heritability estimate of musical ability.

The potential use of genomics in assessing candidates' personal suitability would be most controversial. Many personality traits are reasonably influenced by the genome (i.e., are heritable), including extraversion (53% heritable), neuroticism (41%), agreeableness (41%), conscientiousness (44%), and openness to experience (61%)[11]. Yet tests designed to predict these traits frequently encounter technical and ethical barriers, and easier methods of testing currently exist.

However, this may change as predictive capability improves, and the UK has **no explicit legislation barring the use of genomic analysis in employment scenarios**. On the other hand, some countries have implemented proactive legislation - the Genetic Information Non-discrimination Act (GINA), enacted in the US in 2008, prohibits the use of genomic information in job hiring, redundancy, placement, or promotion decisions[12].

Sport:

Genetic tests can currently be used to screen for health conditions that would pose a risk to athletes, and for sex verification purposes in international competition. Variants of certain genes (including ACTN3, ACE, GALNTL6 and EPOR) have been associated with **elite athletic performance**. One variant of the EPOR gene is associated with an elevated red blood cell count, generating 25 to 50% more red blood cells than usual, and contributing to **improved athletic endurance**[13].

1.23x
No. of times more likely that endurance athletes have a GALNTL6 gene

DTC genomic tests intended to identify athletic potential or inform training regimes currently exist. However, they are not regarded as accurate or useful by prominent sporting bodies[14]. In the future, **gene editing techniques** could be used to potentially enhance the performance of people whose genome does not include advantageous gene variants. However, the World Anti-Doping Agency (WADA) has pre-emptively **outlawed gene doping** and is developing techniques to detect it.

[11] Jang, K (1996) Heritability of the big five personality dimensions and their facets: a twin study. Journal of personality, 64(3), 577-592, DOI: 10.1111/j.1467-6494.1996.tb00522.x

[12] Suter, S. M. (2018). GINA at 10 years: the battle over 'genetic information' continues in court. Journal of Law and the Biosciences, 495-526, 5(3), DOI: https://doi.org/10.1093/jlb/lsz002

[13] Enriquez, J (2012) Genetically enhanced Olympics are coming. Nature, 487(297), DOI: 10.1038/487297a

[14] Tanisawa, K (2019) Sport and exercise genomics: The FIMS 2019 consensus statement update. British Journal of Sports Medicine, 969-975, 54(16), DOI: 10.1136/bjsports-2019-101532

Education:

Over a thousand genes have been identified that relate to educational and cognitive outcomes. However, it is very difficult to accurately predict a given pupil's educational performance using currently available polygenic scores.

Despite this, DTC genomic testing companies are expanding into education-relevant fields and marketing these tests to parents. Three DTC genomic testing providers were offering genetics-informed IQ tests from a saliva sample in 2018[15]. **It is not clear how much traction these tests will gain with parents, or what support teachers will need in response to parents using them.**

1,100
No. of genes currently thought to influence educational attainment.

Used effectively, one benefit of using polygenic prediction is that genomic data can be measured at birth, before other data used by educators is available. This means that it could enable **earlier interventions** to improve educational outcomes. This could include identifying students in need of academic support, **designing learning approaches**, or helping pupils with **learning disabilities**. However, there are **no regulations in the UK governing the use of genomics in education**, and their use could lead to stigmatisation of pupils.

Criminal Justice:

Some gene variants have been associated with behaviours linked to criminal behaviour. Variants of the MAOA and CDH13 genes have been associated with **aggressive behaviour**, and whilst substance abuse is not always a crime, **addictive behaviours can also be heritable**: cannabis addiction, alcohol dependence and cocaine use disorders have heritability estimates of 51 to 59%, 48 to 66%, and 42 to 79% respectively[16]. Developing polygenic scores for susceptibility to substance abuse is a real possibility.

Genomic data has been raised as a **mitigating factor** in a small number of criminal cases in other countries, and this may become more common as the genomic evidence base improves, but there is no precedent for it in the UK. Youth services, social services, or the police may seek to explore the use of genomic prediction to **deter or divert those who may be predisposed to criminal behaviour**. However, polygenic scores are only an estimate of the likelihood of a particular trait manifesting, and **our genes are only one of many influences** on behaviour, including criminal behaviours. It also conflicts with the presumption of innocence, which is fundamental to our system of justice.

5-10%
of criminals convicted for severely violent crimes in Finland possess MAOA and CDH13 gene variants.

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[15] Regalado, A (2018) 'DNA tests for IQ are coming, but it might not be smart to take one. MIT Technology review. Accessed 25 June 2021.

[16] Agrawal, A (2012) The genetics of addiction—a translational perspective. Translational psychiatry, 2(7), DOI: 10.1038/tp.2012.54

Insurance:

Insurers might seek to use polygenic scores for heritable behavioural characteristics (such as **risk-taking behaviour**) and physiological factors (such as **susceptibility to injury**), to **inform insurance policies** in the future. This could impact on individuals' car, home or even holiday insurance policies. Improvements in the accuracy and specificity of polygenic scores could make them more useful for insurance, however these uses would have to overcome public resistance. The UK insurance industry currently follows a **voluntary code** setting strict **limitations on the use of health-related genomic information** in determining eligibility for insurance.

The increased availability of DTC genomic tests could also increase **information asymmetry** between insurers and their customers. If consumers are aware of their genomic predispositions, but do not have to declare these to their insurer, they may affect insurance companies' ability to accurately assess risk and price their products appropriately. Research has predicted that **critical illness claims could increase by an average of 26%** if the use of genetic information in underwriting is not permitted[17], though this is the subject of some debate.

