

00 Facilitator Notes

Introduction

This background information is included to help you run the seminar. It is a matter of discretion when you introduce the background information contained below, if at all. It is not intended that you provide this information before the discussion of each event begins—it is better if the issues people are interested in arise naturally from the discussion. However, you may need to introduce background information during the discussion under various circumstances.

For example:

- (i) people may directly ask you a question (e.g. “Can insurers use genetic test results to set premiums?”);
- (ii) the discussion may be becoming based on a false premise that needs to be corrected (e.g. “Insurers already use genetic test results”);
- (iii) some participants may question the potential realism of the events (e.g. “Genetic testing is about health, not about selling skin cream, this is not realistic”).

You may also want to introduce some of the basic background information towards the end of the discussion, to remind people that many of the issues are real today or may arise at some point in the future.

Step by Step Guide

1. Delegate Guide

On arrival attendees should be given 01 Delegate Guide to read while waiting for everyone else. They can take this away after the simulation.

2. Genetic Test Offer

When the seminar begins, delegates are given 02 Genetic Test Offer

Delegates discuss whether to take the test, and why.

Do people want to know what their genetic code is?

What is the information likely to mean?

Each delegate must decide whether to take the test.

Delegates who decide not to take the test now can decide to take it at any time during the seminar.

3. Results Letters

If a delegate decides to take the test she is given a 03a,b or c letter folded and selected at random. This will tell her she is either genotype A, B or C.

Delegates might discuss whether they want to reveal their test results to others.

4. Press release: New ‘Zapitor’ drug brings hope to Genotype A carriers

Once the conversation has waned, the 04 should be circulated or projected on an OHP/PowerPoint. Once people have been given time to read the document, conversation should either be spontaneous or the facilitator of the seminar may need to stimulate discussion with a question such as:

‘In light of this news are you glad you did/didn’t take the test?’

5. Advertisement for Zapitor

6. Government press release about genetic testing and lack of regulation

People may need reminding that they can choose to open their envelopes during any of these events if they wish. They should be encouraged to say why if they choose to do so.

The issue of regulation may be raised at any point during these 3 items. The following information may be introduced into the discussion if helpful – preferably towards the end of the discussion, once people have thought through the issues themselves.

Medicines are regulated (the company selling them must provide scientific data about tests of their safety and effectiveness in a group of patients). However, genetic tests are largely unregulated. A process of quality assurance is being introduced which will eventually mean that most labs must be able to identify the genotype correctly (in our game this means telling you correctly that you are A, B or C – although this will never be done perfectly). But there is no independent check of (i) whether the gene really increases the risk of the stated disease (known as “clinical validity”); or (ii) whether this is a useful way to decide who gets which medicine (known as “clinical utility”). For example it may be better for health to give the medicine to a larger or smaller group of people, or use a different way to decide who should take it, or recommend a different medicine or lifestyle advice.

Statistical studies are usually done to find out if a gene increases the risk of disease, but these often contradict each other, making “clinical validity” hard to establish. The clinical trials needed to decide whether or not the test is useful (i.e. good for health) are expensive and very few have been attempted (meaning that “clinical utility” has not been assessed).

“Preventive medication” can be given to a much larger group of people than medicines used to treat an illness. Statins (used to lower cholesterol levels) are now the most profitable medicines for pharmaceutical companies.

7. Flyer for type A genotypes

8. Flyer for type B genotypes

At least one company (in New York) is already selling skin cream that is supposedly tailored to your genetic make-up (www.lab21.com). They test a sample of your DNA for some unspecified genetic variations and sell the “genetically tailored” skin cream for \$250 for a small jar, or \$750 for a larger one. Several other companies are developing this type of product.

9. Daily Post article on insurance and genotype A

[Basic information]

At the moment there is a voluntary agreement between the insurance industry and the Government that insurers will not normally use genetic test results to decide who gets insurance or what their premiums can be. This agreement has now been extended to 2011, however the policy after this date is still uncertain.

