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Genetics and early intervention

Exploring ethical and policy questions

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About EIF

The Early Intervention Foundation (EIF) is an independent charity established in 2013 to champion and support the use of effective early intervention to improve the lives of children and young people at risk of experiencing poor outcomes.

Effective early intervention works to prevent problems occurring, or to tackle them head-on when they do, before problems get worse. It also helps to foster a whole set of personal strengths and skills that prepare a child for adult life.

EIF is a research charity, focused on promoting and enabling an evidence-based approach to early intervention. Our work focuses on the developmental issues that can arise during a child's life, from birth to the age of 18, including their physical, cognitive, behavioural and social and emotional development. As a result, our work covers a wide range of policy and service areas, including health, education, families and policing.

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Introduction

Should information that can be found in our DNA be used to support better outcomes for children? While this might sound like science fiction right now, given the pace of scientific discovery and technological progress, the potential to use genetic data to inform the design and delivery of early intervention might realistically become possible in the coming years.

We have known for many decades that differences between humans in all traits – such as cognitive ability, anxiety and conscientiousness – are partially influenced by DNA differences between individuals. In recent years, geneticists have been able to identify DNA variants that appear to be associated with specific traits and characteristics, and to make rough predictions about future outcomes. This means it is becoming increasingly possible to identify – from birth – children who may have an elevated likelihood of outcomes such as struggling at school or being diagnosed with a learning, behaviour or mental health condition.

While such predictions are far from perfect, they do appear to be meaningful. At EIF, our mission is to ensure that effective early intervention is available and used to support children and young people at risk of poor outcomes. To achieve this, it is important that services can identify all children who are at risk of experiencing challenges as they grow up. On the face of it, genetic data – alongside demographic or diagnostic data – might help with this process of identification.

However, incorporating DNA data into early intervention policy or practice would raise ethical questions that are profound and which, given the speed of progress in this area, need to be debated urgently. As an organisation, we are clear that genetic data could only ever be used in early intervention if it has been comprehensively demonstrated that it is safe, effective and ethically justifiable to do so.

So, we set ourselves the following question: **Can genetic data be used to improve outcomes for children and families, without marginalising individuals, entrenching disadvantage or increasing inequalities?** To explore these issues, we convened a series of workshops with experts from a wide range of backgrounds. In this report we set out the key risks and challenges they identified, and highlight areas of consensus and disagreement.

The issues we discuss here are not science fiction but, rather, realistic choices that society will face in the coming decades. We feel that a full and open debate on how society will respond to and address these issues is needed, and so we conclude our report with a set of recommendations – for the political, social policy and research communities – about how to build on this project and make progress in planning 'a collective response to the opportunities and challenges associated with genetic research in relation to early intervention.

Part 1: Background

What does genetics tell us about behaviour?

We have known for many decades that genes and environments, and the interplay between them, explain why individuals differ in many aspects of their behaviour, including personality, intelligence, mental health and motivation. These aspects of behaviour, in turn, play a critical role in shaping children's life-chances.[1]

Understanding heritability

Almost all human behavioural traits are, to some extent, heritable. What does this mean? When a trait, such as motivation, is described as being 50% heritable, it means that 50% of the differences within a sample of people in how motivated they are can be explained by differences at the level of DNA.

Our understanding of heritability, derived primarily from twin and adoption studies, has served important purposes, including comprehensively overturning narratives of blame – usually focused on mothers – around conditions such as schizophrenia and autism, by showing that most of the likelihood of developing these conditions can be explained by genetic rather than environmental factors.

It is important to note that heritability is a population-level statistic, and therefore doesn't tell us anything useful about a single individual. It does, however, tell us how well we could predict a characteristic, such as motivation, from DNA in a particular context – because heritability differs in different environments – if we were to identify all of the relevant genetic variants (a goal which remains a long way off). This gives us a different perspective on how we might be able to support the development of traits that, as a society, we most care about. While we can intervene to support the development of traits regardless of their aetiology – that is, regardless of where their origins lie – it is nevertheless true that understanding the proportions of variance explained by genetic and environmental factors offers a lens for considering different intervention options.

Twin and adoption studies

Twin studies are a natural experiment that work by comparing monozygotic (identical) with dizygotic (fraternal, or non-identical) twins. Monozygotic twins share 100% of their DNA, give or take a rare mutation here and there, while dizygotic twins share 50% of their DNA, the same as non-twin siblings.

The different level of genetic similarity between these two groups has provided psychologists with a unique window on the genetic and environmental landscape. If monozygotic twins are more similar to each other than dizygotic twins on any given aspect of behaviour, this

[1] For definitions of key terms, please see the glossary at the end of this report.

indicates that genes are involved, because the defining difference between the two groups is their degree of genetic similarity.

The twin design therefore allows us to estimate what proportion of individual differences in a specific trait can be explained by DNA differences, but also what proportion can be explained by environments that affect siblings in the same way, and what proportion can be explained by environments that only affect one sibling. Understanding what underpins traits in this way can potentially guide us towards more effective interventions.

Adoption studies work in a similar way, by comparing the similarity of offspring with both their biological and adoptive parents. If children adopted at birth are more similar to their biological parents than they are to their adoptive parents on any given aspect of behaviour, then this indicates a role for genes. These studies report very similar findings to twin studies.

Thus, the finding that pretty much all traits are to some extent heritable – 49% on average – is well established, trustworthy and robust, having been replicated many times and in many different settings.[2] However, it is a finding that was for many years disputed by some. This is partly because of the damaging legacy of eugenic policies, such as forced sterilisations, implemented in many countries during much of the 20th century. And for many years, little progress was made in identifying the genes that would explain the heritability estimates coming from twin and adoption studies.

Polygenic scores

Complex human traits are never explained by just one gene.[3] Over time, geneticists have come to understand that behaviour is explained by many genes, each having a tiny effect, working in conjunction with each other and with the environment. Untangling the secrets of the genome has therefore proved more complex than anyone thought it would be prior to the completion of the Human Genome Project in 2003. However, progress is now being made in the form of genome-wide association studies (GWAS), a development that has led some to argue that we are living through a 'DNA revolution'.[4]

Genome-wide association studies work by scanning genomes from very large samples and identifying individual variants that are statistically associated with a trait of interest. These genetic variants, while individually explaining very little, can be combined into polygenic scores – a composite of all of the variants that have been found to be associated with the trait in question – which have more explanatory power.

EA3: a powerful predictor of educational outcomes?

The most powerful polygenic score to date is known as EA3, where EA refers to educational attainment.[5] This polygenic score is made up of more than 1,000 genetic variants and was derived from a sample of 1.1 million participants.[6] It can explain 11–13% of differences between people in how long they stay in education, and 7–10% of differences in cognitive ability.[7] In a UK context, it has been found to explain 14% of individual differences in GCSE attainment.[8]

2 Polderman et al., 2015.

3 Unlike rare single-gene disorders such as Huntington's disease, for example.

4 Plomin, 2019.

5 Also sometimes known as EduYears.

6 Lee et al., 2018.

7 Allegrini et al., 2019.

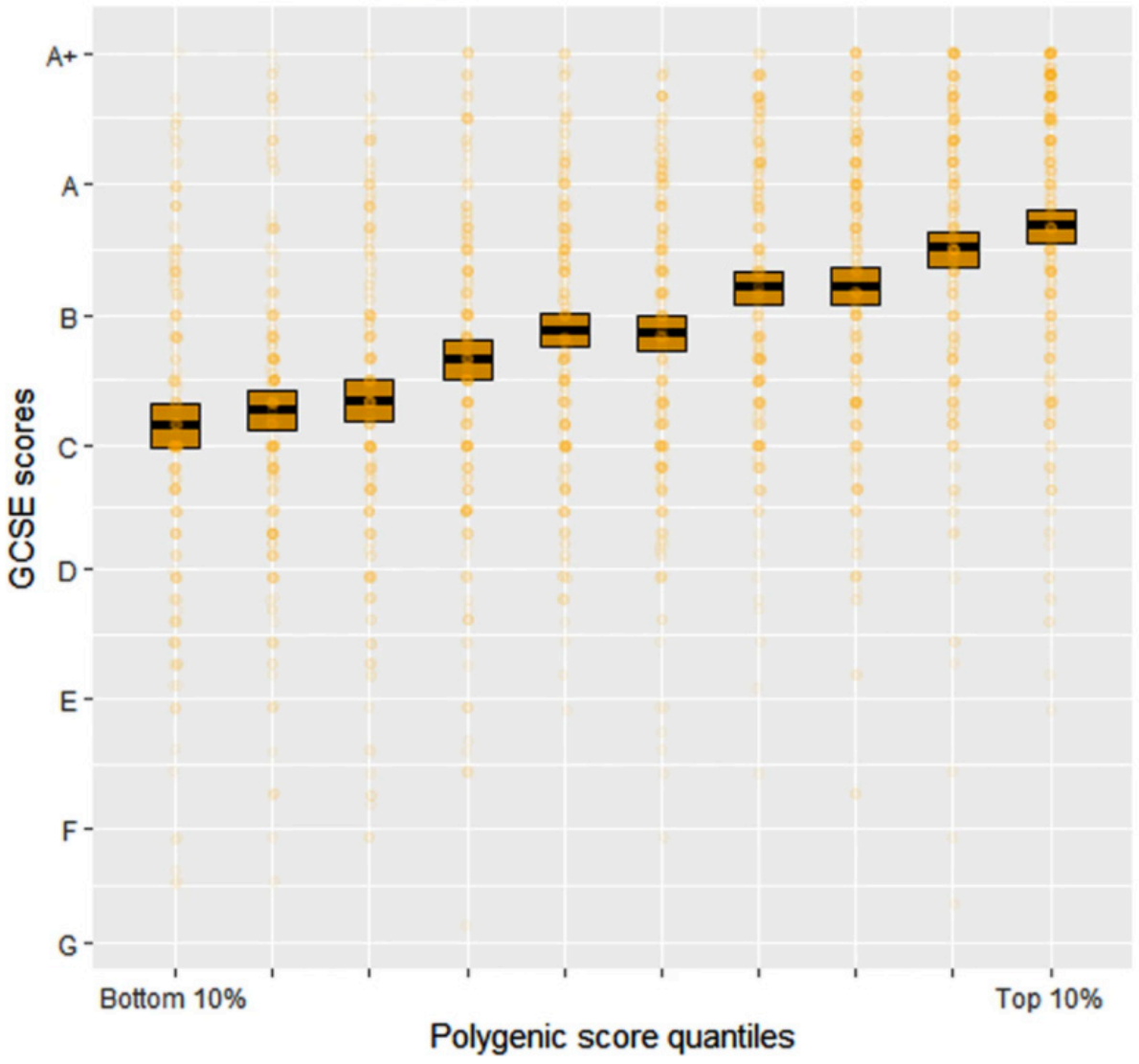
8 von Stumm et al., 2020.

