Genes and Our Genomes: Ethical questions for discussion

Whose rights? Insurance and genetic information

Genetic advances have great potential for improving health, but they also raise questions about privacy and who should have access to personal information such as genetic data. Take a look at the made-up scenario below to explore issues that are far from black and white

For some conditions, there are predictive tests that can be used to show whether someone is likely to develop the disease. These include inherited conditions – such as Huntington's disease – that can be related to the effects of single genes, as well as diseases like breast cancer, where genetic components may increase the risk but are not the determining factors.

This information is valuable to health insurers because, like family history, it enables them to make better predictions about whether their customers are likely to become ill. However, in the UK, insurers can sign up a voluntary code, the Code Genetic Testing and Insurance (2018), that protects people applying for insurance from having to disclose the results of all genetic tests, with the exception of tests for Huntington's disease in life insurance cover applications over £500,000. It is not clear whether other genetic tests will be added to a list of exceptions in the future.

With this in mind, think about the questions below. We've used the insurance industry as an example, but concerns about the misuse of genetic data apply to many groups, including employers, governments and journalists.

Potential situations

My grandmother died from breast cancer, and my mum now has the disease. I'm thinking about having a genetic test that would show if I am at increased risk. I've heard that insurers can't ask for the results, but what if the law changes after I've had the test?" Helen, 26, nursery nurse

Q: Should Helen take a genetic test? Is knowing the results more important than protecting her genetic information for the future?

"The insurance company I work for has accepted the Code on Genetics Testing and Insurance. Therefore, we do not currently ask customers to disclose the results of any genetics tests for breast cancer." James, 35, insurance professional

Q: Do you think it would be right for insurance companies to have access to potential customers' genetic information? Why would it be different to knowing about their family or medical history?

Huntington's is a rare and incurable genetic disease that causes gradual deterioration of the brain. It is caused by carrying a faulty copy of the Huntington gene.

In the UK, Huntington's disease is the only exception to the Code on Genetics Testing and Insurance: in certain circumstances, customers have to disclose the results of a genetic test to insurers. They must do so if they are applying for a life insurance policy worth over £500,000, critical illness insurance over £300,000 or income protection over £30,000 per year.

Not many people want to take out insurance policies worth this much, but those who do will probably pay more in the UK if they have tested positive for Huntington's disease.

The results of a 2016 study on testing for Huntington's disease in the UK showed that between 1993-2014 the majority of people at risk of the disease (80%) did not have the tests. This is thought to be because of anxieties about having the disease and the lack of treatments and personal experiences of relatives with

Huntington's. Those who did have the test said they did so to decrease uncertainty and put in place plans for future care.

QUESTIONS FOR DISCUSSION

- Is it fair that people at risk of one type of disease have to disclose the results of genetic tests, while others don't?
- Should insurers get access to the results of other genetic tests? How should we decide which ones?

REFERENCES

- Genetic Conditions and Insurance: What you need to know and what you need to tell

  https://docs.google.com/file/d/0B0H_jrqJX7xeY0U4eDlnb0JGak0/edit

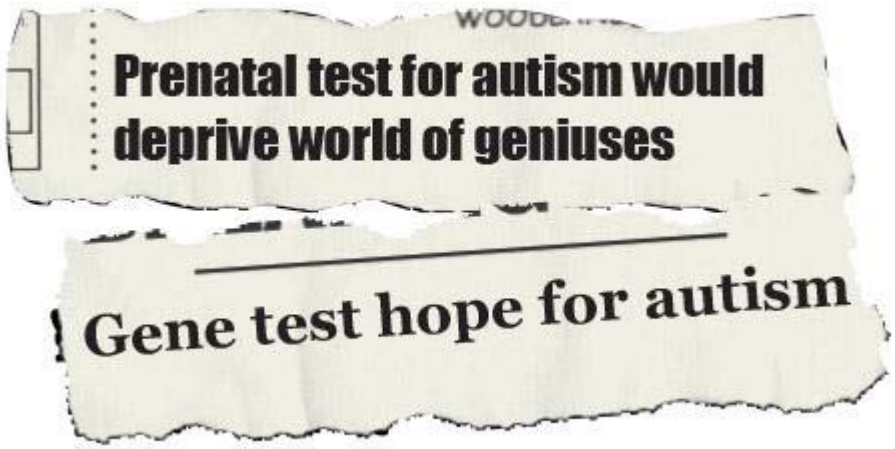
- Code on Genetic Testing and Insurance https://www.gov.uk/government/publications/code-on-genetic-testing-and-insurance

Whose rights? Genetic testing before birth

Genetic advances have great potential for improving health, but they also raise questions about privacy and who should have access to personal information such as genetic data. Take a look at the made-up scenario below to explore issues that are far from black and white

Parents who are worried about their children inheriting harmful mutations now have several options. Prenatal genetic testing can be used to detect mutations in an embryo or fetus that are linked to particular conditions. Using *in vitro* fertilisation, it's also possible to create and select embryos that don't have the harmful mutations. Read the text below and study our imaginary headlines, then see what you think about the questions that follow.

