

A new biological technique could allow us to ‘edit out’ genetic disease in future generations. But what would be the implications?

Genome editing may offer benefits to people with some medical conditions by allowing genetic variants that are associated with serious illness or infertility to be ‘edited out’. The technique could also be used to target characteristics other than those associated with illness and health. Before long, policy makers will have to confront important questions about how far we, as a society, should go in altering fundamental aspects of human biology.

We are the Nuffield Council on Bioethics, an independent organisation that examines ethical questions about the future of biology and medicine. For 25 years we have provided respected independent reviews and advice to professionals and policy makers. We think decisions about genome editing should be informed by a broad debate that involves as many people in our society as possible. We have produced this questionnaire to stimulate thought and debate, and to provide a way of making people’s views heard. No special knowledge is needed to complete the questionnaire, just a willingness to think through the situations described.

More information about the Nuffield Council on Bioethics and why we are running this survey is [available here](#).

If you want to see the survey questions before you start, you can [download a preview here](#).



What are we asking you to do?

The prospect of being able to alter the genome of a future person before they are born raises many important ethical questions. Some of these are explored through three scenarios that are described on the following pages. Although the scenarios are imagined, they aim to describe real situations that could plausibly arise in the future. In each case we ask you to tell us what your views are and how you came to those views.

The whole questionnaire can be completed within 15 minutes, although you may choose to take more time to explain your answers in more detail. In each case please pick the answer that is closest to your view, and explain more fully in the text box. There is no correct answer to any question and you don't have to complete all questions, or give your reasons if you don't want to do so. The information you provide will be used anonymously unless you tell us that you are happy for us to use your name.

You can review and change previous answers or skip forward through the questionnaire at any time until you submit your response by clicking 'submit' on the final page. Once you do this your response will be sent to the Nuffield Council. If you close your browser without clicking 'submit' your answers will be lost.

Scenario 1: Ali and Brian

Ali and Brian are a couple in their early 30s, who are hoping to start a family. After two years of trying without success, they decide to seek help from their doctor who refers them to a specialist fertility clinic.

Further medical investigations show that Brian carries a genetic abnormality that he has inherited from his mother. This means that when Brian's sperm fertilises Ali's eggs, the resulting embryos do not develop.

A new procedure is available to alter the genetic material (DNA) in the embryos to a version that most other people have so that the embryos will develop normally.

The procedure is judged to be safe although, as with all complex procedures, there are some risks and there can be no guarantee of success. As it represents Ali and Brian's only hope of having a child that is genetically related to both of them they decide they would like to go ahead with it.



1. Should the procedure to alter Ali and Brian's embryos be permitted in principle?

- Yes
- No
- It depends

What considerations informed your response?

2. If the treatment is successful, the resulting child will inherit the introduced genetic variant. When the child grows up, they may pass these changes on to any children they themselves have and, potentially, to their future descendants. Is this a good thing?

- It is a good thing, because future generations will be free of the condition affecting Brian's fertility
- It is a good thing on balance, although there are some concerns about making changes that will be inherited by future generations
- Although there would be benefits, these are outweighed by concerns about making changes that will be inherited by future generations
- It can never be appropriate to interfere with genes in a way that will be passed on to future generations

What considerations informed your response?

3. Whose authorisation should be required before Ali and Brian can have access to this treatment? (Select all options that apply.)

- It should be decided by laws made by Parliament
- It should be authorised by a regulatory body that takes both expert advice on safety and public opinions about acceptability into account
- It should be up to scientists and doctors to decide that it is safe enough and appropriate for Ali and Brian to go ahead
- It should be up to Ali and Brian alone to decide whether they have the treatment
- It should be up to someone else (please explain below)
- It should never be allowed

What considerations informed your response?

4. Suppose the procedure could be carried out on Brian's sperm, or on the tissues that produce the sperm in Brian's body. Would it be better to make the alteration in that way?

- Neither altering embryos nor altering sperm is acceptable
- Altering the sperm or tissues that produce sperm is preferable to altering the embryos
- Altering the embryos is preferable to altering the sperm or tissues that produce sperm
- Both approaches are equally acceptable

What considerations informed your response?

5. Suppose that instead of directly altering Brian's sperm or sperm-producing tissue, the editing procedure could be done on cells taken from another part of Brian's body that have been grown on in the laboratory (stem cells). This would mean that the child would not result from reproductive cells (sperm) as is usual, but from laboratory grown stem cells instead. Should this be allowed?

- If it worked, this would be an acceptable alternative
- If it worked, this could be acceptable under certain circumstances (please tell us what these should be)
- It could never be acceptable to produce children using cells other than reproductive cells (eggs and sperm)

What considerations informed your response?

Scenario 2: Chris and Dara

Another couple, Chris and Dara, also want to have a family. They are not affected by infertility but a member of Chris's close family has a serious medical condition caused by a genetic variant. As a result, that family member receives frequent intrusive, medical treatment, has reduced mobility, and their life expectancy is about a third of that of most people.