It is difficult to deny that this is a meaningful level of prediction, similar to some other measures that are commonly used in social policy, such as family income. However, as figure 1 illustrates – where each dot represents an individual's polygenic score and GCSE grade – these predictions are far from perfect. For example, while those in the top 10% of EA3 scores do better on average in terms of GCSE results (with an average grade of A) than those with the lowest 10% of EA3 scores (average grade of C), there is a lot of variation around these averages, with some people in the top decile achieving *lower* results than those in the bottom decile of the distribution.

This research is ongoing, and with a larger sample (3 million participants), EA4 will explain more of the differences between individuals than EA3.[9]

FIGURE 1

Variation in GCSE results by EA3 score



Source: Allegrini et al., 2019

[9] Okbay et al., 2021.

It is important to note that, in addition to the general conceptual, practical and ethical issues that we describe and discuss in this report, there are limitations in the research on EA3. We have already mentioned two: that polygenic scores are reliably predictive at the group level but not at the individual level, and that the heritability of a trait differs in different environmental contexts.

Beyond this, it's also the case that other measures are often more predictive and don't share the same ethical concerns as polygenic scores: prior attainment, for example, captures biological and genetic influences and tells us much more about educational performance in children and young people than EA3 scores.[10] This is why some argue that if polygenic scores are likely to have value, it will be in the context of very early intervention during the preschool years, before other types of data (such as prior attainment) become available.

Another issue centres on genetic nurture: the idea that parents' genes affect their children's behaviour even when they are not passed on biologically, through the rearing environment that they create. This is equivalent to another construct in behavioural genetics, passive genotype–environment correlation, which describes how a child's environment is influenced by their parents' genes as well as their own. For instance, if a parent is genetically predisposed to love reading, they may fill their home with books. In this way, their child will benefit from sharing their DNA with the parent but also from the environment the parent has created. Equally, a parent who is genetically predisposed to antisocial behaviour passes on their genes to their child and also influences their home environment.

Finally, and perhaps most importantly in terms of these limitations, the 1.1 million participants who contributed DNA to the GWAS that identified EA3 were of European ancestry, and therefore EA3 – like other polygenic scores – has substantially less predictive power for those with non-European ancestries.[11],[12] This is a common limitation of GWASs, and geneticists are working hard to recruit a significantly more representative sample of the world's population into genetic studies, as well as developing methodologies to combine samples of different ancestry groups into single studies. Achieving this is an essential prerequisite to using genetic data in early intervention.

What next?

Children and adults differ from their peers for both genetic and environmental reasons, and scientists are beginning to identify some of the specific genetic factors involved. Research using polygenic scores is still at a relatively early stage, but it is moving very quickly. As it does so, it is throwing up fundamental questions about whether we want to use DNA data to predict behaviour and outcomes – and, if so, how this could be done in an ethical and well-regulated way that is beneficial to all.

[10] Morris et al., 2020.

[11] Martin et al., 2019.

[12] Duncan et al., 2019.

Part 1: Background

What contribution could genetic research make to early intervention?

Genetic research is thriving, and scientists around the world are working hard to build polygenic scores for a wide range of vital traits, including heart disease and diabetes, as well as those that are important to the field of early intervention, such as educational attainment and psychiatric or neurodevelopmental conditions. There is a lot of work to be done to increase the predictive power and precision of polygenic scores, not least because those that we have currently can predict well at the group level but not for individuals. Now is the time to figure out whether and how we might want to use these scores. We must take this opportunity to put appropriate safeguarding measures in place and to consider the ramifications of incorporating DNA data into social policy.

At EIF, we are dedicated to ensuring that high-quality evidence is used in the design and delivery of policies for children at risk of poor outcomes. When considering emerging genetic research, the question is not *if* our DNA influences the outcomes we are interested in – the evidence is clear that it does – but **whether such evidence can be used to improve outcomes for children and families, without marginalising individuals, entrenching disadvantage or increasing inequalities**.

To be clear, the focus of our investigation is on the potential of using genetic information gathered after birth, not prior to either birth or conception – although these are separate and important questions.

Our ability to understand the contribution that genetic variants make to a range of outcomes – such as school achievement, predisposition to mental ill health, or specific developmental conditions, such as dyslexia, autism spectrum disorders (ASD) or attention deficit hyperactivity disorder (ADHD) – is growing rapidly. As the science advances, our ability to use this data to identify and support those with an elevated probability of experiencing these outcomes will improve. If we define early intervention as providing support before issues become acute, entrenched or problematic, then using a DNA-based measure of risk – information which is available from birth and fixed throughout life – has some appeal. However, as we set out later in this report, the predictions derived from current screens are quite imprecise, and will produce a lot of false positives – children identified as having an elevated risk who do

It is important to acknowledge that neurodiverse outcomes such as ASD or ADHD should not exclusively be viewed as problems. ASD and ADHD presentation can be perceived very differently by different individuals and their families, and the degree to which these profiles may cause difficulties or confer strengths also varies. Our focus here is on whether the identification (via DNA) of an increased probability of being neurodiverse would lead to early intervention and support being made available that would be beneficial to, and welcomed by, those with ASD, ADHD and other diagnoses.

not go on to develop the outcome – and false negatives: children identified as not having an elevated risk who nevertheless do go on to develop the outcome.[13]

In theory, DNA data identifying babies and young children as being at elevated likelihood of outcomes that might benefit from high quality early intervention could be used in two broad ways:

- to target interventions directly at those at elevated risk
- to provide more regular assessment and monitoring to those at elevated risk, so that support can be provided should issues arise.

Given the current lack of precision and the fact that environmental factors also have a significant impact on outcomes, it seems intuitively obvious that polygenic scores should not be used to target interventions directly. However, they could possibly be used in combination with other known risk factors to identify children who may benefit from regular monitoring.

That said, many early intervention services are provided on a 'targeted indicated' basis, which we define as the provision of services based on increased risk on the grounds of broad personal or social factors, such as economic disadvantage. Examples of services provided on a targeted indicated basis include the provision of 15 hours of free early education for children in England in the bottom 40 per cent of the income distribution, or the pupil premium funding awarded to schools, which is based on the number of pupils who are eligible for free school meals or have been looked after by the state.

Inherent to the provision of targeted indicated services is the idea that it is preferable to provide the intervention on the basis of broad indicators of risk than it is to provide them to everyone (universal services) or to wait until specific needs arise (targeted selective services). Given this, there is some reason to believe that policymakers and the public may be comfortable with the targeting of services on the basis of risk – based on DNA or other factors.

It bears repeating that no behaviour is 100% heritable. This means there is a limit to how accurate any polygenic score can be: they are probabilistic indicators that can only ever identify individuals who have an elevated probability of an outcome or condition in a particular environmental context.

We should also avoid thinking of genes as being deterministic in their effects. While we can't change an individual's DNA, we can influence the environment they live in, and there are good reasons to think that support and intervention can mitigate an underlying genetic risk. Just because short-sightedness has a substantial genetic component does not mean that it cannot be mitigated with glasses or contact lenses, which serve as a relatively cheap and simple environmental intervention.

[13] In places we use the words 'risk' and 'probability' interchangeably in the interests of readability and accurately representing our workshop discussions, but we have tried to make our intention clear.

Part 2: Opening up the debate

The ethics of using genetics in early intervention

The use of genetic information in early intervention, or social policy more generally, raises enormous ethical concerns. These include:

- Would using genetic data be equitable, or would it marginalise or further disadvantage groups which already experience structural inequalities?
- Is genetic data different to other forms of data about an individual, therefore requiring different considerations and regulations?
- Is it ethical to target policies on the basis of risk rather than diagnosis?

Given the enormity of these issues, the pace at which the science is advancing, and the increasing public and policymaker interest in the influence of genetics on social and psychological attributes, now is the time to begin a discussion on whether and how genetic data might be used in social policy, and in early intervention in particular.

In structuring this discussion, we were guided by the following principles:–

The use of genetic data in early intervention and social policy will only be ethically justifiable if:

- **it is used to support children who have an elevated risk of poor outcomes or an increased likelihood of facing greater levels of challenge than their peers**
- **participation is based on fully informed consent**
- **it does not discriminate against individuals or violate their human rights**
- **it can be used to improve outcomes without marginalising individuals, entrenching disadvantage or increasing inequalities**
- **it is not used to justify prejudice against any group or to reinforce scientifically invalid theories, such as eugenics or assertions of biological race; and**
- **there is a high degree of public engagement with and support for its use, including from marginalised and minority communities.**

Part 2: Opening up the debate

Our approach

The key question we set ourselves was: **Can genetic data be used to improve outcomes for children and families, without marginalising individuals, entrenching disadvantage or increasing inequalities?**

We set out to address this through a series of workshops with expert participants drawn from a wide range of backgrounds.