[Additional information]

There is already one exception agreed to the existing agreement: insurers can ask for the results of a test for a genetic disorder called Huntington’s Disease, but only if someone applies for a very high value policy. Other tests exceptions may be made in future, but only after an assessment by the Genetics and Insurance Committee. Insurers are also allowed to use family history to set premiums and to take into account negative test results if people choose to supply them voluntarily.

10. Press release linking genotype C to criminality

The extent to which our genes determine or influence our behaviour is very controversial. However, many researchers are studying links between genes and behaviour. Some claim to be able to identify genetic “predispositions”: including to aggression, criminality or addictive personality.

11. Job advert excluding genotype C

[Basic information]

There is currently no legislation preventing employers from using genetic test results to decide who gets a job, although this has not yet happened in the UK. Although nobody has yet suggested that a “criminality gene” might be checked before employment, some employers have expressed an interest in using other types of test (linked to risk of future illness) at some point in the future.

[Additional information]

The law treats predictions of future behaviour or illness (perhaps based on genetic tests) differently from a history of criminality or illness. People who have committed a past crime are covered by the Rehabilitation of Offenders Act, which sets time limits on when convictions for less serious offences are “spent” and must be ignored by employers (except in some professions such as teaching and law). People with genetic disorders who already have symptoms (or have had them in the past) are covered by the Disability Discrimination Act, which places some requirements on employers to adapt the workplace to their needs. But these acts do not cover people with an adverse genetic test result who have no symptoms of illness or disability, or people who are considered to have a “gene for criminality” but who have not committed any crime.

12. Press article linking genotype A to dementia

[Basic information]

This kind of “nasty surprise” has already happened with a genetic test. A genetic variation called APOE4, linked to an increased risk of heart disease, was later linked to an increased risk of Alzheimer’s Disease.

[Further information]

At the time, the APOE4 test was not in widespread use but a number of geneticists had taken it as part of their research. Some regretted knowing that they had this genetic variation. Medical guidelines now recommend that this test is not used due to the uncertainty of the prediction and the lack of any treatment. However, it has been included in at least one “over the counter” genetic test kit (sold mainly via alternative health practitioners) as part of a panel of tests for heart disease risk – without warning customers about the link with Alzheimer’s Disease (www.genovations.com).

13. Report from Royal Society

The statistical links made between genes and common diseases or behaviour are usually wrong. In 2002, one scientific paper found that only 6 out of 600 links between genes and common diseases were robust once further research was done¹. For example: there are a few genes that cause rare inherited forms of extreme obesity, but of the dozens of genes so far linked to ‘normal’ obesity, none are yet confirmed (they are not statistically significant when all the studies are combined²). The same is true for all genes linked to behaviour in ‘normal’ people³. Some scientists think this problem will

be solved when larger studies are done in future. Other scientists think that most diseases in most people are too complicated – and environmental factors are too important - for a genetic test to give reliable predictions about who is going to get ill.

FINAL DISCUSSION

People may want to revisit the issue of why they opened (or did not open) their envelopes, whether or not they have changed their minds and/or what safeguards they might like to make this decision easier.

Once the seminar is coming to a close, and the final 'event' has been distributed, the facilitator should summarise some final points that return the imagined scenario to real life. It is key that the attendees realise that many of the imaginary events are in fact grounded in reality.

- ¹ Hirschorn JN et al (2002). A comprehensive review of genetic association studies. *Genetics in Medicine*, **4** (2), 45-61.
- ² Rosmond R (2003). Association studies of genetic polymorphisms in central obesity: a critical review. *International Journal of Obesity Related Metabolic Disorders*, **27**, 1141-1151.
- ³ Munafò et al (2003) Genetic polymorphisms and personality in healthy adults: a systematic review and meta-analysis. *Molecular Psychiatry*, **8**, 471-484.