Medical investigations have revealed that there is a high risk that any child Chris and Dara have naturally would be affected by the same condition as that family member.

Chris and Dara have heard of a new procedure that would alter the genetic variant that causes the disease to one that does not. The procedure would be performed on the embryos in the laboratory before they were used for pregnancy.

The procedure is judged to be safe (although, as with all complex procedures, there are some risks and there can be no guarantee of success). Chris and Dara decide they would like to explore this as a way to avoid having a child with the serious condition.



6. Should Chris and Dara be able to use this technique to have a child who is free from the medical condition affecting Chris's family?

- Yes, they should be free to choose this option if it is safe to use
- Yes, but only in certain circumstances (please tell us what these should be)
- No, this option should not be available

What considerations informed your response?

7. The medical condition that may affect Chris and Dara's future child is serious and unavoidable. Would it make any difference...

- ... if there were a much lower chance of the child developing it (say, 3-5%)?
- ... if instead of physical disability it caused a mild cognitive impairment that made independent living difficult but did not otherwise affect physical health?
- ... if the condition would only affect them in late middle age?
- ... if an effective but invasive treatment for the condition was available (e.g. regular blood transfusion)?

- Yes, these factors make a difference; there should be restrictions on when the procedure may be used
- No, these factors make no difference; it is Chris and Dara, as the future parents, who should be able to decide what's best for their family
- No, because the treatment should not be available

What considerations informed your response?

8. Chris and Dara cannot get this treatment because it is currently prohibited by law in the UK. However, suppose that reproductive medicine centres in another country, with similar clinical standards to those in the UK, have begun offering the treatment. Is it acceptable for Chris and Dara to travel abroad for a treatment that is not available in the UK?

- Yes, it is acceptable to seek treatment abroad
- No, it is not acceptable for them to travel abroad for a treatment that is illegal in the UK

What considerations informed your response?

9. Now suppose that the procedure is made lawful in the UK but is only available privately. Chris and Dara can afford to pay for it but it is beyond the means of most people. Do you think it is acceptable for Chris and Dara to pay for the treatment that would not be affordable for most people in their position?

- Yes, it is acceptable for the procedure to be available without there having to be equality of access for all
- No, it should be available to everyone in a similar position if it is available at all, and public authorities should ensure this
- No, because the procedure should not be available to anyone

What considerations informed your response?

10. Now suppose that the procedure has become relatively cheap and is now readily available to everyone who, like Chris and Dara, has a serious genetic condition in their family. What would you think about a couple in Chris and Dara's position, who choose not to use it?

- People should have freedom of choice and there should be no expectation that they should use the procedure
- People should have freedom of choice, but must then accept responsibility for not avoiding a predictable condition that causes harm to their children (and a cost to society)
- They should be encouraged to use the treatment, because child's welfare and the cost to society outweigh the parent's right to freedom to choose

What considerations informed your response?

Scenario 3: Eli and Franc

Eli and Franc live and work in an area with endemic infectious disease that is often fatal, especially in infancy.

Like other members of their community, Eli and Franc take precautions to reduce the risk of contracting the disease. Nevertheless, periodic outbreaks occur with high mortality rates.

There is a rare genetic variant that confers a high level of resistance to the disease. Using genome editing, this variant could be produced artificially in embryos made through IVF in the laboratory. The procedure is judged to be safe (although, as with all complex procedures, there are some risks and there can be no guarantee of success).

Although they are not infertile, Eli and Franc would like to use IVF and have their embryos genetically altered so that their children will be born resistant to the disease.



11. Should Eli and Franc be able to undergo the procedure to alter their embryos so that any resulting children benefit from immunity to the disease?

- Yes
- No
- It depends

What considerations informed your response?

12. Music is very important to Eli and Franc and they would like their child to share their deeply fulfilling musical experience. Suppose a genetic variant associated with musical ability* has been identified. If a simple, additional alteration could be made to Eli and Franc's embryos that would give their child a good chance of having this characteristic, should it be permitted?

*This case is purely hypothetical: while there has been research into the genetic basis of a number of 'musical' traits, no simple link between genetic characteristics and musical ability has been found

- Yes; since the procedure is being used to introduce disease resistance anyway, there's no reason not to undertake another beneficial change at the same time
- No, only the alteration for disease resistance should be permitted
- No, neither alteration should be permitted

What considerations informed your response?

13. Now suppose that, instead of disease resistance or musical ability, Eli and Franc wanted their future children to have a genetic variant associated with exceptional intelligence*. Assuming there was a good reason to believe that this would work, should they be able to do it?

*As with musical ability improving intelligence or other complex human qualities through genes thought to be associated with them is currently not possible and might never be possible.

- Yes
- No
- It depends

What considerations informed your response?

14. Imagine now that, by making a small number of genetic alterations, it is possible to produce traits that go well beyond the range of characteristics seen in human beings today, for example the ability to tolerate long periods without water. If Eli and Franc fear the impact of climate change on their already drought-threatened environment, should they be able to choose this 'drought-tolerance' trait for their children?

