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Genetic
Disorders
UK

TEACHER'S NOTES

SCREENING EVERYONE

OVERVIEW

Aimed at **key stage 4** pupils. This is an activity to stimulate thinking about how widely genetic screening could be used.

LEARNING OBJECTIVES

- To appreciate the potential benefits and harms from a national screening programme for cystic fibrosis (CF) carriers
- For pupils to discuss their personal views on an ethical dilemma and empathise with different perspectives on this issue

CURRICULUM LINKS

- KS4:** the use of contemporary scientific and technological developments and their benefits, drawbacks and risks
- KS4:** to consider how and why decisions about science and technology are made, including those that raise ethical issues, and about the social, economic and environmental effects of such decisions

Activity

- Review how cystic fibrosis affects people and how it is inherited
- Watch the film Ryan's story on www.genesareus.org
- Give pupils the worksheet and give them 15 minutes to complete Q1 independently
- Ask the pupils to discuss the advantages and disadvantages of introducing a CF carrier screening programme in pairs
- Broaden the discussion so the class shares their views and the class votes on this issue (whether the benefits outweigh the potential harms). The group might want to change the proposal (for example alter the age group targeted or change the wording from 'encouraged' to 'offered')
- Ask pupils to complete questions 2-5 on the worksheet
- Discuss their answers as a class

ANSWERS

1. Answered in a table. There are no right or wrong answers, but hopefully the pupils have considered different perspectives.

Potential reasons for being supportive:

- People are entitled to know their own genetic information
- Those found to be carriers of CF will not be coerced into anything, but it will enable them to make informed choices in the future
- Carriers of CF will be reassured that they are healthy and full support and information will be given to reduce the chance of any bad reactions
- 14 year olds are old enough to make this decision and understand the implications
- Screening newborn babies for CF is too late – people need to know before they get pregnant whether they are carriers
- CF is a serious condition and more should be done to prevent it being passed on and reduce the incidence of this condition

Potential reasons for being concerned:

- The screening programme should be voluntary – without people being encouraged to participate
- Carriers of CF might be discriminated against or possibly bullied
- Individuals identified as carriers might find this information hard to cope with (potentially feeling like a freak – possibly isolated and anxious)
- Carriers might find this difficult to discuss with family or girlfriends/boyfriends
- People with CF could feel this programme is trying to prevent anyone ever being born with CF and devalue their existence
- It might give the impression that carriers need to use prenatal testing and selective abortion to prevent passing CF onto children



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2. How would you explain to someone what it means to be a carrier of CF?

Carriers of CF need reassurance that their health is not affected and that they will not need any special treatment. They would need information about the symptoms of CF and how it is inherited.

CF is a genetic condition and it is caused by a change to a gene. We all have two copies of each gene in our body and someone with CF has inherited an alteration in both copies. If someone inherits just one copy of the CF-causing gene variant (allele) they are described as a carrier. There is a chance of passing this allele onto children and having a child affected by CF, but this is only possible if your partner is also a carrier of CF.

3. If you were found to be a carrier of CF, who would you tell?

Pupils will select different people, but they are likely to feel this is private information and no one has a right to be told. They should justify their answers.

4. How would the cost of this screening programme affect the way you feel about it?

Pupils are unlikely to consider the economics, but they might feel it is only worthwhile if it costs less than £1 million or £5 million.

It might be interesting to compare costs with other things that the NHS has to pay for (for example, the average cost for a heart transplant in the UK is £32,000). Population screening programmes are likely to cost millions of pounds to run. The NHS has a limited budget, so it has to prioritise what is needed most.

FURTHER information

- The NHS has detailed information about how the newborn screening programme is organised www.newbornbloodspot.screening.nhs.uk
- In 2011 the NHS National Screening Committee asked the Human Genetics Commission (HGC) to provide advice on the feasibility of social, ethical and legal implications of population preconception genetic screening. This expert group was generally supportive of genetic screening for conditions such as CF, but did not specifically comment on CF. The report entitled 'Increasing options, Informing choice' is available the HGC's website www.hgc.gov.uk

EXTENSION

- Pupils could consider whether screening for any other genetic conditions should be introduced for this age group.

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Screening for cystic fibrosis (CF) has been offered for all babies born in the UK since 2007. This means that parents are encouraged to have their babies tested when they are about five days old which involves collecting a few drops of blood onto a card (Newborn Blood Spot Screening). These drops of blood can be used to screen for a number of important genetic conditions. Sometimes this test identifies carriers of CF, but the majority of carriers are not detected.

Changes in the *CFTR* gene (full name of the gene is cystic fibrosis transmembrane conductance regulator) were found to cause CF in 1989. Once the gene was identified, some people started to question how DNA testing could be used by society.

The case for population screening needs to be strong and generally it is only introduced when

an intervention can prevent a condition getting worse. If newborn babies are identified with CF, they are given specialist help and access to the best treatments.

Some people are keen to increase population screening and give the public more genetic information. They argue that people are in a position to make better decisions when they have more information. Some people feel that teenagers are an important age group to target for screening so they can find out if they might pass a serious genetic condition to future children.

High school pupils in some parts of Canada and Australia have been offered screening in the past to identify carriers of CF. On average, 1 in 25 people in the UK is a carrier of CF and these individuals are healthy.

PROPOSAL

All 14 year olds should be encouraged to have a screening test to identify whether they are a carrier for cystic fibrosis. This would be accompanied by full information and support about the implications.

1 Complete the table below based on how each person might feel about the proposal. Work on your own and consider different perspectives. There are no right or wrong answers

Person	Opinion	Why might they feel this way (please give as many reasons as you can think of)
14 year old	SUPPORTIVE	
Doctor who treats people affected by CF	SUPPORTIVE	
Representative from the Department of Health who tracks the frequency of CF in the population	SUPPORTIVE	
20 year old with CF	CONCERNED	
Parent of teenagers	CONCERNED	
Researcher who studies ethics	CONCERNED	



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2 How would you explain to someone what it means to be a carrier of CF?

3 If you were found to be a carrier of CF, who would you tell?
Explain your answer

- | | |
|-------------|-----------------------------|
| a) Parents | e) GP |
| b) Siblings | f) Friends |
| c) Cousins | g) Girlfriend/
boyfriend |
| d) Teacher | |

4 How would the cost of this screening programme affect the way you feel about it?

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