Prenatal genetic testing



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Parents at high risk of having a child with a genetic condition are offered prenatal genetic tests which test the DNA of the growing foetus. In the UK, screening tests for sickle cell, thalassaemia, Down's, Edward's and Patau's syndromes are offered as standard or if the parents are carriers.

These tests carry a greater risk of miscarriage if they involve retrieving cells directly from the foetus. However, it is now possible to test for many disorders using foetal DNA circulating in the mother's blood, although only a few of these tests are currently being offered in the UK. Such non-invasive techniques could open up the possibilities for detecting a wide range of genetic conditions prenatally.

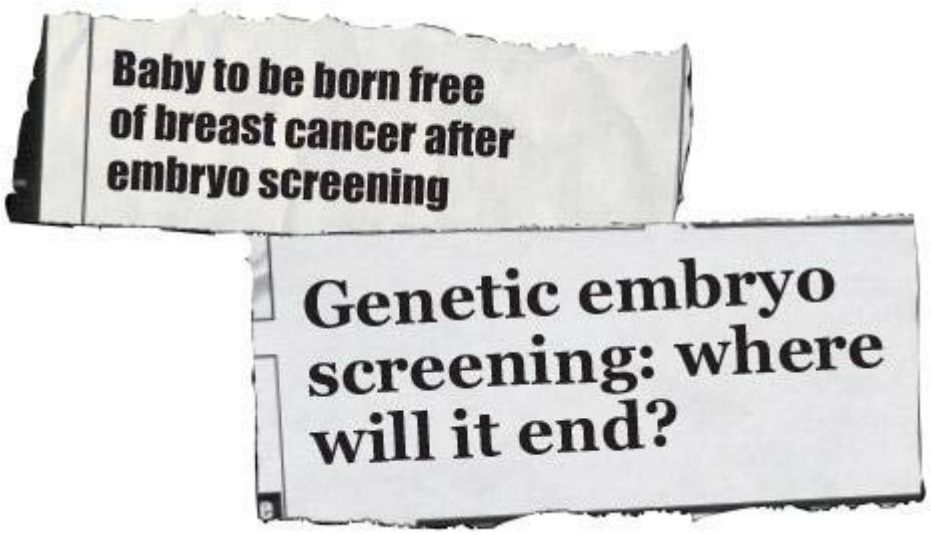
Some people argue that we should do all we can to end suffering for people who live with debilitating conditions. Others think that tests for an increasing number of disorders would discriminate against differently abled people, producing a society that's intolerant of difference.

The headlines show how two papers tell the story in very different ways: the first more positive, the second less so. With these in mind, think about your own views and answer the questions that follow.

QUESTIONS FOR DISCUSSION

- Who do you think should be offered prenatal genetic testing? For what kinds of conditions?
- What impact might more extensive, less invasive prenatal testing have on expectant parents?

Preimplantation genetic diagnosis



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Preimplantation genetic diagnosis is a particular kind of prenatal testing carried out during some IVF procedures. The embryos are created by IVF, then one cell is taken from each embryo and tested for the presence of a particular genetic mutation before an embryo is selected for implantation. This procedure can help people who carry disease-causing mutations that could affect their children. Over 600 conditions have been approved for Preimplantation genetic diagnosis in the UK.

The list of mutations that can be identified using preimplantation genetic diagnosis includes the BRCA1 and BRCA2 mutations that indicate an increased risk of breast cancer. Women with a family history of breast cancer have used the technique to conceive babies free of the mutations.

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QUESTIONS FOR DISCUSSION

- Do you think that parents should be allowed to use preimplantation genetic diagnosis to screen embryos in this way?

Preimplantation tissue typing

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Preimplantation tissue typing allows parents to select an embryo that could become a 'saviour sibling', a brother or sister who can donate 'matched' stem cells to a sick sibling affected by an illness such as leukaemia. Here, parents select an embryo for implantation that has the same tissue type (i.e. that is matched for human leukocyte antigen) as the sick child.

The Human Fertilisation and Embryology Authority (HFEA) licenses preimplantation tissue typing (to produce 'saviour siblings') on a case-by-case basis in the UK. The first such licence was granted in 2002.

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QUESTIONS FOR DISCUSSION

- Do you think it's fair to select an embryo in this way to save a sibling?

Regulating (and unregulated) prenatal procedures

Prenatal diagnosis has no special legislation apart from that covering termination of pregnancy (abortion). The decision about whether to have a test during pregnancy is made between the woman, her family and the doctors looking after her.

Genetic tests during pregnancy are available on the NHS if there is a family history of a condition or if they are offered as part of a population screening programme. The UK National Screening Committee decides which conditions are screened for. Although some additional tests may be available through private clinics, they do not screen the entire genomes or exomes of foetuses or embryos. However, it is now technically possible to carry out whole genome sequencing on embryos prior to implantation. In one case, which was widely condemned for ethical reasons, a scientist also used controversial gene-editing techniques to edit the genomes of twin girls so that they would be resistant to HIV. Many scientists argued that this step came before necessary legislation on genome editing and Chinese biomedical researchers condemned the work as "crazy".