- Yes
- No
- It depends

What considerations informed your response?

15. The scenarios concerning Ali and Brian, Chris and Dara and Eli and Franc, are cases in which humans might take control over their own biology and even over normal evolutionary changes in the species. Do you think a society in which genetic interventions of this kind were widely available would be a better or worse place to live than the one we live in now?

- I expect it would be a better place to live
- I expect it would be a worse place to live
- I expect it would be different, but not necessarily better or worse

What considerations informed your response?

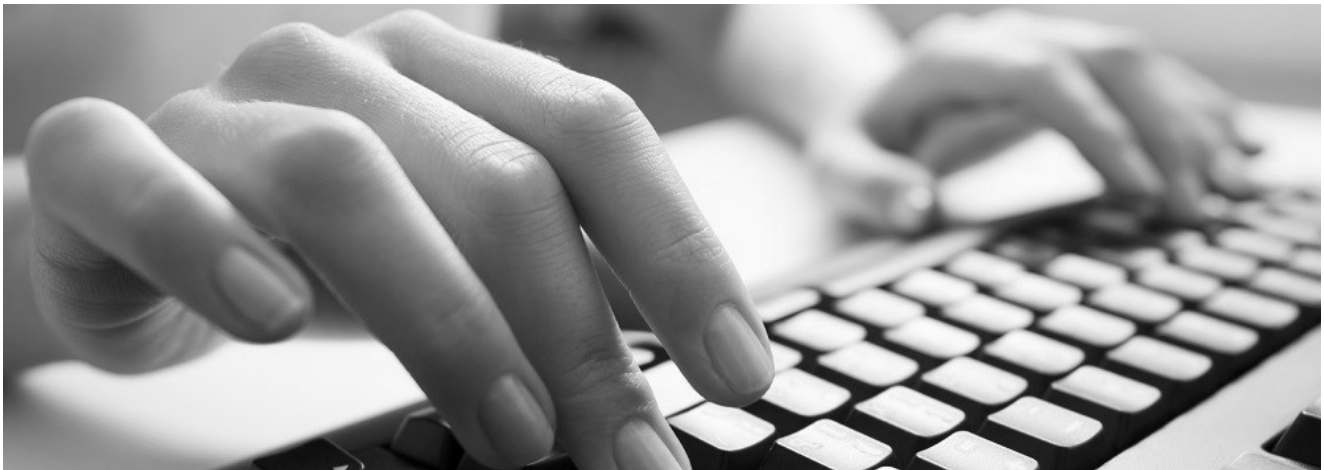
Anything else?

16. Is there anything you would like to add to the answers that you have already given?

Your responses to the questions in this section will help us better understand the groups of people that have contributed to the survey, so we can have a better idea about whether the responses come from wide section of the population. A questionnaire like this will not give us a complete picture of what everyone thinks, but knowing whether there are particular groups of people we have not heard from will help us to identify and take into account perspectives that may be missing.

Some questions we ask in this section are personal – you do not need to answer them if you don't want to. We are asking because we want to know if people with relevant interests or experiences have been able to participate. Your responses in this section will be kept separate from the other information you give: we won't ever link the responses you give to you individually in anything we publish or share with other people.

On the next page you will find information about how we plan to process the answers you provide. You can opt to remain anonymous in any further use we make of the information.



17. How old are you?

- 0-17
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+

18. What is your gender?

- Male
- Female
- Do not identify as male or female

19. Are you a parent?

- Yes
- No

20. Have you or any member of your family been personally affected by a genetic condition, or a condition with a genetic component (such as familial breast cancer), that has involved consultation with a health professional?

- Yes
- No

21. Have you ever had a genetic test (for example, a test to diagnose or exclude a health condition, or a private DNA test to identify risk factors for disease or other genetic characteristics)?

- Yes
- No

22. What is the highest educational qualification you have, if any?

- Primary School
- Secondary School (GCSE, O level or equivalent)
- College of further education / Sixth form (A-Level)
- General National Vocational Qualification (GNVQ)
- University degree (BA, BSc or equivalent)
- Masters degree / Post graduate diploma
- Doctorate
- Other

What was the subject of your degree, if any?

23. What is your nationality?

24. What is your country of residence?

This questionnaire, and the work of which it is a part, has been approved under the Nuffield Council's research ethics procedure.

We will use the information you give to inform the work of the group that is writing the report and help them reach their conclusions. This group and Nuffield Council staff will have direct access to the information you provide.

We may refer to your response or quote directly from it in our report or other publications, in a way that does not disclose your name or any information that could identify you. The information you provide to us and the way we may use it is controlled by the Data Protection Act 1998, which contains measures that protect your anonymity and give you the right to see and to correct any information we may hold about you.

Alternatively, if you are content for us to attribute any quotations we might use to you by name (or by the name of your organisation), please tick below and enter the details.

25. Are you content for the Nuffield Council on Bioethics to attribute quotations from this questionnaire to you by name or by your organisation's name?

Yes

No

If yes, please enter your name or organisational name as you would like it to appear in our publications here