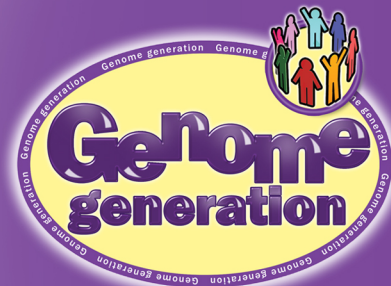


# Genome generation

## A Guide to Scenario 3



### Sam and the insurance company

This scenario is set in the future and assumes that insurance companies will be able to use genetic information to determine insurance premiums.

**Summary:** Scenario 3 deals with a middle-aged man (Sam) with a family history of heart attacks. He wishes to purchase insurance but the insurers ask him to be genotyped. Sam's brother (who has had heart problems himself) is keen for Sam to be tested. He feels that knowing if Sam is at high risk of heart disease will help him to take steps to avoid severe heart problems. Sam fears he will be refused insurance if he takes the test and is not certain he wants to know the results. His wife is firmly against genotyping. The group have to decide if Sam should take the test.

**Initial question:** Should Sam take the test?

**Key issues:** *Who should have access to data? Would you want to know? Impact on families*



### Complexity, sensitive issues & guidance on providing support

This scenario is appropriate for GCSE and A-level.

This scenario explores the potential impact of genetic tests on families and whether it is an advantage or disadvantage to know your risk for a complex disease. It also raises questions about access to genetic information for insurance purposes.

Some students may be sceptical that the tests would have an impact on insurance. Currently insurance companies have committed to a voluntary moratorium on the use of genetic test results until 2017. It is uncertain what will happen after this point.

### Some of the issues or questions that may be explored during discussions

**Who should have access to data about our genes and what are the consequences of this?**

There is concern that improper use of such data could lead to discrimination against people with genetic predispositions for conditions, making it difficult for them to obtain insurance, mortgages or employment.

**Should we allow insurers to ask for this information? Insurance companies exist to make profits.** They already measure risk when assessing insurance premiums (such as taking family history into account). So, why shouldn't they use all of the information available to them?

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### **If a genetic test indicates that you are at risk from heart disease, does it mean you will definitely develop the condition?**

Heart disease is a common condition and a complex disease. This means that there is a combination of environmental factors and genetic factors that can play a role in whether or not a person will develop the disease. A person's genetic makeup is just one part of the story and only highlights an increased risk. It is not the only factor that determines if a person will develop a disease. So, is there any advantage to knowing your genetic risk?

### **Can Sam change his lifestyle if he finds out he is at risk of developing heart disease?**

If Sam finds that he is at risk, he could make lifestyle changes to reduce his risk such as taking regular exercise and eating a healthier diet. So, is it better to know in advance, even if it does mean that he pays higher insurance premiums as a result?

### **Will there be genetic counselling to accompany the test?**

If he takes a test for insurance purposes, who should provide support and counselling to prepare Sam for the results?

### **Should people take responsibility for their own health and lifestyle choices?**

If you found out you were at risk of developing heart disease, should you change your lifestyle? What if the NHS refused to treat people whose genotype indicated an increased risk, but who did not change their lifestyle upon receiving the news? If a person takes the test, should it be compulsory that they take action as a result?

## **Further information – what they might need to know**

### **Genetics of heart disease**

Studies have shown that an individual's risk of heart disease is often increased if they have a family history of the disease. Heart disease is a consequence of complex interactions between many genes and multiple environmental factors. Because the disease is so common, genetic links are difficult to determine. However, there are instances of heart disease with clear genetic links e.g. familial hypercholesterolaemia, a genetic disorder characterised by high blood cholesterol and early development of heart disease.

### **Diet and lifestyle**

Lifestyle plays a significant role in the development of heart disease. For example, there is a correlation between heart disease and diets which are high in saturated fats (and low in fruit and vegetables). It is thought that high fat diets cause an increased rate of damage and hardening of blood vessels. Another example is smoking. People who smoke are almost twice as likely to have a heart attack compared with people who have never smoked. Smoking damages the walls of blood vessels and the body's efforts to repair this damage increases the risks of blood clots.

### **Heart disease mortality**

Diseases of the heart and circulatory system are the main cause of death in the UK, accounting for almost 191,000 deaths each year. Almost half of these deaths are due to heart disease, and around a quarter of these

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are due to stroke. Since the 1980s, heart disease mortality has declined rapidly. Studies have concluded that more than half of this can be attributed to reductions in major risk factors, particularly smoking. Improved therapies and early treatment, (e.g. prescribed medicines such as statins, beta blockers or low dose aspirin) account for the remainder.

### Treatment and recovery

The most important step in the treatment of heart attack is to increase oxygen supply to the heart. Patients are given aspirin and other drugs that thin the blood and stop it from forming clots. Some patients may undergo emergency surgery (angioplasty) to open the blocked blood vessel.

### Further reading

The following news stories can be used in addition to the information cards to provide extra background information to help students understand the major issues raised in this scenario.

Heart disease study finds genetic factors predispose risk of attack

<http://www.guardian.co.uk/science/2010/aug/04/heart-disease-study-genetic-factors-risk-of-attack>

Men can inherit a form of heart disease from father via Y chromosome

<http://www.bbc.co.uk/news/health-16931585>

### Further information for students

Students can find out more information about heart disease from the following websites:

#### NHS Choices

NHS Choices is produced by the National Health Service (NHS) and provides information on a range of different health issues. The pages below provide information on coronary heart disease.

<http://www.nhs.uk/conditions/Heart-attack/Pages/Introduction.aspx>

<http://www.nhs.uk/Conditions/Coronary-heart-disease/Pages/Introduction.aspx>

#### British Heart Foundation

The British Heart Foundation is a UK heart charity dedicated to pioneering research into the causes of heart disease, providing information and ensuring quality care and support for people living with heart disease.

<http://www.bhf.org.uk/heart-health/conditions/heart-attack.aspx>

<http://www.bhf.org.uk/heart-health/conditions/coronary-heart-disease.aspx>

<http://www.bhf.org.uk/heart-health/conditions/cardiovascular-disease.aspx>

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### Follow up activity

Ask the students to produce a short news report (video) or newspaper article (500 words maximum) for a non-scientific audience based on the following scientific press release <http://www.sanger.ac.uk/about/press/2011/110306.html>. They must include details about why the discovery is significant to the medical community and society, how the discovery was made and who was involved.