Genome Generation Express

Activity Guide

The aim of the activity is to encourage learners to explore, discuss and reflect on the social and ethical issues associated with genetic and genomic science. Learners debate the issues presented in the different scenarios and make their own informed decisions about the ethical issues.

Suitable for: age 11-18
Estimated duration: 30 minutes

You will need:

- **Background documents**
- **Viewpoints worksheets**

Introduction

The rapid development of genome sequencing technologies has allowed for many amazing discoveries to be made. We are now entering an era of genomic science where disease diagnosis, treatment and tracking can all be done much more easily and in a more personalised manor than ever before. With this huge potential comes many important societal questions.

There are many important personal, social and ethical questions surrounding genetics and genomics. Everyone's views are different and often there isn't a simple or definitive answer.

Set up

1. Ask the participants to form groups of between three and five people.
2. Give each group one or both of the background case studies to work with.
3. Give each group the related viewpoints worksheets to go with the background case studies they have.

Find out more

What is a genome: https://www.yourgenome.org/theme/what-is-a-genome/

What is genetic testing: https://www.yourgenome.org/theme/what-is-genetic-testing/

Running the activity

Warm up

1. Begin by explaining how DNA is found in all living things. It is the instructions that makes you who you are and it is because of small differences in DNA code that you are different to others in the room.
2. Describe how there is now technology that can 'read' someone's DNA code from a sample of their blood, skin, or other part of their body.
3. Explain how this can be used to diagnose people with genetic conditions as well as giving insight into people's underlying genetic make-up that can affect how likely they are to develop some conditions later in their life.
4. Highlight how this technology has great potential for healthcare. However also highlight that there are some ethical concerns that as a society we need to decide on rules to make sure the technology is used for the right things.

Run the activity

1. Briefly run through the ground rules of discussion, such as listening to and respecting others.
2. Get each group to begin by reading over the background case studies they are working on:

    a. **Should a baby have its genome sequenced?**

    - Summary: In this scenario expectant parents are asked whether they would like to have their child's genome sequenced after it is born. The information would form part of the child's ID card. Initial question: Should the parents have their child's genome sequenced?

    - Key issues: Incidental findings, access to data, impact on families, would you want to know?

b. **Andy's unexpected paternity results**

- 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 Y 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.

3. Ask the groups to write down their initial thoughts on the situation using the blank side of the viewpoints worksheet.
4. Encourage everyone in the groups to discuss their thoughts and why they feel that way. Allow enough time to let everyone get involved in the conversation and have their say.
5. Finally, ask all the groups to read through the example considerations on the back of the viewpoints worksheets. Do any of these points change the group's thoughts on the situation?

Reflect on it

Encourage everyone to wind down their discussions and to feedback to the room what their thoughts were and if they felt they had initially considered all the issues. Re-emphasise to them that this technology is still being developed and becoming more accessible every year - the case studies they have looked at are not just fictional.

Take it further

Want to see how scientists get DNA from a sample? Why not have a go at extracting DNA from fruit yourself?

Extracting DNA from fruit: https://www.yourgenome.org/theme/extracting-dna-from-fruit/