These four workshops each centred on an aspect of the debate on using genetic information: social policy, intervention design, ethics, and ancestry. Each lasted for 2.5 hours and involved a facilitated discussion around key issues.

The first three workshops – on policy, interventions and ethics – followed a similar overall structure, opening with a presentation that offered an introduction to findings from genetic research and a discussion of the central question among the whole group.

Then, the workshops broke into smaller groups to discuss the issues in the context of two hypothetical scenarios:

- The first scenario considered a hypothetical genetic screen that could explain 30% of the variation in educational attainment across all ancestry groups, and asked whether this should be used as part of school-level funding and accountability, in much the same way that eligibility for free school meals is used currently.
- The second scenario considered a hypothetical genetic screen that could identify increased risk of developmental disorders (such as ASD, ADHD or dyslexia), and asked whether this should be used to identify children with increased probability of diagnosis, with a view to intervening to provide appropriate support at an early stage.

The final workshop was somewhat different. The science of genetics has a long and difficult association with issues connected to ancestry, including eugenics and aspects of far-right ideology. While these themes arose and were discussed in all our workshops, we felt it was important to dedicate an entire session to these issues. In collaboration with experts in this area, who provided guidance on the design and delivery of the content, the final workshop focused on the following questions:

- Can genetic data contribute to our understanding of human development without exacerbating structural inequalities?
- If we want this science to advance, we need data from samples that are representative of society. How can we encourage wider participation from those who are not of European ancestries?
- Could behavioural genetics ever be used in social policy in a way that would reduce inequality rather than exacerbate it – for example, by providing objective information on underlying origins of differences?

Throughout the process we took steps to include a wide and diverse range of views and to consider fully the ethical risks associated with the use of genetic data in early intervention policy. Prior to the workshops, we undertook a literature review to identify the main ethical concerns previously identified, which we used to shape the design and facilitation of the workshops.

The workshops themselves brought together experts from a wide range of fields, including education, ethics, genetics, law, social policy, sociology and psychology.[14]

Building on the principles stated above, we were transparent throughout that although we did not have a prior position in favour or in opposition, and wanted to encourage open debate and discussion, we would only see the use of genetic information as ethically justifiable if such approaches did not marginalise individuals, entrench disadvantage or increase inequalities.

The following chapters highlight three general themes that emerged from our discussions, followed by further reflections on the two scenarios that we used to explore and test our principles, perspectives and hypotheses. In all cases, participants' comments are drawn from discussions across all workshops, and not from any single session in particular.

[14] See the appendix to this report for a list of workshop participants.

Part 3: Three key themes emerging from our discussions

In all four workshops, the discussions were rich and nuanced, ranging across important issues, many of which we had anticipated but some we had not. It is not possible to summarise everything that was said, but in this section we set out the most important and consistently raised issues and messages.

Theme 1: Enhancing public and policymaker understanding of genetic research is a key priority

We did not explicitly ask participants about public understanding of genetic research, and yet this came up in every workshop as one of the most prominent topics of discussion. The consensus was that knowledge and understanding is very low, including among policymakers, and this view is supported by evidence.[15] Workshop participants expressed concern about low knowledge and understanding as substantial barriers to progress.

It was recognised that general interest in genetics is high, as a potentially controversial topic that relates to us all. Public and policymaker interest represents an opportunity, because people are open to having a discussion, but also a threat, in that views are often subject to embedded misconceptions, bias and a lack of trust in science and policy that could be challenging to overcome.

Low public knowledge and understanding of genetics is a barrier to progress

Workshop participants argued that since we know that public knowledge and understanding of genetic research and its implications is very low, we have a duty to educate key stakeholders before even considering widespread DNA screening or the incorporation of DNA data into any aspect of social policy. To not do so would exclude the majority of the public from participating in an informed way in decision-making that will have important consequences for them.

However, it was acknowledged that public communication and education in this area is extremely challenging. In the first instance, this is because the science is complex and often expressed in inaccessible language – but also because it is a work in progress and constantly evolving. That findings contravene deep-rooted beliefs for some exacerbates the public education challenge. There was also concern that the complexity of the research is

[15] Chapman et al., 2019; Crosswaite & Asbury, 2019; Selita et al., 2020.

not easily reduced into media-friendly soundbites, and that people form views and make decisions on the basis of limited and quickly digested information, rather than the kind of deep understanding and careful reflection that is needed. In this context, ensuring that messaging around genetics works effectively and responsibly is difficult.

Some participants argued that it is too soon for public communication and education. They proposed that geneticists should wait until they are communicating more settled and 'application-ready' findings, when the mechanisms by which genes influence behaviour are better understood.

Others responded that the public already accepts many medical and social interventions without knowing how or why they work. And, furthermore, genetic research is already relevant and in the public domain, so scientists have a responsibility to raise understanding and to challenge misinterpretations and unjustified applications now.

There was a strong sense that government interest in genetics is a mixed blessing, largely because of concerns about policymakers' limited knowledge and understanding in combination with their power to develop and roll out policy. In essence, all of the concerns that were expressed about knowledge and understanding among the general public were seen as applying to policymakers too. However, it was viewed as even more important that policymakers gain a nuanced understanding of this complex information. Some participants argued that an education programme targeted directly at policymakers would be valuable, although it was recognised that there may be little appetite for this.

Misconceptions are widespread

In addition to low knowledge and understanding, there was strong concern about the potency of misconceptions, the most prevalent of which relates to genetic determinism, or the notion that genes cause behaviour and there is nothing we can do about it. Across all workshops, participants agreed that this misconception is widely held in spite of being unsupported by the science – which says that genetic risk is probabilistic rather than deterministic, and that it operates via a complex interplay with the environment to affect individual differences in behaviour. Enhancing public understanding of this interplay between genes and environments, and dispelling ideas about determinism, were cited as the key priority for public communication and education.

Some argued that a further goal should be to 'change the narrative' so that the heritability of behaviour is understood as a positive rather than a negative. It was felt that people are afraid of the predictive power of genes, in a way that they are not afraid of the predictive power of environments – even negative ones – and that altering this view to align with the evidence is an important public communication challenge. Explaining that genes do not operate deterministically and that our genetic diversity is something to celebrate is part of the story that needs to be told.

Public trust is low

Participants talked about a queasiness that comes with linking genetics to human behavioural traits such as intelligence and attainment, a discomfort that is clearly related to the history of eugenics. It was acknowledged by participants that while all branches of science are open to misuse, genetics has proved more susceptible than most. It is vital that this history is acknowledged in any public engagement on the topic, and that diverse stakeholders work together to ensure that modern genetics does not repeat the abuses of the past. The success of such a collaborative endeavour will be dependent on good public knowledge and understanding, and openness from scientists and policymakers, and will require trust to be developed and maintained: a formidable public engagement challenge.

People described how the queasiness that is felt around this topic becomes even stronger when genetics is discussed in the context of groups that have been systematically discriminated against in the past by both science and policy. For example, it was considered that some minority ethnic groups might resist steps towards bringing advances in genetics into policy, and indeed may resist participating in genetic research, because of a fear that such research will be misused or applied with the end result of harming rather than furthering their interests. It was noted that we have recently seen evidence of this type of distrust during clinical trials for Covid-19 vaccines.

There is also likely to be a lack of trust from people with disabilities and the groups that represent their interests. This stems from previous experiences of being othered. For example, people with schizophrenia have often been presented as a danger to society – a message which feeds prejudicial attitudes and misconceptions. People with learning disabilities are known to be subjected to hate incidents far more commonly than other members of society, with some estimates rising to 88%.[16] This risk is heightened in the context of genetic prediction of outcomes, and therefore it will be essential to consult widely in the disability community to understand concerns about how polygenic scores might be used or misused. Again, it is vital to build trust and to treat public engagement as a genuinely two-way enterprise, if good understanding is to be achieved and progress is to be made.

Many of our workshop participants were mistrustful of the ways in which governments and policymakers might use this science. While in part this relates to concerns about low levels of understanding, as described above, it was also centred on policymakers' priorities and intentions. For example, there was a concern that policymakers tend not to be embedded in the communities that could be most negatively affected by certain developments – such as disadvantaged, disabled or minority ethnic communities – and that a perceived 'us and them' attitude could exacerbate existing disparities.

Despite these concerns there was also a view that there has been a major shift in perceptions of behavioural science during the last decade, and that genetics has become less taboo as a subject than it once was. We are seeing higher levels of openness but, given the trust issues we have described, it is still important to proceed with great caution. In essence, the timing is good for clear public communication, education and engagement, but its success will depend on establishing trusting relationships between different groups of stakeholders.

DNA may differ from other forms of data, and we should recognise its sensitivity and potential misuse

Some participants expressed a view that there is no reason to elevate the significance of genetic data above other forms of personal data, such as demographic or digital data, and that it is important to ward against 'genetic exceptionalism'. Others, however, argued that while DNA data may not be special, it is nevertheless different, and that its unchanging nature, coupled with the speed at which our understanding of its influence on individual differences is developing, means we need to think carefully about the implications of that difference.

Participants raised specific questions about the ownership and use of DNA data gathered by direct-to-consumer testing companies, suggesting an underlying concern that DNA data requires new forms of regulation precisely because it does differ from other forms of data. This also represents a public communication challenge, in that consumers need to fully understand the long-term implications of purchasing a commercial genetic test.

