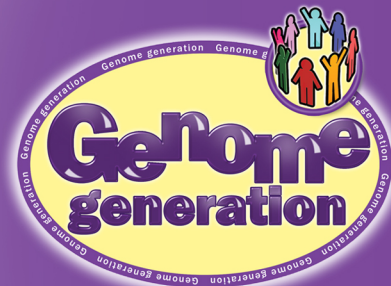


Genome generation

A Guide to Scenario 7



Andy's unexpected paternity results

This scenario is set in the future and assumes that recreational genotyping has reached the point that it is affordable for most people to purchase a genotyping kit as a gift.

Summary: This scenario involves Andy, who buys a genotyping kit online. He finds it fun and therefore decides to buy one for his father. Looking through their results together, Andy notices that there are different markers on the chromosomes of him and his father, indicating that he is not Andy's biological father. The group has to decide whether Andy should tell his father what he's found.

Initial question: Should Andy tell his father the results?

Key issues: *Incidental or unexpected findings; Impact on families; Access to data*



Complexity, sensitive issues & guidance on providing support

This scenario may be more suited to A-level students

The scenario introduces the idea of unexpected findings which can be potentially very upsetting to a family. It also looks at the impact of recreational genotyping, which often takes place without thorough genetic counselling.

The scenario deals with the issue of paternity, so it offers an opportunity to engage with the wider issues of genetic testing, beyond illness and disease.

The controversy in the scenario can be very engaging. This is helpful in terms of encouraging people to engage with the wide-ranging impacts on families. But if discussions become too focused on the family dynamics – try to steer conversations back to the issues of genomic data.

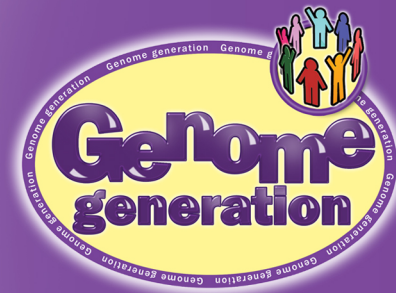
Some of the issues or questions that may be explored during discussions

What impact will the discovery have on the family if the results are discussed?

Since you share your genes with members of your family, the results can have an impact on others – should you share the information with them? Is your genotype really just yours?

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Who should have access to data?

If you share genes with your family, should they be entitled to see your results? But what if there are incidental findings which you or your family would prefer to not know?

Should there be limits to recreational genotyping?

Is it right that people are able to purchase their genotypes without support from genetic counsellors?

Should commercial genotyping be regulated? Who should regulate commercial genotyping organisations?

Is commercial genotyping accessible for all?

Is it fair that commercial genotyping is only available to those who can afford it – should it be available to all? Should the NHS pay for it – is it worth it?

Further information – what they might need to know

The rising popularity of recreational genomics

Recreational genomics is growing in popularity. Direct to consumer (DTC) testing has existed for more than a decade with numerous companies offering services. Current genomic services include: diagnostic tests, carrier status tests, prenatal diagnostic testing, susceptibility/predisposition tests, pharmacogenetic tests, nutrigenetic tests (linking genes and diet), phenotype tests and genetic-relatedness tests.

Regulation

At present most countries do not regulate access to DTC genetic tests and international availability means that individual countries will find it difficult to regulate the industry with domestic legislation alone. Currently (2012) France, Germany, Portugal and Switzerland have specific legislation which say that genetic tests can only be carried out by a medical doctor, with the informed consent of the person concerned. The UK does not currently regulate DTC genetic tests. In the USA, the Food and Drug Administration (FDA) regulates the industry. It has recently recommended that some tests should not be available without the involvement of a physician or genetics specialist.

Contributing to genetic research

Customers of DTC genetic tests may be invited to submit their genetic data for genetic research. The companies involved are in a strong position to carry out genome-wide association studies, which could lead to better understanding of the genetics underlying a variety of conditions.

Accuracy of information

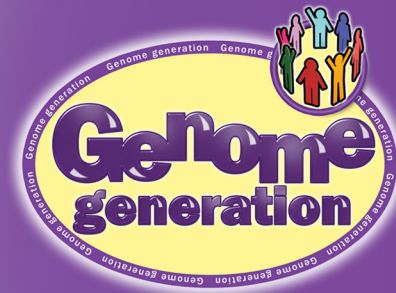
One of the major concerns about the benefits of DTC genetic testing is the accuracy of the data. Research carried out by the US Government Accountability Office found that different companies produced widely differing results from the exact same sample of material.

Security of information

Genetic data is of significant commercial value. When a customer submits their DNA and other personal

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information to a private company they may be making a lot of personal data available with limited privacy safeguards. Bankruptcy is not uncommon in companies offering these services, and in this situation, it is unclear what happens to the data they store.

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.

How spit test can screen your genes

<http://news.bbc.co.uk/1/hi/health/7964019.stm>

Ancestry testing goes for pinpoint accuracy

<http://www.nature.com/news/ancestry-testing-goes-for-pinpoint-accuracy-1.10785>

Further information for students

Students can find out more information about direct to consumer testing from the following websites:

Article by Leslie Pray in Nature

In this article Leslie Pray discusses the advantages and disadvantages of direct to consumer testing.

<http://www.nature.com/scitable/topicpage/dtc-genetic-testing-23andme-dna-direct-and-674>

Council for Responsible Genetics

The Council for Responsible Genetics is an American non-profit organisation that encourages public debate about the social, ethical and environmental implications of genetic technologies. It publishes a bimonthly magazine, GeneWatch, which is dedicated to monitoring the social, ethical and environmental consequences of biotechnologies. This article explores the issues of direct to consumer genetic testing.

<http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pagelid=277>

Follow up activity

Ask the students to work together in groups to investigate public opinion on direct to consumer genetic tests. Students can do this by either creating a survey or questionnaire, or carrying out short video interviews (vox pops). The group must interview a minimum of 10 people. Students need to ask questions that will enable them to find out peoples thoughts on direct to consumer genetic tests, e.g. would they take an online test, what would they want to know about themselves, what wouldn't they want to know, do they have any concerns? To complete the task students must compile a short report on their findings.