

## What if a simple DNA test could predict your future?

What if new-born babies were given a DNA report card that predicted their intelligence, their odds of getting a PhD, their chances of becoming a chain smoker or suffering depression, a heart attack or cancer? Thanks to ongoing genetic studies, a large amount of genetic data is available today involving millions of people. The wealth of information available to researchers allows them to create a polygenic risk score based on the DNA test of a person. This can be used to predict a person's chances of getting a disease, his or her traits and behaviour, and many other things about their future. Are these predictions flawless? Who would benefit from them? What are their implications for a person's life in general?

A single gene goes wrong. This results in diseases like sickle cell anaemia or BRCA breast cancer. With a few exceptions, genetic tests used by doctors today can already detect these rare, deadly variants in a single gene that lead to such uncommon forms of disease. However, most of the 'big killers', such as heart disease, are not caused by mutations in a single gene. These are rather a more complex case of hundreds or more changes in the genetic makeup that collectively influence the outcome. Tests for this type of changes are now possible, however, and produce what is referred to as a polygenic risk score.

Welcome to the world of [polygenic risk scores](#): which promise to 'unlock your future for less than €50' upon submission of an uploaded DNA swab. Polygenic scores, as the name suggests, involve thousands of genes. A [genome](#) is a complete set of genetic instructions in an organism that contains all of the information needed to build that organism and for it to develop and function. These polygenic scores are derived from the combination of all the variants in a person's inherited genome, and can spot risks of killer diseases, including those not manifested in either parent's family history. Access to information from polygenic risk scores for different diseases provide insights that plot genetic architecture against a wide range of outcomes, behaviours and traits. This enables the prediction of risk factors, such as [smoking](#) or high cholesterol.

However, such genetic marker-based scores are not diagnoses, instead they offer a spectrum of probabilities from low to very high risk, and the scientific validity of these risk scores is up for debate. The [accuracy](#) of a polygenic risk score for an individual depends on how closely that person's DNA resembles the DNA of the people whose genomic data was used to develop the score.

### Possible impacts and developments

The availability of direct-to-consumer (DTC) genetic tests online and the possibility of using a polygenic risk score to discover the genetic roots of common ailments, not only open new options for public health care, but also transform the way we access personal genetic data and make informed decisions. However, are consumers of these DTC genetic tests fully aware of the impact the outcomes can have on their lives? Moreover, these predictions could be widely misinterpreted or abused. An individual's genetic profile is, above all, a private matter, leading to questions as to whether such personal data can be protected. Another issue is that individuals have the right not to (want to) know what the future holds, for instance about diseases they cannot prevent. To interpret outcomes from genetic tests, medical framing is strongly recommended. It is therefore questionable, why an individual would choose to receive possibly unsettling medical information without medical guidance. With guidance from a medical professional, genetic testing



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data could be used proactively to make personal health decisions, concerning interventions such as screening, chemoprevention (using medication to prevent cancer in healthy people), or risk-reducing surgery for people with a [high risk score for colorectal cancer](#).

There has been a boom in companies – [Helix](#), [23andMe](#), [Ancestry](#), [Myriad Genetics](#), [UK Biobank](#) and [Broad Institute](#), for example – collecting consumers' DNA data to [create genetic profiles](#). The risk scores obtained could drive the market of wearable devices and trackers, such as heart monitors. Users who download their genetic profile created by such commercial operators can then upload their genetic information to public family history (genealogy) sites and connect with other people of the same lineage. Indeed, one such public genealogy site helped police to [crack a cold case](#). While, with the growing number of people enrolled for DNA tests, the accuracy of predictions is improving, it is obvious that sharing DNA on commercial databases could endanger individual's privacy, and place sensitive information in the hands of a few companies.

Furthermore, like other data-driven technologies, genetic testing data is mostly available for certain racial/ethnic groups, raising concerns about the reliability of the predictions for other populations. This also presents an opportunity to expand the database to include the non-dominant population. A recent study shows that with the amount of DNA information housed in digital stores, more than 60 % of Americans with European ancestry can be identified through their DNA using an open genetic genealogy directory, regardless of whether they have acquired their polygenic score or not. This raises privacy concerns. The rapid expansion of these digital genetic directories makes it possible to trace any individual through their unsecured DNA. Unless the practice of conducting genealogy searches is properly regulated, anybody could experience [genetic surveillance](#). Are individuals protected against potential abuse of such DTC genetic tests, for instance by insurance companies? Insurance companies with access to the polygenic scores could use them to decide not to offer insurance cover or to charge them exorbitant rates to people at a higher risk of disease.

These DNA tests can also be used to predict measurable human traits, including human behaviour. This will lead to predictions about the chances of a person committing crime, or about an individual's IQ. Until a recently, no gene variant had ever been directly linked to IQ. The recent development [linking 206 genetic variants to IQ](#) has, however, resulted in a rapid genetic exploration. Psychologist [Robert Plomin](#) talks about the possibility that human genome data will predict IQ in his book, '[Blueprint](#)'. What if parents and educators used such predictions to determine the academic potential of their children? The polygenic scores could be used to customise education to each child's needs, as not all children respond in the same way to teaching practices. These scores, which could predict the pattern of strengths and weaknesses in each child, could aid educators in [designing different teaching practices](#) for different children. The possibility of this technology to predict educational attainment has spurred many companies to invest in research on the [genetics of educational attainment](#). In vitro fertilisation (IVF) clinics already permit a pre-implantation screening to detect embryos with rare genetic diseases before selecting the cells to be implanted. What if these were combined with IQ predictions and used to [genetically select super-smart babies](#)?

This technology has also found a potential market in applications such as predicting the age at which [Alzheimer's could appear](#), or the [time of an individual's death](#). With the rise of new technologies such as [DNA storage](#) and [genome editing](#), it is not far-fetched to predict that future forecasts based on polygenic scores are here to stay. Is genome prediction a breakthrough in medicine and disease prevention or a dystopia in the making?

## Anticipatory policy-making

The growing popularity and the availability of direct-to-consumer (DTC) genetic testing raises concerns, for instance, about how individuals are warned of the implications of such tests.

A [study](#) on legislation of DTC genetic testing in Europe gives a general overview of the national legislation addressing genetic testing in Europe. It argues that the applicability of relevant legislation is complicated by the fact that DTC genetic testing is provided outside the traditional healthcare system. This makes the classification of DTC genetic testing as a medical or recreational product unclear. These genetic tests are sold online, further raising concerns on jurisdiction and enforcement.