[16] See: https://www.mencap.org.uk/blog/four-things-you-probably-didnt-know-about-disability-hate-crime

Across the workshops, the argument was consistently made that we shouldn't assume that the use of genetic data by policymakers and politicians will be benevolent, with a number of people raising concerns about how governments might choose to use DNA data they hold in the future. Again, this suggests an underlying concern about the need to put new safeguards in place for the retention or use of this sort of data.

However, it is worth noting that the gathering of genetic data is already common in some countries. The Estonian Biobank, for example, has recruited over 20% of the adult population to enable DNA data and full electronic health records, and has a vision to genotype every adult for the purpose of developing personalised medicine.

Low public trust may be a stronger barrier in the UK than elsewhere, and this will need to be better understood and considered in any communication strategy or data protection plan.

We need to identify the optimal methods for communication

Participants reflected on how the challenges they identified could be addressed, but there was general agreement that scientists share responsibility for addressing them.

One clear message was that the communications programme should not begin with issues relating to using polygenic scores for predicting individual outcomes. Instead, it needs to 'take a big step back' and focus on explanations for individual differences in traits such as specific learning difficulties and behaviour problems. Some participants described a lack of compassion shown towards children who struggle with self-regulation, attention and schoolwork, and argued that improving public understanding of the biological basis of these traits would be a very good starting place for a sustainable public communication strategy. By helping people to understand that it is harder for some children to behave in the same way as typically developing children, and that this is partly for biological reasons, we might gradually pave the way towards communications about polygenic risk for certain outcomes, while also supporting particularly vulnerable members of society. In a similar vein, education about how parents may struggle with the same challenges as their children – again, partly for biological reasons – could demonstrate the case for more targeted interventions and support, and potentially make society a little kinder.

Regardless of the message that is to be conveyed at a particular point in time, participants agreed that work is needed to make the language of behavioural genetics accessible to all. We haven't yet come up with straightforward ways of explaining heritability or polygenic risk, and addressing this is a crucial science communication challenge.

As mentioned, collaborative two-way communication will be a key to making headway. This is not simply a case of 'getting the message out', but of careful listening and working towards a shared understanding. As well as the groups already noted, it will be important to involve children and young people in these discussions, and to focus on their genetic education, as there are signs that young people may respond differently to genetic diagnosis than adults, and any decisions made will have a major impact on them.[17]

Finally, there was a strong view that we need to keep hold of the queasiness described earlier. While all agreed that public communication, education and engagement are important, we need to keep front and centre our vigilance against inadvertently repeating the past and using genetic science in a way that might be harmful to anyone, particularly those who are already vulnerable or disadvantaged.

[17] Pavarini et al., 2021; Fields & Asbury, 2021

Conclusion

In summary, there was agreement that **limited knowledge and understanding is one of the major barriers to considering the application of genetic research in social policy and that public communication, education and engagement should therefore be considered a priority for the field**. Any programme of communication, education and engagement will need to be tailored carefully to different audiences, to be genuinely collaborative, and to use language that can be easily understood by all. In this way, scientists can address gaps in knowledge and understanding, and tackle misconceptions, and will need to work closely with policymakers and communities to address issues related to low trust. It was agreed in all workshops that this would be a highly worthwhile endeavour.

Theme 2: Our current understanding is based on samples largely from people of European ancestry, and this is a problem for science and society

The fact that genome-wide association studies are based almost exclusively on samples with European ancestry presents a major challenge. The predominance of this topic in our initial three workshops was the spur for organising our fourth, which focused directly on the issue and drew on the views of participants with specific expertise on ancestry, race and ethnicity research and policy.

We need data from more representative samples

Across all four workshops, the importance of gathering DNA data from a representative range of ancestry groups was acknowledged, as was the fact that the field is working hard to achieve this. Representativeness in GWAS matters, because the polygenic scores that are identified tend to only work for the populations from which they are derived. For example, it was noted that the predictive power of EA3 scores reduces to 2–3% in samples of African American people.

> Throughout this report we use the term ancestry to describe the geographical origin of a population ('European ancestry) as distinct from social constructs such as race ('black African') and ethnicity ('Chinese'). Ancestry is generally accepted as the most objective and scientifically valid term to describe differences between population groups; although this is not to deny the importance of social definitions such as race or the existence of racism.

While it was recognised that the field is genuinely trying to address the problem, participants drew attention to two factors that appear to get in the way of progress. First, there is pressure to make GWAS samples as large as possible, in order to detect genetic variants of small effect. This pressure, while understandable, is somewhat in conflict with the pressure to slow down and put in the groundwork that diversification will require. It was generally agreed that slowing down progress in terms of sample size, in order to achieve gains in representativeness, would be an acceptable trade-off.

Secondly, it was emphasised that – in addition to collecting DNA data from diverse populations – we need to invest in enhancing methods for working with diverse datasets. Too often, data from participants of non-European ancestry is collected but then excluded from analysis, partly for reasons relating to sample sizes, but partly also because including it

in a multi-ancestry approach is complex and the optimal methods are not well understood – although good progress is being made in this area.

Unrepresentative data makes it unethical to apply findings, as this would inevitably exacerbate existing inequalities

There was a clear consensus that a lack of representativeness in GWAS data means that we should not consider using polygenic scores outside of research before the problem has been rectified, as this would risk entrenching disadvantage and increasing inequality. The integration of any polygenic score into policy – even if it can be shown to be useful – would serve a harmful purpose in benefitting one group over others on the basis of ancestry.

Workshop participants emphasised that a polygenic score captures social as well as biological realities – such as the interplay between DNA and factors such as poverty and neighbourhood. Furthermore, it was pointed out that relationships between polygenic scores are correlational rather than causal, and that the interplay between genes and environments differs between societies. For example, in a very equal society we would expect genetic factors to have more influence on outcomes, whereas in a very unequal society, in which some social or ethnic groups have access to opportunities that others don't, environmental factors are likely to have more explanatory power. This represents a wider equity challenge, as a GWAS that draws its sample from groups of non-European ancestry in the UK, US or Europe will not necessarily be equally predictive for the same ancestral group in, say, Asia or Africa.

In sum, the lack of representativeness in GWAS, and the currently limited methods of dealing with multi-ancestry data, were seen as sufficient reason to say that – even if it became a beneficial thing to do – DNA data should not be incorporated into social policy until these problems have been resolved.

Some minority ethnic groups are reluctant to participate in this type of research

It was acknowledged that some marginalised groups are reluctant to engage with genetic and medical research, often for very good historical reasons. This reluctance is likely to be driven by experience and, potentially, by a lack of diversity within the research community.

In the past year we have seen some reluctance among black and minority ethnic communities to taking part in clinical trials related to Covid vaccine development.[18] There are clear and strong historical reasons for this reluctance, which are rooted in repeated experiences of being exploited and othered in the collection of data and the presentation of research findings. There was a good consensus that we must pause to do the structural work that is required to address bias, discrimination and reductionist attitudes to race, ethnicity and identity. Without this work it is unreasonable to ask minority ethnic communities to feel safe in engaging with genetic research, and with scientific developments such as those discussed in this report.

A case was presented that one barrier to progress may be a lack of diversity within the research community, which is heavily skewed towards those of white European ancestry and where recent evidence has highlighted the negative experiences of marginalised groups.[19]

[18] Sethi et al., 2021.

[19] Bell et al., 2021.

Many participants agreed that increasing diversity among those doing the scientific research is one good way of ensuring that the right questions are being asked and populations of interest are engaged in appropriate, sensitive and constructive ways.

It was also argued that recruiting scientists with different ancestries from the UK, US and Europe is not enough: we should be aiming for global diversity. This is important, because the implications of being, say, of South Asian ancestry in South Asia are different to those of being of the same South Asian ancestry living elsewhere. As noted above, the fact that GWAS captures both social and biological realities is a problematic, confounding factor in the research. In terms of equality, it seems intrinsically unjust to work towards the development of polygenic scores that predict well for those, say, of South Asian ancestry living in Europe, but not for the population of, say, India – and so joined-up thinking across nations and continents is needed.

In summary, a lot of groundwork is required to pave the way towards a situation in which GWASs are based on representative samples, and this groundwork must prioritise clear communication and genuine co-construction of the research agenda with currently under-represented groups.

We have a problem with clarity of definitions and therefore with communication

Alongside the issues of equity, trust and co-construction outlined above, clarity and communication were identified as key areas of concern and priorities for resolution.

The language of groups and individuals that is widely used in the social and life sciences was highlighted as particularly problematic. It was generally agreed that even when geneticists talk at the level of groups, the public tends to understand at the level of individuals. To complicate things further, there seems to be an integral conflict in the messages coming from geneticists. On the one hand, most researchers in behavioural genetics and psychology are keen to share evidence that there is much more diversity within than between groups, as a way of arguing against scientific racism and emphasising that race is a social construct rather than a scientific reality. However, the message that current polygenic scores work best for White Europeans, and that we specifically need DNA data from members of minority ethnic groups, appears to undermine this. A more developed understanding and enhanced communication of what is meant by 'groups' – which groups are being referred to – is needed.[20]

A lack of confidence in communicating these ideas reflects their complexity but also the weight of their history. Many researchers in this area are reluctant to talk about race for fear of being wrongly accused of scientific racism. However, the reluctance is also informed by the concept of 'race' as a social construct with no clear biological basis, which is of limited interest to geneticists. Geneticists are interested in ancestry, but the distinction between these two terms is unclear to most people. Indeed, the problem is reinforced by the ways in which government and researchers typically collect diversity data. While it may make sense to gather self-report data on race or ethnicity as a means of tracking discrimination, this is not particularly helpful to geneticists. In discussions of genetics, in relation to minority ethnic populations, there is no shared language to employ – which presents a barrier to effective communication.