The HFEA oversees all IVF procedures and research on embryos in the UK.

QUESTIONS FOR DISCUSSION

- Who should decide what prenatal genetic tests and screening are carried out? Why?
- Should IVF couples be offered whole genome sequencing and even genome-editing to help them become pregnant?

Whose rights? Whole-genome screening

Genetic advances have great potential for improving health, but they also raise questions about privacy and who should have access to personal information such as genetic data. Take a look at the made-up scenario below to explore issues that are far from black and white

Techniques for whole-genome sequencing are becoming faster and cheaper by the year. In the future, it could be possible to sequence your genome for a few hundred pounds and find out the conditions you are most at risk of developing. Doctors could also identify harmful mutations that you might pass on to your children or even (see above) carry out whole-genome sequencing on embryos.

However, it seems unlikely that we will ever know every gene that contributes to the risk of every disease, and some diseases are a result of our lifestyles as much as our genes. The best way to stay healthy may be to follow age-old advice about diet and exercise, but perhaps knowing you are at high risk for heart disease would give you an added incentive to stay in shape.

Imagine that in the future, whole-genome sequencing allows doctors to produce personalised health profiles based on our DNA, including individual risk ratings for some of the most common diseases. Now read the following and think about how you would answer the questions.

POTENTIAL SCENARIOS FOR DISCUSSION

"In my family there's a history of heart disease and stroke. I try to stay healthy, but what if I just have 'bad genes'?" Luke, 18, student

- **Should Luke get his genome sequenced? How should he approach dealing with the results?**

"I want my children to have the best possible chance to grow up healthy. That's why I'm getting whole-genome sequencing done on my embryos." Sarah, 30, solicitor

- **Should Sarah be given access to her children's genetic information? What impact could this have on her parenting?**

Should everyone in the UK be added to the National DNA Database?

Background information

In the 1980s, Professor Sir Alec Jeffreys developed DNA fingerprinting – a technique to create a unique numerical profile from a person's DNA. He realised the potential this technology had to advance forensic science and in 1995 the National DNA Database was launched to allow the police to store DNA profiles. As of June 2019, the DNA of an estimated 5,038,468 people was held in the database.

In England and Wales, DNA samples are taken from anyone arrested for a recordable offence (any offence for which a record will be kept on the Police National Computer). They are also collected from crime scenes. Under the 2012 Protection of Freedoms Act 2012, DNA profiles can be retained indefinitely for adults convicted of crimes, whereas the profiles of people who are charged but not convicted must be removed from the database after three years, with some exceptions. Actual samples of DNA must be destroyed within six months, following analysis.

The vast majority of DNA is exactly the same between individuals, but there are small variations. For the purpose of the database, non-coding regions of DNA called short tandem repeats are examined to create profiles. These profiles can be used to identify a person's sex but cannot be used to gain any information on a person's health. The chance of two unrelated individuals having matching profiles is less than 1 in a billion.

Lesson activities

Introduction

What does your class know about the National DNA Database? Have your students heard about it on the news? You may wish to consider the following facts:

- 80 per cent of people on the England and Wales database are male (as of June 2019).11,940 children under the age of 16, including eight under the age of 10, have their DNA in the England and Wales database.
- 479,905 people (8% of the total) in the DNA database are described as black under ethnic origin. According to August 2018 figures, there are 1,864,890 black people in England and Wales, suggesting that over a quarter of black people are on the DNA database.
- Assessing the effectiveness of the UK National DNA database is complex. However, in 2015-16, crime scene profiles produced a match in the database in 63% of cases, whilst the Biometrics Commissioner for the UK said that DNA was involved in 0.3% of recorded crimes resulting in an "output", which could include charging a suspect or issuing a caution.

The UK National DNA Database costs £2.5 million a year to run.

Voting

Ask students for their initial thoughts on whether everyone in the UK should be added to the National DNA Database. This will be repeated at the end to see if opinions have changed.

A nationwide DNA database?

Read the following press article and letter about Rwanda adding all of its citizens to a proposed nationwide DNA database.

- Rwanda sparks human rights concerns in proposing world's first nationwide DNA database

https://www.independent.co.uk/news/world/africa/rwanda-dna-database-human-rights-privacy-a8832051.html

- World's first required national DNA database is in the works

https://americanmilitarynews.com/2019/03/worlds-first-required-national-dna-database-is-in-the-works/

- Letter to Rwandan ministers from GeneWatch UK

http://www.genewatch.org/uploads/f03c6d66a9b354535738483c1c3d49e4/GeneWatch_letter.pdf

You might like to consider the following questions:

- How would you feel about the same policy being implemented in your own country?
- Should there even be a DNA database at all?
- Should the database be held by the police, or should it be independent?

Group discussion

Have any of the views in the resources challenged what your students think? Ask them to work in groups and come up with a list of reasons why everyone should be added to the database and a list of reasons why they shouldn't. Then ask them to share their ideas with the class.

Final vote

Ask students to vote again on whether everyone in the UK should be added to the National DNA Database – have their views changed? If so, why?