The risks and opportunities of genomic data

Developments in genomics are changing how we conceptualise privacy and anonymity, with implications for data security in both research and commercial (i.e., DTC) genomic databases. **Genomic data is valuable information** so should be protected, and the risks to privacy are **not limited to the individual**; their immediate family and close relations may be affected by any disclosure, for example if they share the risk of a health condition which might affect their insurance. DTC genomic testing therefore poses privacy risks of which its **customers might not be fully aware**.

Research projects are seeking to maximise the utility of large genomic datasets whilst minimising the risk to individual privacy. They use a **variety of approaches**, including mediated access to data through dedicated portals, and data encryption schemes. The privacy and security measures employed by these databases represent best practice. **Policymakers and other processors of genomic data could learn from this approach and improve the protection of UK citizens' genomic data.**

Despite the commendable approach of research databases to uphold privacy and security, they (along with third party genomic databases and DTC genomic companies) operate under a **patchwork of regulations and laws**, including those on consumer protection, data protection, the human tissue act, medical device regulations, and advertising guidelines[18]. This complex situation does not provide clarity to the organisations that curate and run the databases on their obligations to

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[17] Howard, R (2016) Genetic Testing Model for CI: If Underwriters of Individual Critical Illness Insurance Had No Access to Known Results of Genetic Tests. Canadian Institute of Actuaries. Accessed 21 June 2021.

[18] House of Commons Science and Technology Committee (2021) Direct-to-consumer genomic testing – first report. Accessed 28 June 2021.

protect this data, or to provide reassurance to people volunteering their genomic information.

Genetic material and genomic sequences represent **useful intellectual property**. However, the question of whether genes can or should be patented remains **controversial**. Companies contend that their genetic discoveries are valuable assets that should be protected, whilst others see this as a land grab for a natural resource. Possible impacts of patenting genetic material include **limiting open research**, and the potential for **increased costs for medical tests**. Policymakers should consider **whether the current system encourages innovation** amongst biopharmaceutical companies, or if enhanced patent rights might limit research as we understand more about the genome.

Public opinion is generally positive about the potential benefits of genomics, particularly around forensic science. However, there are some **'red-lines'** where the public feel genomics could disadvantage vulnerable people, and are wary of private businesses accessing their genomic information.

Conclusion

Genomics is already part of our daily lives. The UK's strength in genomics has been integral to our ability to monitor the transmission of COVID-19 and identify new variants of the virus. We are still in the infancy of understanding the complexity of genomic data, and its place within a rich context of social and environmental influences, but this **very rapidly changing**.

We have worked with over 30 subject and policy experts from within the science and technology sectors, academia, and across government to develop our report. They have helped us to understand the current landscape of genomics, and the **reality of what we can and cannot learn from genomic data, now and in the future**. Their expertise has ensured that our report reflects the current evidence base on genomic science and its applications.

The rapid technological and scientific advances in genomic science mean that **genomic data and its potential applications are increasingly relevant to policymakers**. The public are also starting to gain exposure to genomics through the healthcare system, and through DTC genomics companies offering a range of genomic services. Given the increasing deployment of genomic science in many sectors, **regulations need to keep pace with the science**, particularly outside the healthcare sector.

Proactive policy on genomics across sectors may be needed to protect UK citizens' privacy, anonymity, and the security of their genomic information. Applications of genomics are likely to proliferate as the science progresses and technological barriers are overcome. **It is important that policy is informed by the ethical and legal challenges that may arise, and that the legal framework is able to respond to these developments**.

As our understanding of genomic science improves, governments around the world will face three key decision points:

1. **Whether and when it is appropriate to use genomics to inform policy or deliver services**. Each decision will require careful consideration of the ethics and any unintended consequences that could arise. There is an overarching need to address the lack of non-European ancestry in genomic data, or risk entrenching or increasing structural inequalities.

2. **Whether the complex mix of laws, regulations and voluntary codes that currently governs genomics outside of healthcare settings remains fit for purpose**. As potential applications of genomics increase, with implications for more sectors and lives, this question will become urgent. A structured framework governing the collection and use of genomic data outside of health could help protect citizens and provide clarity and certainty to innovators. However, over-regulation risks stifling innovation, and striking a balance will be key to making the most of genomics.

3. **How to bring the public into decisions about using genomics and supporting them to navigate the consumer market**. If governments hope to make more use of genomic data, that will ultimately need the public's consent. As the number of tests grow, so too will the potential consequences for citizens of nefarious uses of genomic information or misinterpreted results.

There are no certainties as to how genomic technologies will develop, or how people might *attempt* to use genomic information. However, the direction of travel is becoming clearer. **Now is the time to consider what *might* be possible, and what actions government and the public *could* take** to maximise the benefits and mitigate the risks of our growing knowledge in this field.

The scope of our report

Genomics is not just a health policy issue. It could impact a huge variety of policy areas, from education and criminal justice to employment and insurance. Our report focuses on human genomics outside the health sphere. It also explores genomic applications in agriculture, ecology, and synthetic biology, to provide a sense of the breadth of its potential use in other sectors.

There is a huge amount to cover and consider, not all of which can be included in our report. Rather, we hope that it provides the basis for discussion within government departments and enables futures-focused exploration of potential scenarios.