[20] Although considered a more objective concept than race or ethnicity, ancestry is a social construct where the borders between groups are fuzzy, rather than precisely defined. And while there is more genetic similarity than difference between ancestry groups, these small differences can mean that polygenic scores constructed from samples which are predominantly of White European ancestry have less predictive power when used in other ancestry groups (see Martin et al., 2019, and Duncan et al., 2019).

There is clearly a lot of work to be done in terms of developing fit-for-purpose diversity measures and communicating these issues clearly to the public. However, this is work that could transform narratives around race, ethnicity and identity – or at least contribute positively to these debates – and become a useful tool in the fight against racism. It was noted that, in order to counter racist notions supported by poorly understood or deliberately misused science, geneticists may need to become more willing to speak openly about what is known and what remains unclear.

It was generally agreed that substantive progress needs to be made on these issues before we even consider links to policy.

Conclusion

It was clear in our discussions that researchers fully acknowledge the importance of diversifying GWAS samples, but a lot remains to be done in order to achieve this. It was also clear that there is a need to effectively incentivise the change of pace that genuine diversification will require.

There was a high level of consensus that progress could be supported by further diversification of the research community, and by taking a proactive, genuine and meaningful approach to the co-construction of research and its presentation with the communities that are affected by it. Further areas for development include more sophisticated methods for analysing multi-ancestry data, and greater clarification of terms around 'groups' and ancestral differences, which might support more effective communication. Ultimately, **there was unanimous agreement from participants that any application of polygenic scores in the context of social policy will be premature so long as this diversity deficit persists**.

Theme 3: DNA data can help researchers to better understand development and identify what works to support those at risk of poor outcomes

Participants broadly agreed that there is much we do not fully understand about child and adolescent development, and that understanding the role of genes is central to making progress in this area. Many saw a beneficial role for DNA data in both scientific and intervention research.

Genetic research can enhance the evaluation of interventions

Participants welcomed a strong focus on experimental intervention research that can reveal causal relationships between experiences and outcomes. However, several participants pointed out that it is not uncommon for carefully designed interventions to show little or no effect. One explanation for this is that interventions may not work in the same way for everyone, and that divergent effects are 'washed out' when we look at average impact. We therefore need to ask what works for whom, and under what circumstances. This is where participants agreed that genetic research may add real value.

By gathering DNA from participants in evaluation studies, such as randomised control trials, we can assess not just whether interventions work better for girls or boys, or for affluent or disadvantaged pupils, but whether they work differently in the context of different genetic profiles. This additional level of nuance has the potential to significantly advance our understanding of what works for whom.

It was also acknowledged that this can be done retrospectively, adding to the value of existing research. For instance, if DNA data was to be gathered from participants in intervention studies that have already taken place, then the data from those studies could be reanalysed from this new perspective, and our understanding updated on that basis.

One concern that was raised centred on the need to consider fairness in allocating individuals to interventions. If we reach the point where it is possible to reliably predict that a child with a particular genotype is more likely to respond to a particular intervention, we need to consider what this capability means for equality of access to opportunities, and whether it might lead to widening or entrenching existing inequalities.

Also, participants argued that if researchers in genetics become increasingly involved in intervention research, they will need to be clear about how they are defining an intervention, namely as a way of responding where a child is facing a particular challenge, or as a way of preventing that challenge from arising in the first place. This is a key question that would benefit from further and deeper consideration.

Genetic research adds value to basic science research in child and adolescent development, which can guide intervention planning

Participants agreed that there is a great deal we still do not know about how children develop and how to shape society so that it supports their optimal development – or even, for that matter, about what optimal development looks like. Understanding the interplay between genes and environments will be central to unpicking some of the most important issues in developmental and intervention research. By understanding associations between genetic factors, including polygenic scores such as EA3, and other factors, such as socioeconomic status, family dynamics, peer relationships and educational opportunities, we can develop stronger hypotheses about the interventions that will benefit children and young people.

One strength of DNA data is that it does not change over time. However, because everything else does change, and because genes do not operate in a vacuum, it was agreed that DNA data will never be a sufficiently strong basis for prediction on its own (outside of single-gene disorders). It will always need to be used in conjunction with other types of data.

On this front, participants welcomed the growing trend for longitudinal cohort studies to gather DNA from their participants. In combination with rich environmental measures, it may be possible to estimate the direct effect of environmental factors, such as parental discipline, sibling interactions or parent–teacher relationships. This was seen as an excellent step towards increasing our understanding of how children develop, and what they need to help them on their way.

Don’t let the tail wag the dog

Participants argued that it is important for genetics researchers to keep their practical reasons for pursuing a potential link between genes and early intervention at the forefront of their minds, and avoid pursuing projects which, however academically interesting, have limited real world implications.

In a similar vein, it was pointed out that policy must be led by questions about problems that need fixing and how best to fix them, rather than by consideration of how we might be able to use interesting new technologies, including those based on genetic information.

Conclusion

Overall, **there was a great deal of positivity about the value that DNA data and findings from genetic research can add to scientific and intervention research**. Integrating rich data about environments with DNA data gives us an opportunity to learn more about developmental processes and to design and deliver more tailored and effective interventions. This was an area of strong consensus for workshop participants and was, with the caveats noted above, viewed as a less ethically challenging area for development than some of the others discussed during the workshops. We set out some specific recommendations for the research community in the final chapter of this report.

Part 4: Exploring two hypothetical scenarios

In addition to identifying these important overarching themes, we explored benefits and risks associated with the use of DNA data in two hypothetical scenarios.

Scenario 1: Using polygenic scores to identify those at risk of poor educational attainment and to make school funding decisions

Although potentially useful in the future, there are currently significant risks to using polygenic scores to identify those at risk of poor educational attainment, and to making policy or funding decisions on this basis.

We know that some groups of children perform better in education, on average, than others. In England, many aspects of educational policy have been designed to try to address this attainment gap. For example, the pupil premium provides additional funding to schools for each pupil who has been in receipt of free school meals (FSM) in the last six years, or been looked after, adopted or taken into care. The government states that the purpose of the premium is to provide additional funding to schools to help them improve the attainment of disadvantaged children, noting that evidence shows that children from disadvantaged backgrounds 'generally face extra challenges in reaching their potential at school, and often do not perform as well as their peers'.[21]

We set out to explore whether workshop participants thought that those with a low polygenic score for educational attainment should be eligible for the pupil premium or another similar top-up, on the basis of potentially facing increased challenges relative to their peers.

Since EA3 explains a similar level of variation in educational outcomes as some measures of family income, there is good reason to see it as conceptually similar to FSM status.[22] Like polygenic scores, FSM eligibility works well at a group level but is a poor predictor at an individual level. Many FSM children do well educationally, while many children who struggle academically are not FSM-eligible – and the same is true of children with a low EA3 score (see figure 1). This influences the design of the pupil premium, which is not focused on targeting interventions at specific children, but on providing additional funding so that schools can identify, and provide additional support for, children who are

[21] See: https://www.gov.uk/government/publications/pupil-premium/pupil-premium

[22] The majority of pupils who qualify for the pupil premium do so because of their FSM eligibility.

struggling. Implicit in this is the notion that it is preferable to allocate funding on a crude and imperfect measure than to make no adjustments for factors we know to be associated with poor performance.

Across the workshops, views on this were mixed. While some argued that it would be unethical not to use information we know could potentially help to identify and support those at risk of performing poorly, most participants were cautious about the likely benefits and identified a range of important concerns.

Stigma associated with being identified as 'higher risk'

Several participants discussed whether being categorised as at risk on the basis of a low polygenic score would be inherently different to being categorised as at risk on the basis of family income, as people may perceive genetic risk as something that is more fundamental to the self than economic disadvantage. Some argued there is a risk that polygenic scores could be self-fulfilling, particularly if children, parents and teachers interpret the risk deterministically, decreasing their motivation to engage fully in education – and recent research has provided preliminary evidence that this may be the case.[23]

However, others thought that it should be possible to communicate information on genetic risk in a way that is not stigmatising or deterministic. Participants agreed that more research is needed to enhance our understanding of what works to increase public understanding.

Discrimination and structural inequality

Participants consistently raised concerns centred on a lack of understanding as to what 'traditional' measures of educational attainment are actually capturing. Similarly, EA3 is a crude measure which captures a multitude of factors associated with how long someone remains in education. Heritable cognitive ability or academic aptitude will be part of this, but so too will other heritable behavioural characteristics, such as conscientiousness, motivation and resilience, as well as wider factors, such as household finances, attitudes to education and economic opportunities.[24] As one workshop participant pointed out, had we looked at this issue in the 19th century, we would have found a strong correlation between time spent in education and the Y chromosome – but this, of course, reflects wider structural issues in society at the time, in terms of males having much greater access to education, rather than a causal link between being biologically male and attainment.

These are critical issues, and it is beyond the scope of this project to think through all of the possible ways in which the misapplication of this research could disadvantage certain groups. It is worth reasserting that it is a fundamental principle of our work that genetic data should not be used if it risks entrenching or exacerbating existing inequalities. Notwithstanding this, however, it remains the case that most of the measures we use in the social sciences are imperfect attempts to capture an underlying construct or characteristic. For this reason, some participants argued that low polygenic scores are conceptually similar to FSM eligibility, with many of the same limitations in terms of understanding what exactly is being captured.

[23] Matthews et al., 2021.

[24] Krapohl et al., 2014.

Issues of resources and addressing disadvantages

Another concern that participants cited was that the pupil premium is designed to provide additional resources to disadvantaged children, and to compensate them for the additional investment that their more affluent peers would receive from their parents. For this reason, we should not see FSM-eligibility and low polygenic scores as analogous when considering hypothetical changes to pupil premium calculations.

However, others saw the primary intent of pupil premium as providing additional resources to *schools* based on the proportion of their pupils who are at elevated risk of poor attainment. On this basis, there is little reason to see those at increased risk on genetic grounds as being less in need of additional resources than those who are at increased risk because of any aspect of their environment.

A related point raised by some participants was that while there was widespread public support for addressing the impact of environmental factors such as poverty on education, there would be less support for doing so on the basis of biology. Some thought that addressing environmental influences is often seen as attempting to give everyone an equal chance to succeed on the basis of natural ability (meritocracy), whereas trying to address biological risk factors might be seen as trying to equalise outcomes, which would not be supported. It was also argued, however, that the 'genetic lottery' makes a huge difference to success in a meritocratic society, and that this is not necessarily just.

Others suggested that as a society we need to be clear on whether the priority in education is reducing the variance in educational outcomes (closing the gap) or increasing the mean (improvement for all). This raises profound questions about social justice, the role of the state and the intent of current policies, which are worthy of much more exploration and research. Public acceptability of the use of genetic data in education may rest on how this narrative is framed. Widespread acceptance *may be* possible if policies are seen as trying to give individuals as much opportunity to succeed educationally as possible, given their biological dispositions.

Understanding what works to support those at elevated risk

One consistent message was that identifying those who are at elevated risk does not tell us how best to support them. We have argued elsewhere that it is unethical to screen for risk of vulnerabilities in the absence of high-quality and effective services.[25] Several participants pointed out that polygenic scores will only identify those at elevated risk, not which areas of education a child might find most challenging. Others argued that there are many other things we could and should do to improve the education system which do not require us to make use of sensitive genetic information, and that the use of such information may be a distraction from wider systemic issues. Some participants argued that no one had yet put forward a convincing argument as to how incorporating genetic information would lead to an education system that is better than what we have currently.

However, it was also put forward that the use of imperfect genetic data on risk may not be meaningfully different to current arrangements. As things stand, schools are provided with pupil premium funds, without fully understanding how poverty impacts on educational attainment or the most effective way to address this in all circumstances. The logic is that schools will be best placed to support pupils who are struggling, but that increased funding will be necessary to provide this support, whatever form it takes. A low polygenic

[25] Asmussen et al., 2020.

score could work in the same way, with additional government funding for those who are at increased risk, and schools given autonomy over how to use that money to best support their pupils.

Conclusion

We heard many complex and nuanced arguments for and against the hypothetical scenario of using genetic data as a guiding factor for school funding and accountability. **Overall, the view was cautious and sceptical, with many arguing that the risks outweighed the benefits.** All of the concerns raised are serious issues worth further debate and research.

However, in our view none of these conclusively establish that the use of such information would be unethical or ineffective if used to support those at risk of poor attainment. **While it is not yet clear that genetic data *could* be used to support better outcomes in education, if it were possible to create a polygenic score that worked equally well in all ancestry groups and explained a similar level of variation in academic achievement to FSM eligibility, we suggest that there is no *a priori* reason to think we should not use such data**.

Scenario 2: Screening for genetic risk to identify those in need of risk-based early intervention

DNA-based risk can be identified from birth, potentially allowing for early identification and support for a range of conditions.

Workshop participants were asked to consider whether screening at birth for an increased genetic risk of developmental disorders would be a potentially useful mechanism for identifying those who may be in need of additional support, and for tailoring interventions. Many participants were open to the potential benefits of a polygenic score that could explain a substantial amount of variance in a specific trait, albeit with some significant caveats.

It depends on how we want to use the data

Participants were able to imagine ways in which polygenic scores could be used to the benefit of individuals and society. Indeed, some argued that if we are capable of identifying a risk, and if we know how to respond to that risk, then it seems unethical not to do so.

Some participants discussed using findings from genetic research broadly, and DNA data specifically, to drive environmental enrichment for 0–5-year-olds. By understanding more about the underpinnings of preschool behaviour, and by identifying areas of possible genetic risk for individuals, it was argued that we may be in a stronger position to build environments, such as nurseries and schools, that are capable of meeting a very wide array of needs.

In a similar vein, it was argued that as children grow and leave formal education, we need to remodel the landscape of opportunity so that it acknowledges and celebrates individual differences, and that findings from genetic research can be used to support this. It was felt that we should not necessarily be pushing to get individuals who are 'at risk' to the same level as those 'not at risk' but, instead, thinking about opportunities that can accommodate a wider and more diverse range of strengths.

Discussion also focused on the benefits of identifying risk of neurodevelopmental conditions such as ASD, ADHD or dyslexia with a view to providing earlier access to support, resources and early intervention. Many participants expressed agreement with the view that we should treat the genetic probability of a neurodevelopmental condition, or a learning or behaviour difficulty or disability, in a similar way to how we currently treat a genetic predisposition to breast cancer risk. Years ago, breast cancer risk was sometimes responded to with a very direct and invasive intervention: a mastectomy. These days, it is much more common to respond to an elevated risk with a heightened level of monitoring,

in the form of regular mammograms. This was viewed as an appealing model by many in our discussions: that if we can identify a risk that a child will struggle with reading, self-regulation, attention or social communication at birth, via a DNA sample, then they should be added to a register of children who are more regularly screened than the general population. In the event that they develop the difficulties they are at higher risk of, support and resources can be put in place quickly, without waiting for a formal diagnosis to occur.

In spite of these positive views, there was acute awareness and nervousness in all workshops that decisions about how DNA data – or indeed any data – is used are rooted in value systems which are unpredictable, change over time and differ between groups. It was agreed that data protection and regulation in this area is urgently needed, particularly in relation to personal insurance and issues around consenting to participate for children and young people.

It was also argued that scientists, including geneticists, do not operate in a vacuum and must take the political, historical and regulatory contexts of their science into account when designing and disseminating it. This is part of their duty to uphold the public good.

Finally, workshop participants specified some of the ways in which they would definitely not want to see DNA data used. In particular, there was a strong consensus that it should only be used to provide access to opportunities, and never to select children out of opportunities or for purposes of early stratification. Secondly, there was a great deal of concern around using polygenic scores in the context of prenatal screening. It was deemed wholly inappropriate to use these probabilistic risk indices, with high false positive and false negative rates, in this way.

The risk of self-fulfilling prophecies, and a problem with labels

As was the case in scenario 1, many participants expressed concern about stigma (including self-stigma) and about the impact of polygenic scores on motivation and behaviour. Specific concerns that were raised included how new parents might respond to being told their baby was 'at risk' of learning or behaviour problems, and whether this might have a negative impact on their own wellbeing and expectations, and the wellbeing and experiences of their child. There was also a concern that responses might be moderated by culture: that a notification of a child's potential difficulty might elicit harsher reactions in some cultures or communities than others, and that researchers and policymakers need to be mindful of this. It was argued that if polygenic scores were routinely made available as part of the adoption process, then this might negatively affect adoptive parents' decision-making, thereby disadvantaging children in need of a family. Finally, concern was expressed about the extent to which polygenic scores represent a threat to a child's right to an 'open future'. If parents, teachers and medical professionals – and perhaps the children themselves – have access to this information, then this might have a negative effect on what is expected of, offered to, or attempted by them that is not justified on the basis of a probabilistic risk indicator that is unreliable at the level of the individual.

While the most commonly accepted potential benefit of powerful polygenic risk scores related to triggering high-quality early intervention, these discussions made it clear that we need to be sure that the benefits of such intervention outweigh the risks. It was also agreed that research is needed on potential unintended consequences, and that this should happen now, before the prevalence and predictive validity of polygenic scores increases.

In addition to concerns about self-fulfilling prophecies, participants had strong views on the dominant medical culture of diagnostic labelling. Genetic research strongly suggests that

most learning and behavioural diagnoses operate on a spectrum of severity, rather than being disorders that you either have or don't have. Many participants argued that future polygenic risk scores should be symptom or skill-specific, rather than diagnosis-specific, and that a focus on symptom alleviation may be more valuable and less stigmatising than a focus on 'umbrella' diagnoses. It was suggested that being told your child is at increased risk of struggling with attention could potentially be less anxiety-inducing and threatening than being told they are at risk of 'having' ADHD.

Some participants went a step further, arguing that losing diagnostic labels would be essential to the ethical use of DNA predictors. However, they also argued that research is needed into how polygenic scores may affect stigma and self-stigma.

Understanding how to use the information

Some participants argued that while there may be broad lessons for early intervention policy within genetic research, DNA data currently has little useful to add to that. This was for three main reasons: that (1) we don't have the interventions that would make DNA screening clinically actionable; (2) we don't have systems that can support further differentiation or enrichment of environments to better meet individuals' predispositions; and (3) we already have a lot of data that we don't use.

Participants pointed out that predicting risk from DNA is only helpful if we have a bank of evidence-based and highly efficacious interventions that we know can alleviate the symptoms that a child is identified as being at increased risk of. This is not currently the case for most symptoms and therefore, some argued, a focus on developing and testing interventions has to come first. Others pointed out that, while this is true, we do know *something* about how to support children with developmental disorders, and it may be unethical to deny them access to support because we have not yet designed the optimal package of support. Furthermore, it was pointed out that a polygenic score that explained even as much as 20–30% of variance in an aspect of learning or behaviour would not pass the criteria for the national screening committee. This would require a test that is simple, reliable and has an appropriate and economically justified intervention, such as the heel prick test that identifies phenylketonuria (PKU) a few days after birth, triggering a dietary intervention for affected infants. Anything less involves taking a way a child's right 'not to know' without sufficient justification or benefit. In summary: we're not there yet.

Secondly, several participants made a case that the history of social welfare in the UK shows a longstanding and ongoing lack of resources for special educational needs and disabilities, including lengthy waiting lists for referrals related to learning and behaviour problems and child mental health. In this context, it seems unrealistic to talk about DNA screening leading to more enriched and personalised responses. These participants argued that there are fundamental systemic and resourcing issues to fix before even considering this level of fine-tuning. Instead, it might be more valuable to focus on children with known genetic abnormalities who are currently not sufficiently supported within the education system.

Finally, the point was made that we already have a great deal of data, including family history data, that the system does not currently have the capacity to take into account in any meaningful way. This line of argument suggests that systemic reform is needed prior to considering the use of DNA data in the context of social policy and, in addition, that we need to develop a clearer understanding of what a polygenic score can tell us over and above what we already know about an individual from the demographic, family history and behavioural data that is already available.

Is it useful?

On the other hand, some participants put forward a case that we won't know how useful polygenic scores could be in the context of early intervention – or indeed whether they are useful at all – until we try them out. They argued that if polygenic scores reach a stage where they are explain 20–30% of individual differences in a specific trait or symptom, then these have a good chance of being helpful for targeting individuals who may benefit from extra support. Furthermore, we could experiment with combining these scores with other non-DNA predictors to explore whether prediction becomes stronger and more sensitive when they are included.

Nonetheless, the ethical challenges inherent in 'trying this out' empirically were widely acknowledged. For instance, it was recognised that DNA screening for complex traits related to learning and behaviour would only ever be ethical if it was optional, as is currently the case for prenatal screening. That said, these participants also argued that it might be unethical *not* to study the potential of this approach to help identify individuals at increased risk of challenges that high-quality early intervention can mitigate.

Conclusion

Participants were generally open to the possibility that polygenic scores may – in the future – play a useful role in identifying children at risk of learning and behaviour problems, triggering more regular screening, and prompting earlier intervention for those with emerging symptoms. However, they were sceptical about whether we have the necessary interventions to respond appropriately, or the infrastructure to support them. They were also concerned about ethical issues, such as a child's right to an open future.

We noted a consistent call for research that can pave the way forward. Specifically, research should focus on:

- potential unintended consequences of using polygenic scores in the context of social policy, including the impact on others' expectations of a child, stigma and self-stigma
- the systemic reforms that would need to be in place to optimise and regulate the use of DNA data
- enhancing understanding of what exactly DNA data adds to what we already know.

We agree with the views of the participants that polygenic scores could be useful in the future to identify those at elevated risks, although this would present a range of ethical issues which would need to be addressed first, including raising public understanding of and engagement with the issues discussed in this report.

We also agree that the optimal approach to using these scores would be for monitoring those identified at risk – as is the case with breast cancer – rather than automatically intervening, for instance. This represents a good basis for strategic thinking about how the approach could work if the science reaches a stage where polygenic scores are sufficiently powerful and reliable to be useful at the individual level, and we have evidence-based interventions with which to respond to identified needs.

Part 5: Beyond policy: using DNA information to enhance research on child development

There was strong agreement across the workshops that it was too early for genetic data to directly inform social policy. However, as we noted in part 3, there was strong agreement across the workshops that DNA data, and specifically polygenic scores, provide us with an opportunity to better understand complex human behaviour and design better prevention and intervention programmes. Twin and adoption studies have shown that all behavioural and psychological traits are heritable, but also that environmental factors explain a large proportion of individual differences. Workshop participants were excited by the opportunities that integrating rich data about environments and DNA provide us with to better understand developmental processes, and to improve the design and evaluation of interventions.

Two areas frequently mentioned in discussion were the use of genetic data to improve the accuracy of evaluations, such as randomised control trials, and the insights that could be obtained through the gathering of genetic data as part of longitudinal studies.

Excluding DNA data from research creates many biases and there are many opportunities for more genetically informed research to be conducted over the coming years to further our understanding of child development.

- **Developmental trends in complex traits:** Integrating DNA data into studies allows us to study stability and change in complex traits across the lifespan, potentially helping us to identify the optimal window for intervention for certain outcomes, such as how best to support to children who are at elevated risk of experiencing mental health difficulties.
- **Better understanding of the multiple factors influencing complex traits:** Research has shown that the genetic component of complex traits such as educational achievement is explained by many genetically influenced cognitive and non-cognitive factors, such as personality, motivation and home and school environment.[26] DNA data will allow us to disentangle these traits, for example, to understand the relative importance of cognitive and non-cognitive traits to educational outcomes.
- **Multivariate links between traits:** We know that genetic factors associated with one trait, such as cognitive ability, are to some extent also associated with other traits, such as ASD.[27] Using DNA data helps us to get closer to the links between these associations. This knowledge could be an important step in understanding both risk and protective factors associated with various outcomes and important information that would support the design of intervention and prevention programmes.
- **Intergenerational transmission:** Various traits, such as educational achievement, as well as and psychiatric and neurodevelopmental conditions, run in families. However, these associations could be explained by genes, environment, or a combination of both. DNA data could allow to get us closer to understanding why family members resemble each other. Integrating DNA data from mother-father-child trios could further our understanding of the developmental mechanisms that explain this intergenerational transmission.

[26] Krapohl et al., 2014.

[27] Hill et al., 2016.

Part 6: Conclusions and recommendations

Key findings

Given the novel and controversial topics we discussed, and the range of experts who participated in our workshops, we did not expect to reach consensus on all of the issues we considered. Indeed, identifying areas of disagreement as well as areas of consensus was a specific aim of the project.

We wanted to begin an important conversation about whether and how the rapidly advancing field of genetic research could be used in early intervention and social policy, and to better understand the potential benefits and risks in order to inform future directions. We firmly believe there is a window of opportunity for this work, and it is important that society is encouraged and enabled to debate these issues now, before it is too late.

Nevertheless, some areas of consensus did emerge.

- **Improving understanding of genetic research** was identified as a key priority. There was agreement that limited knowledge is one of the major barriers to considering the application of genetic research in social policy, and that a programme of public communication, which is tailored to different audiences, genuinely collaborative, and uses language that can be easily understood by all is needed to address low knowledge, poor understanding and misconceptions, and low trust.
- **Addressing the over-representation of people of European ancestry in DNA samples** is much needed. There was a high level of consensus that progress in this area could be supported by further diversification of the research community, and by taking a proactive, genuine and meaningful approach to the co-construction of research and its presentation with the communities that are affected by it. There was unanimous agreement from participants that any application of polygenic scores to social policy cannot take place until these issues have been addressed.
- **There is considerable potential in using DNA data in research to better understand development and identify what works to support those at risk of poor outcomes.** This was an area of strong consensus and viewed as a less ethically challenging than other areas discussed. Two areas which were identified as particularly promising were:
  - Collecting genetic data as a routine part of longitudinal cohort studies in order to better understand the interplay between genetics and the environment, and to make more accurate estimates of the role that environmental factors play in influencing outcomes.
  - Improving the precision of estimates from randomised control trials and other impact evaluations by including genetic data alongside socioeconomic or psychosocial indicators to help understand what works for whom.

  However, given that the majority of polygenic scores are derived from a population predominantly of European ancestry, it would not be appropriate to use them in more diverse populations.

In addition to these areas, there was one further area of strong, athough not unanimous, agreement.

The majority of participants believed **that polygenic scores could be useful in the future to identify those at elevated risks, although this would present a range of ethical issues which would need to be addressed first, including raising public understanding of and engagement with the issues discussed in this report.** The optimal approach to using these scores would be for monitoring those identified at risk rather than automatically intervening, as we do with breast cancer for instance.

On the issue of whether genetic information could be used in the education system by channelling additional funds to pupils identified as being at elevated risk of doing poorly in school, opinion was much more divided. While there was some cautious support for the argument that this could help to more effectively support those at risk of doing poorly, overall the feeling was that **the risks of using DNA information to shape school funding currently outweigh the potential benefits, and that there are more pressing matters that should be addressed to improve educational outcomes**.

Overall, we believe the nuance of these findings is testament to the complexity of this issue and the diverse expertise of the workshop participants. Given our commitment to using the best available evidence to design and deliver early intervention, we are of the view that, as a society, we should continue to explore whether genetic information can be used to support those at risk of poor outcomes.

However, this needs to be approached with the utmost caution and in full recognition of the controversial history of the science and the complex risks identified in this report. In our view, it is crucial that this initial exploration is built upon further, to start a much wider and deeper conversation about whether and how genetic information should be used in social policy. Part of this has to be building a far wider understanding of the potential benefits and limitations of the research, and facilitating a more prominent public debate on whether such research has a useful role to play in supporting better outcomes.

With this in mind, we thank the participants in our workshops for their thoughtful and thought-provoking contributions.

Recommendations

For government

Given their diversity of backgrounds, the agreement among our workshop participants on the need for caution in using genetic data to inform social policy and early intervention was striking. The overwhelming view of participants was that this should not be considered without a considerable level of public engagement and debate, and that the prerequisite for this is increasing understanding among the public and policymakers of the science and the potential benefits, risks and ethical challenges associated with its use.

Given this we are calling on government to take the following steps:–

- **Establish an independent body to advise government on the ethics of using genetic data in social policy.** Given the sensitivity of genetic data, the controversial history of the topic, and the complex ethical issues it presents, in our view it is essential to establish a body which is formally independent of government. This body should draw on wide and diverse expertise, from areas such as bioethics, law and public policy, and should consult extensively with the public to provide robust and independent advice, on whether and how to proceed. Non-departmental public bodies offer a model for an organisation to have a role in government processes whilst operating at arm's length from any government department or minister. However, over time it may be appropriate for this or an alternative body to take regulatory powers, following a similar model to the Human Fertilisation and Embryology Authority. This body will also need to work closely with the Government Office for Science.
- **Launch a comprehensive programme of public awareness-raising, engagement and deliberation.** Genetic research is advancing rapidly, and we have raised concerns in this report about the limited public understanding of the science and the danger of the science being applied to policy before ethical issues have been properly explored. Given this, it is critical that government begins to raise awareness and understanding among the public. This process should include multiple strands of activity, focused on both raising awareness and encouraging debate, and a strong focus on ensuring that vulnerable and marginalised groups are included in developing and discussing potential options.

For parliament

We also believe that there is a need for greater parliamentary engagement, and so we call for:

- **The science and technology committee to hold an inquiry into the implications of genetic research for UK social policy.** The committee has recently concluded an inquiry into direct-to-consumer genetic tests. An inquiry into the ethical and practical issues of using genetic data in social policy could build on this work and would be an important step towards greater parliamentary and government focus on the issues we have identified in this report.

For the research community

In our view, it is essential that charities, think-tanks and civil society organisations now engage with the topic of genetics and the potential implications for their research.

There was complete agreement across our workshops that more use should be made of DNA data in social science studies and evaluations, as this presents us with an opportunity to gain a deeper understanding of the interplay between genes and the environment, developmental mechanisms, and the intergenerational transmission of outcomes. We call on all researchers conducting work on child development and effective interventions – regardless of discipline or area of focus – to engage with the rapidly emerging evidence that genetics provides us with, and to consider how they might conduct genetically informed work.

Our view is that funders should play a more active role in promoting the diversification and use of genetic data. In particular:–

- **Funders of the UK Biobank and other repositories of DNA data should prioritise work that is already underway to diversify current samples and ensure they are representative of society.** This should include a programme of engagement with marginalised groups to understand concerns and barriers to participation, and global collaboration to ensure equity of outcome in societies around the world.
- **Major research funders, including UKRI, should increase their focus on the use of genetic data within the work they fund.** This includes routinely considering the gathering of genetic data in any new longitudinal or cohort projects, and calling on researchers working on children and family issues to consider if and how they will take account of genetic effects in their work.
- **Funders of evaluation of children's policies should explore whether genetic data could be used to strengthen the impact evaluations they fund.**

Glossary

Selected and adapted from Knopik et al., 2017.

- **Adoption study:** A technique to estimate the genetic and environmental components explaining individual differences in a trait of interest. Most often, adoptees are compared to their biological parents, who did not raise them, and to their adoptive parents. This method may also be used to make comparisons between genetically related siblings and genetically unrelated siblings.
- **Ancestry:** Ancestry usually refers to the geographical origin of a population (for example, European ancestry) as distinct from social constructs such as race (such as black African) or ethnicity (such as Chinese). Ancestry is generally accepted as the most objective and scientifically valid term to describe differences between population groups. However, the borders around ancestry groups are arbitrary, and this then makes ancestry a socially constructed grouping.[28]
- **DNA (deoxyribonucleic acid):** DNA is the basic hereditary molecule that contains the genetic code for life. We use DNA markers to study the differences between individuals. DNA is organised into 23 pairs of chromosomes. There are two functions of DNA: replication and coding for proteins.
- **Ethnicity:** Ethnicity is often used for grouping individuals based on their cultural background and their identification. Ethnicity is a social construct, often based on shared language and traditions. This term is used to group individuals into distinct categorical groups, with arbitrary boundaries between them.[29]
- **Gene:** The basic unit of heredity, genes are the parts of a chromosome that carry the genetic information that is passed from parents to their offspring. A gene is a unit of DNA that codes for a protein. Variants of genes are called alleles (there can be many for a gene). We have two copies of every gene (which may be different alleles).
- **Gene–environment correlation:** Genetic differences between people are correlated with environmental differences between them. Individuals create, modify and select environmental experiences that are correlated with their genetic propensities. There are three types of gene-environment correlations:
  - **Passive** gene–environment correlation: where children inherit both genetic and environmental factors from their parents – for example, the children of musicians would inherit genetic factors that are associated with higher musical ability and would also be exposed to an environment with lots of activities related to music.
  - **Active** gene–environment correlation: where children actively create their environmental experiences based on their genetic propensities – for example, a musical child seeking out opportunities to learn instruments or join a choir.
  - **Evocative** gene–environment correlation: where children evoke environmental experiences that are correlated with their genetic propensities – for example, a musical child would be more likely to be noticed by the music teacher at school, who in turn would provide enhanced opportunities to that child.

[28] See Ahmadzadeh, 2021.

[29] ibid

- **Genetic nurture:** Genetic nurture is used to describe the phenomenon whereby genetic variants not transmitted from parents to children still predict outcomes in offspring.[30] The environmental experiences that parents create for their children are correlated with offspring outcomes independent of offspring genotype, providing a clear example of passive gene–environment correlation.
- **Genome:** The genome comprises the entire set of chromosomes for an organism. Every chromosome is made up of DNA, each strand of which contains many genes. The human genome contains about 4 billion DNA base pairs.
- **Genomics:** A branch of genetics and a form of molecular biology concerned with the structure, function, evolution and mapping of genomes.
- **Genome-wide association study (GWAS):** This approach assesses the association between DNA variation throughout the genome and phenotype of interest. For complex traits, such as educational achievement or cognitive ability, GWASs use a sample of hundreds of thousands of individuals to detect genetic variants of small effect.
- **Genotype:** An individual's combination of alleles at a particular locus.
- **Phenotype:** A phenotype is an individual's actual observed characteristics or traits which result from a combination of the effects of genotype and environment, such as an individual's educational achievement, reading ability or height.
- **Polygenic score:** A polygenic score is an aggregate of the estimated effects of all genetic variants found to be associated with a phenotype (weighted by effect size). This composite score is then used to predict variation in the outcome of interest in an independent study. DNA does not change, and thus polygenic scores predict outcomes equally well (or badly) at birth or later in life. However, phenotypes are modified by environmental experiences throughout development.
- **Race:** Race categories were developed as a taxonomic grouping of humans. These categories are often associated with physical characteristics such as skin colour and hair texture. These categories, however, are considered to be a social construct – that is, there are no biological measures that can be reliably used to put individuals into these categorical groups.[31]
- **Twin study:** Compares the resemblance of monozygotic (MZ or identical) twins and dizygotic (DZ or non-identical) twins to estimate the genetic and environmental components explaining individual differences in a trait.

[30] Kong et al,. 2018.

[31] See Ahmadzadeh, 2021.

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Appendix: Workshop participants

The following people attended one of the four workshops we hosted and have consented to being named. However, the views expressed in this report are EIF's, and being named as a workshop participant does not imply an individual's endorsement of, or agreement with, all of those views.

- Dr Yasmin Ahmadzadeh – Research Associate, King's College London
- Professor Claire Alexander – Professor of Sociology, University of Manchester
- Professor Daniel Ansari – Professor of Developmental Cognitive Neuroscience & Learning, Western University
- Professor Daniel J. Benjamin – Professor, Behavioral Decision Making Group, UCLA Anderson School of Management, and Human Genetics Department, UCLA David Geffen School of Medicine
- Professor Ewan Birney – Professor and Deputy Director General, European Molecular Biology Laboratory (EMBL)
- Dr Claudine Bowyer-Crane – Associate Research Director, National Institute of Economic and Social Research (NIESR)
- Professor Bobbie Farsides – Professor of Clinical and Biomedical Ethics, Brighton and Sussex Medical School
- Professor Kathryn Paige Harden – Professor, Department of Psychology, University of Texas at Austin
- Dr Omar Khan – Director, Transforming Access and Student Outcomes in Higher Education (TASO)
- Professor Yulia Kovas – Professor of Genetics and Psychology, Goldsmiths, University of London
- Professor Karoline Kuchenbaecker – Faculty of Brain Science, University College London
- Dr David R. Lawrence – Research Fellow, University of Edinburgh
- Professor Cathryn Lewis – Professor of Genetic Epidemiology & Statistics, King's College London
- Professor Lindsey Macmillan – Professor of Economics and Director, UCL Centre for Education Policy and Equalising Opportunities (CEPEO)
- Dr Margherita Malanchini – Lecturer in Psychology, Queen Mary University of London
- Dr Daphne Martschenko – Postdoctoral Research Fellow, Stanford Center for Biomedical Ethics
- Dr Lucas J. Matthews – Postdoctoral Researcher, Columbia University
- Professor Mark Mon-Williams – Professor of Cognitive Psychology, University of Leeds
- Dr Tim Morris – Senior Research Associate, University of Bristol

- Dr Bonamy Oliver – Associate Professor in Developmental Psychology, UCL Institute of Education
- Dr Erik Parens – Senior Research Scholar, The Hastings Center
- Professor Nick Pearce – Professor of Public Policy, University of Bath, and chair of the Early Intervention Foundation
- Professor Kate Pickett – Professor of Epidemiology, University of York
- Professor Robert Plomin – Research Professor of Behavioural Genetics, Institute of Psychiatry, Psychology & Neuroscience, Kings College London
- Dr Veera Manikandan Rajagopal – Postdoctoral Researcher, Aarhus University
- Dr Jonathan Roberts – Genetic Counsellor, Wellcome Genome Campus/Addenbrooke's Hospital
- Dr Adam Rutherford – Honorary Research Fellow in Genetics, UCL
- Dr Fatos Selita – barrister; attorney (NYS); Goldsmiths, University of London
- Dr Nadia Siddiqui – Associate Professor of Education, Durham University
- Professor Ilina Singh – Professor of Neuroscience & Society, University of Oxford
- Dr Umar Toseeb – Senior Lecturer, Psychology and Education Research Centre, University of York
- Dr Patrick Turley – Assistant Professor (Research) of Economics, University of Southern California
- Professor Essi Viding – Professor in Developmental Psychopathology, University College London
- Professor Sophie von Stumm – Professor of Psychology in Education, University of York
- Hugh Whittall – former Director of the Nuffield Council on Bioethics